Congenital anomalies in Australia
2002–2003

The Australian Institute of Health and Welfare is Australia's national health and welfare statistics and information agency. The Institute's mission is *better information and statistics for better health and wellbeing*.

The AIHW National Perinatal Statistics Unit (NPSU) is a collaborating unit of the AIHW, and was established in 1979. The NPSU is a formally affiliated institution of the University of New South Wales and is linked to the Faculty of Medicine, School of Women's and Children's Health, and is located at the Sydney Children's Hospital. It aims to improve the health of Australian mothers and babies by monitoring reproductive and perinatal health. It is also involved in perinatal data development activities and epidemiological research. The NPSU maintains national data collections on perinatal health, maternal deaths, congenital anomalies and assisted reproduction technology.

Please note that as with all statistical reports there is the potential for minor revisions of data in this report over its life. Please refer to the online version at <www.npsu.unsw.edu.au>.

BIRTH ANOMALIES SERIES
Number 3

Congenital anomalies in Australia 2002–2003

Samanthi Abeywardana
Elizabeth A Sullivan

2008

AIHW National Perinatal Statistics Unit
Sydney

Cat. no. PER 41

This publication is part of the AIHW National Perinatal Statistics Unit's Congenital Anomalies series. A complete list of the Institute's publications is available from the Institute's website <http://www.aihw.gov.au>. A compete list of the AIHW National Perinatal Statistics Unit's publications is available on the NPSU's website at <http://www.npsu.unsw.edu.au>.

ISSN <1449-8405 >
ISBN <978 1 74024 770 2>

Suggested citation

Abeywardana S & Sullivan EA 2008. Congenital anomalies in Australia 2002–2003. Birth anomalies series no. 3 Cat. no. PER 41. Sydney: AIHW National Perinatal Statistics Unit.

Any enquiries about or comments on this publication should be directed to:
AIHW National Perinatal Statistics Unit
Sydney Children's Hospital
Level 2 McNevin Dickson Building
Randwick Hospitals Campus
Randwick NSW 2031
AUSTRALIA
Phone: (02) 9382 1014
Email: npsu@unsw.edu.au

Published by the AIHW National Perinatal Statistics Unit
Printed by

Contents

Acknowledgments

This report was made possible by the enormous efforts of the data providers and the many experts in the field who provided their valuable cooperation. We wish to thank all of the state and territory data providers who contributed by providing the data, and for answering our queries to ensure accuracy and quality. The AIHW National Perinatal Statistics Unit (NPSU) would like to thank the National Congenital Anomalies Steering Committee, the State and Territory Implementation Committee for Congenital Anomalies and the Australian Institute of Health and Welfare for their guidance in preparing this report.

The NPSU also would like to express its appreciation to National Congenital Anomalies Steering Committee and the State and Territory Implication Committee for peer reviewing this report.

We would like to thank following staff members of the state and territory perinatal data collections and the birth defect registries for their contribution for this report:

New South Wales:
Dr Lee Taylor, Ms Sue Travis, Ms Christine Errat

Victoria:
Associate Professor Jane Halliday, Ms Merilyn Riley

South Australia:
Associate Professor Annabelle Chan, Ms Phillipa van Essan

Western Australia:
Professor Carol Bower, Ms Edwina Rudy, Ms Ann Callaghan, Mr Peter Cosgrove

Queensland:
Ms Sue Cornes, Ms Joanne Bunney, Ms Vesna Dune

Australian Capital Territory:
Ms Maureen Bourne

Tasmania:
Mr Peter Mansfield, Ms Helen Galea

Ms Cecilia Burke from the AIHW coordinated the publication of this report.

Acronyms and abbreviations

ABS	Australian Bureau of Statistics
ACAMS	Australian Congenital Anomalies System
ACT	Australian Capital Territory
AHMAC	Australian Health Ministers' Advisory Council
AIHW	Australian Institute of Health and Welfare
AMC	Arthrogryposis multiplex congenita (congenital arthrogyposis)
APSU	Australian Paediatric Surveillance Unit
ASCCSS	Australian Standard Classification of Countries for Social Statistics
ASGC	Australian Statistical Geographical Classification
BPA	British Paediatric Association
BPA Classification of Diseases	British Paediatric Association Classification of Diseases
CHARGE	Coloboma, heart disease, atresia of choanae, retarded mental development and growth, genital hypoplasia, ear abnormalities-deafness
CI	Confidence Interval
DSS	Data Set Specification
FAS	Fetal alcohol syndrome
FSANZ	Food Standards Australia New Zealand
g	grams
HDSC	Health Data Standards Committee
HGSA	Human Genetics Society of Australasia
ICBDSR	International Clearinghouse for Birth Defects Surveillance and Research
ICD	International Classification of Diseases
ICD-9	International Classification of Diseases, 9th Revision
ICD-9-CM	International Classification of Diseases, 9th Revision, Clinical Modification
ICD-10-AM	International Statistical Classification of Diseases and Related Health Problems, 10th Revision, Australian Modification
METeOR	Metadata online registry
NCASC	National Congenital Anomalies Steering Committee
NCC	National Coding Centre
NCCH	National Centre for Classification in Health
NHDD	National Health Data Dictionary

NHIMPC	National Health Information Management Principal Committee
NHMRC	National Health and Medical Research Council
NMDS	National Minimum Data Set
NPDC	National Perinatal Data Collection
NPDDC	National Perinatal Data Development Committee
NPSU	National Perinatal Statistics Unit
NSW	New South Wales
NT	Northern Territory
NTD	Neural tube defect
PR	Prevalence Ratio
PWS	Prader-Willi syndrome
Qld	Queensland
RACP	Royal Australian College of Physicians
SA	South Australia
SACC	Standard Australian Classification of Countries
SIMC	Statistical Information Management Committee
SLA	Statistical Local Area
STICCA	State and Territory Implementation Committee for Congenital Anomalies
Tas	Tasmania
TOP	Termination of pregnancy
UNSW	University of New South Wales
Vic	Victoria
WA	Western Australia
WHO	World Health Organization

Symbols

n.p.	Not published
. .	Not applicable

Summary

Congenital anomalies are rare conditions which often result in long-term morbidity or death. Most babies who survive with major congenital anomalies need specialist medical care, surgical intervention, intensive care management, long-term hospitalisation and rehabilitation which involve a considerable amount of resources. This second report on congenital anomalies in Australia presents epidemiological data on 33 selected conditions because they are monitored internationally by the International Clearinghouse of Birth Defects Surveillance and Research.

Most common congenital anomalies

Hypospadias is the most commonly reported condition at birth, but severity of the condition is not reported to the national data collection. Trisomy 21 (Down's syndrome) is the next most commonly reported condition at birth (11.1 per 10,000 births), but many affected pregnancies are detected early and managed by early termination. An estimated 63.6% of the fetuses diagnosed with trisomy 21 were managed by terminations of pregnancy or were fetal deaths. When terminations of pregnancy were included, the estimated rate for trisomy 21 was 26.3 per 10,000 pregnancies. Trisomy 21 was more common with advancing maternal age. Other chromosomal abnormalities such as trisomy 13 and trisomy 18 also had a large proportion of fetal deaths or terminations of pregnancy and were more common in women aged 40 years or older.

Neural tube defects

Neural tube defects were diagnosed in about 4.2 per 10,000 births. The estimated rate based on information from the four states collecting the terminations of pregnancy data shows that the prevalence of neural tube defects was 9.8 per 10,000 pregnancies in 2002–2003. However, the 2002–2003 rate was lower than the rate reported for the period 1998–2001. About 76% of the pregnancies affected with neural tube defects were managed by early terminations of pregnancy or were fetal deaths.

Information from the Australian Congenital Anomalies Monitoring System (ACAMS) will be used to provide a baseline prevalence of neural tube defects in Australia prior to the introduction of mandatory fortification of bread flour with folic acid. This public health initiative is aimed at preventing neural tube defects and data from ACAMS will be used in the future evaluation of the initiative.

Indigenous mothers and their babies

A higher rate of congenital anomalies was reported for the births of Indigenous women compared to non-Indigenous women (356 per 10,000 births versus 308 per 10,000 births). Nearly 72% of the Indigenous women whose pregnancies were affected with a congenital anomaly were aged less than 30 years whereas only 43% of the non-Indigenous women with affected pregnancies were less than 30 years of age. It is hoped in future reports that data will be available from the Northern Territory where an approximately three in ten births are to Indigenous women.

More males than females diagnosed with congenital anomalies

The proportion of males diagnosed with a reported congenital anomaly was higher than the proportion of females for many of the reported conditions (e.g. hydrocephalus, most of the reported congenital heart diseases, oesophageal atresia and polycystic kidneys).

The need for more information

A program of national data development is underway to develop a national minimum data set on congenital anomalies. In conjunction with this is the development of a set of clinical definitions by the Australian Paediatric Surveillance Unit. Both these initiatives will improve the quality of national information on congenital anomalies.

Further data development is needed on the jurisdictional coverage and quality of termination of pregnancy data to support national reporting of congenital anomalies. Anomalies causing severe disabilities are more likely to be managed by terminations of pregnancy or end in fetal deaths (e.g. neural tube defects, Down's syndrome) whereas surgically correctable conditions (e.g. many cardio vascular anomalies) and the conditions that do not cause major disability are unlikely to lead to termination of pregnancy. Only four states collect and provide data on terminations of pregnancy at less than 20 weeks with diagnosis of congenital anomalies. Further to this, only South Australia and Western Australia have mandatory notification of termination of pregnancy irrespective of gestational age.

National consistency in the data collection of terminations of pregnancy will more accurately report the burden of congenital anomalies in Australia. This will result in more accurate information for use in policy development and the planning of services for the prevention and management of congenital anomalies in Australia.

1 Introduction

Congenital Anomalies in Australia 2002–2003 is the third report in a new series on congenital anomalies produced by the Australian Institute of Health and Welfare's (AIHW) National Perinatal Statistics Unit (NPSU). The second report, *Congenital Anomalies in Australia 1998–2001* was published in October 2007 as an Internet only publication.

These reports compile the available data from states and territories to update national information on selected congenital anomalies. The reports illustrate characteristics and outcomes of the births and demographic and pregnancy characteristics of the mothers. Information on terminations of pregnancy before 20 weeks of gestation for congenital anomalies is also presented for some jurisdictions. There is variability among the states and territories in the scope of their congenital anomalies data collections, the sources of notification of anomalies, the definitions and classifications used, the method of data collection and the available resources. Therefore the data provided for this report are not comparable among the states and territories. This has been considered in the presentation of the data and information has been provided to assist with interpretation. The Northern Territory data are not included in this report as the Northern Territory does not have resources to provide data to the expected standard. Therefore, the Northern Territory population is not included in the denominator for calculations.

The NPSU has collected data from all states and territories since 1981 and reported it in the Birth Defects Series until 1997. The data have been provided by state and territory health authorities primarily from their birth defects registries and congenital anomalies and perinatal data collections. The NPSU has undertaken a project to develop the existing system with the intention of providing nationally consistent high quality data.

The following work is in progress as part of this project:

- Development of a minimum dataset for congenital anomalies
- Development of clinical definitions for congenital anomalies
- Development of ICD-10-AM classification for congenital anomalies to provide a unique coding system
- Reporting of congenital anomalies up to one year of age from all states and territories
- Reporting of terminations of pregnancy, irrespective of gestational age from all states and territories.

The National Centre for Classification in Health is working in collaboration with the NPSU to develop the ICD-10-AM classification system for congenital anomalies. Mapping of the ICD-9-BPA to Chapter 17 of the ICD-10-AM has been completed and the focus is now on developing a more descriptive classification system.

The Australian Paediatric Surveillance Unit is working on developing definitions for congenital anomalies that are reported annually. Proper definitions and coding will minimise variations in reporting. However the Australian Congenital Anomalies Monitoring System (ACAMS) will only be able to collect data on births with congenital anomalies and terminations of pregnancy due to congenital anomalies. Some fetuses with anomalies are aborted spontaneously, mostly in early pregnancy, and it is unlikely that these data can be collected, making it impossible to find the exact rates of congenital anomalies.

Background

Congenital anomalies are a significant public health concern in Australia, and remain a major reason for hospitalisation in infancy and childhood. Congenital anomalies are also a major cause of neonatal and infant mortality. These conditions cause considerable emotional and economic burden to affected families and to society. The aetiology is unknown for about 60% of cases (Al-Yaman 2002). A small number of anomalies could be due to exposure to environmental pollutants, and most conditions are believed to be multifactorial in origin.

Birth defect registries in other countries have reported major congenital anomalies in 2–4% of all births. Previous national reports between 1981 and 1996 have shown that around 1.6% of the births in Australia had major congenital anomalies. Some conditions have shown a decline over the years mainly due to early detection and management by termination of pregnancy. The ACAMS is attempting to provide this information as accurately as possible.

Availability of good quality data will assist in monitoring the prevalence and trends of congenital anomalies and in planning health services for those conditions. These data will also assist in measuring the impact of preventive measures such as the use of peri-conceptional folic acid to prevent neural tube defects. In June 2007, the Commonwealth Government in partnership with state and territory governments agreed to implement mandatory folic acid fortification of bread flour within a two-year timeframe. This important initiative is aimed at preventing neural tube defects. The congenital anomalies dataset will be able to monitor the impact of mandatory fortification. The existing data will be able to provide baseline prevalence figures over the past two decades. These data will also enable monitoring of other likely outcomes of folic acid fortification such as reduction in other congenital anomalies. Some studies have shown better outcomes on other congenital anomalies such as congenital heart defects after increased maternal intake of folic acid.

Aims of the Australian Congenital Anomalies Monitoring System (ACAMS)

- Improve ascertainment and quality of data by providing a framework and setting standardised definitions, classifications and collection methods in all jurisdictions.
- Provide high quality, nationally consistent data for use in policy development and planning, including identifying areas of need and funding requirements.
- Enable national compilation and reporting of conditions not currently compiled and reported at the national level.
- Enable the evaluation of national health promotion activities aimed at preventing congenital anomalies.
- Enable research at the national level, including assisting with planning and managing collaborative research.
- Facilitate Australia's participation in international reporting and research.
- Provide a context for the evaluation of reported clusters of congenital anomalies.
- Assist in reducing the burden of disease within the Australian population.

2 Data sources and methods

Australian Congenital Anomalies Monitoring System (ACAMS)

The data are based on notifications to birth defects registries in New South Wales, Victoria, Western Australia and South Australia, and on data collected by perinatal data collections in Queensland, Tasmania and the Australian Capital Territory. The Northern Territory was unable to provide unit record data on congenital anomalies. Therefore, no data for the Northern Territory are included in this report.

The state and territory health authorities undertake data processing, analysis and publication of their own reports. Each state and the Australian Capital Territory provided data in an electronic format to NPSU. Because of editing and subsequent updates of state and territory databases, the numbers in this report may differ from those published in reports by the states and territories. See Appendix B for a list of state and territory reports.

Births in 2002–2003 were reported to the National Perinatal Data Collection (NPDC) by the states and territories and many of the data elements requested for inclusion in the ACAMS are included in the NPDC. Therefore the states and territories were asked to provide a key to match the births with congenital anomalies reported to the ACAMS to their birth record in the NPDC. Victoria and South Australia were able to provide this information. The data elements were extracted from the NPDC for the births for these two states. Other states and territories provided all data items requested to the ACAMS from their data collections.

Scope

Criteria for inclusion

Information of births (live births and fetal deaths of at least 20 weeks gestation or at least 400 grams birthweight) with one or more congenital anomaly notified to state or territory birth defect registries or perinatal data collections in 2002–2003 are included in this report. Terminations of pregnancy at 20 weeks gestation or later or at least 400 grams birthweight due to congenital anomalies are recorded as fetal deaths in all states and territories. Some states and territories can distinguish fetal deaths from terminations of pregnancy performed at 20 weeks of gestation or later. Only New South Wales, Victoria, Western Australia and South Australia provided information on terminations of pregnancy due to congenital anomalies, at less than 20 weeks of gestation.

However the period of collection of data is different in each of these jurisdictions.

Periods of notification

Monitoring is affected by the availability and use of prenatal screening programs and diagnostic testing services, and whether the results of prenatal diagnostic tests are notified to congenital anomaly collections. Therefore, the prevalence of some congenital anomalies could be under reported. The period of detection varies considerably among the state and territory collections and ranges from prenatal diagnosis to detection up to 15 years of age. All states and territories except Queensland, Australian Capital Territory and Tasmania have a period of notification up to one year of age or beyond. Queensland, Australian Capital Territory and Tasmania data collections include only anomalies detected during the birth episode prior to discharge from the hospital. Queensland notifies prenatally diagnosed anomalies only if they are apparent at birth.

The prevalence of some congenital anomalies is also affected by whether induced abortions following prenatal diagnosis of a congenital anomaly are undertaken, and whether these congenital anomalies are notified to congenital anomalies data collections. Currently, the extent of the notification is not clear for terminations of pregnancy with congenital anomalies.

For this report, the data for New South Wales include births and termination of pregnancy at less than 20 weeks of gestation (TOP) with congenital anomalies notified up to one year of age. The data for Victoria, Western Australia and South Australia include births and TOP with congenital anomalies notified up to 15 years, 6 years and 5 years of age respectively. Queensland, Tasmania and the Australian Capital Territory include births with congenital anomalies notified in the perinatal period.

Terminations of pregnancy at 20 weeks or more gestation or at least 400 grams birthweight due to congenital anomalies although recorded as births, can be identified separately from births for all jurisdictions except New South Wales and Tasmania.

Northern Territory data are not included in this report.

Table 1.1: Notification of terminations of pregnancy for congenital anomalies, by state and territory, 2002–2003

Notifications		NSW	Vic	Qld	WA	SA	Tas	ACT	NT
Termination of pregnancy at <20 weeks, following prenatal diagnosis of a congenital anomaly	Yes	✓	✓	..	✓	✓	..	..	..
	No	..	..	✓	..	..	✓	✓	✓
Termination of pregnancy ≥20 weeks following prenatal diagnosis of a congenital anomaly	Yes	✓	✓	✓	✓	✓	✓	..	..
	No	..	..	..	..	..	..	✓	✓

Sources of notification

Table 1.2: Notifications of congenital anomalies, by state and territory, 2002–2003

Source of notification	NSW	Vic	Qld	WA	SA	Tas	ACT
Routine data collections							
Hospital morbidity data	✓	✓	..	✓	✓	..	✓
Perinatal/midwives data	✓	✓	✓	✓	✓	✓	✓
Death certificates/mortality data	..	✓	✓	✓	✓	..	..
Primary healthcare staff							
Notification by hospitals/clinicians/lab	✓	..	..	✓	✓	..	..
Referral hospital record reviews	✓	..	..	..	✓	..	..
General practitioners	..	✓	..	✓	..	..	..
Early childhood centre staff	..	✓	..	✓	..	..	..
Rural healthcare workers	..	..	..	✓	..	..	..
Other	..	✓	..	..	✓	..	..
Disability services staff	..	..	..	✓	✓	..	..
Specialist medical officers							
Paediatricians	✓	✓	✓	✓	✓	..	..
Obstetricians		✓		✓	✓		
Other	✓	✓	✓	✓	✓	..	..
Screening and diagnosis services							
Prenatal diagnosis (clinician/lab)	✓	✓	..	✓	..	..	..
Cytogenetic/pathology reports	✓	✓	✓	✓	✓	..	..
Ultrasound reports	..	✓	..	✓	..	..	..
Newborn/genetic screening/diagnosis reports	✓	✓	..	✓	✓	..	..
Other (e.g. parent)	✓	✓	..	✓	..	..	..
Autopsy reports	✓	..	..	✓	✓	..	..
Induced abortion data	..	✓	..	✓	✓	..	..
Unknown	✓	✓	..	..	..	..	..

Note: Northern Territory did not provide data for this report.

Selected conditions included for national reporting

Congenital anomalies

The congenital anomalies presented in this report were agreed by the National Congenital Anomalies Steering Committee (NCASC). The selection is based on the 'sentinel' conditions reported on by the International Clearinghouse for Birth Defects Surveillance and Research (ICBDSR). Some of the conditions reported by the ICBDSR are not included in this report or are presented differently. Undescended testis and prune belly sequence are not included because the NCASC agreed that they are difficult to define. Unspecified abdominal wall defects are not presented.

Descriptions of Congenital anomalies

Currently, there are no internationally agreed definitions for congenital anomalies. Instead, the ICBDSR reports conditions based on the descriptions used in their reports. We used same descriptions for this report. The Australian Paediatric Surveillance Unit in collaboration with the NPSU is currently developing a set of clinical definitions for the conditions presented in this report.

Classification of congenital anomalies

The classification used to code congenital anomalies varied among the states and territories and between years for some jurisdictions. For New South Wales, Victoria, Western Australia and South Australia, congenital anomalies were classified using the Royal College of Paediatrics and Child Health's (formerly the British Paediatric Association [BPA]) Classification of Diseases (BPA 1979) for 2002–2003. For Queensland, ICD-9-BPA was used for the first half of 2002 and the International Statistical Classification of Diseases and Related Health Problems, 10th Revision; Australian Modification (ICD-10-AM) was used for the second half of 2002 and 2003. For Tasmania and the Australian Capital Territory ICD-10-AM was used for all cases.

The International Classification of Diseases (ICD) was developed by the World Health Organization (WHO) to enable international comparability for mortality statistics. The clinical modification of the 9th Revision of ICD was developed in the United States and provided a better classification for morbidity statistics. The National Coding Centre developed the Australian version of ICD-9-CM in 1995.

The ICD is hierarchical, with a small number of disease chapters, including one on congenital malformations that are divided into a large number of more specific disease groupings (represented by three-character codes). These disease groupings can mostly be divided into an even larger number of more specific disease categories, represented by four and five-character codes.

The ICD-9-BPA is an expansion of ICD-9 where more detail is required for the classification to be useful for paediatrics. A fifth character has been added to the fourth character level of ICD-9 to provide greater precision and specificity where necessary. It is also a contraction of ICD-9 in that it omits codes for conditions not commonly encountered in paediatrics.

New South Wales, Victoria, Western Australia and South Australia have extended ICD-9-BPA to specify other congenital anomalies.

Measures reported

In Chapter 3, information is presented on babies with selected congenital anomalies and on women who gave birth to babies with the selected congenital anomalies. The number of babies is marginally higher than the number of women who gave birth because of multiple births.

Reported rate

Information on live births and fetal deaths of at least 20 weeks gestation or at least 400 grams birthweight is available for all states and territories. Terminations of pregnancy at least at 20 weeks gestation or at least 400 grams birthweight are included as births. The measure based on live births provides information about the burden of disease and disability associated with the selected congenital anomaly. The measure based on live births and fetal deaths provides information about the rate of the selected congenital anomaly among all births. Information on termination of pregnancy at less than 20 weeks gestation is available for four states: New South Wales, Victoria, Western Australia and South Australia. The rates for termination of pregnancy at less than 20 weeks are provided as estimated rates because the denominator includes only the births and reported fetal deaths.

The definitions of the numerators and denominators used to derive the rates for each congenital anomaly are described in Tables 1.3 and 1.4.

Table 1.3: Numerators and denominators used for calculating birth rates from all states and territories

Numerator[(a)]	Denominator[(b)]
All births	
Number of live births and fetal deaths with the selected congenital anomaly	Number of live births and fetal deaths
Live births	
Number of live births with the selected congenital anomaly	Number of live births
Fetal deaths	
Number of fetal deaths with the selected congenital anomaly	Number of fetal deaths
Women who gave birth	
Number of women who gave birth to babies with the selected congenital anomaly	Number of women who gave birth to a liveborn or stillborn baby

(a) Reported to the Australian Congenital Anomalies Monitoring System.

(b) Reported to the National Perinatal Data Collection (see Appendix A).

Table 1.4: Numerators and denominators used for calculating birth and termination of pregnancy rates from states providing data on TOP at less than 20 weeks

Numerator[(a)]	Denominator[(b)]
Births and termination of pregnancies	
Number of live births, fetal deaths and termination of pregnancies[(c)] with the selected congenital anomaly	Number of live births and fetal deaths
Women who gave birth or who had a termination of pregnancy	
Number of women who gave birth to a baby with the selected congenital anomaly or who had a termination of pregnancy[(c)] for the selected congenital anomaly	Number of women who gave birth to a liveborn or stillborn baby

(a) Reported to the Australian Congenital Anomalies Monitoring System.

(b) Reported to the National Perinatal Data Collection (see Appendix A).

(c) Terminations of pregnancy at less than 20 weeks gestation.

Denominator data

The denominator data used in the calculation of rates are presented in Appendix A. There are twelve different denominators used throughout the report including: number of live births, number of fetal deaths in Australia and in four states, sex, birthweight and gestational age of the baby, age group, Indigenous status, parity, and plurality and remoteness area of usual residence of the mother.

Data elements included for national reporting

Characteristics of babies and of their mothers are presented for each congenital anomaly in Chapter 3. For babies, information on sex, gestational age and birthweight are presented under baby characteristics. For women who gave birth, information on age group, Indigenous status, Remoteness Area of usual residence, country of birth, parity and plurality are presented under maternal characteristics.

The data elements are based on data elements defined in the *National Health Data Dictionary* (NHDD).

Notes on data elements — baby characteristics

Sex

Data on the sex of each baby were reported as male, female, indeterminate or not stated.

Gestational age

The estimated gestational age of the baby is given in completed weeks. This may be calculated from the first day of the last menstrual period, ultrasound findings and/or be determined by clinical assessment. WHO identifies preterm as less than 37 completed weeks of gestation, term as 37 completed weeks to less than 42 completed weeks of gestation and post-term as 42 or more completed weeks of gestation. Preterm birth is associated with morbidity and mortality in newborn babies. For this report, the duration of the mother's pregnancy rather than the gestational age of the baby was requested from the states and territories.

Birthweight

Birthweight is the first weight of the liveborn or stillborn baby obtained after birth, or the weight of the neonate or infant on the date admitted if this is different from the date of birth. The weight of infants is only recorded if they are admitted to hospital and if they weigh at least 9,000 grams and are aged less than 365 days. Birthweight is an indicator of a baby's health status. Babies are defined as being of low birthweight if their weight at birth is less than 2,500 grams.

Notes on data elements — Maternal characteristics

Age

The AIHW NPSU calculated the age of mothers at the birth by subtracting their date of birth from the date of birth of their baby. Maternal age is presented by five-year age groups.

Indigenous status

The Indigenous status of the mother was provided by all states and territories except Tasmania.

In this report, the Indigenous women include mothers who were in the categories of Aboriginal but not Torres Strait Islander origin, Torres Strait Islander but not Aboriginal origin, or of Aboriginal and Torres Strait Islander origin. The category reported as non-Indigenous was of neither Aboriginal nor Torres Strait Islander origin.

Remoteness of area of usual residence

The NHDD specifies that data on usual residence should be provided as the state or territory and the Statistical Local Area (SLA) of usual residence. For this report, data on the area of usual residence of mothers were provided as state/territory and SLA for Victoria, South Australia and the Australian Capital Territory. For Victoria and South Australia, state/territory and SLA was only provided if the woman's usual residence was in Victoria or South Australia respectively. The postcode was provided for all states and territories. For this report, postcodes have been assigned to Remoteness Areas to enable reporting of women who gave birth by remoteness of area of usual residence. This is based on the Australian Standard Geographical Classification (ASGC) remoteness structure (ABS 2001).

Because of the small numbers in the data presented, the Remoteness Areas of usual residence categories in this report are presented under three headings: major cities, regional and remote. (Inner regional and Outer regional are reported as Regional; Remote and Very remote are reported as Remote.)

Country of birth

Country of birth details were requested to be provided using the Australian Bureau of Statistic's (ABS) Australian Standard Classification of Countries for Social Statistics (ASCCSS) (ABS 1990). Victoria, Queensland and Tasmania provided country of birth details using the ASCCSS. The data from New South Wales, Western Australia, South Australia and Australian Capital Territory were provided using the Standard Australian Classification of Countries (ABS 1998), and were mapped by the NPSU to the ASCCSS. The ASCCSS categories include Australia, New Zealand, United Kingdom, Europe, Middle East and North Africa, Asia, North America, South Central America/ Caribbean, Africa, Other countries and unknown.

However, if any condition had less than three affected women, they were reported under the 'other countries' category.

Parity

Parity is defined as the number of previous pregnancies that resulted in live births or fetal deaths. In this report, the parity category is 'primiparous' for the first pregnancy, or 'multiparous', which was coded as one to eight or more. For 2002–2003, New South Wales and Tasmania did not provide data on parity.

Plurality

Plurality refers to the number of babies resulting from a single pregnancy. In this report, the plurality category is 'singleton' for single births, and multiple for twins, triplets, quadruplets, quintuplets, sextuplets and other.

Statistical significance

The significance for maternal characteristics was calculated using prevalence ratios and confidence intervals around those ratios.

Prevalence ratio (PR) = prevalence in exposed/prevalence in unexposed confidence intervals around prevalence ratios were calculated using method described by Armittage & Berry, 1994.

Confidence intervals given for each category in maternal characteristics tables were calculated using an exact method (Armitage & Berry, 1994). Data were not available for some jurisdictions to distinguish fetal deaths from terminations of pregnancy at 20 weeks or more gestation. Therefore confidence intervals were not computed for selected baby characteristics such as birthweight and gestational age specific rates because of this lack of comparability of data.

State and territory comparisons

There are differences among the states and territories in the scope of their data collections. In particular, terminations of pregnancy at less than 20 weeks gestation are not included for Queensland, Tasmania and the Australian Capital Territory. The prevalence of conditions for which termination of pregnancy following prenatal diagnosis is a treatment option may be underestimated in these jurisdictions. Therefore, data have not been presented by state and territory for separate conditions.

Conventions

Throughout the report, for totals, percentages may not add up to 100.0, and subtotals may not add up to the sum of the percentages for the categories. This is due to rounding of figures in calculations.

Minor changes to data presentation, including where a jurisdiction has not provided a data item or data have not been published for other reasons, are detailed in the footnotes to the tables.

3 Selected congenital anomalies

Introduction

This chapter presents data on 33 selected congenital anomalies. As noted in Chapter 2, the selection of the congenital anomalies was based on those reported to the International Clearinghouse for Birth Defects Surveillance and Research (ICBDSR) and was agreed by the National Congenital Anomalies Steering Committee (NCASC). Clinical descriptions used for each condition in this report are the definitions used by ICBDSR with minor changes to adjust for available data. These descriptions have not been modified, as a separate project is underway developing a set of clinical definitions for the Australian context.

The total number of anomalies reported does not represent the total number of the babies who had congenital anomalies because some babies had more than one anomaly. Therefore, the total number of conditions will exceed the total number of babies who had congenital anomalies.

There were 15,251 women who had given birth to babies with one or more congenital anomaly representing 3.1% of the total number of women who had given birth in the period 2002–2003. Of those women 21.3% were aged 35 years or older. About 4% of the women who had affected pregnancies had multiple births.

Of the births with congenital anomalies 95% babies were born alive. More male babies were reported to have anomalies than female babies (59% versus 41%). About 20% of the babies affected were born before 36 weeks of gestation.

Babies born to Indigenous women represented 3.5% of the affected births. Of those Indigenous babies, 55.7% were males. About 32% of affected Indigenous babies were born preterm and 3.6% were multiple births. Among those births, 94.9% were live births.

The rate of Indigenous women who had a pregnancy affected with congenital anomalies is higher than the rate seen in non-Indigenous women (356 per 10,000 births versus 308 per 10,000 births). Nearly 72% of the Indigenous women whose pregnancies were affected with a congenital anomaly were less than 30 years of age and 11.1% were 35 years or older. The proportion of non-Indigenous women less than 30 years of age who had a pregnancy affected with a congenital anomaly was 43%. About 21% non-Indigenous affected women were 35 years or older. The rates of many major congenital anomalies were higher among Indigenous women than among non-Indigenous women. The rate of central nervous system defects reported among Indigenous women was 21.5 per 10,000 births whereas non-Indigenous women had a rate of 11.1 per 10,000 births. However, the rate of renal agenesis and cystic kidneys was lower among Indigenous women compared with non-Indigenous women (5.5 per 10,000 births in Indigenous versus 9.6 per 10,000 births in non-Indigenous).

Some anomalies had much higher estimated rates (that include data on terminations at less than 20 weeks gestation) than the birth rates indicating high termination rates. However, only South Australia and Western Australia have legislations for mandatory collection of termination of pregnancy data leading to possible under reporting of these conditions in other states. Because of this reason comparison between states are not appropriate. The availability of complete and accurate data on terminations of pregnancies due to congenital anomalies would assist in estimating exact prevalence of those anomalies which would support in policy making, funding and planning for management of these conditions.

1 Anencephaly

Description: A congenital anomaly characterised by the total or partial absence of the cranial vault, the covering skin, and the brain missing or reduced to a small mass. Includes infants with craniorachischisis, iniencephaly and other neural tube defects such as encephalocele or open spina bifida, when associated with anencephaly. Excludes acephaly, that is, absence of head observed in amorphous acardiac twins.

ICD-9-BPA codes: 740.00–740.29 ICD-10-AM codes: Q00.0–Q00.2

Anencephaly is not compatible with life. The anomaly is usually managed by termination of pregnancy. Many cases are terminated in early pregnancy. There was a slight decline in reported cases at birth between 2002 and 2003 for all births (Table 2.1.1). The data provided by the four states that include TOP before 20 weeks show that 4.1 per 10,000 pregnancies were affected by this anomaly (Table2.1.2), which is a lower rate than in previous years (Figure 1). Two-thirds of the affected pregnancies were terminated before 20 weeks of pregnancy and more than 80% of births were preterm deliveries. The rate of babies born with anencephaly was almost same for both sexes. More than 67% of births had a birthweight of less than 1500 grams (Table 2.1.3).

Compared with older women, younger women had a higher rate of births with anencephaly. Most of the women who gave birth to a baby with anencephaly (77.2%) were in the 20–34 years age group (Table 2.1.6) and 85% of women who had early termination (less than 20 weeks) were also in this age group. The rate of births with this anomaly was two fold higher among Indigenous women than among non-Indigenous women, but the difference was not statistically significant. Multiple births had a 13-fold higher rate of births with anencephaly than singletons and the difference was statistically significant (prevalence ratio (PR) =14.6, CI 7.5-28.1).

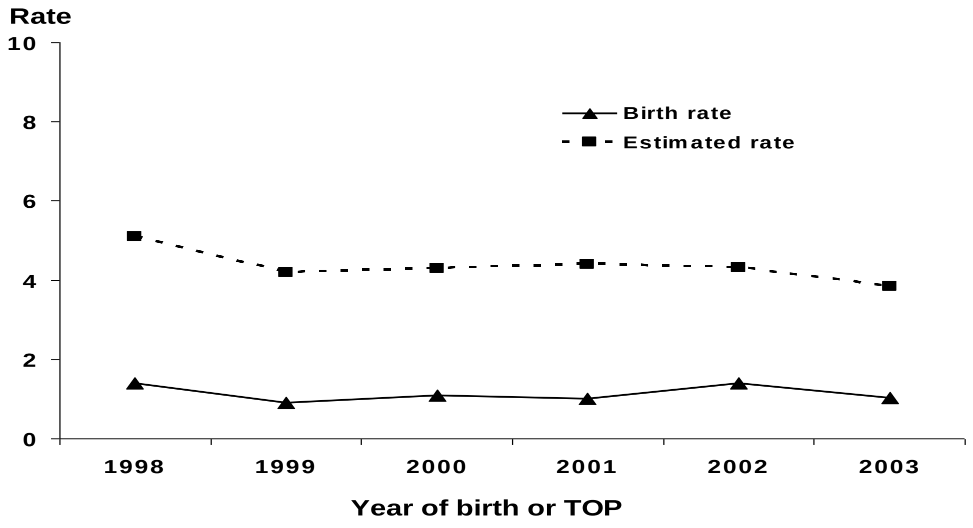

Figure 1: Rate of anencephaly among all births[(a)] and estimated rate[(b)] 1998–2003

(a) Birth rate includes anencephaly among live births and fetal deaths in Australia per 10,000 live births and fetal deaths.

(b) Estimated rate includes anencephaly among fetal deaths, live births and TOP before 20 weeks reported by New South Wales, Victoria, Western Australia and South Australia per 10,000 live births and fetal deaths.

Reported rates of anencephaly

Table 2.1.1: Number and rate of anencephaly by outcome[a], Australia, 2002–2003

	2002		2003		2002–2003	
Outcome	**Number**	**Rate**	**Number**	**Rate**	**Number**	**Rate**
Live births[b]	12	0.5	10	0.4	22	0.4
Fetal deaths[c]	23	137.1	16	89.6	39	112.7
All births[d]	35	1.4	26	1.0	61	1.2

(a) Includes all births with at least 20 weeks of gestation or at least 400 grams birthweight.

(b) For live births, the rate is per 10,000 live births.

(c) For fetal deaths, the rate is per 10,000 fetal deaths.

(d) For all births, the rate is per 10,000 live births and fetal deaths.

Table 2.1.2: Number and estimated rate of anencephaly by outcome, four Australian states[a], 2002–2003

	2002		2003		2002–2003	
Outcome	**Number**	**Rate**	**Number**	**Rate**	**Number**	**Rate**
Live births[b]	10	0.5	8	0.4	18	0.5
Fetal deaths[c]	19	150.3	13	94.5	32	121.3
All births[d]	29	1.5	21	1.1	50	1.3
Births and TOP[e]	83	4.3	74	3.8	157	4.1

(a) Includes data for New South Wales, Victoria, Western Australia and South Australia.

(b) For live births, the rate is per 10,000 live births.

(c) For fetal deaths, the rate is per 10,000 fetal deaths.

(d) For all births, the rate is per 10,000 live births and fetal deaths.

(e) Includes TOP at less than 20 weeks gestation and all births with at least 20 weeks of gestation or at least 400 grams birthweight.

Baby characteristics

Table 2.1.3: Births[(a)] with anencephaly by baby characteristics, Australia, 2002–2003

Characteristic	Number	Per cent	Rate per 10,000 births
Sex			
Male	29	47.5	1.1
Female	30	49.2	1.2
Indeterminate/ Not stated	2	3.3	..
Gestational age[(a)] (weeks)			
Less than 25	27	44.3	109.4
25–36	22	36.1	5.9
37+	11	18.0	0.2
Unknown	1	1.6	..
Birthweight (grams)			
Less than 1500	41	67.2	54.7
1500 –2499	11	18.0	4.1
2,500+	7	11.5	0.2
Unknown	2	3.3	..

(a) Includes all births with at least 20 weeks of gestation or at least 400 grams birthweight.

Maternal characteristics

Table 2.1.4: Number of women who gave birth to babies with anencephaly, Australia, 2002–2003

	2002		2003		2002–2003	
	Number	Rate[(a)]	Number	Rate[(a)]	Number	Rate[(a)]
Women who gave birth	33	1.3	24	1.0	57	1.2

(a) The rate is per 10,000 women who gave birth.

Table 2.1.5: Reported number of pregnancies affected with anencephaly and the estimated rate, four Australian states[(a)], 2002–2003

	2002		2003		2002–2003	
	Number	Rate[(b)]	Number	Rate[(b)]	Number	Rate[(b)]
Women who gave birth[(c)]	28	1.5	19	1.0	47	1.2
Women who gave birth or had a TOP[(d)]	82	4.4	72	3.8	154	4.1

(a) Includes data for New South Wales, Victoria, Western Australia and South Australia.

(b) The rate is per 10,000 women who gave birth.

(c) Includes women who gave birth to a baby with at least 20 weeks of gestation or at least 400 grams birthweight.

(d) Includes TOP at less than 20 weeks gestation and all births with at least 20 weeks of gestation or at least 400 grams birthweight.

Table 2.1.6: Maternal characteristics of births[a] with anencephaly, Australia, 2002–2003

Characteristic	Number	Per cent	Rate[e]	Confidence intervals
Maternal age group				
Less than 20	4	7.0	1.8	0.5–4.5
20–24	9	15.8	1.2	0.6–2.3
25–29	20	35.1	1.4	0.9–2.2
30–34	15	26.3	0.9	0.5–1.5
35–39	8	14.0	1.0	0.4–2.1
40 and over	1	1.8	0.6	0.0–3.6
Indigenous status [b]				
Indigenous	4	7.0	2.7	0.7–6.9
Non-Indigenous	52	91.2	1.1	0.8–1.5
Not stated	1	1.8	..	..
Remoteness Area				
Major cities	41	73.2	1.2	0.9–1.7
Regional	15	26.8	1.0	0.6–1.7
Remote	0	0.0	..	..
Country of birth[c]				
Australia	39	68.4	1.0	0.7–1.4
Asia	8	14.0	2.0	0.9–3.9
Other countries	6	10.5	..	..
Not stated	4	7.02	..	..
Parity [d]				
Primiparous	12	35.3	0.9	0.5–1.6
Multiparous	22	64.7	1.2	0.7–1.8
Plurality				
Singleton	45	80.4	0.9	0.7–1.2
Multiple	11	19.6	13.1	6.5–23.4

(a) Includes all births with at least 20 weeks of gestation or at least 400 grams birthweight.

(b) Excludes data from Tasmania.

(c) Mother's country of birth was classified using ASCCSS system. If the number of women affected was less than three in any country, those women were included under 'Other countries' category.

(d) Excludes data from New South Wales and Tasmania.

(e) The rate is per 10,000 women who gave birth.

2 Spina bifida

Description: A family of congenital anomaly in the closure of the spinal column characterised by herniation or exposure of the spinal cord and/or meninges through an incompletely closed spine. Includes meningocele, meningomyelocele, myelocele, myelomeningocele and rachischisis. Spina bifida is not counted when present with anencephaly. Excludes spina bifida occulta and sacrococcygeal teratoma without dysraphism.

ICD-9-BPA codes: 741.00–741.99 ICD-10-AM codes: Q05.0–Q 05.9

The rate of spina bifida at birth remains constant, with an overall rate of 2.7 per 10,000 births in 2002–2003 (Table 2.2.1). The data provided by the four states that include TOP before 20 weeks show that 4.7 per 10,000 pregnancies were affected by this anomaly (Table 2.2.2). This is a lower rate than the rate in 1998–2001 (Figure 2). Among births and early terminations, there were more females than males affected with spina bifida (Table 2.2.3). Many affected pregnancies were terminated early in pregnancy. About 85% of the early terminations were performed between 17 and 19 weeks of gestational age. Data from the four states providing information on TOP show that 30.2% of babies with spina bifida were born alive.

Among women who gave birth, 79% were in the 20–34 years age group and 78% of the women who had early terminations were also in this age group. Indigenous women had a higher rate of affected pregnancies than non-Indigenous women but the difference was not significant. The rate of multiple births was nearly threefold higher than the singleton births and the difference was statistically significant (PR=2.7, CI 1.2–6.2). All early terminations were singleton pregnancies. Women born in North America had the highest rate of affected births. There was no difference in the rates of affected births in women living in remote areas and women living in cities.

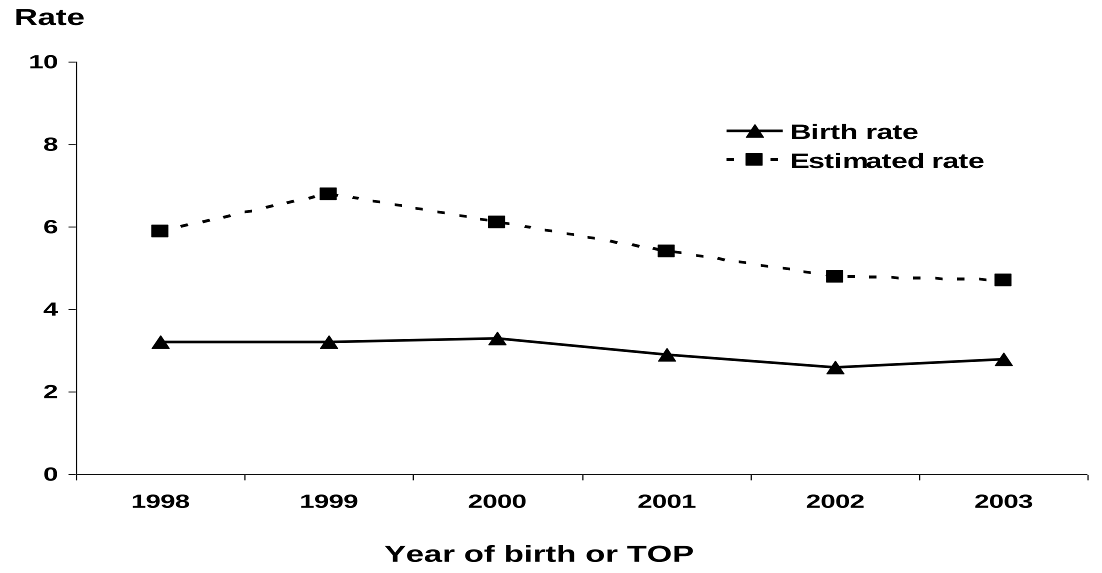

Figure 2: Rate of spina bifida among all births[(a)] and estimated rate[(b)], 1998–2003

(a) Birth rate includes spina bifida among live births and fetal deaths in Australia per 10,000 live births and fetal deaths.

(b) Estimated rate includes spina bifida among fetal deaths, live births and TOP before 20 weeks reported by New South Wales, Victoria, Western Australia and South Australia per 10,000 live births and fetal deaths.

Reported rates of spina bifida

Table 2.2.1: Number and rate of spina bifida by outcome[(a)], Australia, 2002–2003

	2002		2003		2002–2003	
Outcome	**Number**	**Rate(a)**	**Number**	**Rate(a)**	**Number**	**Rate(a)**
Live births(b)	39	1.6	34	1.4	73	1.5
Fetal deaths(c)	26	155.0	36	201.7	62	179.1
All births(d)	65	2.6	70	2.8	135	2.7

(a) Includes all births with at least 20 weeks of gestational age or at least 400 grams birthweight.

(b) For live births, the rate is per 10,000 live births.

(c) For fetal deaths, the rate is per 10,000 fetal deaths.

(d) For all births, the rate is per 10,000 live births and fetal deaths.

Table 2.2.2: Number and the estimated rate of spina bifida by outcome, four Australian states[(a)], 2002–2003

	2002		2003		2002–2003	
Outcome	**Number**	**Rate**	**Number**	**Rate**	**Number**	**Rate**
Live births(b)	30	1.6	25	1.3	55	1.4
Fetal deaths(c)	23	182.0	30	218.2	53	200.8
All births(d)	53	2.8	55	2.9	108	2.8
Births and TOP(e)	91	4.8	91	4.7	182	4.7

(a) Includes data for New South Wales, Victoria, Western Australia and South Australia.

(b) For live births, the rate is per 10,000 live births.

(c) For fetal deaths, the rate is per 10,000 fetal deaths.

(d) For all births, the rate is per 10,000 live births and fetal deaths.

(e) Includes TOP at less than 20 weeks gestation and all births with at least 20 weeks of gestation or at least 400 grams birthweight.

Baby characteristics

Table 2.2.3: Births[(a)] with spina bifida by baby characteristics, Australia, 2002–2003

Characteristic	Number	Per cent	Rate per 10,000 births
Sex			
Male	60	44.4	2.3
Female	72	53.3	2.9
Indeterminate/not stated	3	2.2	..
Gestational age (weeks)			
Less than 25	60	44.4	243.1
25–36	16	11.9	4.3
37+	59	43.7	1.3
Birthweight (grams)			
Less than 1500	69	51.1	92.0
1500–2499	11	8.2	4.1
2,500+	53	39.3	1.1
Unknown	2	1.5	..

(a) Includes all births with at least 20 weeks of gestation or at least 400 grams birthweight.

Maternal characteristics

Table 2.2.4: Number of women who gave birth to babies with spina bifida, Australia, 2002–2003

	2002		2003		2002–2003	
	Number	Rate[(a)]	Number	Rate[(a)]	Number	Rate[(a)]
Women who gave birth	65	2.6	69	2.8	134	2.7

(a) The rate is per 10,000 women who gave birth.

Table 2.2.5: Reported number of pregnancies affected with spina bifida and the estimated rate, four Australian states[(a)], 2002–2003

	2002		2003		2002–2003	
	Number	Rate[(b)]	Number	Rate[(b)]	Number	Rate[(b)]
Women who gave birth[(c)]	53	2.8	54	2.9	107	2.8
Women who gave birth or had a TOP[(d)]	91	4.8	100	5.3	191	5.1

(a) Includes data for New South Wales, Victoria, Western Australia and South Australia.

(b) The rate is per 10,000 women who gave birth.

(c) Includes women who gave birth to a baby with at least 20 weeks of gestation or at least 400 grams birthweight.

(d) Includes TOP at less than 20 weeks gestation and all births with at least 20 weeks of gestation or at least 400 grams birthweight.

Table 2.2.6: Maternal characteristics of births[(a)] with spina bifida, Australia, 2002–2003

Characteristic	Number	Per cent	Rate[(e)]	Confidence intervals
Maternal age group				
Less than 20	5	3.7	2.2	0.7–5.2
20–24	22	16.4	3.0	1.9–4.5
25–29	35	26.1	2.5	1.7–3.5
30–34	49	36.6	2.9	2.2–3.9
35–39	18	13.4	2.3	1.4–3.7
40 and over	5	3.7	3.2	1.0–7.5
Indigenous status [(b)]				
Indigenous	7	5.3	4.7	1.9–9.7
Non-Indigenous	123	93. 9	2.6	2.2–3.1
Not stated	1	0.8	..	..
Remoteness Area				
Major cities	84	64.1	2.5	2.0–3.1
Regional	42	32.1	2.9	2.1–3.9
Remote	5	3.8	3.9	1.3–9.1
Country of birth [(c)]				
Australia	103	76.9	2.7	2.2–3.3
United Kingdom	4	3.0	2.5	0.7–6.3
Middle East and North Africa	5	3.7	4.4	1.4–10.3
Asia	3	2.2	0.8	0.2–2.2
North America	4	3.0	13.7	3.7–35.1
Other countries	4	3.0	..	..
Not stated	11	8.2	..	..
Parity [(d)]				
Primiparous	34	39.1	2.6	1.8–3.6
Multiparous	53	60.9	2.9	2.1–3.8
Plurality				
Singleton	128	95.5	2.6	2.2–3.1
Multiple	6	4.5	7.1	2.6–15.5

(a) Includes all births with at least 20 weeks of gestation or at least 400 grams birthweight.

(b) Excludes data from Tasmania.

(c) Mother's country of birth was classified using ASCCSS system. If the number of women affected was less than three in any country, those women were included under 'Other countries' category.

(d) Excludes data from New South Wales and Tasmania.

(e) The rate is per 10,000 women who gave birth.

3 Encephalocele

Description: A congenital anomaly characterised by herniation of the brain and/or meninges through a defect in the skull. Encephalocele is not counted when present with spina bifida or anencephaly.

ICD-9-BPA codes: 742.00–742.09 ICD-10-AM codes: Q01.0- Q01.2, Q01.8, Q01.9

The rate of encephalocele in births was 0.5 per 10,000 births from 2002–2003 (Table 2.3.1). The data from the four states providing information on TOP show an estimated rate that is twice the rate at birth (Table 2.3.2).

Of the reported births, the rate of female births was twofold higher than the males. About half of the babies were born at term (Table 2.3.3). For 44% of the births, the birthweight was 2,500 grams or more (Table 2.3.3).

Twenty-four women gave birth to a baby with encephalocele during the two-year period (Table 2.3.4), and 75% of them were aged 20–34 years. The rates of encephalocele births did not differ markedly between Indigenous and non-Indigenous women or between primiparous and multiparous women. There was no difference between women living in regional areas and women living in cities. Encephalocele affected births were not reported from remote areas (Table 2.3.6).

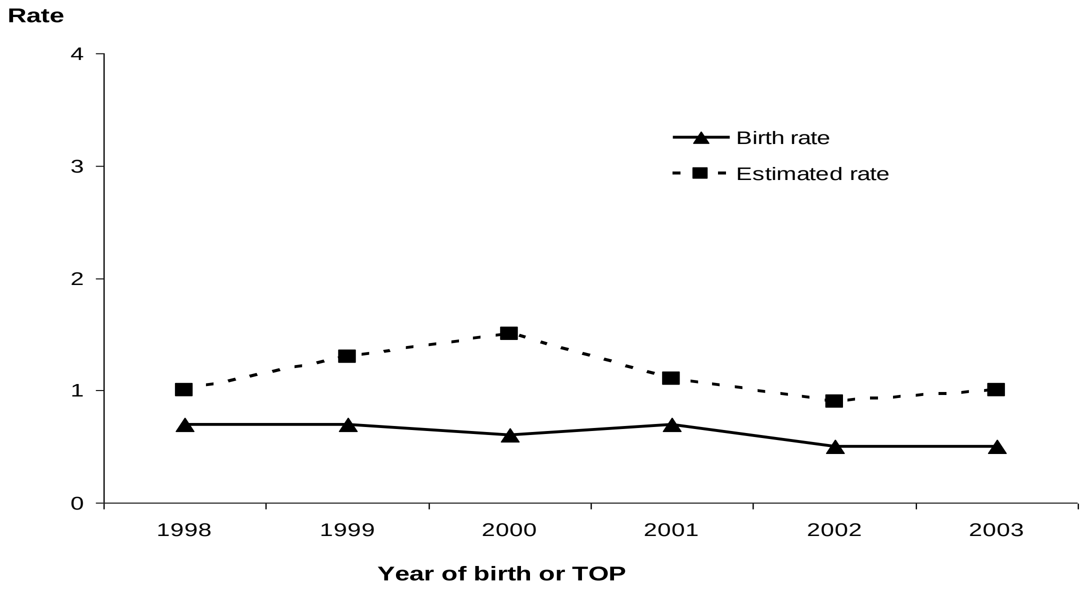

Figure 3: Rate of encephalocele among all births[a] and estimated rate[b], 1998–2003

(a) Birth rate includes encephalocele among live births and fetal deaths in Australia per 10,000 live births and fetal deaths.

(b) Estimated rate includes encephalocele among fetal deaths, live births and TOP before 20 weeks reported by New South Wales, Victoria, Western Australia and South Australia per 10,000 live births and fetal deaths.

Reported rates of encephalocele

Table 2.3.1: Number and rate of encephalocele by outcome[(a)], Australia, 2002–2003

	2002		2003		2002–2003	
Outcome	**Number**	**Rate**	**Number**	**Rate**	**Number**	**Rate**
Live births(b)	7	0.3	7	0.3	14	0.3
Fetal deaths(c)	5	29.8	6	33.6	11	31.8
All births(d)	12	0.5	13	0.5	25	0.5

(a) Includes all births with at least 20 weeks of gestational age or at least 400 grams birthweight.

(b) For live births, the rate is per 10,000 live births.

(c) For fetal deaths, the rate is per 10,000 fetal deaths.

(d) For all births, the rate is per 10,000 live births and fetal deaths.

Table 2.3.2: Number and the estimated rate of encephalocele by outcome, four Australian states (a), 2002–2003

	2002		2003		2002–2003	
Outcome	**Number**	**Rate**	**Number**	**Rate**	**Number**	**Rate**
Live births(b)	4	0.2	7	0.4	11	0.2
Fetal deaths(c)	5	39.6	6	43.6	11	49.3
All births(d)	9	0.5	13	0.7	22	0.6
Births and TOP(e)	18	0.9	20	1.0	38	1.0

(a) Includes data for New South Wales, Victoria, Western Australia and South Australia.

(b) For live births, the rate is per 10,000 live births.

(c) For fetal deaths, the rate is per 10,000 fetal deaths.

(d) For all births, the rate is per 10,000 live births and fetal deaths.

(e) Includes TOP at less than 20 weeks gestation and all births with at least 20 weeks of gestation or at least 400 grams birthweight.

Baby characteristics

Table 2.3.3: Births[(a)] with encephalocele by baby characteristics, Australia, 2002–2003

Characteristic	Number	Per cent	Rate per 10,000 births
Sex			
Male	7	28.0	0.3
Female	17	68.0	0.7
Not stated	1	4.0	..
Gestational age (weeks)			
Less than 25	10	40.0	40.5
25–36	2	8.0	0.5
37+	13	52.0	0.3
Birthweight (grams)			
Less than 1500	9	36.0	12.0
1500 –2499	4	16.0	1.5
2,500+	11	44.0	0.2
Unknown	1	4.0	..

(a) Includes all births with at least 20 weeks of gestation or at least 400 grams birthweight.

Maternal characteristics

Table 2.3.4: Number of women who gave birth to babies with encephalocele, Australia, 2002–2003

	2002		2003		2002–2003	
	Number	Rate[(a)]	Number	Rate[(a)]	Number	Rate[(a)]
Women who gave birth	11	0.5	13	0.5	24	0.5

(a) The rate is per 10,000 women who gave birth.

Table 2.3.5: Reported number of pregnancies affected with encephalocele and the estimated rate, four Australian states[(a)], 2002–2003

	2002		2003		2002–2003	
	Number	Rate[(b)]	Number	Rate[(b)]	Number	Rate[(b)]
Women who gave birth[(c)]	8	0.4	13	0.7	21	0.6
Women who gave birth or had a TOP[(d)]	17	0.9	20	1.1	37	1.0

(a) Includes data for New South Wales, Victoria, Western Australia and South Australia.

(b) The rate is per 10,000 women who gave birth.

(c) Includes women who gave birth to a baby with at least 20 weeks of gestation or at least 400 grams birthweight.

(d) Includes TOP at less than 20 weeks gestation and all births with at least 20 weeks of gestation or at least 400 grams birthweight.

Table 2.3.6: Maternal characteristics of births[(a)] with encephalocele, Australia, 2002–2003

Characteristic	Number	Per cent	Rate[(e)]	Confidence intervals
Maternal age group				
Less than 20	0	0.0	..	..
20–24	3	12.5	0.4	0.1–1.2
25–29	4	16.7	0.3	0.1–0.7
30–34	11	45.8	0.7	0.3–1.2
35–39	5	20.8	0.7	0.2–1.5
40 and over	1	4.2	0.6	0.0–3.6
Indigenous status [(b)]				
Indigenous	1	4.2	0.7	0.0–3.7
Non-Indigenous	23	95.8	0.5	0.3–0.7
Remoteness Area				
Major cities	17	70.8	0.5	0.3–0.8
Regional	7	29.2	0.5	0.2–1.0
Remote	0	0.0	..	..
Country of birth [(c)]				
Australia	17	70.8	0.4	0.3–0.7
Asia	3	12.5	0.8	0.2–2.2
Other countries	4	16.7	..	..
Parity [(d)]				
Primiparous	6	40.0	0.5	0.2–1.0
Multiparous	9	60.0	0.5	0.2–0.9
Plurality				
Singleton	23	95.8	0.5	0.3–0.7
Multiple	1	4.2	1.2	0.0–6.6

(a) Includes all births with at least 20 weeks of gestation or at least 400 grams birthweight.

(b) Excludes data from Tasmania.

(c) Mother's country of birth was classified using ASCCSS system. If the number of women affected was less than three in any country, those women were included under 'Other countries' category.

(d) Excludes data from New South Wales and Tasmania.

(e) The rate is per 10,000 women who gave birth.

4 Neural tube defects

This section includes all babies with anencephaly, spina bifida and encephalocele.

ICD-9-BPA codes: 740.00–742.09

ICD-10-AM codes: Q00.0–Q00.2, Q05.0–Q05.9, Q01.0–Q01.2, Q01.8, Q01.9

The rate of neural tube defects in all births was 4.2 per 10,000 births in 2002–2003 (Table 2.4.1). About 51% of births resulted in fetal deaths. The estimated rate observed in four states providing TOP data was 9.8 per 10,000 pregnancies, a rate twofold higher than the rate at birth, indicating a high rate of early terminations of pregnancies (Table 2.4.2). However, this rate is lower than the rate in the period 1998–2001 (Figure 4). These data from four states show that 76.3% of pregnancies were managed by early terminations or resulted in fetal deaths.

More females than males had neural tube defects during the period 2002–2003. Nearly half of the affected babies were born before 25 weeks of gestational age. Among the births at 20–24 weeks gestation, the rate of births with neural tube defects was 389 per 10,000 births (Table 2.4.3).

Of the women who had given birth to a baby with anencephaly, 79.0% were in the 20–34 years age group. Almost 80% of the women who had terminations of pregnancy because of a neural tube defect were in the 20–34 years age group. Indigenous women had a twofold higher rate of neural tube affected births than non-Indigenous women and the difference was statistically significant (PR=2.0, CI 1.1–3.6). There was no difference among affected births between women living in remote areas and cities. The rate of affected births was four times as high for women who had multiple births than for women who had singleton births (PR=4.6, CI 2.7-7.7). The highest rate of affected births was seen among women born in North America (Table 2.4.6).

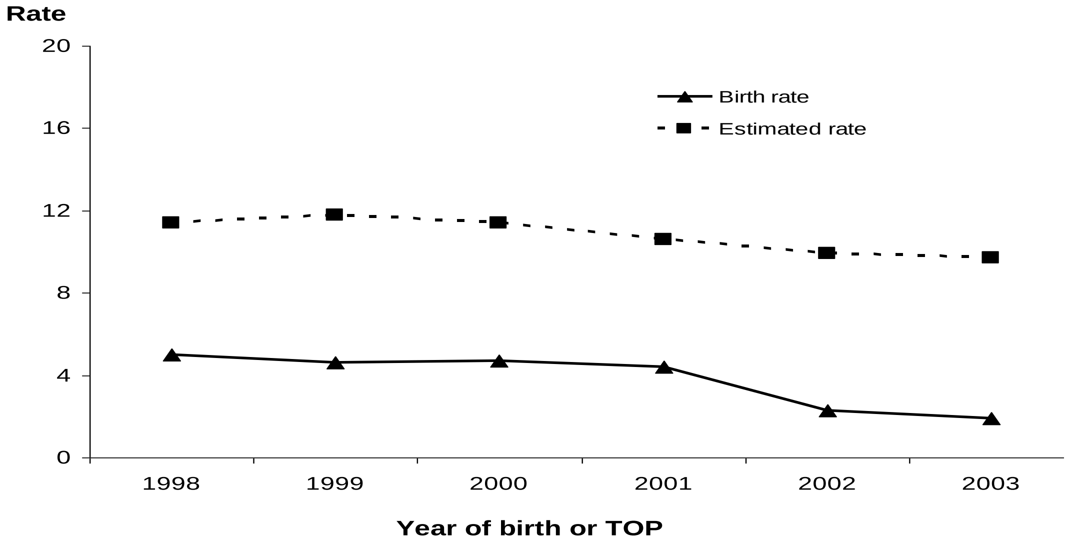

Figure 4: Rate of all neural tube defects among all births[(a)] and estimated rate[(b)], 1998–2003

(a) Birth rate includes neural tube defects among live births and fetal deaths in Australia per 10,000 live births and fetal deaths.

(b) Estimated rate includes neural tube defects among fetal deaths, live births and TOP before 20 weeks reported by New South Wales, Victoria, Western Australia and South Australia per 10,000 live births and fetal deaths.

Reported rates of neural tube defects

Table 2.4.1: Number and rate of neural tube defects by outcome[(a)], Australia, 2002–2003

	2002		2003		2002–2003	
Outcome	**Number**	**Rate**	**Number**	**Rate**	**Number**	**Rate**
Live births[(b)]	57	2.3	48	1.9	105	2.1
Fetal deaths[(c)]	53	316.0	55	308.1	108	312.0
All births[(d)]	110	4.4	103	4.1	213	4.2

(a) Includes all births with at least 20 weeks of gestational age or at least 400 grams birthweight.

(b) For live births, the rate is per 10,000 live births.

(c) For fetal deaths, the rate is per 10,000 fetal deaths.

(d) For all births, the rate is per 10,000 live births and fetal deaths.

Table 2.4.2: Number and the estimated rate of neural tube defects by outcome, four Australian states[(a)], 2002–2003

	2002		2003		2002–2003	
Outcome	**Number**	**Rate**	**Number**	**Rate**	**Number**	**Rate**
Live births[(b)]	43	2.3	37	1.9	89	2.3
Fetal deaths[(c)]	46	363.9	47	341.8	84	318.3
All births[(d)]	89	4.6	84	4.4	173	4.5
Births and TOP[(e)]	190	9.9	186	9.7	376	9.8

(a) Includes data for New South Wales, Victoria, Western Australia and South Australia.

(b) For live births, the rate is per 10,000 live births.

(c) For fetal deaths, the rate is per 10,000 fetal deaths.

(d) For all births, the rate is per 10,000 live births and fetal deaths.

(e) Includes TOP at less than 20 weeks gestation and all births with at least 20 weeks of gestation or at least 400 grams birthweight.

Baby characteristics

Table 2.4.3: Births[a] with neural tube defects by baby characteristics, Australia, 2002–2003

Characteristic	Number	Per cent	Rate per 10,000 births
Sex			
Male	94	44.1	3.6
Female	113	53.1	4.6
Indeterminate/ Not stated	6	2.8	..
Gestational age (weeks)			
Less than 25	96	45.1	389.0
25–36	35	16.4	9.5
37+	81	38.0	1.7
Unknown	1	0.5	..
Birthweight (grams)			
Less than 1500	114	53.5	152.0
1500–2499	24	11.3	9.0
2,500+	71	33.3	1.5
Unknown	4	1.9	..

(a) Includes women who gave birth to a baby with at least 20 weeks of gestation or at least 400 grams birthweight.

Maternal characteristics

Table 2.4.4: Number of women who gave birth to babies with neural tube defects, Australia, 2002–2003

	2002		2003		2002–2003	
	Number	Rate[a]	Number	Rate[a]	Number	Rate[a]
Women who gave birth	107	4.3	100	4.0	207	4.2

(a) The rate is per 10,000 women who gave birth.

Table 2.4.5: Reported number of pregnancies affected with neural tube defects and the estimated rate, four Australian states[a], 2002–2003

	2002		2003		2002–2003	
	Number	Rate[b]	Number	Rate[b]	Number	Rate[b]
Women who gave birth[c]	87	4.6	81	4.3	168	4.5
Women who gave birth or had a TOP[d]	188	10.0	183	9.7	371	9.8

(a) Includes data for New South Wales, Victoria, Western Australia and South Australia.

(b) The rate is per 10,000 women who gave birth.

(c) Includes women who gave birth to a baby with at least 20 weeks of gestation or at least 400 grams birthweight.

(d) Includes TOP at less than 20 weeks gestation and all births with at least 20 weeks of gestational age or at least 400 grams birthweight.

Table 2.4.6: Maternal characteristics of births[a] with neural tube defects, Australia, 2002–2003

Characteristic	Number	Per cent	Rate[e]	Confidence intervals
Maternal age group				
Less than 20	8	3.9	3.5	1.5–7.0
20–24	33	15.9	4.5	3.1–6.3
25–29	58	28.0	4.1	3.1–5.4
30–34	73	35.3	4.4	3.4–5.5
35–39	29	14.0	3.8	2.5–5.4
40 and over	6	2.9	3.8	1.4–8.3
Indigenous status [b]				
Indigenous	12	5.9	8.1	4.2–14.1
Non-Indigenous	190	93.1	4.0	3.5–4.7
Not stated	2	1.0	..	..
Remoteness Area				
Major cities	136	67.0	4.0	3.4–4.8
Regional	62	30.5	4.2	3.2–5.4
Remote	5	2.5	3.9	1.3–9.1
Country of birth [c]				
Australia	154	74.4	4.0	3.4–4.7
United Kingdom	5	2.4	3.1	1.0–7.1
Europe	3	1.5	2.3	0.5–6.7
Middle East and North Africa	6	2.9	5.3	2.0–11.6
Asia	14	6.8	3.5	1.9–5.9
North America	4	1.9	13.7	3.7–35.1
South Central America/Caribbean	3	1.5	10.3	2.1–30.2
Other countries	2	1.0	..	..
Not stated	16	7.7	..	..
Parity [d]				
Primiparous	50	37.9	3.8	2.8–5.0
Multiparous	82	62.1	4.4	3.5–5.5
Plurality				
Singleton	191	92.7	3.9	3.4–4.5
Multiple	15	7.3	17.8	10.0–29.4

(a) Includes all births with at least 20 weeks of gestation or at least 400 grams birthweight.

(b) Excludes data from Tasmania.

(c) Mother’s country of birth was classified using ASCCSS system. If the number of women affected was less than three in any country, those women were included under ‘Other countries’ category.

(d) Excludes data from New South Wales and Tasmania.

(e) The rate is per 10,000 women who gave birth.

5 Microcephaly

Description: A congenital anomaly with a small cranium, defined by an occipito-frontal circumference (OFC) three standard deviations below the age- and sex-appropriate distribution curves. Excludes microcephaly associated with anencephaly or encephalocele.

ICD-9-BPA codes: 742.1 ICD-10-AM codes: Q02

Microcephaly can be present at birth or it may develop in the first few years of life. Babies born with microcephaly have a smaller than normal head that may fail to grow as they progress through infancy. About 1.9 per 10,000 births had microcephaly diagnosed during 2002–2003 (Table 2.5.1) and the number of early terminations was very small. The rate in 2003 was lower than the rate in previous years (Figure 5).

The rate of babies born with microcephaly was almost equal for both sexes. The rate of affected births was 28.4 per 10,000 births at gestational age 20–24 weeks. Two-thirds of the babies were born at term and half of the babies had birthweights of 2,500 grams or more (Table 2.5.3).

Teenage mothers and mothers over 40 years of age had a higher rate of births with this anomaly, but the difference was not significant. The rate of affected pregnancies was significantly higher among Indigenous women compared with non-Indigenous women (PR=4.1, CI 2.2–7.7). The rates of affected pregnancies did not differ between women living in cities and women living in remote areas or between primiparous and multiparous women. Almost all (99%) babies born with microcephaly were singletons (Table 2.5.6).

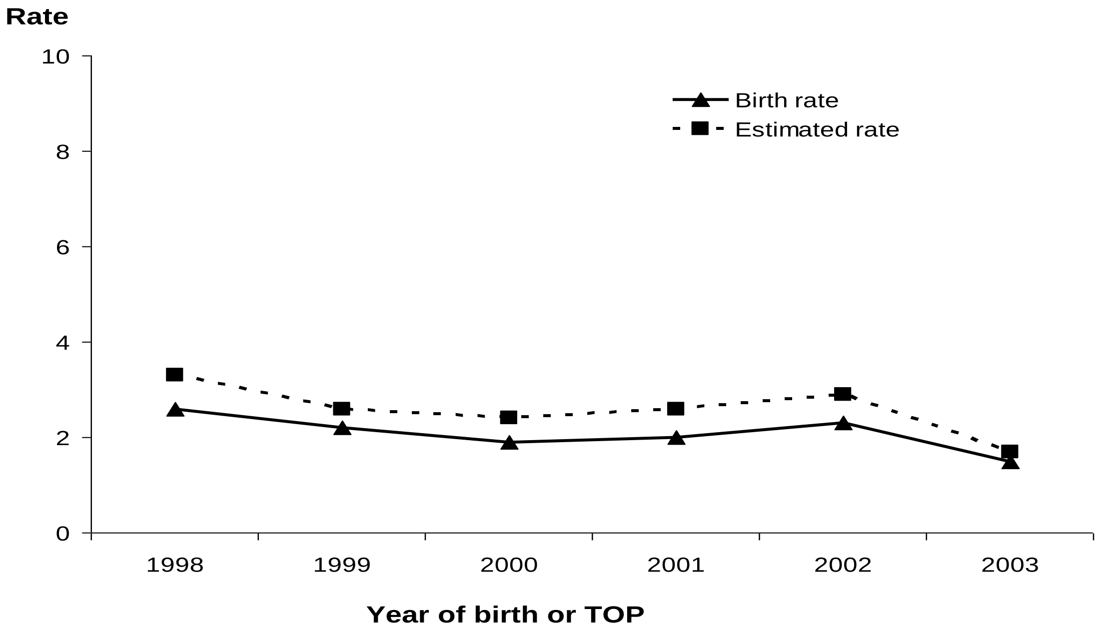

Figure 5: Rate of microcephaly among all births[(a)] and estimated rate[(b)],1998–2003

(a) Birth rate includes microcephaly among live births and fetal deaths in Australia per 10,000 live births and fetal deaths.

(b) Estimated rate includes microcephaly among fetal deaths, live births and TOP before 20 weeks reported by New South Wales, Victoria, Western Australia and South Australia per 10,000 live births and fetal deaths.

Reported rates of microcephaly

Table 2.5.1: Number and rate of microcephaly by outcome[(a)], Australia, 2002–2003

	2002		2003		2002–2003	
Outcome	**Number**	**Rate**	**Number**	**Rate**	**Number**	**Rate**
Live births(b)	55	2.2	32	1.3	87	1.7
Fetal deaths(c)	3	17.9	5	28.0	8	23.1
All births(d)	58	2.3	37	1.5	95	1.9

(a) Includes all births with at least 20 weeks of gestational age or at least 400 grams birthweight.

(b) For live births, the rate is per 10,000 live births.

(c) For fetal deaths, the rate is per 10,000 fetal deaths.

(d) For all births, the rate is per 10,000 live births and fetal deaths.

Table 2.5.2: Number and the estimated rate of microcephaly by outcome, four Australian states (a), 2002–2003

	2002		2003		2002–2003	
Outcome	**Number**	**Rate**	**Number**	**Rate**	**Number**	**Rate**
Live births(b)	52	2.7	28	1.5	80	2.1
Fetal deaths(c)	3	23.7	4	29.1	7	26.5
All births(d)	55	2.9	32	1.7	87	2.3
Births and TOP(e)	56	2.9	33	1.7	89	2.6

(a) Includes data for New South Wales, Victoria, Western Australia and South Australia.

(b) For live births, the rate is per 10,000 live births.

(c) For fetal deaths, the rate is per 10,000 fetal deaths.

(d) For all births, the rate is per 10,000 live births and fetal deaths.

(e) Includes TOP at less than 20 weeks gestation and all births with at least 20 weeks of gestation or at least 400 grams birthweight.

Baby characteristics

Table 2.5.3: Births[(a)] with microcephaly by baby characteristics, Australia, 2002–2003

Characteristic	Number	Per cent	Rate per 10,000 births
Sex			
Male	49	51.6	1.9
Female	45	47.4	1.8
Not stated	1	1.1	..
Gestational age (weeks)			
Less than 25	7	7.4	28.4
25–36	25	26.3	6.8
37+	62	65.3	1.3
Unknown	1	1.1	..
Birthweight (grams)			
Less than 1500	17	17. 9	22.7
1500 –2499	28	29.5	10.5
2,500+	50	52.6	1.1

(a) Includes all births with at least 20 weeks of gestation or at least 400 grams birthweight.

Maternal characteristics

Table 2.5.4: Number of women who gave birth to babies with microcephaly, Australia, 2002–2003

	2002		2003		2002–2003	
	Number	Rate[(a)]	Number	Rate[(a)]	Number	Rate[(a)]
Women who gave birth	207	4.2	37	1.5	95	1.9

(a) The rate is per 10,000 women who gave birth.

Table 2.5.5: Reported number of pregnancies affected with microcephaly and the estimated rate, four Australian states[(a)], 2002–2003

	2002		2003		2002–2003	
	Number	Rate[(b)]	Number	Rate[(b)]	Number	Rate[(b)]
Women who gave birth[(c)]	55	2.9	32	1.7	87	2.3
Women who gave birth or had a TOP[(d)]	56	3.0	33	1.7	89	2.4

(a) Includes data for New South Wales, Victoria, Western Australia and South Australia.

(b) The rate is per 10,000 women who gave birth.

(c) Includes women who gave birth to a baby with at least 20 weeks of gestation or at least 400 grams birthweight.

(d) Includes TOP at less than 20 weeks gestation and all births with at least 20 weeks of gestation or at least 400 grams birthweight.

Table 2.5.6: Maternal characteristics of births[(a)] affected with microcephaly, Australia, 2002–2003

Characteristic	Number	Per cent	Rate[(e)]	Confidence intervals
Maternal age group				
Less than 20	8	8.4	3.5	1.5–7.0
20–24	16	16.8	2.2	1.2–3.5
25–29	22	23.2	1.6	1.0–2.4
30–34	24	25.3	1.4	0.9–2.1
35–39	19	20.0	2.5	1.5–3.9
40 and over	6	6.3	3.8	1.4–8.3
Indigenous status [(b)]				
Indigenous	11	11.6	7.4	3.7–13.2
Non-Indigenous	83	87.4	1.8	1.4–2.2
Not stated	1	1.1	..	..
Remoteness Area				
Major cities	67	70.5	2.0	1.5–2.5
Regional	24	25.3	1.6	1.0–2.4
Remote	4	4.2	3.1	0.8–8.0
Country of birth [(c)]				
Australia	63	66.3	1.7	1.3–2.1
United Kingdom	4	4.2	2.5	0.7–6.3
Asia	9	9.5	2.3	1.0–4.3
Other	4	4.2	..	..
Not stated	15	15.8	..	..
Parity [(d)]				
Primiparous	31	41.3	2.4	1.6–3.4
Multiparous	44	58.7	2.4	1.7–3.2
Plurality				
Singleton	94	99.0	1.9	1.6–2.4
Multiple	1	1.0	1.2	0.0–6.6

(a) Includes all births with at least 20 weeks of gestation or at least 400 grams birthweight.

(b) Excludes data from Tasmania.

(c) Mother's country of birth was classified using ASCCSS system. If the number of women affected was less than three in any country, those women were included under 'Other countries' category.

(d) Excludes data from New South Wales and Tasmania.

(e) The rate is per 10,000 women who gave birth.

6 Arhinencephaly/Holoprosencephaly

Description: A congenital anomaly of the brain, characterised by various degrees of incomplete lobation of the brain hemispheres. The olfactory nerve tract may be absent. Holoprosencephaly includes cyclopia, ethmocephaly, cebocephaly and premaxillary agenesis.

ICD-9-BPA codes: 742.2 ICD-10-AM codes: Q04.1, Q04.2

The overall rate of arhinencephaly/holoprosencephaly at birth was about 0.7 per 10,000 births in 2002–2003 (Table 2.6.1). The rate of births and TOP from four states was 1.6 per 10,000 pregnancies (Table 2.6.2) indicating many affected pregnancies were managed by TOP (55.6%). The overall rate has not changed since 1998 (Figure 6).

There were more females than males among affected births, but the proportion was similar among early terminations. Only 22% of the affected babies were born at term and 58% were born before 25 weeks of gestation (Table 2.6.3).

The rate of affected births was nearly fourfold higher for Indigenous women than for non-Indigenous women and the difference was statistically significant (PR=3.9, CI 1.4–10.9). There was no difference by maternal age group or the mother's areas of residence. All babies born with this anomaly were singletons (Table 2.6.6).

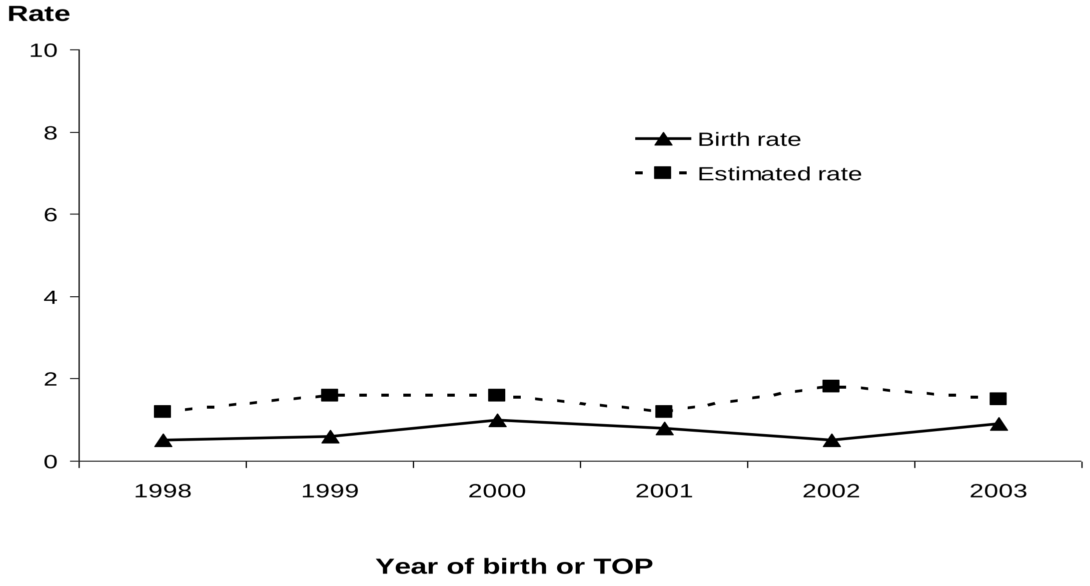

Figure 6: Rate of arhinencephaly/holoprosencephaly among all births[(a)] and estimated rate[(b)], 1998–2003

(a) Birth rate includes arhinencephaly/holoprosencephaly among live births and fetal deaths in Australia per 10,000 live births and fetal deaths.

(b) Estimated rate includes arhinencephaly/holoprosencephaly among fetal deaths, live births and TOP before 20 weeks reported by New South Wales, Victoria, Western Australia and South Australia per 10,000 live births and fetal deaths.

Reported rates of arhinencephaly/holoprosencephaly

Table 2.6.1: Number and rate of arhinencephaly/holoprosencephaly by outcome[(a)], Australia, 2002–2003

	2002		2003		2002–2003	
Outcome	**Number**	**Rate**	**Number**	**Rate**	**Number**	**Rate**
Live births(b)	6	0.2	14	0.6	20	0.4
Fetal deaths(c)	7	41.7	9	50.2	16	46.2
All births(d)	13	0.5	23	0.9	36	0.7

(a) Includes all births with at least 20 weeks of gestational age or at least 400 grams birthweight.

(b) For live births, the rate is per 10,000 live births.

(c) For fetal deaths, the rate is per 10,000 fetal deaths.

(d) For all births, the rate is per 10,000 live births and fetal deaths.

Table 2.6.2: Number and the estimated rate of arhinencephaly/holoprosencephaly by outcome, four Australian states[(a)], 2002–2003

	2002		2003		2002–2003	
Outcome	**Number**	**Rate**	**Number**	**Rate**	**Number**	**Rate**
Live births(b)	4	0.2	8	0.4	12	0.3
Fetal deaths(c)	7	55.4	9	65.6	16	60.6
All births(d)	11	0.6	17	0.9	28	0.7
Births and TOP(e)	35	1.8	28	1.5	63	1.6

(a) Includes data for New South Wales, Victoria, Western Australia and South Australia.

(b) For live births, the rate is per 10,000 live births.

(c) For fetal deaths, the rate is per 10,000 fetal deaths.

(d) For all births, the rate is per 10,000 live births and fetal deaths.

(e) Includes TOP at less than 20 weeks gestation and all births with at least 20 weeks of gestation or at least 400 grams birthweight.

Baby characteristics

Table 2.6.3: Births[(a)] with arhinencephaly/holoprosencephaly by baby characteristics, Australia, 2002–2003

Characteristic	Number	Per cent	Rate per 10,000 births
Sex			
Male	16	44.4	0.6
Female	20	55.6	0.8
Gestational age (weeks)			
Less than 25	21	58.3	85.1
25–36	7	19.4	1.9
37+	8	22.2	0.2
Birthweight (grams)			
Less than 1500	22	61.11	29.3
1500 –2499	5	13.9	1.9
2,500 +	8	22.2	0.2
Unknown	1	2.8	..

(a) Includes all births with at least 20 weeks of gestation or at least 400 grams birthweight.

Maternal characteristics

Table 2.6.4: Number of women who gave birth to babies with arhinencephaly/holoprosencephaly, Australia, 2002–2003

	2002		2003		2002–2003	
	Number	Rate[(a)]	Number	Rate[(a)]	Number	Rate[(a)]
Women who gave birth	13	0.5	23	0.9	36	0.7

(a) The rate is per 10,000 women who gave birth.

Table 2.6.5: Reported number of pregnancies affected with arhinencephaly/holoprosencephaly and the estimated rate, four Australian states[(a)], 2002–2003

	2002		2003		2002–2003	
	Number	Rate[(b)]	Number	Rate[(b)]	Number	Rate[(b)]
Women who gave birth[(c)]	11	0.6	17	0.9	28	0.7
Women who gave birth or had a TOP[(d)]	35	1.9	28	1.5	63	1.7

(a) Includes data for New South Wales, Victoria, Western Australia and South Australia.

(b) The rate is per 10,000 women who gave birth.

(c) Includes women who gave birth to a baby with at least 20 weeks of gestation or at least 400 grams birthweight.

(d) Includes TOP at less than 20 weeks gestation and all births with at least 20 weeks of gestation or at least 400 grams birthweight.

Table 2.6.6: Maternal characteristics of births[(a)] affected with arhinencephaly/ holoprosencephaly, Australia, 2002–2003

Characteristic	Number	Per cent	Rate[(e)]	Confidence intervals
Maternal age group				
Less than 20	3	8.3	1.3	0.3–3.9
20–24	11	30.6	1.5	0.7–2.7
25–29	8	22.2	0.6	0.2–1.1
30–34	9	25.0	0.5	0.2–1.0
35–39	5	13.9	0.7	0.2–1.5
40 and over	3	8.3	1.3	0.3–3.9
Indigenous status (b)				
Indigenous	4	11.1	2.7	0.7–6.9
Non-Indigenous	31	86.1	0.7	0.4–0.9
Not stated	1	2.8	..	..
Remoteness Area				
Major cities	26	72.2	0.8	0.5–1.1
Regional	10	27.8	0.7	0.3–1.3
Remote	0	0.0	..	..
Country of birth (c)				
Australia	29	80.6	0.8	0.5–1.1
Other countries	7	19.4	..	..
Parity (d)				
Primiparous	12	46.2	0.9	0.5–1.6
Multiparous	14	53.8	0.8	0.4–1.3
Plurality				
Singleton	36	100.0	0.7	0.5–1.0
Multiple	0	0.0	..	..

(a) Includes all births with at least 20 weeks of gestation or at least 400 grams birthweight.

(b) Excludes data from Tasmania.

(c) Mother's country of birth was classified using ASCCSS system. If the number of women affected was less than three in any country, those women were included under 'Other countries' category.

(d) Excludes data from New South Wales and Tasmania.

(e) The rate is per 10,000 women who gave birth.

7 Hydrocephaly

Description: A congenital anomaly characterised by dilatation of the cerebral ventricles, not associated with primary brain atrophy, with or without enlargement of the head, and diagnosed at birth. The anomaly is not counted when present with encephalocele or spina bifida.

This excludes, macrocephaly without dilatation of ventricular system, skull of macerated fetus, hydranencephaly, holoprosencephaly and postnatally acquired hydrocephalus.

ICD-9-BPA codes: 742.30–742.39 ICD-10-AM codes: Q03.0, Q03.1, Q03.8, Q03.9

Hydrocephaly occurred in 4.8 per 10,000 births during the period 2002–2003 (Table 2.7.1). The data from the states providing information on TOP show that 6.8 per 10,000 pregnancies were affected by hydrocephaly (Table 2.7.2). About 22% of the affected pregnancies were terminated before 20 weeks. Of those early terminations, 81% were performed between 17 and 19 weeks. Fetal deaths accounted for 31.5% of the births.

There were more male babies (55.6%) born with hydrocephaly than females, and more males were seen among early terminations. Among the births before 25 weeks gestation, the hydrocephaly birth rate was 284 per 10,000 births. Only about one-third of the births occurred at term (Table 2.7.3).

Women aged 40 years or older had the highest rate of affected pregnancies. The rate of this anomaly for women having multiple births was five times the rate for women having singleton births and this difference was statistically significant (PR=5.0, CI 3.1–8.0). The rates did not differ by Indigenous status, areas of residence or parity of the women (Table 2.7.6).

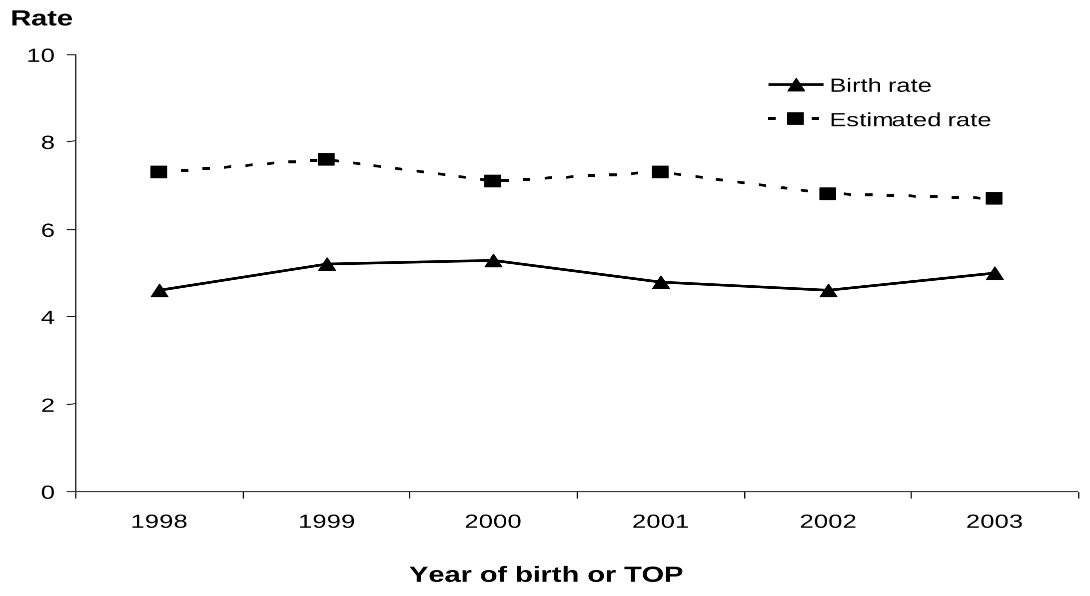

Figure 7: Rate of hydrocephaly among all births[(a)] and estimated rate[(b)], 1998–2003

(a) Birth rate includes hydrocephaly among live births and fetal deaths in Australia per 10,000 live births and fetal deaths.

(b) Estimated rate includes hydrocephaly among fetal deaths, live births and TOP before 20 weeks reported by New South Wales, Victoria, Western Australia and South Australia per 10,000 live births and fetal deaths.

Reported rates of hydrocephaly

Table 2.7.1: Number and rate of hydrocephaly by outcome[a], Australia, 2002–2003

	2002		2003		2002–2003	
Outcome	**Number**	**Rate**	**Number**	**Rate**	**Number**	**Rate**
Live births(b)	79	3.2	86	3.4	165	3.3
Fetal deaths(c)	36	214.7	40	224.1	76	219.5
All births(d)	115	4.6	126	5.0	241	4. 8

(a) Includes all births with at least 20 weeks of gestational age or at least 400 grams birthweight.

(b) For live births, the rate is per 10,000 live births.

(c) For fetal deaths, the rate is per 10,000 fetal deaths.

(d) For all births, the rate is per 10,000 live births and fetal deaths.

Table 2.7.2: Number and the estimated rate of hydrocephaly by outcome, four Australian states[a], 2002–2003

	2002		2003		2002–2003	
Outcome	**Number**	**Rate**	**Number**	**Rate**	**Number**	**Rate**
Live births(b)	69	3.6	69	3.6	138	3.6
Fetal deaths(c)	33	261.1	37	269.1	70	265.3
All births(d)	102	5.3	106	5.5	208	5.4
Births and TOP(e)	131	6.8	129	6.7	260	6.8

(a) Includes data for New South Wales, Victoria, Western Australia and South Australia.

(b) For live births, the rate is per 10,000 live births.

(c) For fetal deaths, the rate is per 10,000 fetal deaths.

(d) For all births, the rate is per 10,000 live births and fetal deaths.

(e) Includes TOP at less than 20 weeks gestation and all births with at least 20 weeks of gestation or at least 400 grams birthweight.

Baby characteristics

Table 2.7.3: Births[(a)] with hydrocephaly by baby characteristics, Australia, 2002–2003

Characteristic	Number	Per cent	Rate per 10,000 births
Sex			
Male	134	55.6	5.2
Female	106	44.0	4.3
Indeterminate/ Not stated	1	0.4	..
Gestational age (weeks)			
Less than 25	70	29.1	283.6
25–36	74	30.7	20.
37+	95	39.4	2.0
Unknown	2	0.8	..
Birthweight (grams)			
Less than 1500	112	46.5	149.4
1500 –2499	33	13.7	12.3
2,500+	96	39.8	2.0

(a) Includes all births with at least 20 weeks of gestation or at least 400 grams birthweight.

Maternal characteristics

Table 2.7.4: Number of women who gave birth to babies with hydrocephaly, Australia, 2002–2003

	2002		2003		2002–2003	
	Number	Rate[(a)]	Number	Rate[(a)]	Number	Rate[(a)]
Women who gave birth	114	4.6	124	5.0	238	4.8

(a) The rate is per 10,000 women who gave birth.

Table 2.7.5: Reported number of pregnancies affected with hydrocephaly and the estimated rate, four Australian states[(a)], 2002–2003

	2002		2003		2002–2003	
	Number	Rate[(b)]	Number	Rate[(b)]	Number	Rate[(b)]
Women who gave birth[(c)]	101	5.4	105	5.6	206	5.5
Women who gave birth or had a TOP[(d)]	130	6.9	128	6.8	258	6.8

(a) Includes data for New South Wales, Victoria, Western Australia and South Australia.

(b) The rate is per 10,000 women who gave birth.

(c) Includes women who gave birth to a baby with at least 20 weeks of gestation or at least 400 grams birthweight.

(d) Includes TOP at less than 20 weeks gestation and all births with at least 20 weeks of gestation or at least 400 grams birthweight.

Table 2.7.6: Maternal characteristics of births[(a)] affected with hydrocephaly, Australia, 2002–2003

Characteristic	Number	Per cent	Rate[(e)]	Confidence intervals
Maternal age group				
Less than 20	9	3.8	4.1	1.8–7.6
20–24	30	12.6	4.1	2.7–5.8
25–29	71	29.8	5.1	4.0–6.4
30–34	68	28.6	4.1	3.2–5.2
35–39	43	18.1	5.6	4.1–7.5
40 and over	16	6.7	10.2	5.8–16.6
Indigenous status [(b)]				
Indigenous	10	4.2	6.7	3.2–12.4
Non-Indigenous	225	95.3	4.8	4.2–5.5
Not stated	1	0.4	..	..
Remoteness Area				
Major cities	160	68.1	4.8	4.0–5.6
Regional	67	28.5	4.6	3.5–5.8
Remote	7	3.0	5.5	2.2–11.2
Not stated	1	0.4	..	..
Country of birth [(c)]				
Australia	167	70.2	4.4	3.7–5.1
United Kingdom	6	2.5	3.7	1.4–8.0
Europe	7	2.9	5.3	2.2–11.0
Middle East and North Africa	8	3.4	7.1	3.1–13.9
Asia	21	8.8	5.3	3.2–8.1
North America	3	1.3	10.3	2.1–30.1
Other countries	8	3.4	..	..
Not stated	18	7. 6	..	..
Parity [(d)]				
Primiparous	80	44.2	6.1	4.9–7.6
Multiparous	98	54.1	5.3	4.3–6.5
Not stated	3	1.7	..	..
Plurality				
Singleton	219	92.0	4.5	3.9–5.1
Multiple	19	8.1	22.6	13.6–35.2

(a) Includes all births with at least 20 weeks of gestation or at least 400 grams birthweight.

(b) Excludes data from Tasmania.

(c) Mother's country of birth was classified using ASCCSS system. If the number of women affected was less than three in any country, those women were included under 'Other countries' category.

(d) Excludes data from New South Wales and Tasmania.

(e) The rate is per 10,000 women who gave birth.

8 Anophthalmos/Microphthalmos

Description: Apparently absent or small eyes. Some normal adnexal elements and eyelids are usually present. In microphthalmos, the corneal diameter is usually less than 10 mm and the antero-posterior diameter of the globe is less than 20 mm.

ICD-9-BPA codes: 743.0–743.1 **ICD-10-AM codes: Q11.0–Q11.2**

Anophthalmos/microphthalmos was reported in 0.6 per 10,000 pregnancies in 2002–2003 (Table 2.8.1). Fetal deaths or terminations of pregnancies are not common for this anomaly. During the period 2002–2003, only four terminations of pregnancy before 20 weeks were reported for this condition. The rate of affected pregnancies has not changed since 1998 (Figure 8).

More males than females were born with this anomaly (58.1%). More than half were born at term (54.8%) with two-thirds of the births having a birthweight of 2,500 grams or more (Table 2.8.3).

Women aged 40 years or older had the highest rate of anophthalmos/microphthalmos births. Almost all women who gave birth with this anomaly were non-Indigenous. The rates did not differ significantly by areas of residence, parity or plurality (Table 2.8.6).

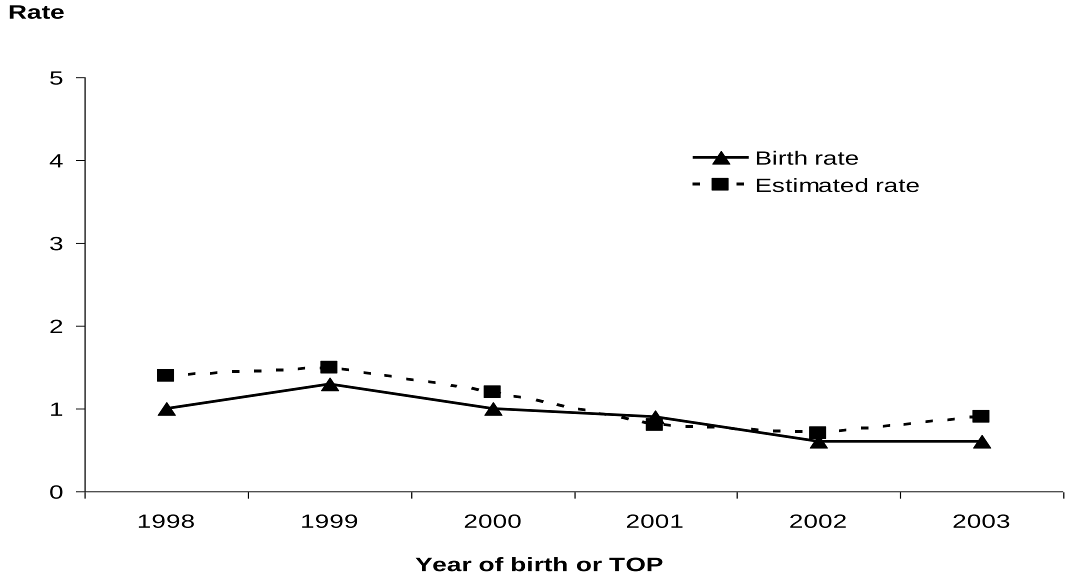

Figure 8: Rate of anophthalmos/microphthalmos among all births[(a)] and estimated rate[(b)], 1998–2003

(a) Birth rate includes anophthalmos/microphthalmos among live births and fetal deaths in Australia per 10,000 live births and fetal deaths.

(b) Estimated rate includes anophthalmos/microphthalmos among fetal deaths, live births and TOP before 20 weeks reported by New South Wales, Victoria, Western Australia and South Australia per 10,000 live births and fetal deaths.

Reported rates of anophthalmos/microphthalmos

Table 2.8.1: Number and rate of anophthalmos/microphthalmos by outcome[a], Australia, 2002–2003

	2002		2003		2002–2003	
Outcome	**Number**	**Rate**	**Number**	**Rate**	**Number**	**Rate**
Live births[b]	12	0.5	12	0.5	24	0.5
Fetal deaths[c]	4	23.9	3	16.8	7	20.2
All births[d]	16	0.6	15	0.6	31	0.6

(a) Includes all births with at least 20 weeks of gestational age or at least 400 grams birthweight.

(b) For live births, the rate is per 10,000 live births.

(c) For fetal deaths, the rate is per 10,000 fetal deaths.

(d) For all births, the rate is per 10,000 live births and fetal deaths.

Table 2.8.2: Number and the estimated rate of anophthalmos/microphthalmos by outcome, four Australian states[a], 2002–2003

	2002		2003		2002–2003	
Outcome	**Number**	**Rate**	**Number**	**Rate**	**Number**	**Rate**
Live births[b]	8	0.4	11	0.6	19	0.5
Fetal deaths[c]	4	31.6	3	21.8	7	26.5
All births[d]	12	0.6	14	0.7	26	0.7
Births and TOP[e]	13	0.7	17	0.9	30	0.8

(a) Includes data for New South Wales, Victoria, Western Australia and South Australia.

(b) For live births, the rate is per 10,000 live births.

(c) For fetal deaths, the rate is per 10,000 fetal deaths.

(d) For all births, the rate is per 10,000 live births and fetal deaths.

(e) Includes TOP at less than 20 weeks gestation and all births with at least 20 weeks of gestation or at least 400 grams birthweight.

Baby characteristics

Table 2.8.3: Births[(a)] with anophthalmos/microphthalmos by baby characteristics, Australia, 2002–2003

Characteristic	Number	Per cent	Rate per 10,000 births
Sex			
Male	18	58.1	0.7
Female	13	41.9	0.5
Gestational age (weeks)			
Less than 25	6	19.4	24.3
25–36	8	25.8	2.2
37+	17	54.8	0.4
Birthweight (grams)			
Less than 1500	7	22.6	9.3
1500 –2499	3	9.7	1.1
2,500+	21	67.7	0.5

(a) Includes all births with at least 20 weeks of gestation or at least 400 grams birthweight.

Maternal characteristics

Table 2.8.4: Number of women who gave birth to babies with anophthalmos/microphthalmos, Australia, 2002–2003

	2002		2003		2002–2003	
	Number	Rate[(a)]	Number	Rate[(a)]	Number	Rate[(a)]
Women who gave birth	16	0.7	14	0.6	30	0.6

(a) The rate is per 10,000 women who gave birth.

Table 2.8.5: Reported number of pregnancies affected with anophthalmos/microphthalmos and the estimated rate, four Australian states[(a)], 2002–2003

	2002		2003		2002–2003	
	Number	Rate[(b)]	Number	Rate[(b)]	Number	Rate[(b)]
Women who gave birth[(c)]	12	0.6	13	0.7	25	0.7
Women who gave birth or had a TOP[(d)]	13	0.7	16	0.9	29	0.8

(a) Includes data for New South Wales, Victoria, Western Australia and South Australia.

(b) The rate is per 10,000 women who gave birth.

(c) Includes women who gave birth to a baby with at least 20 weeks of gestation or at least 400 grams birthweight.

(d) Includes TOP at less than 20 weeks gestation and all births with at least 20 weeks of gestation or at least 400 grams birthweight.

Table 2.8.6: Maternal characteristics of births[(a)] affected with anophthalmos/microphthalmos, Australia, 2002–2003

Characteristic	Number	Per cent	Rate[(e)]	Confidence intervals
Maternal age group				
Less than 20	1	3.3	0.4	0.0–2.5
20–24	5	16.7	0.7	0.2–1.6
25–29	5	16.7	0.4	0.1–0.8
30–34	9	30.0	0.5	0.2–1.0
35–39	8	26.7	1.0	0.4–2.1
40 and over	2	6.7	1.3	0.2–4.6
Indigenous status [(b)]				
Indigenous	1	3.3	0.7	0.0–3.7
Non-Indigenous	29	96.7	0.6	0.4–0.9
Remoteness Area				
Major cities	18	60.0	0.5	0.3–0.8
Regional	9	30. 0	0.6	0.3–1.2
Remote	2	6.7	1.6	0.2–5.6
Not stated	1	3.3	..	..
Country of birth [(c)]				
Australia	17	56.7	0.4	0.3–0.7
Asia	4	13.3	1.0	0.3–2.6
Other countries	5	16.7	..	..
Not stated	4	13.3	..	..
Parity [(d)]				
Primiparous	5	20.0	0.4	0.1–0.9
Multiparous	20	80.0	1.1	0.7–1.7
Plurality				
Singleton	28	93.3	0.6	0.4–0.8
Multiple	2	6.7	2.4	0.3–8.6

(a) Includes all births with at least 20 weeks of gestation or at least 400 grams birthweight.

(b) Excludes data from Tasmania.

(c) Mother's country of birth was classified using ASCCSS system. If the number of women affected was less than three in any country, those women were included under 'Other countries' category.

(d) Excludes data from New South Wales and Tasmania.

(e) The rate is per 10,000 women who gave birth.

9 Microtia

Description: A congenital anomaly characterised by absent parts of the pinna (with or without atresia of the ear canal) commonly expressed in grades (I–IV) of which the extreme form (grade IV) is anotia, absence of pinna. This anomaly excludes small, normally shaped ears, imperforate auditory meatus with a normal pinna, dysplastic and low set ears.

ICD-9-BPA codes: 744.21 ICD-10-AM codes: Q17.2

Microtia affected 0.8 per 10,000 births each year (Table 2.9.1). Fetal deaths with this anomaly are rare and TOPs were not reported for this anomaly during the period 2002–2003. The reported fetal deaths could be due to other associated anomalies. The estimated rate from the four states providing TOP data was higher in 2002 than in the other reported years (Figure 9).

There were more males than females born with microtia. Most (95%) babies with microtia were born at term and had a birthweight of 2,500 grams or more (Table 2.9.3).

The rates did not differ by maternal age group or parity. All affected mothers were non-Indigenous and lived in regional or city areas. All affected babies were singleton births (Table 2.9.6).

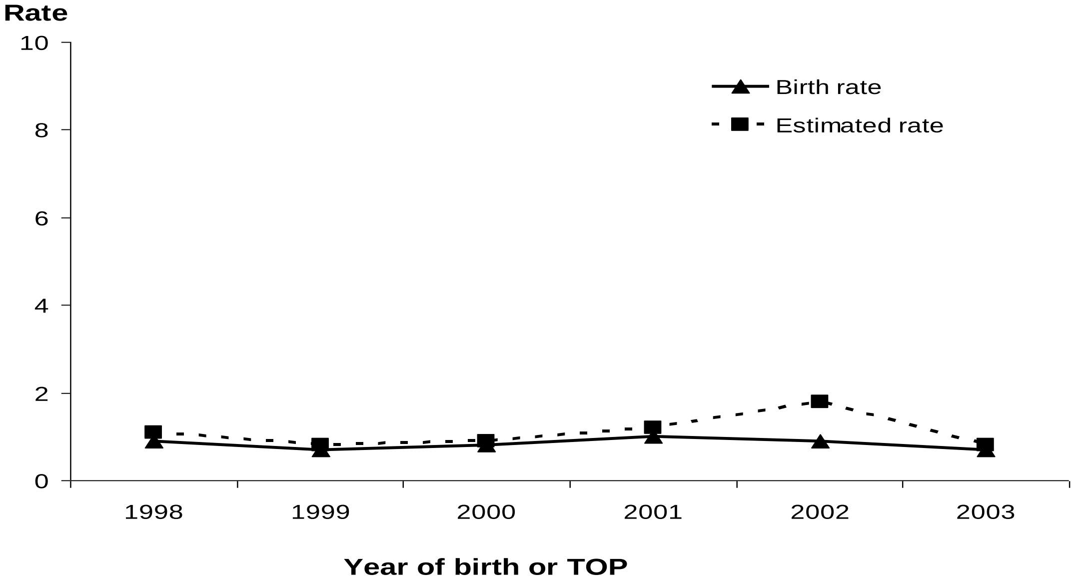

Figure 9: Rate of microtia among all births[(a)] and estimated rate[(b)], 1998–2003

(a) Birth rate includes all microtia among live births and fetal deaths in Australia per 10,000 live births and fetal deaths.

(b) Estimated rate includes all microtia among fetal deaths, live births and TOP before 20 weeks reported by New South Wales, Victoria, Western Australia and South Australia per 10,000 live births and fetal deaths.

Reported rates of microtia

Table 2.9.1: Number and rate of microtia by outcome[a], Australia, 2002–2003

	2002		2003		2002–2003	
Outcome	**Number**	**Rate**	**Number**	**Rate**	**Number**	**Rate**
Live births[b]	22	0.9	18	0.7	40	0.8
Fetal deaths[c]	1	6.0	0	0.0	1	2.9
All births[d]	23	0.9	18	0.7	41	0.8

(a) Includes all births with at least 20 weeks of gestational age or at least 400 grams birthweight.

(b) For live births, the rate is per 10,000 live births.

(c) For fetal deaths, the rate is per 10,000 fetal deaths.

(d) For all births, the rate is per 10,000 live births and fetal deaths.

Table 2.9.2: Number and the estimated rate of microtia by outcome, four Australian states[a], 2002–2003

	2002		2003		2002–2003	
Outcome	**Number**	**Rate**	**Number**	**Rate**	**Number**	**Rate**
Live births[b]	20	1.1	16	0.8	36	0.9
Fetal deaths[c]	1	7.9	0	0.0	1	3.8
All births[d]	21	1.8	16	0.8	37	1.0
Births and TOP[e]	21	1.8	16	0.8	37	1.0

(a) Includes data for New South Wales, Victoria, Western Australia and South Australia.

(b) For live births, the rate is per 10,000 live births.

(c) For fetal deaths, the rate is per 10,000 fetal deaths.

(d) For all births, the rate is per 10,000 live births and fetal deaths.

(e) Includes TOP at less than 20 weeks gestation and all births with at least 20 weeks of gestation or at least 400 grams birthweight.

Baby characteristics

Table 2.9.3: Births[(a)] with microtia by baby characteristics, Australia, 2002–2003

Characteristic	Number	Per cent	Rate per 10,000 births
Sex			
Male	27	65.9	1.0
Female	14	34.2	0.6
Gestational age (weeks)			
Less than 25	0	0.0	0.0
25–36	2	4.9	0.5
37+	39	95.1	0.8
Birthweight (grams)			
Less than 1500	1	2.4	1.3
1500 –2499	6	14.6	2.2
2,500+	34	82.9	0.7

(a) Includes all births with at least 20 weeks of gestation or at least 400 grams birthweight.

Maternal characteristics

Table 2.9.4: Number of women who gave birth to babies with microtia, Australia, 2002–2003

	2002		2003		2002–2003	
	Number	Rate[(a)]	Number	Rate[(a)]	Number	Rate[(a)]
Women who gave birth	23	0.9	18	0.7	41	0.8

(a) The rate is per 10,000 women who gave birth.

Table 2.9.5: Reported number of pregnancies affected with microtia and the estimated rate, four Australian states[(a)], 2002–2003

	2002		2003		2002–2003	
	Number	Rate[(b)]	Number	Rate[(b)]	Number	Rate[(b)]
Women who gave birth[(c)]	21	1.1	16	0.9	37	1.0
Women who gave birth or had a TOP[(d)]	21	1.1	16	0.9	37	1.0

(a) Includes data for New South Wales, Victoria, Western Australia and South Australia.

(b) The rate is per 10,000 women who gave birth.

(c) Includes women who gave birth to a baby with at least 20 weeks of gestation or at least 400 grams birthweight.

(d) Includes TOP at less than 20 weeks gestation and all births with at least 20 weeks of gestation or at least 400 grams birthweight.

Table 2.9.6: Maternal characteristics of births[(a)] affected with microtia Australia, 2002–2003

Characteristic	Number	Per cent	Rate[(e)]	Confidence intervals
Maternal age group				
Less than 20	1	2.4	0.4	0.0–2.5
20–24	5	12.2	0.7	0.2–1.6
25–29	12	29.3	0.9	0.4–1.5
30–34	19	46.3	1.1	0.7–1.8
35–39	3	7.3	0.4	0.1–1.1
40 and over	1	2.4	0.6	0.0–3.6
Indigenous status (b)				
Indigenous	0	0.0	..	..
Non-Indigenous	41	100.0	0.9	0.6–1.2
Remoteness Area				
Major cities	32	78.1	1.0	0.7–1.3
Regional	8	19.5	0.5	0.2–1.1
Remote	0	0.0	..	..
Not stated	1	2.4	..	..
Country of birth (c)				
Australia	28	68.3	0.7	0.5–1.0
Asia	5	12.2	1.3	0.4–2.9
Other countries	8	19.5	..	..
Parity (d)				
Primiparous	7	38.9	0.5	0.2–1.1
Multiparous	11	61.1	0.6	0.3–1.1
Plurality				
Singleton	41	100.0	0.8	0.6–1.1
Multiple	0	0.0	..	..

(a) Includes all births with at least 20 weeks of gestation or at least 400 grams birthweight.

(b) Excludes data from Tasmania.

(c) Mother's country of birth was classified using ASCCSS system. If the number of women affected was less than three in any country, those women were included under 'Other countries' category.

(d) Excludes data from New South Wales and Tasmania.

(e) The rate is per 10,000 women who gave birth.

10 Transposition of great vessels

Description: A cardiac defect where the aorta exits from the right ventricle and the pulmonary artery from the left ventricle, with or without the presence of other cardiac defects. This anomaly includes double outlet ventricle, the so-called corrected transposition.

ICD-9-BPA codes: 745.10–745.19 ICD-10-AM codes: Q20.1, Q20.3, Q20.5

About four babies per 10,000 births were diagnosed with transposition of great vessels during 2002–2003 (Table 2.10.1) and this rate was steady during 1998–2003 (Figure 10). The data from the four states that include TOP data show that less than 10 terminations were performed during 2002–2003, for pregnancies affected with this anomaly (Table 2.10.2).

A higher proportion of males (63%) than females had this anomaly. Among babies born before 25 weeks of gestation, this condition affected 97.2 per 10,000 births. Nearly three-quarters of affected babies were born at term (Table 2.10.3) and 76.7% had a birthweight of 2,500 grams or more (Table 2.10.3).

There was no difference in maternal age group in babies affected with this anomaly. Indigenous women had a higher rate of affected pregnancies than non-Indigenous women. More women living in remote areas were affected compared with women living in cities and regional areas. These differences were not statistically significant. Most babies (98%) born with transposition of great vessels were singletons (Table 2.10.6).

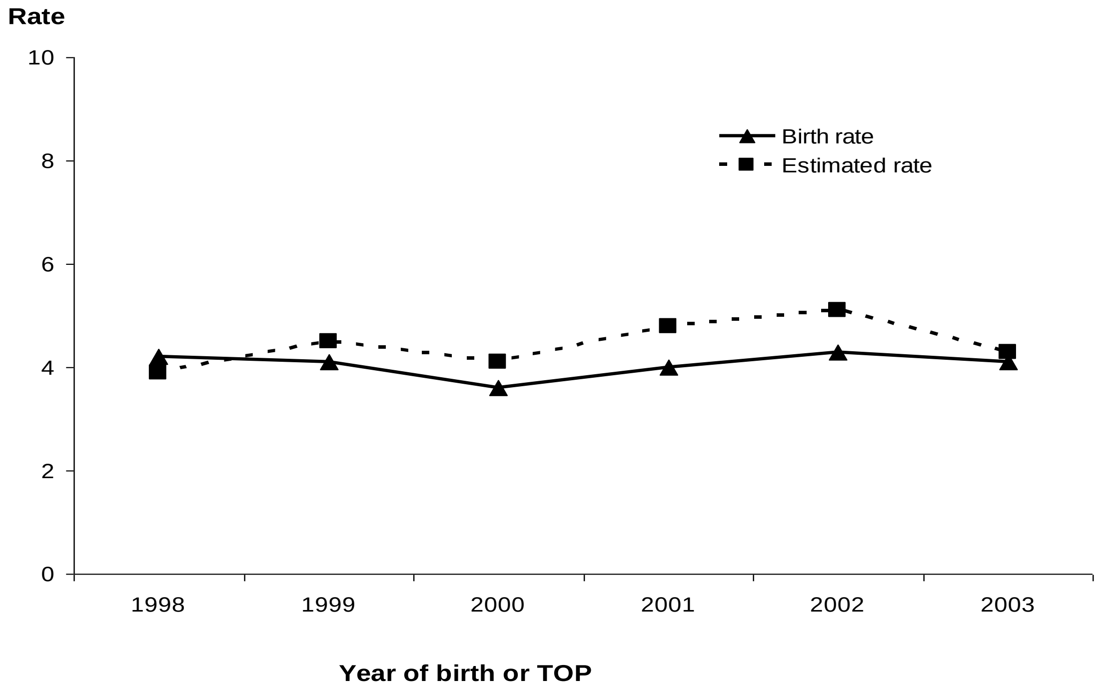

Figure 10: Rate of transposition of great vessels among all births[(a)] and estimated rate[(b)], 1998–2003

(a) Birth rate includes transposition of great vessels among live births and fetal deaths in Australia per 10,000 live births and fetal deaths.

(b) Estimated rate includes transposition of great vessels among fetal deaths, live births and TOP before 20 weeks reported by New South Wales, Victoria, Western Australia and South Australia per 10,000 live births and fetal deaths.

Reported rates of transposition of great vessels

Table 2.10.1: Number and rate of transposition of great vessels by outcome[a], Australia, 2002–2003

	2002		2003		2002–2003	
Outcome	**Number**	**Rate**	**Number**	**Rate**	**Number**	**Rate**
Live births[b]	95	3.8	91	3.6	186	3.7
Fetal deaths[c]	12	71.6	12	67.2	24	69.3
All births[d]	107	4.3	103	4.1	210	4.2

(a) Includes all births with at least 20 weeks of gestational age or at least 400 grams birthweight.

(b) For live births, the rate is per 10,000 live births.

(c) For fetal deaths, the rate is per 10,000 fetal deaths.

(d) For all births, the rate is per 10,000 live births and fetal deaths.

Table 2.10.2: Number and the estimated rate of transposition of great vessels by outcome, four Australian states[a], 2002–2003

	2002		2003		2002–2003	
Outcome	**Number**	**Rate**	**Number**	**Rate**	**Number**	**Rate**
Live births[b]	80	4.2	72	3.8	152	4.0
Fetal deaths[c]	12	94.9	10	72.7	22	83.4
All births[d]	92	4.8	82	4.3	174	4.5
Births and TOP[e]	98	5.1	83	4.3	181	4.7

(a) Includes data for New South Wales, Victoria, Western Australia and South Australia.

(b) For live births, the rate is per 10,000 live births.

(c) For fetal deaths, the rate is per 10,000 fetal deaths.

(d) For all births, the rate is per 10,000 live births and fetal deaths.

(e) Includes TOP at less than 20 weeks gestation and all births with at least 20 weeks of gestation or at least 400 grams birthweight.

Baby characteristics

Table 2.10.3: Births[a] with transposition of great vessels by baby characteristics, Australia, 2002–2003

Characteristic	Number	Per cent	Rate per 10,000 births
Sex			
Male	132	62.9	5.1
Female	78	37.1	3.2
Gestational age (weeks)			
Less than 25	24	11.4	97.2
25–36	30	14.3	8.1
37+	156	74.3	3.4
Birthweight (grams)			
Less than 1500	29	13.8	38.7
1500 –2499	20	9.5	7.5
2,500+	161	76.7	3.4

(a) Includes all births with at least 20 weeks of gestation or at least 400 grams birthweight.

Maternal characteristics

Table 2.10.4: Number of women who gave birth to babies with transposition of great vessels, Australia, 2002–2003

	2002		2003		2002–2003	
	Number	Rate[a]	Number	Rate[a]	Number	Rate[a]
Women who gave birth	105	4.3	103	4.1	208	4.2

(a) The rate is per 10,000 women who gave birth.

Table 2.10.5: Reported number of pregnancies affected with transposition of great vessels and the estimated rate, four Australian states[a], 2002–2003

	2002		2003		2002–2003	
	Number	Rate[b]	Number	Rate[b]	Number	Rate[b]
Women who gave birth[c]	90	4.8	82	4.3	172	4.6
Women who gave birth or had a TOP[d]	96	5.1	83	4.4	179	4.7

(a) Includes data for New South Wales, Victoria, Western Australia and South Australia.

(b) The rate is per 10,000 women who gave birth.

(c) Includes women who gave birth to a baby with at least 20 weeks of gestation or at least 400 grams birthweight.

(d) Includes TOP at less than 20 weeks gestation and all births with at least 20 weeks of gestation or at least 400 grams birthweight.

Table 2.10.6: Maternal characteristics of births[(a)] affected with transposition of great vessels, Australia, 2002–2003

Characteristic	Number	Per cent	Rate[(e)]	Confidence intervals
Maternal age group				
Less than 20	13	6.3	5.8	3.1–9.8
20–24	35	17.1	4.7	3.3–6.6
25–29	55	26.8	3.9	3.0–5.1
30–34	61	29.8	3.7	2.8–4.7
35–39	32	15.6	4.2	2.9–5.9
40 and over	9	4.4	5.8	2.6–10.9
Indigenous status [(b)]				
Indigenous	11	5.3	7.4	3.7–13.2
Non-Indigenous	194	93.7	4.1	3.6–4.8
Not stated	2	1.0	..	..
Remoteness Area				
Major cities	139	67.2	4.1	3.5–4.9
Regional	60	29.0	4.1	3.1–5.3
Remote	8	3.9	6.2	2.7–12.3
Country of birth [(c)]				
Australia	153	73. 6	3.9	3.3–4.6
United Kingdom	6	2.9	3.7	1.4–8.0
Europe	5	2.4	3.8	1.2–8.9
Middle East and North Africa	4	1.9	3.5	1.0–9.1
Asia	9	4.3	2.3	1.0–4.3
South Central America/ Caribbean	3	1.4	10.3	2.1–30.1
Africa (excluding North Africa)	3	1.4	5.2	1.1–15.3
Other countries	10	5.8	..	..
Not stated	19	9.1	..	..
Parity [(d)]				
Primiparous	59	41.0	4.5	3.4–5.8
Multiparous	85	59.0	4.6	3.7–5.7
Plurality				
Singleton	204	98.1	4.2	3.6–4.8
Multiple	4	1.9	4.8	1.3–12.2

(a) Includes all births with at least 20 weeks of gestation or at least 400 grams birthweight.

(b) Excludes data from Tasmania.

(c) Mother's country of birth was classified using ASCCSS system. If the number of women affected was less than three in any country, those women were included under 'Other countries' category.

(d) Excludes data from New South Wales and Tasmania.

(e) The rate is per 10,000 women who gave birth.

11 Tetralogy of Fallot

Description: A condition characterised by ventricular septal defect, overriding aorta, infundibular pulmonary stenosis, and often right ventricular hypertrophy.

ICD-9-BPA codes: 745.20–745.21 ICD-10-AM codes: Q21.3

Tetralogy of Fallot affected 3.2 per 10,000 births and this rate remained constant between 1998 and 2003 (Table 2.11.1, Figure 11). The four states that provide information on TOP did not show a significant difference (only 5.2% early terminations were performed) in the prevalence of the anomaly when the termination data were added (Table 2.11.2).

There were more males than females, and nearly two-thirds of the babies with tetralogy of Fallot were born at term with a birthweight of 2,500 grams or more.

There was no difference in the age group of women who had a pregnancy with this anomaly. Women living in regional areas had a lower rate of births with this anomaly than women living in cities (PR=0.4, CI 0.3–0.7). Indigenous women had a higher rate of affected births than non-Indigenous women (PR=2.0, CI 1.01–3.9). The rates did not differ by parity or plurality (Table 2.11.6).

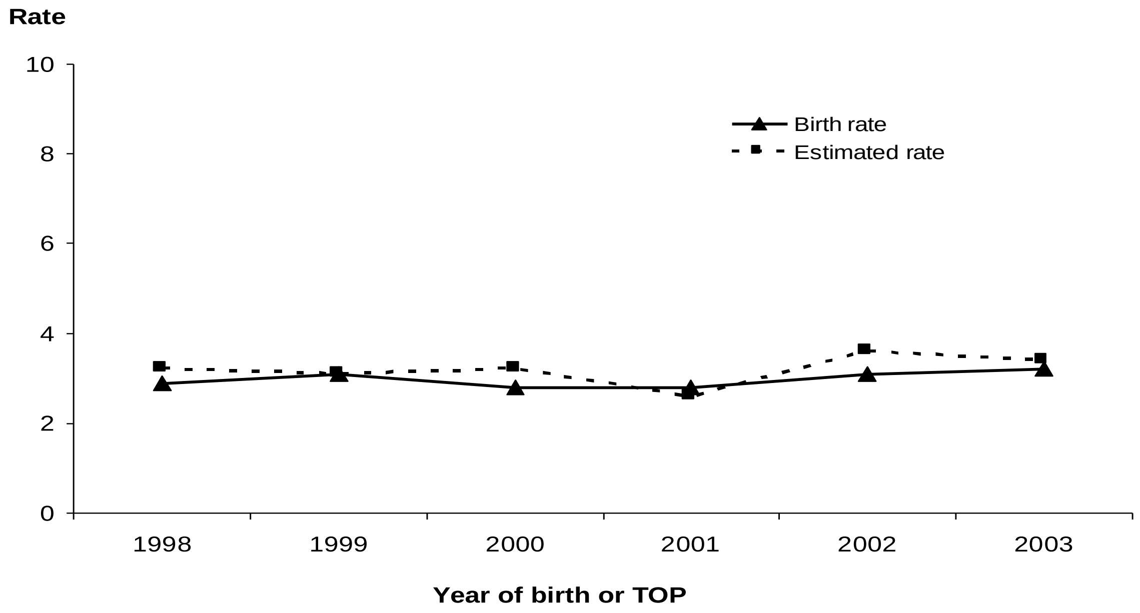

Figure 11: Rate of tetralogy of Fallot among all births[(a)] and estimated rate[(b)], 1998–2003

(a) Birth rate includes tetralogy of Fallot among live births and fetal deaths in Australia per 10,000 live births and fetal deaths.

(b) Estimated rate includes tetralogy of Fallot among fetal deaths, live births and TOP before 20 weeks reported by New South Wales, Victoria, Western Australia and South Australia per 10,000 live births and fetal deaths.

Reported rates of tetralogy of Fallot

Table 2.11.1: Number and rate of tetralogy of Fallot by outcome[(a)], Australia, 2002–2003

	2002		2003		2002–2003	
Outcome	**Number**	**Rate**	**Number**	**Rate**	**Number**	**Rate**
Live births[(b)]	75	3.0	74	2.9	149	3.0
Fetal deaths[(c)]	3	17.9	8	44.8	11	31.8
All births[(d)]	78	3.1	82	3.2	160	3.2

(a) Includes all births with at least 20 weeks of gestational age or at least 400 grams birthweight.

(b) For live births, the rate is per 10,000 live births.

(c) For fetal deaths, the rate is per 10,000 fetal deaths.

(d) For all births, the rate is per 10,000 live births and fetal deaths.

Table 2.11.2: Number and the estimated rate of tetralogy of Fallot by outcome, four Australian states[(a)], 2002–2003

	2002		2003		2002–2003	
Outcome	**Number**	**Rate**	**Number**	**Rate**	**Number**	**Rate**
Live births[(b)]	62	3.3	57	3.0	119	3.1
Fetal deaths[(c)]	3	23.7	6	43.6	9	34.1
All births[(d)]	65	3.4	63	3.3	128	3.3
Births and TOP[(e)]	69	3.6	66	3.4	135	3.5

(a) Includes data for New South Wales, Victoria, Western Australia and South Australia.

(b) For live births, the rate is per 10,000 live births.

(c) For fetal deaths, the rate is per 10,000 fetal deaths.

(d) For all births, the rate is per 10,000 live births and fetal deaths.

(e) Includes TOP at less than 20 weeks gestation and all births with at least 20 weeks of gestation or at least 400 grams birthweight.

Baby characteristics

Table 2.11.3: Births[(a)] with tetralogy of Fallot by baby characteristics, Australia, 2002–2003

Characteristic	Number	Per cent	Rate per 10,000 births
Sex			
Male	95	59.4	3.7
Female	65	40.6	2.7
Gestational age (weeks)			
Less than 25	13	8.1	52. 7
25–36	37	23.1	10.0
37+	108	67.5	2.3
Unknown	2	1.3	..
Birthweight (grams)			
Less than 1500	23	14.4	30.7
1500 –2499	37	23.1	13.8
2,500+	100	62.5	2.1

(a) Includes all births with at least 20 weeks of gestation or at least 400 grams birthweight.

Maternal characteristics

Table 2.11.4: Number of women who gave birth to babies with tetralogy of Fallot, Australia, 2002–2003

	2002		2003		2002–2003	
	Number	Rate(a)	Number	Rate(a)	Number	Rate(a)
Women who gave birth	76	3.1	81	3.3	157	3.2

(a) The rate is per 10,000 women who gave birth.

Table 2.11.5: Reported number of pregnancies affected with tetralogy of Fallot and the estimated rate, four Australian states[(a)], 2002–2003

	2002		2003		2002–2003	
	Number	Rate(b)	Number	Rate(b)	Number	Rate(b)
Women who gave birth(c)	64	3.4	62	3.3	126	3.3
Women who gave birth or had a TOP(d)	68	3.6	65	3.4	133	3.5

(a) Includes data for New South Wales, Victoria, Western Australia and South Australia.

(b) The rate is per 10,000 women who gave birth.

(c) Includes women who gave birth to a baby with at least 20 weeks of gestation or at least 400 grams birthweight.

(d) Includes TOP at less than 20 weeks gestation and all births with at least 20 weeks of gestation or at least 400 grams birthweight.

Table 2.11.6 Maternal characteristics of births[(a)] affected with tetralogy of Fallot, Australia, 2002–2003

Characteristic	Number	Per cent	Rate[(e)]	Confidence intervals
Maternal age group				
Less than 20	9	5.8	4.0	1.8–7.6
20–24	23	14.9	3.1	2.0–4.7
25–29	41	26.6	2.9	2.1–4.0
30–34	44	28.6	2.6	1.9–3.5
35–39	30	19.5	3.9	2.6–5.6
40 and over	7	4.6	4.5	1.8–9.2
Indigenous status [(b)]				
Indigenous	9	5.7	6.1	2.8–11.5
Non-Indigenous	145	92.4	3.1	2.6–3.6
Not stated	3	1.9	..	..
Remoteness Area				
Major cities	127	79.4	3.8	3.1–4.5
Regional	25	15.6	1.7	1.1–2.5
Remote	5	3.1	3.9	1.3–9.1
Not stated	3	1.9	..	..
Country of birth [(c)]				
Australia	107	68.2	2.8	2.3–3.4
Europe	4	2.6	3.1	0.8–7.8
Middle East and North Africa	5	3.2	4.4	1.4–10.3
Asia	6	3.8	1.5	0.6–3.3
North America	15	9.6	51.5	28.8–84.7
Other countries	5	3.2	..	..
Not stated	15	9.6	..	..
Parity [(d)]				
Primiparous	58	50.9	4.4	3.4–5.7
Multiparous	56	49.1	3.0	2.3–3.9
Plurality				
Singleton	154	98.1	3.2	2.7–3.7
Multiple	3	1.9	3.6	0.7–10.4

(a) Includes all births with at least 20 weeks of gestation or at least 400 grams birthweight.

(b) Excludes data from Tasmania.

(c) Mother's country of birth was classified using ASCCSS system. If the number of women affected was less than three in any country, those women were included under 'Other countries' category.

(d) Excludes data from New South Wales and Tasmania.

(e) The rate is per 10,000 women who gave birth.

12 Hypoplastic left heart syndrome

Description: A cardiac defect with a hypoplastic left ventricle, associated with aortic and/or mitral valve atresia, with or without another cardiac defect.

ICD-9-BPA codes: 746.7 ICD-10-AM codes: Q23.4

Hypoplastic left heart syndrome was reported in 1.6 per 10,000 births in 2002–2003 (Table 2.12.1). The data provided by the four states that include TOP data show that 2.1 per 10,000 pregnancies are affected and this rate has been stable since 1999 (Figure 12). Of the affected pregnancies, 40% were diagnosed and terminated early or were stillbirths (Table 2.12.2).

This condition was more common in males (71%) than in females. The anomaly was detected in 85.1 per 10,000 babies born between 20 and 24 weeks gestation. More than half of the affected babies were born at term with a birthweight of 2,500 grams or more (Table 2.12.3).

More than 86% of women who had a baby with hypoplastic left heart syndrome were aged between 20 and 34 years. Women who had multiple births had a significantly higher rate of affected births than the women who had singleton births (PR=5.4, CI 2.5–11.7). The rates did not differ by Indigenous status, women's areas of residence or parity (Table 2.12.6).

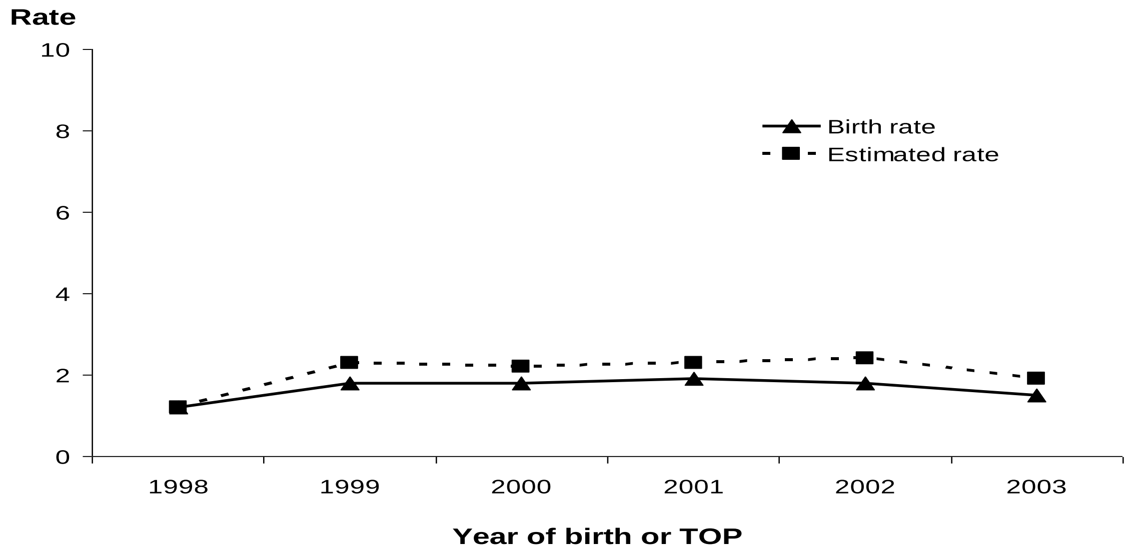

Figure 12: Rate of hypoplastic left heart syndrome among all births[(a)] and estimated rate[(b)], 1998–2003

(a) Birth rate includes hypoplastic left heart syndrome among live births and fetal deaths in Australia per 10,000 live births and fetal deaths.

(b) Estimated rate includes hypoplastic left heart syndrome among fetal deaths, live births and TOP before 20 weeks reported by New South Wales, Victoria, Western Australia and South Australia per 10,000 live births and fetal deaths.

Reported rates of Hypoplastic left heart syndrome

Table 2.12.1: Number and rate of hypoplastic left heart syndrome by outcome[(a)], Australia, 2002–2003

	2002		2003		2002–2003	
Outcome	**Number**	**Rate**	**Number**	**Rate**	**Number**	**Rate**
Live births[(b)]	36	1.4	32	1.3	68	1.4
Fetal deaths[(c)]	10	59.6	5	28.0	15	43.3
All births[(d)]	46	1.8	37	1.5	83	1.6

(a) Includes all births with at least 20 weeks of gestational age or at least 400 grams birthweight.

(b) For live births, the rate is per 10,000 live births.

(c) For fetal deaths, the rate is per 10,000 fetal deaths.

(d) For all births, the rate is per 10,000 live births and fetal deaths.

Table 2.12.2: Number and the estimated rate of hypoplastic left heart syndrome by outcome, four Australian states[(a)] only, 2002–2003

	2002		2003		2002–2003	
Outcome	**Number**	**Rate**	**Number**	**Rate**	**Number**	**Rate**
Live births[(b)]	27	1.4	21	1.1	48	1.3
Fetal deaths[(c)]	10	79.1	4	29.1	14	53.1
All births[(d)]	37	1.9	25	1.3	62	1.6
Births and TOP[(e)]	45	2.4	36	1.9	81	2.1

(a) Includes data for New South Wales, Victoria, Western Australia and South Australia.

(b) For live births, the rate is per 10,000 live births.

(c) For fetal deaths, the rate is per 10,000 fetal deaths.

(d) For all births, the rate is per 10,000 live births and fetal deaths.

(e) Includes TOP at less than 20 weeks gestation and all births with at least 20 weeks of gestation or at least 400 grams birthweight.

Baby characteristics

Table 2.12.3: Births[(a)] with hypoplastic left heart syndrome by baby characteristics, Australia, 2002–2003

Characteristic	Number	Per cent	Rate per 10,000 births
Sex			
Male	59	71.1	2.3
Female	23	27.7	0.9
Indeterminate/ Not stated	1	1.2	..
Gestational age (weeks)			
Less than 25	21	25.3	85.1
25–36	14	16.9	3.9
37+	46	55.4	1.0
Unknown	2	2.4	..
Birthweight (grams)			
Less than 1500	26	31.3	34.7
1500 –2499	12	14.5	4.5
2,500+	45	54.2	1.0

(a) Includes all births with at least 20 weeks of gestation or at least 400 grams birthweight.

Maternal characteristics

Table 2.12.4: Number of women who gave birth to babies with hypoplastic left heart syndrome, Australia, 2002–2003

	2002		2003		2002–2003	
	Number	Rate(a)	Number	Rate(a)	Number	Rate(a)
Women who gave birth	46	1.9	36	1. 5	82	1.7

(a) The rate is per 10,000 women who gave birth.

Table 2.12.5: Reported number of pregnancies affected with hypoplastic left heart syndrome and the estimated rate, four Australian states[(a)], 2002–2003

	2002		2003		2002–2003	
	Number	Rate(b)	Number	Rate(b)	Number	Rate(b)
Women who gave birth(c)	37	2.0	25	1.3	62	1.6
Women who gave birth or had a TOP(d)	45	2.4	36	1.9	81	2.1

(a) Includes data for New South Wales, Victoria, Western Australia and South Australia.

(b) The rate is per 10,000 women who gave birth.

(c) Includes women who gave birth to a baby with at least 20 weeks of gestation or at least 400 grams birthweight.

(d) Includes TOP at less than 20 weeks gestation and all births with at least 20 weeks of gestational age or at least 400 grams birthweight.

Table 2.12.6: Maternal characteristics of births[(a)] affected with hypoplastic left heart syndrome, Australia, 2002–2003

Characteristic	Number	Per cent	Rate[(e)]	Confidence intervals
Maternal age group				
Less than 20	3	3.7	1.3	0.3–3.9
20–24	17	20.7	2.3	1.3–3.7
25–29	28	34.2	2.0	1.3–2.9
30–34	26	31.7	1.6	1.0–2.3
35–39	7	8.5	0.9	0.4–1.9
40 and over	1	1.2	0.6	0.0–3.6
Indigenous status [(b)]				
Indigenous	2	2.4	1.3	0.2–4.9
Non-Indigenous	79	96.3	1.7	1.3–2.1
Not stated	1	1.2	..	..
Remoteness Area				
Major cities	52	63.4	1.5	1.2–2.0
Regional	28	34.2	1.9	1.3–2.8
Remote	1	1.2	0.8	0.0–4.3
Not stated	1	1.2	..	..
Country of birth [(c)]				
Australia	58	70.7	1.5	1.2–2.0
Europe	4	4.9	3.1	0.3–7.8
Asia	4	4.9	1.0	0.3–2.6
North America	4	4.9	1.4	3.7–35.1
Other countries	4	4.9	..	..
Not stated	8	9.8	..	..
Parity [(d)]				
Primiparous	28	40.0	2.1	1.4–3.1
Multiparous	41	58.6	2.0	1.6–3.0
Not stated	1	1.4	..	..
Plurality				
Singleton	75	91.5	1.54	1.2–1.9
Multiple	7	8.5	8.31	3.3–17.1

(a) Includes all births with at least 20 weeks of gestation or at least 400 grams birthweight.

(b) Excludes data from Tasmania.

(c) Mother's country of birth was classified using ASCCSS system. If the number of women affected was less than three in any country, those women were included under 'Other countries' category.

(d) Excludes data from New South Wales and Tasmania.

(e) The rate is per 10,000 women who gave birth.

13 Coarctation of the aorta

Description: An obstruction in the descending aorta, almost invariably at the insertion of the ductus arteriosus.

ICD-9-BPA codes: 747.10–747.19 ICD-10-AM codes: Q25.1

Coarctation of the aorta was reported in 3.6 per 10,000 births (Table 2.13.1) in 2002–2003. The rate was higher than the rate reported in the period 1998–2001 (Figure 13). There were few fetal deaths or terminations of pregnancy reported for this condition. The data from the four states providing information on TOP showed that the estimated rate increased from 3.7 per 10,000 pregnancies in 2002 to 4.5 per 10,000 pregnancies in 2003 (Table 2.13.2).

There were more males (53.6%) than females with coarctation of the aorta. More than three-quarters (77.1%) of the affected babies were born at term. About one-third of the affected babies were below 2,500 grams birthweight (Table 2.13.3).

The rate of births affected with this anomaly was highest in women older than 40 years. The rate was also greater for women who had multiple births than for those who had singleton births (PR=2.4, CI 1.1–5.0) (Table 2.13.6). The rate of having an affected birth with this anomaly did not differ significantly by women's areas of residence, parity or Indigenous status.

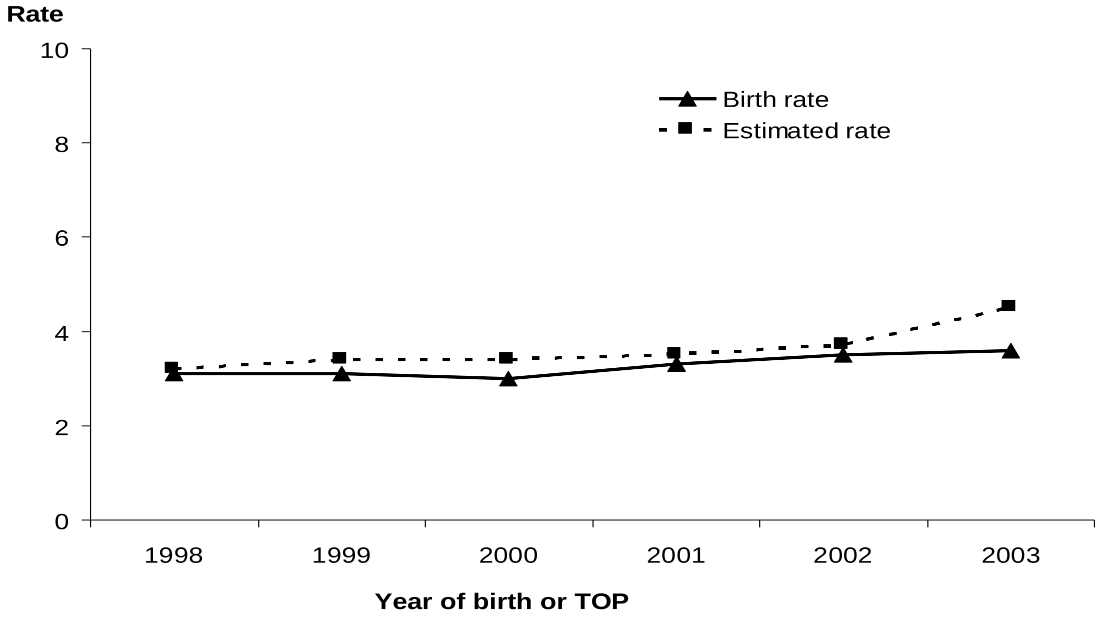

Figure 13: Rate of coarctation of the aorta among all births[a] and estimated rate[b], 1998–2003

(a) Birth rate includes coarctation of the aorta among live births and fetal deaths in Australia per 10,000 live births and fetal deaths.

(b) Estimated rate includes coarctation of the aorta among fetal deaths, live births and TOP before 20 weeks reported by New South Wales, Victoria, Western Australia and South Australia per 10,000 live births and fetal deaths.

Reported rates of coarctation of the aorta

Table 2.13.1: Number and rate of coarctation of aorta by outcome[(a)], Australia, 2002–2003

	2002		2003		2002–2003	
Outcome	**Number**	**Rate**	**Number**	**Rate**	**Number**	**Rate**
Live births[(b)]	81	3.2	87	3.5	168	3.4
Fetal deaths[(c)]	6	35.8	5	28.0	11	31.8
All births[(d)]	87	3.5	92	3.6	179	3.6

(a) Includes all births with at least 20 weeks of gestational age or at least 400 grams birthweight.

(b) For live births, the rate is per 10,000 live births.

(c) For fetal deaths, the rate is per 10,000 fetal deaths.

(d) For all births, the rate is per 10,000 live births and fetal deaths.

Table 2.13.2: Number and the estimated rate of coarctation of aorta by outcome, four Australian states[(a)], 2002–2003

	2002		2003		2002–2003	
Outcome	**Number**	**Rate**	**Number**	**Rate**	**Number**	**Rate**
Live births[(b)]	62	3.3	73	3.8	135	3.5
Fetal deaths[(c)]	5	39.6	4	29.1	9	34.1
All births[(d)]	67	3.5	77	4.0	144	3.8
Births and TOP[(e)]	71	3.7	86	4.5	157	4.1

(a) Includes data for New South Wales, Victoria, Western Australia and South Australia.

(b) For live births, the rate is per 10,000 live births.

(c) For fetal deaths, the rate is per 10,000 fetal deaths.

(d) For all births, the rate is per 10,000 live births and fetal deaths.

(e) Includes TOP at less than 20 weeks gestation and all births with at least 20 weeks of gestation or at least 400 grams birthweight.

Baby characteristics

Table 2.13.3: Births[(a)] with coarctation of aorta by baby characteristics, Australia, 2002–2003

Characteristic	Number	Per cent	Rate per 10,000 births
Sex			
Male	96	53.6	3.70
Female	83	46.4	3.4
Gestational age (weeks)			
Less than 25	9	5.0	36.5
25–36	32	17.9	8.6
37+	138	77.1	3.0
Birthweight (grams)			
Less than 1500	20	11.2	26.7
1500 –2499	36	20.1	13.4
2,500+	123	68.7	2.6

(a) Includes all births with at least 20 weeks of gestation or at least 400 grams birthweight.

Maternal characteristics

Table 2.13.4: Number of women who gave birth to babies with coarctation of aorta, Australia, 2002–2003

	2002		2003		2002–2003	
	Number	Rate[(a)]	Number	Rate[(a)]	Number	Rate[(a)]
Women who gave birth	87	3.5	92	3.7	179	3.6

(a) The rate is per 10,000 women who gave birth.

Table 2.13.5: Reported number of pregnancies affected with coarctation of aorta and the estimated rate, four Australian states[(a)], 2002–2003

	2002		2003		2002–2003	
	Number	Rate[(b)]	Number	Rate[(b)]	Number	Rate[(b)]
Women who gave birth[(c)]	67	3.6	77	4.1	144	3.8
Women who gave birth or had a TOP[(d)]	71	3.8	86	4.5	157	4.2

(a) Includes data for New South Wales, Victoria, Western Australia and South Australia.

(b) The rate is per 10,000 women who gave birth.

(c) Includes women who gave birth to a baby with at least 20 weeks of gestation or at least 400 grams birthweight.

(d) Includes TOP at less than 20 weeks gestation and all births with at least 20 weeks of gestation or at least 400 grams birthweight.

Table 2.13.6: Maternal characteristics of births[(a)] affected with coarctation of aorta, Australia, 2002–2003

Characteristic	Number	Per cent	Rate[(e)]	Confidence intervals
Maternal age group				
Less than 20	5	2.8	2.2	0.7–5.2
20–24	30	17.0	4.1	2.7–5.8
25–29	53	29.9	3.8	2.8–5.0
30–34	55	31.1	3.3	2.5–4.3
35–39	25	14.1	3.3	2.1–4.8
40 and over	9	5.1	5.8	2.6–10.9
Indigenous status [(b)]				
Indigenous	7	3.9	4.7	1.9–9.7
Non-Indigenous	169	94.4	3.6	3.1–4.2
Not stated	3	1.7	..	..
Remoteness Area				
Major cities	128	71.9	3.8	3.2–4.5
Regional	44	24.7	3.0	2.2–4.0
Remote	6	3.4	4.7	1.7–10.2
Country of birth [(c)]				
Australia	123	68.7	3.2	2.7–3.8
United Kingdom	9	5.0	5.5	2.5–10.5
Middle East and North Africa	5	2.8	4.4	1.4–10.3
Asia	9	5.0	2.3	1.0–4.3
Other countries	9	5.0	..	..
Not stated	24	13.4	..	..
Parity [(d)]				
Primiparous	50	36.0	3.8	2.8–5.0
Multiparous	89	64.0	4.8	3.9–5.9
Plurality				
Singleton	172	96.1	3.5	3.0–4.1
Multiple	7	3.9	8.3	3.3–17.1

(a) Includes all births with at least 20 weeks of gestation or at least 400 grams birthweight.

(b) Excludes data from Tasmania.

(c) Mother's country of birth was classified using ASCCSS system. If the number of women affected was less than three in any country, those women were included under 'Other countries' category.

(d) Excludes data from New South Wales and Tasmania.

(e) The rate is per 10,000 women who gave birth.

14 Choanal atresia

Description: Congenital obstruction (membranous or osseous) of the posterior choana or choanae. Exclude choanal stenosis and congestion of nasal mucosa.

ICD-9-BPA codes: 748.0 ICD-10-AM codes: Q30.0

Choanal atresia is a rare condition. The rate in births decreased slightly during the period 2002–2003 with an overall rate of 0.8 per 10,000 births. There was a considerable reduction in number of reported pregnancies with this condition in 2003 (Figure 14). No fetal deaths or terminations of pregnancy due to this condition were reported during the period 2002–2003 (Table 2.14.1).

There was no difference in the proportion of male and female babies affected with this anomaly. Nearly one-third of the babies (32.5%) were preterm and 27.5% of them had a birthweight of less than 2,500 grams (Table 2.14.3).

A quarter of women were older than 34 years of age. There were no Indigenous babies born with choanal atresia during this period, and 80% of the women lived in major cities. Nearly equal proportions of babies were born to primiparous and multiparous women. The rate did not differ by plurality (Table 2.14.6).

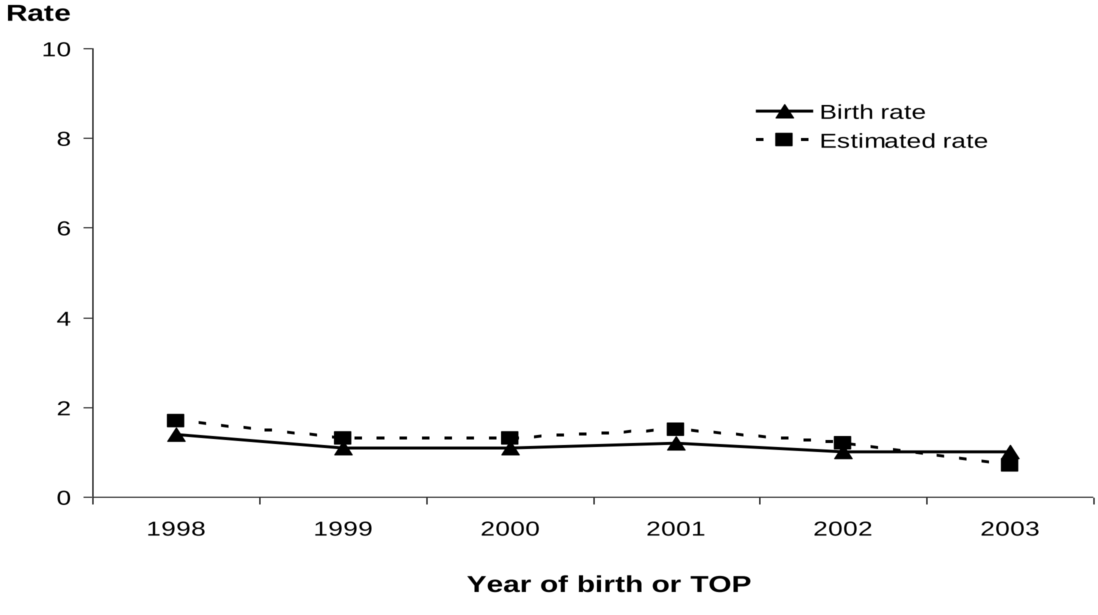

Figure 14: Rate of choanal atresia among all births(a) and estimated rate(b), 1998–2003

(a) Birth rate includes choanal atresia among live births and fetal deaths in Australia per 10,000 live births and fetal deaths.

(b) Estimated rate includes choanal atresia among fetal deaths, live births and TOP before 20 weeks reported by New South Wales, Victoria, Western Australia and South Australia per 10,000 live births and fetal deaths.

Reported rates of choanal atresia

Table 2.14.1: Number and rate of choanal atresia by outcome[(a)], Australia, 2002–2003

	2002		2003		2002–2003	
Outcome	**Number**	**Rate**	**Number**	**Rate**	**Number**	**Rate**
Live births(b)	25	1.0	15	0.6	40	0.8
Fetal deaths(c)	0	0.0	0	0.0	0	0.0
All births(d)	25	1.0	15	1.0	40	0.8

(a) Includes all births with at least 20 weeks of gestational age or at least 400 grams birthweight.

(b) For live births, the rate is per 10,000 live births.

(c) For fetal deaths, the rate is per 10,000 fetal deaths.

(d) For all births, the rate is per 10,000 live births and fetal deaths.

Table 2.14.2: Number and the estimated rate of choanal atresia by outcome, four Australian states[(a)], 2002–2003

	2002		2003		2002–2003	
Outcome	**Number**	**Rate**	**Number**	**Rate**	**Number**	**Rate**
Live births(b)	23	1.2	13	0.7	36	0.9
Fetal deaths(c)	0	0.0	0	0.0	0	0.0
All births(d)	23	1.2	13	0.7	36	0.9
Births and TOP(e)	23	1.2	13	0.7	36	0.9

(a) Includes data for New South Wales, Victoria, Western Australia and South Australia.

(b) For live births, the rate is per 10,000 live births.

(c) For fetal deaths, the rate is per 10,000 fetal deaths.

(d) For all births, the rate is per 10,000 live births and fetal deaths.

(e) Includes TOP at less than 20 weeks gestation and all births with at least 20 weeks of gestation or at least 400 grams birthweight.

Baby characteristics

Table 2.14.3: Births[(a)] with choanal atresia by baby characteristics, Australia, 2002–2003

Characteristic	Number	Per cent	Rate per 10,000 births
Sex			
Male	20	50.0	0.8
Female	19	47.5	0.8
Indeterminate/ Not stated	1	2.5	..
Gestational age (weeks)			
Less than 25	0	0.0	0.0
25–36	13	32.5	3.5
37+	27	67.5	0.6
Birthweight (grams)			
Less than 1500	3	7.5	4.0
1500 –2499	8	20.0	3.0
2,500+	29	72.5	0.6

(a) Includes all births with at least 20 weeks of gestation or at least 400 grams birthweight.

Maternal characteristics

Table 2.14.4: Number of women who gave birth to babies with choanal atresia, Australia, 2002–2003

	2002		2003		2002–2003	
	Number	Rate(a)	Number	Rate(a)	Number	Rate(a)
Women who gave birth	25	1.0	15	0.6	40	0.8

(a) The rate is per 10,000 women who gave birth.

Table 2.14.5: Reported number of pregnancies affected with choanal atresia and the estimated rate, four Australian states[(a)], 2002–2003

	2002		2003		2002–2003	
	Number	Rate(b)	Number	Rate(b)	Number	Rate(b)
Women who gave birth(c)	23	1.2	13	0.7	36	1.0
Women who gave birth or had a TOP(d)	23	1.2	13	0.7	36	1.0

(a) Includes data for New South Wales, Victoria, Western Australia and South Australia.

(b) The rate is per 10,000 women who gave birth.

(c) Includes women who gave birth to a baby with at least 20 weeks of gestation or at least 400 grams birthweight.

(d) Includes TOP at less than 20 weeks gestation and all births with at least 20 weeks of gestation or at least 400 grams birthweight.

Table 2.14.6: Maternal characteristics of births[(a)] with choanal atresia, Australia, 2002–2003

Characteristic	Number	Per cent	Rate[(e)]	Confidence intervals
Maternal age group				
Less than 20	1	2.5	0.4	0.0–2.5
20–24	4	10.0	0.5	0.1–1.4
25–29	10	25.0	0.7	0.3–1.3
30–34	15	37.5	0.9	0.5–1.5
35–39	9	22.5	1.2	0.5–2.2
40 and over	1	2.5	0.6	0.0–3.6
Indigenous status [(b)]				
Indigenous	0	0.0	..	..
Non-Indigenous	40	100.0	0.9	0.6–1.2
Remoteness Area				
Major cities	32	80.0	1.0	0.7–1.3
Regional	8	20.0	0.5	0.2–1.1
Remote	0	0.0	..	..
Country of birth [(c)]				
Australia	23	67.7	0.6	0.4–0.9
Asia	3	8.8	0.8	0.2–2.2
Other countries	8	23.5	..	..
Parity [(d)]				
Primiparous	15	53.6	1.1	0.6–1.9
Multiparous	13	46.4	0.7	0.4–1.2
Plurality				
Singleton	38	95.0	0.8	0.6–1.1
Multiple	2	5.0	2.4	0.3–8.6

(a) Includes all births with at least 20 weeks of gestation or at least 400 grams birthweight.

(b) Excludes data from Tasmania.

(c) Mother’s country of birth was classified using ASCCSS system. If the number of women affected was less than three in any country, those women were included under ‘Other countries’ category.

(d) Excludes data from New South Wales and Tasmania.

(e) The rate is per 10,000 women who gave birth.

15 Cleft palate without cleft lip

Description: A congenital anomaly characterised by a closure defect of the hard and/or soft palate behind the foramen incisivum without a cleft lip. This anomaly includes sub-mucous cleft palate, but excludes cleft palate with a cleft lip, a functional short palate and high narrow palate.

ICD-9-BPA codes: 749.00–749.09 ICD-10-AM codes: Q35.0–Q35.9

Cleft palate without cleft lip was reported in 8.1 per 10,000 births. This overall rate has increased to 9.1 when the rate was estimated using data from the four states that include TOP data. The reported number of fetal deaths or early terminations of pregnancy with this anomaly was small and these deaths or terminations could be due to other associated anomalies. However there was an increase in the number of notified pregnancies with cleft palate without cleft lip in 2003 (Figure 15). The data from four states providing information on TOP show that the estimated rate increased from 7.7 per 10,000 pregnancies in 2002 to 10.4 per 10,000 pregnancies in 2003 (Table 2.15.2).

The proportion of females with this anomaly was higher (56.9%) than males. This anomaly was seen in 52.7 per 10,000 babies born before 25 weeks of gestation. Of the babies who had this anomaly 83.0% were born at term and most of the babies (82.7%) had a birthweight of 2,500 grams or more (Table 2.15.3).

Women aged 40 years or older and women born in South Central America or the Caribbean region had the highest rates of affected births. Multiple births had a significantly higher rate of affected babies than singleton births (PR=1.9, CI 1.1–3.3). The rates did not differ significantly by Indigenous status or areas of residence (Table 2.15.6).

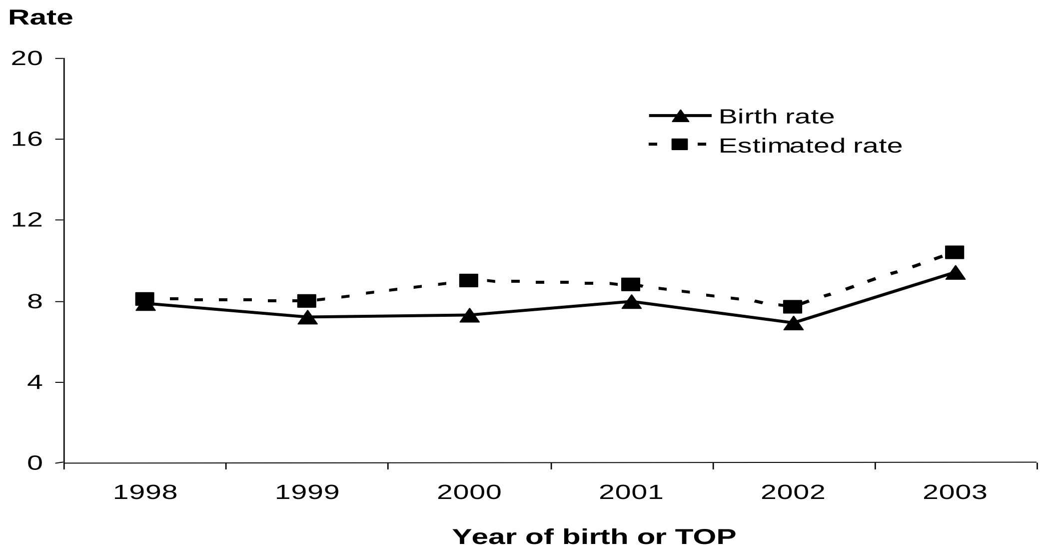

Figure 15: Rate of cleft palate without cleft lip among all births[(a)] and estimated rate[(b)], 1998–2003

(a) Birth rate includes cleft palate without cleft lip among live births and fetal deaths in Australia per 10,000 live births and fetal deaths.

(b) Estimated rate includes cleft palate without cleft lip among fetal deaths, live births and TOP before 20 weeks reported by New South Wales, Victoria, Western Australia and South Australia per 10,000 live births and fetal deaths.

Reported rates of cleft palate without cleft lip

Table 2.15.1: Number and rate of cleft palate without cleft lip by outcome[(a)], Australia, 2002–2003

	2002		2003		2002–2003	
Outcome	**Number**	**Rate**	**Number**	**Rate**	**Number**	**Rate**
Live births[(b)]	168	6.7	230	9.2	398	7.9
Fetal deaths[(c)]	6	35.8	7	39.2	13	37.6
All births[(d)]	174	6.9	237	9.4	411	8.1

(a) Includes all births with at least 20 weeks of gestational age or at least 400 grams birthweight.

(b) For live births, the rate is per 10,000 live births.

(c) For fetal deaths, the rate is per 10,000 fetal deaths.

(d) For all births, the rate is per 10,000 live births and fetal deaths.

Table 2.15.2: Number and the estimated rate of cleft palate without cleft lip by outcome, four Australian states [(a)], 2002–2003

	2002		2003		2002–2003	
Outcome	**Number**	**Rate**	**Number**	**Rate**	**Number**	**Rate**
Live births[(b)]	139	7.3	189	9.9	328	8.6
Fetal deaths[(c)]	6	47.5	7	50.9	13	49.3
All births[(d)]	145	7.6	196	10.2	341	8.9
Births and TOP[(e)]	147	7.7	201	10.4	348	9.1

(a) Includes data for New South Wales, Victoria, Western Australia and South Australia.

(b) For live births, the rate is per 10,000 live births.

(c) For fetal deaths, the rate is per 10,000 fetal deaths.

(d) For all births, the rate is per 10,000 live births and fetal deaths.

(e) Includes TOP at less than 20 weeks gestation and all births with at least 20 weeks of gestation or at least 400 grams birthweight.

Baby characteristics

Table 2.15.3: Births[(a)] with cleft palate without cleft lip by baby characteristics, Australia, 2002–2003

Characteristic	Number	Per cent	Rate per 10,000 births
Sex			
Male	177	43.1	6.8
Female	234	56.9	9.6
Gestational age (weeks)			
Less than 25	13	3.2	52.7
25–36	54	13.1	14.6
37+	341	83.0	7.3
Unknown	3	0.7	..
Birthweight (grams)			
Less than 1500	24	5.8	32.0
1500 –2499	46	11.2	17.2
2,500+	340	82.7	7.2

(a) Includes all births with at least 20 weeks of gestation or at least 400 grams birthweight.

Maternal characteristics

Table 2.15.4: Number of women who gave birth to babies with cleft palate without cleft lip, Australia, 2002–2003

	2002		2003		2002–2003	
	Number	Rate[(a)]	Number	Rate[(a)]	Number	Rate[(a)]
Women who gave birth	170	6.9	237	9.5	407	8.2

(a) The rate is per 10,000 women who gave birth.

Table 2.15.5: Reported number of pregnancies affected with cleft palate without cleft lip and the estimated rate, four Australian states[(a)], 2002–2003

	2002		2003		2002–2003	
	Number	Rate[(b)]	Number	Rate[(b)]	Number	Rate[(b)]
Women who gave birth[(c)]	142	7.5	196	10.4	338	9.0
Women who gave birth or had a TOP[(d)]	144	7.6	201	10.6	345	9.1

(a) Includes data for New South Wales, Victoria, Western Australia and South Australia.

(b) The rate is per 10,000 women who gave birth.

(c) Includes women who gave birth to a baby with at least 20 weeks of gestation or at least 400 grams birthweight.

(d) Includes TOP at less than 20 weeks gestation and all births with at least 20 weeks of gestation or at least 400 grams birthweight.

Table 2.15.6: Maternal characteristics of births[(a)] affected with cleft palate without cleft lip, Australia, 2002–2003

Characteristic	Number	Per cent	Rate[(e)]	Confidence intervals
Maternal age group				
Less than 20	16	4.0	7.1	4.1–11.5
20–24	72	17.8	9.8	7.6–12.3
25–29	103	25.4	7.4	6.0–8.9
30–34	120	29.6	7.2	5.9–8.6
35–39	73	18.0	9.5	7.5–12.0
40 and over	21	5.2	13.4	8.3–20.5
Indigenous status [(b)]				
Indigenous	16	4.0	10.8	6.1–17.5
Non-Indigenous	386	95.5	8.2	7.4–9.1
Not stated	2	0.5	..	..
Remoteness Area				
Major cities	285	70.7	8.5	7.5–9.5
Regional	109	27.1	7.4	6.1–9.0
Remote	9	2.2	7.0	3.2–13.3
Country of birth [(c)]				
Australia	280	68.8	7.3	6.5–8.2
New Zealand	7	1.7	5.5	2.2–11.4
United Kingdom	16	3.9	9.8	5.6–16.0
Middle East and North Africa	11	2.7	9.7	4.9–17.4
Asia	37	9.1	9.3	6.6–12.8
South Central America/Carribean	6	1.5	20.6	7.6–44.8
Other countries	12	2.9	..	..
Not stated	38	9.3	..	..
Parity [(d)]				
Primiparous	119	44.6	9.1	7.5–10.9
Multiparous	148	55.4	8.0	6.8–9.4
Plurality				
Singleton	394	96.8	8.1	7.3–8.9
Multiple	13	3.2	15.4	8.2–26.4

(a) Includes all births with at least 20 weeks of gestation or at least 400 grams birthweight.

(b) Excludes data from Tasmania.

(c) Mother's country of birth was classified using ASCCSS system. If the number of women affected was less than three in any country, those women were included under 'Other countries' category.

(d) Excludes data from New South Wales and Tasmania.

(e) The rate is per 10,000 women who gave birth.

16 Cleft lip with or without cleft palate

Description: A congenital anomaly characterised by a partial or complete clefting of the upper lip, with or without clefting of the alveolar ridge or the hard palate. Excludes a midline cleft of the upper or lower lip and an oblique facial fissure (going towards the eye).

ICD-9-BPA codes: 749.10–749.19, 749.20–749.29

ICD-10-AM codes: Q36.0, Q36.1, Q36.9, Q37.0–Q37.5, Q37.8, Q37.9

There were 9.2 per 10,000 births with cleft lip with or without cleft palate reported during the period 2002–2003 (Table 2.16.1) and this rate was steady over the six year period, 1998–2003 (Figure 16, Table 2.16.2). About 17% of the affected pregnancies were terminated in early pregnancy or resulted in fetal deaths. Most of the fetal deaths or terminations of pregnancy (95%) had multiple abnormalities.

This anomaly was more commonly seen in males than in females. Among the babies born before 25 weeks of gestation, 150 per 10,000 births had this anomaly. Most babies (80.0%) were born at term with a birthweight of 2,500 grams or more (Table 2.16.3).

Maternal age group was not associated with the anomaly. The rate of births with the anomaly was significantly higher among Indigenous women than non Indigenous women (PR=1.6, CI 1.01–2.4). The areas of residence, parity or plurality were not significantly different in these women (Table 2.16.6).

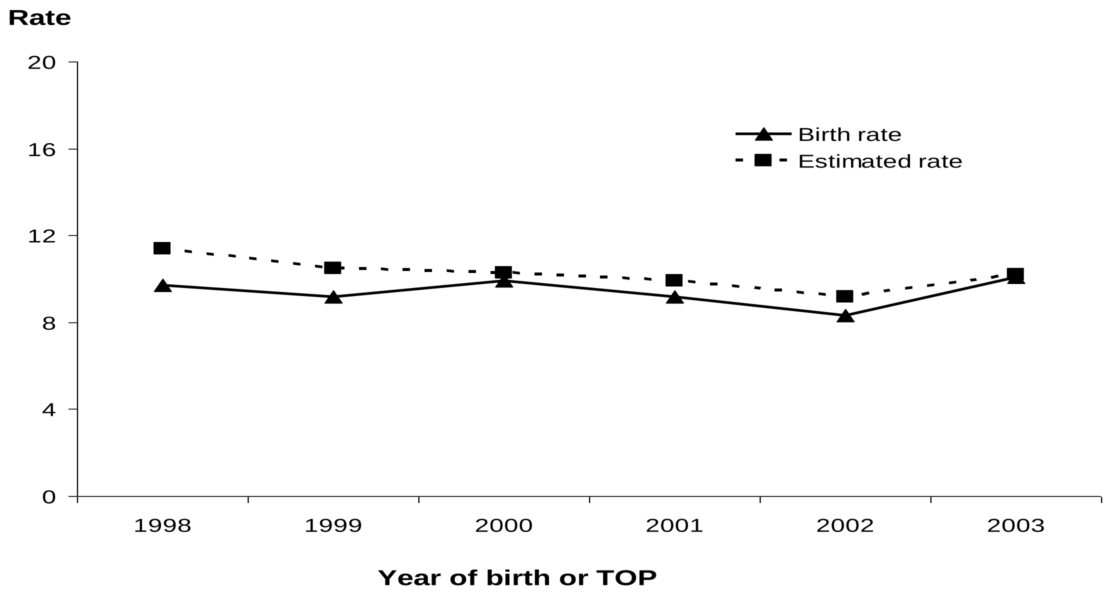

Figure 16: Rate of cleft lip with or without cleft palate among all births[(a)] and estimated rate[(b)], 1998–2003

(a) Birth rate includes cleft lip with or without cleft palate among live births and fetal deaths in Australia per 10,000 live births and fetal deaths.

(b) Estimated rate includes cleft lip with or without cleft palate among fetal deaths, live births and TOP before 20 weeks reported by New South Wales, Victoria, Western Australia and South Australia per 10,000 live births and fetal deaths.

Reported rates of cleft lip with or without cleft palate

Table 2.16.1: Number and rate of cleft lip with or without cleft palate by outcome[a], Australia, 2002–2003

	2002		2003		2002–2003	
Outcome	**Number**	**Rate**	**Number**	**Rate**	**Number**	**Rate**
Live births[b]	193	7.7	230	9.2	423	8.4
Fetal deaths[c]	15	89.4	26	145.7	41	118.4
All births[d]	208	8.3	256	10.1	464	9.2

(a) Includes all births with at least 20 weeks of gestational age or at least 400 grams birthweight.

(b) For live births, the rate is per 10,000 live births.

(c) For fetal deaths, the rate is per 10,000 fetal deaths.

(d) For all births, the rate is per 10,000 live births and fetal deaths.

Table 2.16.2: Number and the estimated rate of cleft lip with or without cleft palate by outcome, four Australian states[a], 2002–2003

	2002		2003		2002–2003	
Outcome	**Number**	**Rate**	**Number**	**Rate**	**Number**	**Rate**
Live births[b]	148	7.8	161	8.4	309	8.1
Fetal deaths[c]	14	110.8	25	181.8	39	147.8
All births[d]	162	8. 5	186	9.7	348	9.1
Births and TOP[e]	177	9.2	196	10.2	373	9.7

(a) Includes data for New South Wales, Victoria, Western Australia and South Australia.

(b) For live births, the rate is per 10,000 live births.

(c) For fetal deaths, the rate is per 10,000 fetal deaths.

(d) For all births, the rate is per 10,000 live births and fetal deaths.

(e) Includes TOP at less than 20 weeks gestation and all births with at least 20 weeks of gestation or at least 400 grams birthweight.

Baby characteristics

Table 2.16.3: Births[(a)] with cleft lip with or without cleft palate by baby characteristics, Australia, 2002–2003

Characteristic	Number	Percent	Rate per 10,000 births
Sex			
Male	295	63.6	11.4
Female	169	36.4	6.9
Gestational age (weeks)			
Less than 25	37	8.0	149.9
25–36	54	11.6	14.6
37+	371	80.0	8.0
Unknown	2	0.4	..
Birthweight (grams)			
Less than 1500	47	10.1	62.7
1500 –2499	40	8.6	14.9
2,500+	374	80.6	8.0
Unknown	3	0.7	..

(a) Includes all births with at least 20 weeks of gestation or at least 400 grams birthweight.

Maternal characteristics

Table 2.16.4: Number of women who gave birth to babies with cleft lip with or without cleft palate, Australia, 2002–2003

	2002		2003		2002–2003	
	Number	Rate[(a)]	Number	Rate[(a)]	Number	Rate[(a)]
Women who gave birth	204	8.3	254	10.2	458	9.2

(a) The rate is per 10,000 women who gave birth.

Table 2.16.5: Reported number of pregnancies affected with cleft lip with or without cleft palate and the estimated rate, four Australian states[(a)], 2002–2003

	2002		2003		2002–2003	
	Number	Rate[(b)]	Number	Rate[(b)]	Number	Rate[(b)]
Women who gave birth[(c)]	158	8.4	185	9.8	343	9.1
Women who gave birth or had a TOP[(d)]	173	9.2	195	10.3	368	9.7

(a) Includes data for New South Wales, Victoria, Western Australia and South Australia.

(b) The rate is per 10,000 women who gave birth.

(c) Includes women who gave birth to a baby with at least 20 weeks of gestation or at least 400 grams birthweight.

(d) Includes TOP at less than 20 weeks gestation and all births with at least 20 weeks of gestation or at least 400 grams birthweight.

Table 2.16.6: Maternal characteristics of births[(a)] affected with cleft lip with or without cleft palate, Australia, 2002–2003

Characteristic	Number	Per cent	Rate[(e)]	Confidence intervals
Maternal age group				
Less than 20	24	5.3	10.6	6.8–15.8
20–24	83	18.2	11.3	9.0–13.9
25–29	135	29.6	9.7	8.1–11.4
30–34	122	26.8	7.3	6.1–8.7
35–39	75	16.5	9.8	7.7–12.2
40 and over	17	3.7	10.9	6.3–17.4
Indigenous status [(b)]				
Indigenous	21	4.7	14.1	8.7–21.6
Non-Indigenous	424	95.1	9.0	8.2–9.9
Not stated	1	0.2	..	..
Remoteness Area				
Major cities	292	65.5	8.7	7.7–9.7
Regional	139	31.2	9.5	8.0–11.2
Remote	14	3.1	10.9	6.0–18.3
Not stated	1	0.2	..	..
Country of birth [(c)]				
Australia	343	74.9	9.0	8.0–10.0
United Kingdom	16	3.5	9.8	5.6–16.0
Europe	7	1.5	5.3	2.1–11.0
Middle East and North Africa	4	0.9	3.5	1.0–9.0
Asia	36	7.9	9.1	6.3–12.5
Africa (excluding North Africa)	7	1.5	12.3	4.9–25.3
Other countries	9	2.0	..	..
Not stated	36	7.9	..	..
Parity [(d)]				
Primiparous	123	39.5	9.4	7.8–11.2
Multiparous	185	59.5	10.0	8.6–11.6
Not stated	3	1.1	..	..
Plurality				
Singleton	448	97.8	9.2	8.4–10.1
Multiple	10	2.2	11.9	5.7–21.8

(a) Includes all births with at least 20 weeks of gestation or at least 400 grams birthweight.

(b) Excludes data from Tasmania.

(c) Mother's country of birth was classified using ASCCSS system. If the number of women affected was less than three in any country, those women were included under 'Other countries' category.

(d) Excludes data from New South Wales and Tasmania.

(e) The rate is per 10,000 women who gave birth.

17 Oesophageal atresia/stenosis

Description: A congenital anomaly characterised by the absence of continuity or narrowing of the oesophagus, with or without tracheal fistula, including tracheoesophageal fistula with or without mention of atresia or stenosis of oesophagus.

ICD-9-BPA codes: 750.30– 750.38 ICD-10-AM codes: Q39.0–Q39.3

The reported rate of oesophageal atresia during 2002–2003 was 2.0 per 10,000 births (Table 2.17.1). The overall rate hasn't been changed since 1998 (Figure 17). The information from states providing early termination data shows that nearly a quarter (23.5%) of affected pregnancies were terminated or resulted in fetal deaths.

More males (58.6%) than females were affected with this anomaly. More than half (56.6%) were born at term with a birthweight of 2,500 grams or more (Table 2.17.3).

Women aged 40 years or older had the highest rate of affected pregnancies. Multiparous women had a significantly lower rate of births with this anomaly than primiparous women (PR=0.5, CI 0.3–0.7). Indigenous women had a lower rate of affected pregnancies than non-Indigenous women, but the difference was not significant. The rates did not differ by areas of residence or with multiple births (Table 2.17.6).

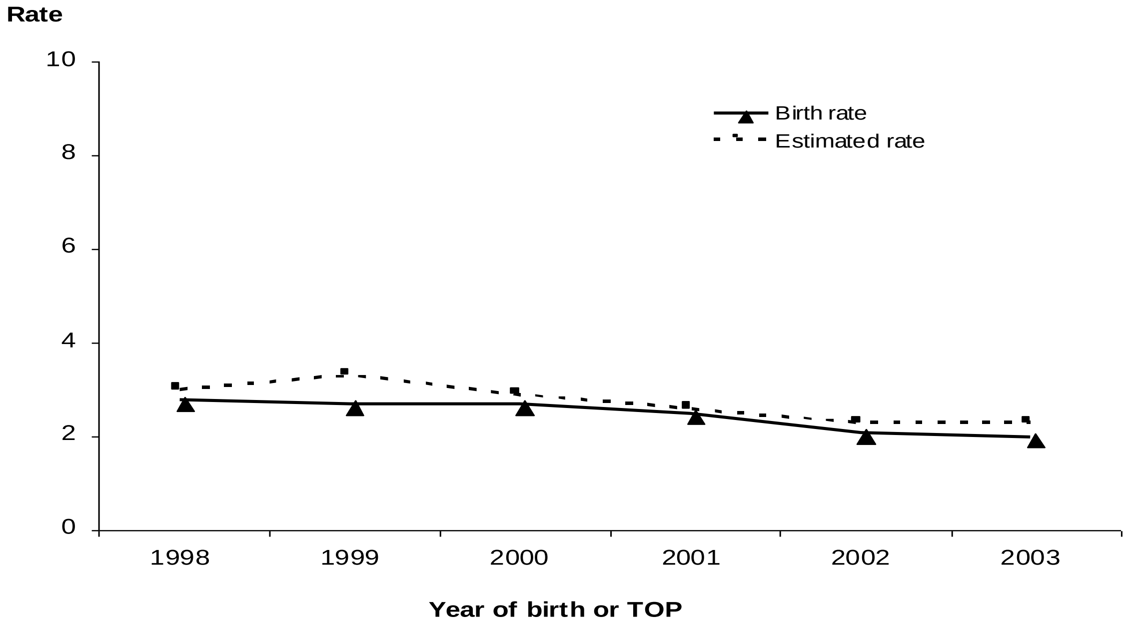

Figure 17: Rate of oesophageal atresia/stenosis among all births[(a)] and estimated rate[(b)], 1998–2003

(a) Birth rate includes oesophageal atresia /stenosis among live births and fetal deaths in Australia per 10,000 live births and fetal deaths.

(b) Estimated rate includes oesophageal atresia /stenosis among fetal deaths, live births and TOP before 20 weeks reported by New South Wales, Victoria, Western Australia and South Australia per 10,000 live births and fetal deaths.

Reported rates of oesophageal atresia/stenosis

Table 2.17.1: Number and rate of oesophageal atresia/stenosis by outcome[a], Australia, 2002–2003

	2002		2003		2002–2003	
Outcome	**Number**	**Rate**	**Number**	**Rate**	**Number**	**Rate**
Live births[b]	42	1.7	42	1.7	84	1.7
Fetal deaths[c]	9	53.7	6	33.6	15	43.3
All births[d]	51	2.0	48	1.9	99	2.0

(a) Includes all births with at least 20 weeks of gestational age or at least 400 grams birthweight.

(b) For live births, the rate is per 10,000 live births.

(c) For fetal deaths, the rate is per 10,000 fetal deaths.

(d) For all births, the rate is per 10,000 live births and fetal deaths.

Table 2.17.2: Number and the estimated rate of oesophageal atresia/stenosis by outcome, four Australian states[a], 2002–2003

	2002		2003		2002–2003	
Outcome	**Number**	**Rate**	**Number**	**Rate**	**Number**	**Rate**
Live births[b]	31	1.6	35	1.8	66	1.7
Fetal deaths[c]	7	55.4	5	36.4	12	45.5
All births[d]	38	2.0	40	2.1	78	2.0
Births and TOP[e]	43	2.2	43	2.2	86	2.2

(a) Includes data for New South Wales, Victoria, Western Australia and South Australia.

(b) For live births, the rate is per 10,000 live births.

(c) For fetal deaths, the rate is per 10,000 fetal deaths.

(d) For all births, the rate is per 10,000 live births and fetal deaths.

(e) Includes TOP at less than 20 weeks gestation and all births with at least 20 weeks of gestation or at least 400 grams birthweight.

Baby characteristics

Table 2.17.3: Births[a] with oesophageal atresia/stenosis by baby characteristics, Australia, 2002–2003

Characteristic	Number	Percent	Rate per 10,000 births
Sex			
Male	58	58.6	2.2
Female	41	41.4	1.7
Gestational age (weeks)			
Less than 25	9	9.1	36.5
25–36	34	34.3	9.2
37+	56	56.6	1.2
Birthweight (grams)			
Less than 1500	15	15.2	20.0
1500 –2499	29	29.3	10.8
2,500+	54	54.6	1.2
Unknown	1	1.0	..

(a) Includes all births with at least 20 weeks of gestation or at least 400 grams birthweight.

Maternal characteristics

Table 2.17.4: Number of women who gave birth to babies with oesophageal atresia/stenosis, Australia, 2002–2003

	2002		2003		2002–2003	
	Number	Rate[a]	Number	Rate[a]	Number	Rate[a]
Women who gave birth	49	2.0	48	1.9	97	2.0

(a) The rate is per 10,000 women who gave birth.

Table 2.17.5: Reported number of pregnancies affected with oesophageal atresia/stenosis and the estimated rate, four Australian states[a], 2002–2003

	2002		2003		2002–2003	
	Number	Rate[b]	Number	Rate[b]	Number	Rate[b]
Women who gave birth[c]	37	2.0	40	2.1	77	2.0
Women who gave birth or had a TOP[d]	42	2.2	43	2.3	85	2.3

(a) Includes data for New South Wales, Victoria, Western Australia and South Australia.

(b) The rate is per 10,000 women who gave birth.

(c) Includes women who gave birth to a baby with at least 20 weeks of gestation or at least 400 grams birthweight.

(d) Includes TOP at less than 20 weeks gestation and all births with at least 20 weeks of gestation or at least 400 grams birthweight.

Table 2.17.6: Maternal characteristics of births[(a)] affected with oesophageal atresia/stenosis, Australia, 2002–2003

Characteristic	Number	Per cent	Rate[(e)]	Confidence intervals
Maternal age group				
Less than 20	2	2.1	0.9	0.1–3.2
20–24	15	15.5	2.0	1.1–3.4
25–29	25	25.8	1.8	1.2–2.6
30–34	30	30.9	1.8	1.2–2.6
35–39	19	19.6	2.5	1.5–3.9
40 and over	6	6.2	3.8	1.4–8.3
Indigenous status [(b)]				
Indigenous	1	1.0	0.7	0.7–3.7
Non-Indigenous	95	97.9	2.0	1.6–2.5
Not stated	1	1.0	..	..
Remoteness Area				
Major cities	67	69.1	2.0	1.5–2.5
Regional	26	26.8	1.8	1.2–2.6
Remote	4	4.1	3.1	0.8–8.0
Country of birth [(c)]				
Australia	64	66.0	1.7	1.3–2.1
United Kingdom	3	3.1	1.8	0.4–5.4
Europe	3	3.1	2.3	0.5–6.7
Asia	8	8.3	2.0	0.9–4.0
Other countries	4	4.0	..	..
Not stated	15	15.5	..	..
Parity [(d)]				
Primiparous	46	61.3	3.5	2.6–4.7
Multiparous	29	38.7	1.6	1.1–2.3
Plurality				
Singleton	93	95.9	1.9	1.5–2.3
Multiple	4	4.1	4.8	1.3–12.2

(a) Includes all births with at least 20 weeks of gestation or at least 400 grams birthweight.

(b) Excludes data from Tasmania.

(c) Mother's country of birth was classified using ASCCSS system. If the number of women affected was less than three in any country, those women were included under 'Other countries' category.

(d) Excludes data from New South Wales and Tasmania.

(e) The rate is per 10,000 women who gave birth.

18 Small intestinal atresia/stenosis

Description: Complete or partial occlusion of the lumen of a segment of the small intestine. It can involve a single area or multiples areas of the duodenum, jejunum or ileum.

ICD-9-BPA codes: 751.10–751.19 ICD-10-AM codes: Q41.0-Q41.2

Small intestinal atresia/stenosis was reported in 2.4 per 10,000 births during the period 2002–2003 (Table 2.18.1). This rate has been steady since 1999 (Figure 18). Fetal deaths or early terminations of pregnancy were not common outcomes for small intestinal atresia/stenosis. Including information from the four states that provide TOP data, gives an estimated rate of 2.8 per 10,000 pregnancies (Table 2.18.2).

There was no difference in the proportion of male and female affected babies. Half of the babies (49.2%) with small intestinal atresia or stenosis were born pre-term. Half of the babies (52.5%) had a birthweight of 2,500 grams or more (Table 2.18.3).

There was no difference between maternal age groups of the affected babies. The rates did not differ by Indigenous status, parity, multiple births or areas of residence of women who gave birth to affected babies (Table 2.18.6).

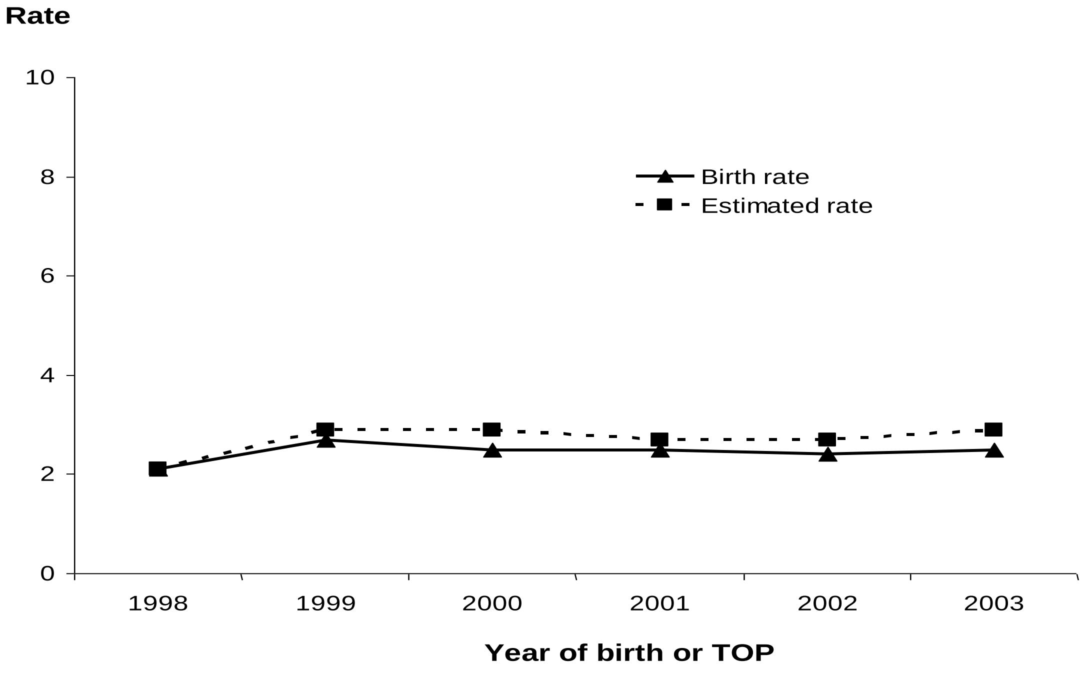

Figure 18: Rate of small intestinal atresia/stenosis among all births[(a)] and estimated rate[(b)], 1998–2003

(a) Birth rate includes small intestinal atresia/stenosis among live births and fetal deaths in Australia per 10,000 live births and fetal deaths.

(b) Estimated rate includes small intestinal atresia/stenosis among fetal deaths, live births and TOP before 20 weeks reported by New South Wales, Victoria, Western Australia and South Australia per 10,000 live births and fetal deaths.

Reported rates small intestinal atresia/stenosis

Table 2.18.1: Number and rate of small intestinal atresia/stenosis by outcome[(a)], Australia, 2002–2003

	2002		2003		2002–2003	
Outcome	**Number**	**Rate**	**Number**	**Rate**	**Number**	**Rate**
Live births(b)	52	2.1	58	2.3	110	2.2
Fetal deaths(c)	8	47.7	4	22.4	12	34.7
All births(d)	60	2.4	62	2.5	122	2.4

(a) Includes all births with at least 20 weeks of gestational age or at least 400 grams birthweight.

(b) For live births, the rate is per 10,000 live births.

(c) For fetal deaths, the rate is per 10,000 fetal deaths.

(d) For all births, the rate is per 10,000 live births and fetal deaths.

Table 2.18.2: Number and the estimated rate of small intestinal atresia/stenosis by outcome, four Australian states(a), 2002–2003

	2002		2003		2002–2003	
Outcome	**Number**	**Rate**	**Number**	**Rate**	**Number**	**Rate**
Live births(b)	42	2.2	49	2.6	91	2.4
Fetal deaths(c)	8	63.3	4	29.1	12	45.6
All births(d)	50	2.6	53	2.8	103	2.7
Births and TOP(e)	51	2.7	55	2.9	106	2.8

(a) Includes data for New South Wales, Victoria, Western Australia and South Australia.

(b) For live births, the rate is per 10,000 live births.

(c) For fetal deaths, the rate is per 10,000 fetal deaths.

(d) For all births, the rate is per 10,000 live births and fetal deaths.

(e) Includes TOP at less than 20 weeks gestation and all births with at least 20 weeks of gestation or at least 400 grams birthweight.

Baby characteristics

Table 2.18.3: Births[a] with small intestinal atresia/stenosis by baby characteristics, Australia, 2002–2003

Characteristic	Number	Per cent	Rate per 10,000 births
Sex			
Male	60	49.2	2.3
Female	62	50.8	2.5
Gestational age (weeks)			
Less than 25	5	4.1	20.3
25–36	55	45.1	14.9
37+	62	50.8	1.3
Birthweight (grams)			
Less than 1500	16	13.1	21.3
1500 –2499	40	32.8	14.9
2,500+	64	52.5	1.4
Unknown	2	1.6	..

(a) Includes all births with at least 20 weeks of gestation or at least 400 grams birthweight.

Maternal characteristics

Table 2.18.4: Number of women who gave birth to babies with small intestinal atresia/stenosis, Australia, 2002–2003

	2002		2003		2002–2003	
	Number	Rate[(a)]	Number	Rate[(a)]	Number	Rate[(a)]
Women who gave birth	59	2.4	61	2. 5	120	2.4

(a) The rate is per 10,000 women who gave birth.

Table 2.18.5: Reported number of pregnancies affected with small intestinal atresia/stenosis and the estimated rate, four Australian states[a], 2002–2003

	2002		2003		2002–2003	
	Number	Rate(b)	Number	Rate(b)	Number	Rate(b)
Women who gave birth(c)	49	2.6	52	2.8	101	2.7
Women who gave birth or had a TOP(d)	50	2.7	54	2.9	104	2.8

(a) Includes data for New South Wales, Victoria, Western Australia and South Australia.

(b) The rate is per 10,000 women who gave birth.

(c) Includes women who gave birth to a baby with at least 20 weeks of gestation or at least 400 grams birthweight.

(d) Includes TOP at less than 20 weeks gestation and all births with at least 20 weeks of gestation or at least 400 grams birthweight.

Table 2.18.6: Maternal characteristics of births[(a)] affected with small intestinal atresia/stenosis, Australia, 2002–2003

Characteristic	Number	Per cent	Rate[(e)]	Confidence intervals
Maternal age group				
Less than 20	6	5.1	2.7	1.0–5.8
20–24	16	13.6	2.2	1.2–3.5
25–29	23	19.5	1.6	1.5–2.5
30–34	48	40.7	2.9	2.1–3.8
35–39	20	17.0	2.6	1.6–4.0
40 and over	5	4.2	3.2	1.0–7.5
Indigenous status [(b)]				
Indigenous	4	3.4	2.7	0.7–6.9
Non-Indigenous	113	95.0	2.4	2.0–2.9
Not stated	2	1.7	..	..
Remoteness Area				
Major cities	81	68.1	2.4	1.9–3.0
Regional	36	30.2	2.5	1.7–3.4
Remote	2	1.7	1.6	0.2–5.6
Country of birth [(c)]				
Australia	89	74.2	2.3	1.9–2.9
United Kingdom	3	2.5	1.8	0.4–5.4
Europe	5	4.2	3.8	1.2–8.9
Middle East and North Africa	3	2.5	2.7	0.6–7.8
Asia	8	6.7	2.0	0.9–3.9
Other countries	2	1.7	..	..
Not stated	10	8.3	..	..
Parity [(d)]				
Primiparous	38	44.7	2.9	2.1–4.0
Multiparous	47	55.3	2.5	1.9–3.4
Plurality				
Singleton	117	97.5	2.4	2.0–2.9
Multiple	3	2.5	3.6	0.7–10.4

(a) Includes all births with at least 20 weeks of gestation or at least 400 grams birthweight.

(b) Excludes data from Tasmania.

(c) Mother's country of birth was classified using ASCCSS system. If the number of women affected was less than three in any country, those women were included under 'Other countries' category.

(d) Excludes data from New South Wales and Tasmania.

(e) The rate is per 10,000 women who gave birth.

19 Anorectal atresia/stenosis

Description: A congenital anomaly characterised by absence of continuity of the anorectal canal or of communication between rectum and anus, or narrowing of anal canal, with or without fistula to neighbouring organs. It excludes mild stenosis which does not need correction, and ectopic anus.

ICD-9-BPA codes: 751.20–751.24 ICD-10-AM codes: Q42.0–Q42.3

Anorectal atresia/stenosis was diagnosed in 3.1 per 10,000 births in 2002–2003 (Table 2.19.1). This rate was steady over the period 1998–2003 (Figure 19). The information provided by the four states that include TOP data shows that 25.7% of affected pregnancies were resulted in fetal deaths or terminations of pregnancy. The estimated rate was 3.6 per 10,000 pregnancies (Table 2.19.2).

More males (58.9%) than females were born with this anomaly. Two-thirds of the babies born were full term and had a birthweight of 2,500 grams or more (Table 2.19.3).

Women aged 40 years or older had the highest rate of affected births. Women who had multiple births had a significantly higher rate of births with this anomaly (PR=3.2, CI 1.6–6.5). The rates did not differ by Indigenous status, parity or areas of residence of women who had given birth to affected babies (Table 2.19.6).

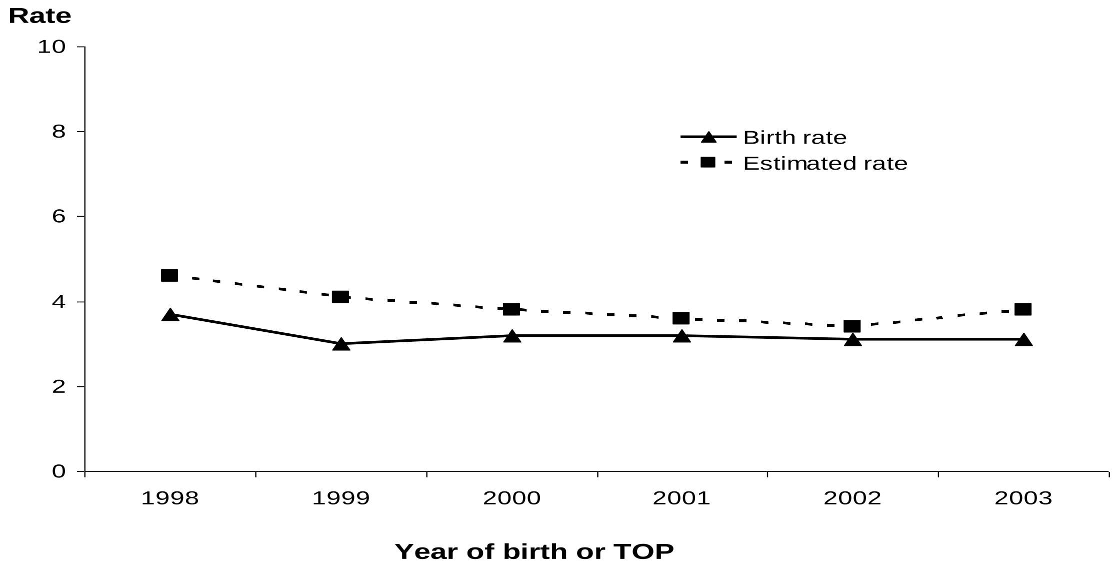

Figure 19: Rate of anorectal atresia/stenosis among all births[(a)] and estimated rate[(b)], 1998–2003

(a) Birth rate includes anorectal atresia/stenosis among live births and fetal deaths in Australia per 10,000 live births and fetal deaths.

(b) Estimated rate includes anorectal atresia/stenosis among fetal deaths, live births and TOP before 20 weeks reported by New South Wales, Victoria, Western Australia and South Australia per 10,000 live births and fetal deaths.

Reported rates of anorectal atresia/stenosis

Table 2.19.1: Number and rate of anorectal atresia/stenosis by outcome(a), Australia, 2002–2003

	2002		2003		2002–2003	
Outcome	**Number**	**Rate**	**Number**	**Rate**	**Number**	**Rate**
Live births(b)	71	2.8	69	2.7	140	2.8
Fetal deaths(c)	8	47.7	10	56.0	18	52.0
All births(d)	79	3.1	79	3.1	158	3.1

(a) Includes all births with at least 20 weeks of gestational age or at least 400 grams birthweight.

(b) For live births, the rate is per 10,000 live births.

(c) For fetal deaths, the rate is per 10,000 fetal deaths.

(d) For all births, the rate is per 10,000 live births and fetal deaths.

Table 2.19.2: Number and the estimated rate of anorectal atresia/stenosis by outcome, four Australian states(a), 2002–2003

	2002		2003		2002–2003	
Outcome	**Number**	**Rate**	**Number**	**Rate**	**Number**	**Rate**
Live births(b)	48	2.5	56	2.9	104	2.7
Fetal deaths(c)	6	47.5	10	72.8	16	60.6
All births(d)	54	2.8	66	3.4	120	3.1
Births and TOP(e)	66	3.4	74	3.8	140	3.6

(a) Includes data for New South Wales, Victoria, Western Australia and South Australia.

(b) For live births, the rate is per 10,000 live births.

(c) For fetal deaths, the rate is per 10,000 fetal deaths.

(d) For all births, the rate is per 10,000 live births and fetal deaths.

(e) Includes TOP at less than 20 weeks gestation and all births with at least 20 weeks of gestation or at least 400 grams birthweight.

Baby characteristics

Table 2.19.3: Births[(a)] with anorectal atresia/stenosis by baby characteristics, Australia, 2002–2003

Characteristic	Number	Per cent	Rate per 10,000 births
Sex			
Male	93	58.9	3.6
Female	63	39.9	2.6
Indeterminate	2	1.3	..
Gestational age (weeks)			
Less than 25	16	10.1	64.8
25–36	34	21.5	9.2
37+	106	67.1	2.3
Unknown	2	1.3	..
Birthweight (grams)			
Less than 1500	22	13.9	29.3
1500 –2499	31	19.6	11.6
2,500+	105	66.5	2.2

(a) Includes all births with at least 20 weeks of gestation or at least 400 grams birthweight.

Maternal characteristics

Table 2.19.4: Number of women who gave birth to babies with anorectal atresia/stenosis, Australia, 2002–2003

	2002		2003		2002–2003	
	Number	Rate[(a)]	Number	Rate[(a)]	Number	Rate[(a)]
Women who gave birth	78	3.2	75	3.0	153	3.1

(a) The rate is per 10,000 women who gave birth.

Table 2.19.5: Reported number of pregnancies affected with anorectal atresia/stenosis and the estimated rate, four Australian states[(a)], 2002–2003

	2002		2003		2002–2003	
	Number	Rate[(b)]	Number	Rate[(b)]	Number	Rate[(b)]
Women who gave birth[(c)]	54	2.9	62	3.3	116	3.1
Women who gave birth or had a TOP[(d)]	66	3.5	70	3.7	136	3.6

(a) Includes data for New South Wales, Victoria, Western Australia and South Australia.

(b) The rate is per 10,000 women who gave birth.

(c) Includes women who gave birth to a baby with at least 20 weeks of gestation or at least 400 grams birthweight.

(d) Includes TOP at less than 20 weeks gestation and all births with at least 20 weeks of gestation or at least 400 grams birthweight.

Table 2.19.6: Maternal characteristics of births[(a)] affected with anorectal atresia/stenosis, Australia, 2002–2003

Characteristic	Number	Per cent	Rate[(e)]	Confidence intervals
Maternal age group				
Less than 20	7	4.6	3.1	1.2–6.4
20–24	27	17.7	3.7	2.4–5.3
25–29	42	27.5	3.0	2.2–4.1
30–34	40	26.1	2.4	1.7–3.3
35–39	27	17.7	3.5	2.3–5.1
40 and over	10	6.5	6.4	3.1–11.8
Indigenous status [(b)]				
Indigenous	5	3.4	3.4	1.1–7.8
Non–Indigenous	144	96.6	3.1	2.6–3.6
Remoteness Area				
Major cities	102	68.5	3.0	2.5–3.7
Regional	43	28.9	2.9	2.1–4.0
Remote	3	2.0	2.3	0.5–6.8
Not stated	1	0.7	..	..
Country of birth [(c)]				
Australia	99	64.7	2.6	2.1–3.2
United Kingdom	9	5.9	5.5	2.5–10.5
Asia	20	13.1	5.0	3.1–7.8
North America	3	2.0	10.3	2.1–30.1
Africa (excluding North Africa)	4	2.6	7.0	1.9–17.9
Other countries	7	4.6	..	..
Not stated	11	7.2	..	..
Parity [(d)]				
Primiparous	53	44.2	4.1	3.0–5.3
Multiparous	67	55.8	3.6	2.8–4.6
Plurality				
Singleton	145	94.8	3.0	2.5–3.5
Multiple	8	5.2	9.5	4.1–18.7

(a) Includes all births with at least 20 weeks of gestation or at least 400 grams birthweight.

(b) Excludes data from Tasmania.

(c) Mother's country of birth was classified using ASCCSS system. If the number of women affected was less than three in any country, those women were included under 'Other countries' category.

(d) Excludes data from New South Wales and Tasmania.

(e) The rate is per 10,000 women who gave birth.

20 Hirschsprung's disease

Description: A condition characterised by partial or complete bowel obstruction resulting from absence of peristalsis in a segment of bowel due to an aganglionic section of the bowel.

ICD-9-BPA codes: 751.30–751.33 ICD-10-AM codes: Q43.1

There were 1.3 cases of Hirschsprung's disease per 10,000 births reported between 2002 and 2003 (Table 2.20.1). The rate has not changed since 1998 (Figure 20). There were no fetal deaths or terminations of pregnancy reported for this condition during this period (Table 2.20.1).

More than two-thirds (66.7%) of the babies born with this anomaly were males and most babies (88.9%) were born at term with birthweights of 2,500 grams or more (Table 2.20.3).

The highest rate of babies affected with Hirschsprung's disease was reported for mothers aged 40 years or older. Multiple births had a fourfold higher rate of births with this anomaly than singleton births which was statistically significant (PR=4, CI 1.5–11.0). The rates did not differ by other maternal characteristics such as Indigenous status, parity, or the areas of residence (Table 2.20.6).

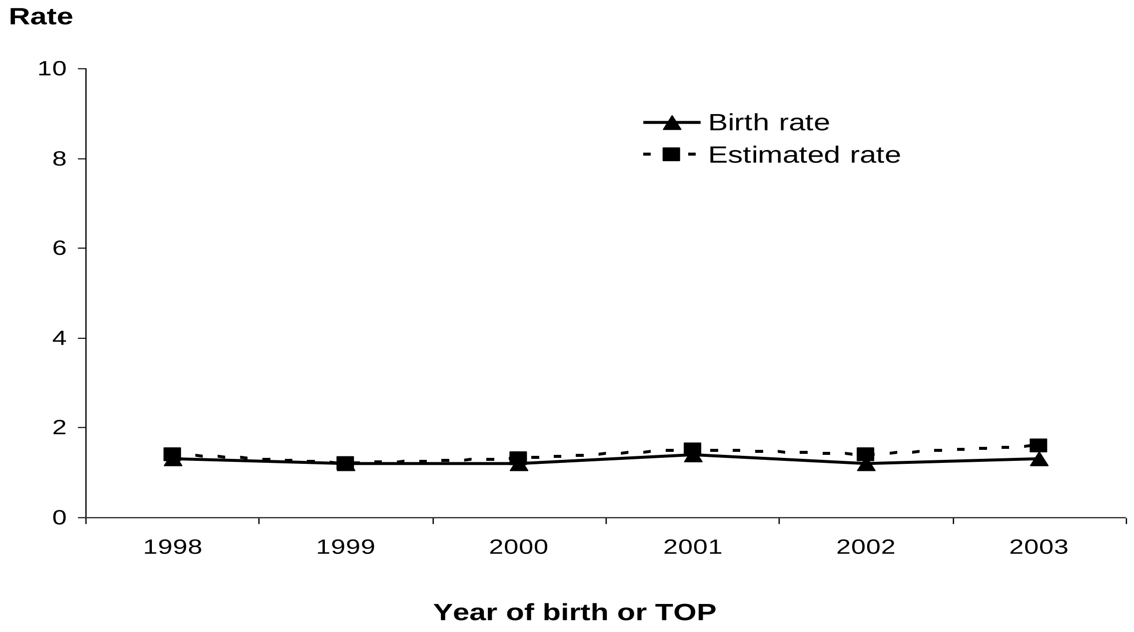

Figure 20: Rate of Hirschsprung's disease among all births[a] and estimated rate[b], 1998–2003

(a) Birth rate includes Hirschsprung's disease among live births and fetal deaths in Australia per 10,000 live births and fetal deaths.

(b) Estimated rate includes Hirschsprung's disease among fetal deaths, live births and TOP before 20 weeks reported by New South Wales, Victoria, Western Australia and South Australia per 10,000 live births and fetal deaths.

Reported rates of Hirschsprung's disease

Table 2.20.1: Number and rate of Hirschsprung's disease by outcome[(a)], Australia, 2002–2003

	2002		2003		2002–2003	
Outcome	**Number**	**Rate**	**Number**	**Rate**	**Number**	**Rate**
Live births[(b)]	31	1.2	32	1.3	63	1.3
Fetal deaths[(c)]	0	0.0	0	0.0	0	0.0
All births[(d)]	31	1.2	32	1.3	63	1.3

(a) Includes all births with at least 20 weeks of gestational age or at least 400 grams birthweight.

(b) For live births, the rate is per 10,000 live births.

(c) For fetal deaths, the rate is per 10,000 fetal deaths.

(d) For all births, the rate is per 10,000 live births and fetal deaths.

Table 2.20.2: Number and the estimated rate of Hirschsprung's disease by outcome, four Australian states[(a)], 2002–2003

	2002		2003		2002–2003	
Outcome	**Number**	**Rate**	**Number**	**Rate**	**Number**	**Rate**
Live births[(b)]	26	1.4	30	1.6	56	1.5
Fetal deaths[(c)]	0	0.0	0	0.0	0	0.0
All births[(d)]	26	1.4	30	1.6	56	1.5
Births and TOP[(e)]	26	1.4	30	1.6	56	1.5

(a) Includes data for New South Wales, Victoria, Western Australia and South Australia.

(b) For live births, the rate is per 10,000 live births.

(c) For fetal deaths, the rate is per 10,000 fetal deaths.

(d) For all births, the rate is per 10,000 live births and fetal deaths.

(e) Includes TOP at less than 20 weeks gestation and all births with at least 20 weeks of gestation or at least 400 grams birthweight.

Baby characteristics

Table 2.20.3: Births[(a)] with Hirschsprung's disease by baby characteristics, Australia, 2002–2003

Characteristic	Number	Per cent	Rate per 10,000 births
Sex			
Male	42	66.7	1.6
Female	21	33.3	0.9
Gestational age (weeks)			
Less than 25	0	0.0	0.0
25–36	6	9.5	1.6
37+	56	88.9	1.2
Unknown	1	1.6	..
Birthweight (grams)			
Less than 1500	1	1.6	1.3
1500 –2499	8	12.7	3.0
2,500 +	53	84.1	1.1
Unknown	1	1.6	..

(a) Includes all births with at least 20 weeks of gestation or at least 400 grams birthweight.

Maternal characteristics

Table 2.20.4: Number of women who gave birth to babies with Hirschsprung's disease, Australia, 2002–2003

	2002		2003		2002–2003	
	Number	Rate[(a)]	Number	Rate[(a)]	Number	Rate[(a)]
Women who gave birth	30	1.2	32	1.3	62	1.3

(a) The rate is per 10,000 women who gave birth.

Table 2.20.5: Reported number of pregnancies affected with Hirschsprung's disease and the estimated rate, four Australian states[(a)], 2002–2003

	2002		2003		2002–2003	
	Number	Rate[(b)]	Number	Rate[(b)]	Number	Rate[(b)]
Women who gave birth[(c)]	25	1.3	30	1.6	55	1.5
Women who gave birth or had a TOP[(d)]	25	1.3	30	1.6	55	1.5

(a) Includes data for New South Wales, Victoria, Western Australia and South Australia.

(b) The rate is per 10,000 women who gave birth.

(c) Includes women who gave birth to a baby with at least 20 weeks of gestation or at least 400 grams birthweight.

(d) Includes TOP at less than 20 weeks gestation and all births with at least 20 weeks of gestation or at least 400 grams birthweight.

Table 2.20.6: Maternal characteristics of births[(a)] affected with Hirschsprung's disease, Australia, 2002–2003

Characteristic	Number	Per cent	Rate[(e)]	Confidence intervals
Maternal age group				
Less than 20	2	3.3	0.9	0.1–3.2
20–24	11	18.3	1.5	0.7–2.7
25–29	10	16.7	0.7	0.3–1.3
30–34	23	38.3	1.4	0.9–2.1
35–39	9	15.0	1.2	0.5–2.2
40 and over	5	8.3	3.2	1.0–7.5
Indigenous status [(b)]				
Indigenous	1	1.6	0.7	0.0–3.7
Non-Indigenous	59	95.2	1.3	1.0–1.6
Not stated	2	3.2	..	..
Remoteness Area				
Major cities	48	77.4	1.4	1.1–1.9
Regional	14	22.6	1.0	0.5–1.6
Remote	0	0.0	..	..
Country of birth [(c)]				
Australia	45	72.6	1.2	0.9–1.6
Asia	6	9.7	1.5	0.6–3.3
Other countries	4	6.5	..	..
Not stated	7	11.3	..	..
Parity [(d)]				
Primiparous	15	30.6	1.1	0.6–1.9
Multiparous	34	69.4	1.8	1.3–2.6
Plurality				
Singleton	58	93.6	1.2	0.9–1.5
Multiple	4	6.5	4.8	1.3–12.2

(a) Includes all births with at least 20 weeks of gestation or at least 400 grams birthweight.

(b) Excludes data from Tasmania.

(c) Mother's country of birth was classified using ASCCSS system. If the number of women affected was less than three in any country, those women were included under 'Other countries' category.

(d) Excludes data from New South Wales and Tasmania.

(e) The rate is per 10,000 women who gave birth.

21 Hypospadias

Description: A congenital anomaly characterised by the opening of the urethra on the ventral side of the penis, irrespective of the severity of the condition.

ICD-9-BPA codes: 752.60 ICD-10-AM codes: Q540–Q543, Q548, Q549

This condition is categorised as first degree when the urethral meatus opens on the glans penis, second degree when the urethra opens on the shaft and third degree when the urethra opens on the perineum. The national data collection does not receive the information on the severity of the condition. Therefore rates are given for all reported cases.

Hypospadias is the most common congenital anomaly reported to the national data collection and is limited to males. The overall rate of hypospadias was 23.8 per 10,000 all births or 46.4 per 10,000 male births (Table 2.21.1). The rate did not differ significantly when the early termination data from four states were included (47.5 per 10,000 male births) (Table 2.21.2).

Only 16% of the affected babies were born preterm and 83% had a birthweight of 2,500 grams or more (Table 2.21.3).

All maternal age groups had similar rates of affected births. The rate did not differ significantly among Indigenous and non-Indigenous women. Women who had multiple births had a significantly higher rate of births with hypospadias than women who had singleton births(PR=2.8, CI 2.1–3.7). The rate of births affected with this anomaly was significantly higher for primiparous women than for multiparous women (PR=1.2, CI 1.1–1.4). Women's areas of residence did not have a significant difference (Table 2.21.6).

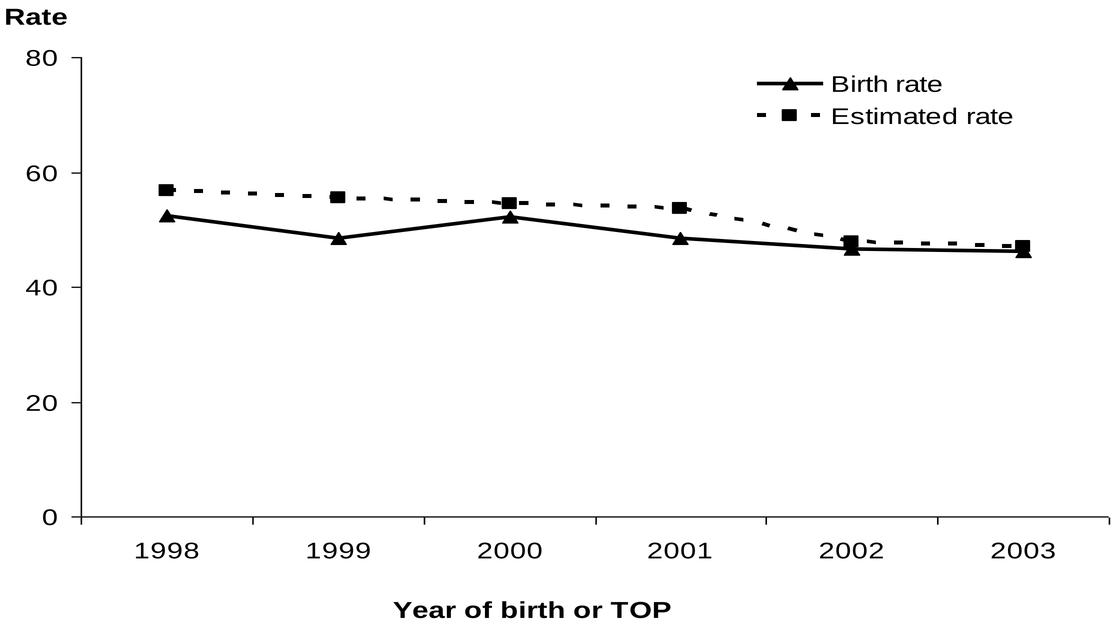

Figure 21: Rate of hypospadias among male births[(a)] and estimated rate[(b)], 1998–2003

(a) Birth rate includes all hypospadias among male live births and male fetal deaths in Australia per 10,000 male live births and male fetal deaths.

(b) Estimated rate includes all hypospadias among fetal deaths, live births and TOP before 20 weeks reported by New South Wales, Victoria, Western Australia and South Australia per 10,000 live births and fetal deaths.

Reported rates of hypospadias

Table 2.21.1: Number and rate of hypospadias by outcome[(a)], Australia, 2002–2003

	2002		2003		2002–2003	
Outcome	**Number**	**Rate**	**Number**	**Rate**	**Number**	**Rate**
Live births[(b)]	597	46.6	601	46.5	1198	46.5
Fetal deaths[(c)]	3	35.0	1	11.0	4	22.0
All births[(d)]	600	46.6	602	46.2	1202	46.4

(a) Includes all births with at least 20 weeks of gestational age or at least 400 grams birthweight.

(b) For live births, the rate is per 10,000 live births.

(c) For fetal deaths, the rate is per 10,000 fetal deaths.

(d) For all births, the rate is per 10,000 live births and fetal deaths.

Note : Rates are given per all male births and male fetal deaths.

Table 2.21.2: Number and the estimated rate of hypospadias by outcome, four Australian states[(a)], 2002–2003

	2002		2003		2002–2003	
Outcome	**Number**	**Rate**	**Number**	**Rate**	**Number**	**Rate**
Live births[(b)]	467	47.8	464	47.2	931	47.5
Fetal deaths[(c)]	2	31.0	1	14.0	3	22.0
All births[(d)]	469	47.7	465	47.0	934	47.3
Births and TOP[(e)]	471	47.9	466	47.1	937	47.5

(a) Includes data for New South Wales, Victoria, Western Australia and South Australia.

(b) For live births, the rate is per 10,000 male live births.

(c) For fetal deaths, the rate is per 10,000 male fetal deaths.

(d) For all births, the rate is per 10,000 male live births and male fetal deaths.

(e) Includes TOP at less than 20 weeks gestation and all births with at least 20 weeks of gestation or at least 400 grams birthweight.

Note : Rates are given per all male births and male fetal deaths.

Baby characteristics

Table 2.21.3: Births[a] with hypospadias by baby characteristics, Australia, 2002–2003

Characteristic	Number	Per cent	Rate per 10,000 births
Sex			
Male	1,197	99.7	46.2
Female	4	0.3	0.2
Gestational age (weeks)			
Less than 25	2	0.2	8.1
25–36	190	15.8	51.3
37+	1004	83.5	21.6
Unknown	6	0.5	..
Birthweight (grams)			
Less than 1500	52	4.3	69.4
1500 –2499	152	12.7	56.7
2,500+	997	83.0	21.2

(a) Includes all births with at least 20 weeks of gestation or at least 400 grams birthweight.

Maternal characteristics

Table 2.21.4: Number of women who gave birth to babies with hypospadias, Australia, 2002–2003

	2002		2003		2002–2003	
	Number	Rate[a]	Number	Rate[a]	Number	Rate[a]
Women who gave birth	591	23.9	591	23.7	1,182	23.8

(a) The rate is per 10,000 women who gave birth.

Table 2.21.5: Reported number of pregnancies affected withhypospadias and the estimated rate, four Australian states[a], 2002–2003

	2002		2003		2002–2003	
	Number	Rate[b]	Number	Rate[b]	Number	Rate[b]
Women who gave birth[c]	464	24.6	454	24.0	918	24.3
Women who gave birth or had a TOP[d]	466	24.7	455	24.0	921	24.4

(a) Includes data for New South Wales, Victoria, Western Australia and South Australia.

(b) The rate is per 10,000 women who gave birth.

(c) Includes women who gave birth to a baby with at least 20 weeks of gestation or at least 400 grams birthweight.

(d) Includes TOP at less than 20 weeks gestation and all births with at least 20 weeks of gestation or at least 400 grams birthweight.

Table 2.21.6: Maternal characteristics of births[a] affected with hypospadias, Australia, 2002–2003

Characteristic	Number	Per cent	Rate[e]	Confidence intervals
Maternal age group				
Less than 20	55	4.7	24.4	18.4–31.7
20–24	180	15.2	24.4	21.0–28.2
25–29	340	28.8	24.3	21.8–27.0
30–34	379	32.1	22.7	20.4–25.0
35–39	186	15.8	24.2	20.9–28.0
40 and over	40	3.4	25.6	18.3–34.8
Indigenous status [b]				
Indigenous	27	2.3	18.2	12.0–26.4
Non-Indigenous	1150	97.6	24.5	23.1–25.9
Remoteness Area				
Major cities	832	70.6	24.7	23.1–26.5
Regional	319	27.1	21.8	19.4–24.3
Remote	27	2.3	21.0	13.9–30.6
Country of birth [c]				
Australia	924	78.2	24.2	22.6–25.8
New Zealand	5	0.4	3.9	1.3–9.2
United Kingdom	46	3.9	28.3	20.7–37.7
Europe	24	2.0	18.3	11.7–27.3
Middle East and North Africa	25	2.1	22.1	14.3–32.6
Asia	58	4.9	14.6	11.1–18.9
North America	3	0.3	10.3	2.1–30.1
South Central America/Caribbean	6	0.5	20.6	7.6–44.8
Africa (excluding North Africa)	9	0.8	15.8	7.2–30.0
Other countries	8	0.7	..	..
Not stated	74	6.3	..	..
Parity [d]				
Primiparous	441	46.2	33.8	30.7–37.1
Multiparous	513	53.5	27.8	25.4–30.3
Not stated	3	0.3	..	..
Plurality				
Singleton	1,127	95.4	23.1	21.8–24.5
Multiple	54	4.6	64.1	48.2–83.6

(a) Includes all births with at least 20 weeks of gestation or at least 400 grams birthweight.

(b) Excludes data from Tasmania.

(c) Mother's country of birth was classified using ASCCSS system. If the number of women affected was less than three in any country, those women were included under 'Other countries' category.

(d) Excludes data from New South Wales and Tasmania.

(e) The rate is per 10,000 women who gave birth.

22 Epispadias

Description: A congenital anomaly characterised by the opening of the urethra on the dorsal surface of the penis. Not counted when part of exstrophy of the bladder.

ICD-9-BPA codes: 752.61 ICD-10-AM codes: Q64.0

Females also can have this type of anomaly when the urethra develops too far anteriorly, exiting in the clitoris or even more forward.

This condition is very rare and the overall rate of this anomaly was 0.3 per 10,000 births (Table 2.22.1). Fetal deaths were rare and reported cases could be due to other associated anomalies. No terminations of pregnancy were reported for epispadias (Table 2.22.2).

Nearly all births with this anomaly are males, but occasionally a female birth is reported. Most babies were born at term (88.2%) with a birthweight of 2,500 grams or more (Table 2.22.3).

All maternal age groups had similar rates of affected pregnancies. There were no Indigenous women among reported births with epispadias. Rates did not differ by women's areas of residence, parity or plurality (Table 2.22.6).

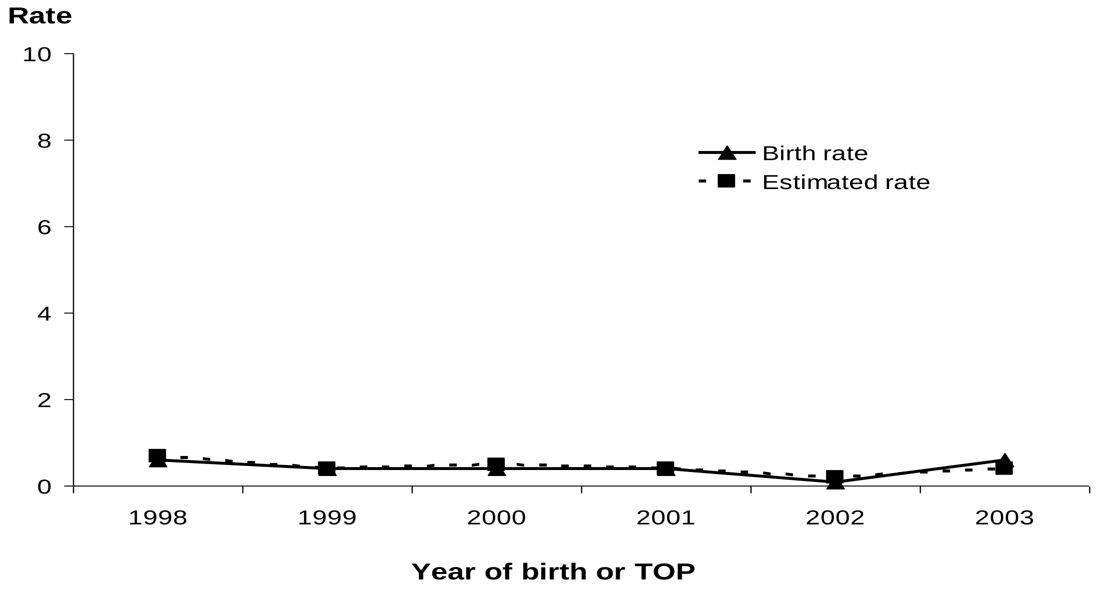

Figure 22: Rate of epispadias among all births(a) and estimated rate(b), 1998–2003

(a) Birth rate includes all epispadias among live births and fetal deaths in Australia per 10,000 live births and fetal deaths.

(b) Estimated rate includes all epispadias among fetal deaths, live births and TOP before 20 weeks reported by New South Wales, Victoria, Western Australia and South Australia per 10,000 live births and fetal deaths.

Reported rates of epispadias

Table 2.22.1: Number and rate of epispadias by outcome[a], Australia, 2002–2003

	2002		2003		2002–2003	
Outcome	**Number**	**Rate**	**Number**	**Rate**	**Number**	**Rate**
Live births[b]	3	0.1	13	0.5	16	0.3
Fetal deaths[c]	0	0.0	1	5.6	1	2.9
All births[d]	3	0.1	14	0.6	17	0.3

(a) Includes all births with at least 20 weeks of gestational age or at least 400 grams birthweight.

(b) For live births, the rate is per 10,000 live births.

(c) For fetal deaths, the rate is per 10,000 fetal deaths.

(d) For all births, the rate is per 10,000 live births and fetal deaths.

Table 2.22.2: Number and the estimated rate of epispadias by outcome, four Australian states[a], 2002–2003

	2002		2003		2002–2003	
Outcome	**Number**	**Rate**	**Number**	**Rate**	**Number**	**Rate**
Live births[b]	3	0.2	7	0.4	10	0.3
Fetal deaths[c]	0	0.0	1	7.3	1	3.8
All births[d]	3	0.2	8	0.4	11	0.3
Births and TOP[e]	3	0.2	8	0.4	11	0.3

(a) Includes data for New South Wales, Victoria, Western Australia and South Australia.

(b) For live births, the rate is per 10,000 live births.

(c) For fetal deaths, the rate is per 10,000 fetal deaths.

(d) For all births, the rate is per 10,000 live births and fetal deaths.

(e) Includes TOP at less than 20 weeks gestation and all births with at least 20 weeks of gestation or at least 400 grams birthweight.

Baby characteristics

Table 2.22.3: Births[a] with epispadias by baby characteristics, Australia, 2002–2003

Characteristic	Number	Percent	Rate per 10,000 births
Sex			
Male	16	94.1	0.6
Female	1	5.9	0.0
Gestational age (weeks)			
Less than 25	1	5.9	4.1
25–36	1	5.9	0.3
37+	15	88.2	0.3
Birthweight (grams)			
Less than 1500	2	11.8	2.7
1500 –2499	0	0.0	0.0
2,500+	15	88.2	0.3

(a) Includes all births with at least 20 weeks of gestation or at least 400 grams birthweight.

Maternal characteristics

Table 2.22.4: Number of women who gave birth to babies with epispadias, Australia, 2002–2003

	2002		2003		2002–2003	
	Number	Rate(a)	Number	Rate(a)	Number	Rate(a)
Women who gave birth	3	0.1	14	0.6	17	0.3

(a) The rate is per 10,000 women who gave birth.

Table 2.22.5: Reported number of pregnancies affected with epispadias and the estimated rate, four Australian states[a], 2002–2003

	2002		2003		2002–2003	
	Number	Rate(b)	Number	Rate(b)	Number	Rate(b)
Women who gave birth(c)	3	0.2	8	0.4	11	0.3
Women who gave birth or had a TOP(d)	3	0.2	8	0.4	11	0.3

(a) Includes data for New South Wales, Victoria, Western Australia and South Australia.

(b) The rate is per 10,000 women who gave birth.

(c) Includes women who gave birth to a baby with at least 20 weeks of gestation or at least 400 grams birthweight.

(d) Includes TOP at less than 20 weeks gestation and all births with at least 20 weeks of gestation or at least 400 grams birthweight.

Table 2.22.6: Maternal characteristics of births[(a)] with epispadias, Australia, 2002–2003

Characteristic	Number	Per cent	Rate[(e)]	Confidence intervals
Maternal age group				
Less than 20	2	11.8	0.9	0.1–3.2
20–24	2	11.8	0.3	0.0–1.0
25–29	6	35.3	0.4	0.2–0.9
30–34	3	17.7	0.2	0.0–0.5
35–39	4	23.5	0.5	0.1–1.3
Indigenous status (b)				
Indigenous	0	0.0	0.0	..
Non-Indigenous	16	100.0	0.3	0.2–0.6
Remoteness Area				
Major cities	11	68.8	0.3	0.2–0.6
Regional	5	31.3	0.3	0.1–0.8
Remote	0	0.0	..	..
Country of birth (c)				
Australia	12	70.6	0.3	0.2–0.5
Other countries	4	29.4	..	..
Parity (d)				
Primiparous	4	33.3	0.3	0.1–0.8
Multiparous	8	66.7	0.4	0.2–0.9
Plurality				
Singleton	16	94.1	0.3	0.2–0.5
Multiple	1	5.9	1.2	0.0–6.6

(a) Includes all births with at least 20 weeks of gestation or at least 400 grams birthweight.

(b) Excludes data from Tasmania.

(c) Mother's country of birth was classified using ASCCSS system. If the number of women affected was less than three in any country, those women were included under 'Other countries' category.

(d) Excludes data from New South Wales and Tasmania.

(e) The rate is per 10,000 women who gave birth.

23 Renal agenesis/dysgenesis

Description: A congenital anomaly characterised by unilateral or bilateral absence or dysplasia of kidneys.

ICD-9-BPA codes: 753.00–753.01 ICD-10-AM codes: Q60.0-Q60.6

Bilateral renal agenesis is uncommon and is fatal. It is characterised by failure of the kidneys to develop in the fetus. Unilateral renal agenesis is much more common, but is not usually of any major concern, if the other kidney is healthy.

During the period 2002–2003, renal agenesis/dysgenesis was reported in 4.9 per 10,000 births (Table 2.23.1). The data provided by the four states that include TOP data show that 30.7%of affected pregnancies were resulted in fetal deaths or terminations in early pregnancy. The rate has slightly declined from 1998–2003 (Figure 23). The estimated rate of renal agenesis and dysgenesis increased from 4.8 per 10,000 births to 5.6 per 10,000 pregnancies when the TOP data were included (Table 2.23.2).

Nearly two-thirds (64.6%) of the births with this anomaly were males. The rate of renal agenesis and dysgenesis was 162 per 10,000 among the babies born before 25 weeks gestation. About one-third of affected births were preterm and two-thirds of the births had birthweights of 2,500 grams or more (Table 2.23.3).

The highest rate of births with renal agenesis was seen among teenage pregnancies. The rate fluctuated among other age groups. Women who had multiple births had a significantly higher rate of babies with this anomaly than the singleton births (PR=3.3, CI 1.9–5.7). The rates did not differ by Indigenous status, areas of residence or parity (Table 2.23.6).

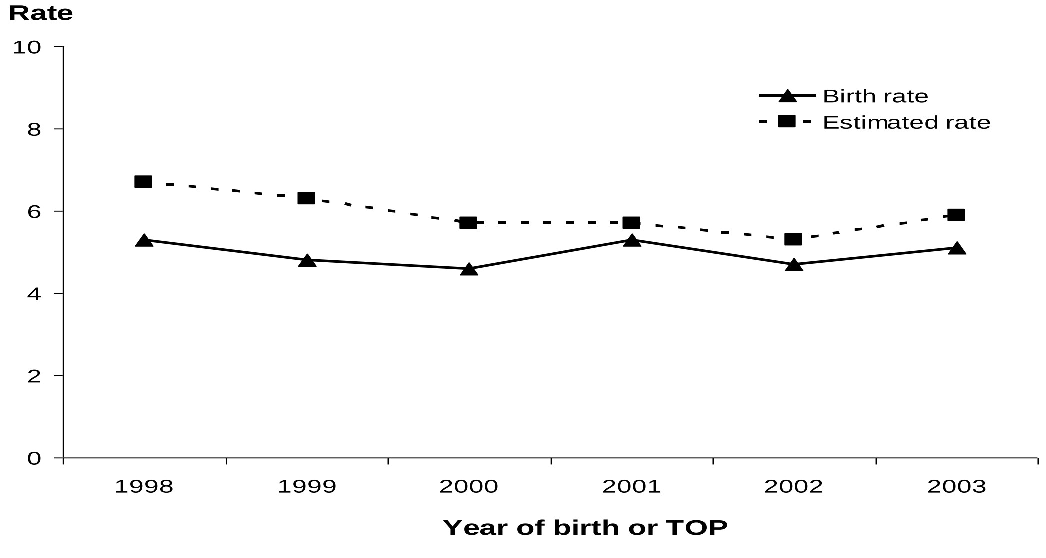

Figure 23: Rate of renal agenesis and dysgenesis among all births[(a)] and estimated rate[(b)], 1998–2003

(a) Birth rate includes all renal agenesis and dysgenesis among live births and fetal deaths in Australia per 10,000 live births and fetal deaths.

(b) Estimated rate includes all renal agenesis and dysgenesis among fetal deaths, live births and TOP before 20 weeks reported by New South Wales, Victoria, Western Australia and South Australia per 10,000 live births and fetal deaths.

Reported rates of renal agenesis/dysgenesis

Table 2.23.1: Number and rate of renal agenesis/dysgenesis by outcome(a), Australia, 2002–2003

	2002		2003		2002–2003	
Outcome	**Number**	**Rate**	**Number**	**Rate**	**Number**	**Rate**
Live births(b)	105	4.2	98	3.9	203	4.1
Fetal deaths(c)	14	83.5	30	168.1	44	127.1
All births(d)	119	4.7	128	5.1	247	4.9

(a) Includes all births with at least 20 weeks of gestational age or at least 400 grams birthweight.

(b) For live births, the rate is per 10,000 live births.

(c) For fetal deaths, the rate is per 10,000 fetal deaths.

(d) For all births, the rate is per 10,000 live births and fetal deaths.

Table 2.23.2: Number and the estimated rate of renal agenesis/dysgenesis by outcome, four Australian states(a), 2002–2003

	2002		2003		2002–2003	
Outcome	**Number**	**Rate**	**Number**	**Rate**	**Number**	**Rate**
Live births(b)	77	4.0	72	3.8	149	3.9
Fetal deaths(c)	11	87.0	24	174. 5	35	133.2
All births(d)	88	4.6	96	5.0	184	4.8
Births and TOP(e)	102	5.3	113	5.9	215	5.6

(a) Includes data for New South Wales, Victoria, Western Australia and South Australia.

(b) For live births, the rate is per 10,000 live births.

(c) For fetal deaths, the rate is per 10,000 fetal deaths.

(d) For all births, the rate is per 10,000 live births and fetal deaths.

(e) Includes TOP at less than 20 weeks gestation and all births with at least 20 weeks of gestation or at least 400 grams birthweight.

Baby characteristics

Table 2.23.3: Births[(a)] with renal agenesis/dysgenesis cases by baby characteristics, Australia, 2002–2003

Characteristic	Number	Per cent	Rate per 10,000 births
Sex			
Male	159	64.6	6.1
Female	85	34.6	3.5
Indeterminate/ Not stated	2	0.8	..
Gestational age[(a)] (weeks)			
Less than 25	40	16.2	162.1
25–36	41	16.6	11.1
37+	164	66.4	3.5
Unknown	2	0.8	..
Birthweight (grams)			
Less than 1500	49	19.9	65.4
1500 –2499	34	13.8	12.7
2,500+	163	66.3	3.5

(a) Includes all births with at least 20 weeks of gestation or at least 400 grams birthweight.

Maternal characteristics

Table 2.23.4: Number of women who gave birth to babies with renal agenesis/dysgenesis, Australia 2002–2003

	2002		2003		2002–2003	
	Number	Rate[(a)]	Number	Rate[(a)]	Number	Rate[(a)]
Women who gave birth	116	4.7	126	5.1	242	4.9

(a) The rate is per 10,000 women who gave birth.

Table 2.23.5: Reported number of pregnancies affected with renal agenesis/dysgenesis and the estimated rate, four Australian states[(a)], 2002–2003

	2002		2003		2002–2003	
	Number	Rate[(b)]	Number	Rate[(b)]	Number	Rate[(b)]
Women who gave birth[(c)]	86	4.6	94	5.0	180	4.8
Women who gave birth or had a TOP[(d)]	100	5.3	111	5.9	211	5.6

(a) Includes data for New South Wales, Victoria, Western Australia and South Australia.

(b) The rate is per 10,000 women who gave birth.

(c) Includes women who gave birth to a baby with at least 20 weeks of gestation or at least 400 grams birthweight.

(d) Includes TOP at less than 20 weeks gestation and all births with at least 20 weeks of gestation or at least 400 grams birthweight.

Table 2.23.6: Maternal characteristics of births[(a)] affected with renal agenesis/dysgenesis, Australia, 2002–2003

Characteristic	Number	Per cent	Rate[(e)]	Confidence intervals
Maternal age group				
Less than 20	14	5.8	6.2	3.4–10.4
20–24	41	17.0	5.6	4.0–7.5
25–29	69	28.6	4.9	3.8–6.2
30–34	70	29.1	4.2	3.3–5.3
35–39	41	17.0	5.3	3.8–7.2
40 and over	6	2.5	3.8	1.4–8.3
Indigenous status [(b)]				
Indigenous	5	2.1	3.4	1.1–7.8
Non-Indigenous	228	97.4	4.9	4.2–5.5
Not stated	1	0.4	..	..
Remoteness Area				
Major cities	165	70.5	4.9	4.2–5.7
Regional	64	27.4	4.4	3.4–5.6
Remote	5	2.1	3.9	1.3–9.1
Country of birth [(c)]				
Australia	183	75.6	4.8	4.1–5.5
United Kingdom	7	2.9	4.3	1.7–8.9
Europe	6	2.5	4.6	1.7–9.9
Asia	14	5.8	3.5	1.9–5.9
Other countries	8	3.3	..	..
Not stated	24	9.9	..	..
Parity [(d)]				
Primiparous	76	39.6	5.8	4.6–7.3
Multiparous	116	60.4	6.3	5.2–7.5
Plurality				
Singleton	228	94.6	4.7	4.1–5.3
Multiple	13	5.4	15.4	8.2–26.4

(a) Includes all births with at least 20 weeks of gestation or at least 400 grams birthweight.

(b) Excludes data from Tasmania.

(c) Mother’s country of birth was classified using ASCCSS system. If the number of women affected was less than three in any country, those women were included under ‘Other countries’ category.

(d) Excludes data from New South Wales and Tasmania.

(e) The rate is per 10,000 women who gave birth.

24 Cystic kidney

Description: A congenital anomaly characterised by multiple cysts in the kidney. Include infantile polycystic kidney, multicystic kidney, other forms of cystic kidney and unspecified cystic kidney.

ICD-9-BPA codes: 753.10–753.18 ICD-10-AM codes: Q61.0-Q61.5

Cystic kidneys were reported in 4.6 per 10,000 births during 2002–2003 (Table 2.24.1). This rate was constant during the 1998-2003 (Figure 24). Information provided from the four states that include TOP data shows that 5.3 per 10,000 pregnancies were affected by this anomaly (Table 2.24.2). About 29.6% of the affected pregnancies were managed by early terminations of pregnancy or resulted in fetal deaths.

There were more males (58.5%) than females with cystic kidneys. Among babies born before 25 weeks of gestation, 142 per 10,000 births were affected with cystic kidneys. More than 38% of births were preterm and 33.6% had a birthweight lower than 2,500 grams (Table 2.24.3).

The highest rate of cystic kidneys was seen among babies of women aged 40 years or older. Only 1.4% of affected women identified themselves as Indigenous in these two years. Non-Indigenous women had a higher rate of affected births than Indigenous women, but the difference was not statistically significant. Women who had multiple births had a significantly higher rate of births with cystic kidneys (PR=3.3, CI 1.9–5.9). The rate was highest among women born in South Central America/Caribbean. The rates did not differ by women's areas of residence or parity (Table 2.24.6).

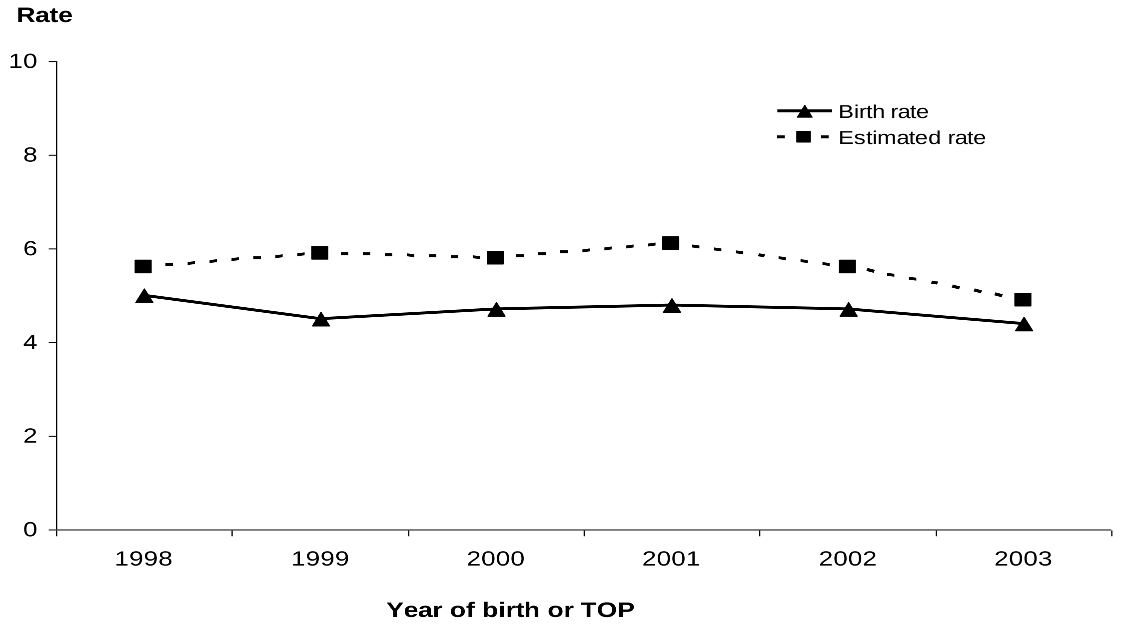

Figure 24: Rate of cystic kidney among all births[(a)] and estimated rate[(b)], 1998–2003

(a) Birth rate includes all cystic kidneys among live births and fetal deaths in Australia per 10,000 live births and fetal deaths.

(b) Estimated rate includes all cystic kidneys among fetal deaths, live births and TOP before 20 weeks reported by New South Wales, Victoria, Western Australia and South Australia per 10,000 live births and fetal deaths.

Reported rates of cystic kidney

Table 2.24.1: Number and rate of cystic kidney by outcome[a], 2002–2003

	2002		2003		2002–2003	
Outcome	Number	Rate	Number	Rate	Number	Rate
Live births[b]	101	4.0	88	3.5	189	3.8
Fetal deaths[c]	18	107.3	23	128.9	41	118.4
All births[d]	119	4.7	111	4.4	230	4.6

(a) Includes all births with at least 20 weeks of gestational age or at least 400 grams birthweight.

(b) For live births, the rate is per 10,000 live births.

(c) For fetal deaths, the rate is per 10,000 fetal deaths.

(d) For all births, the rate is per 10,000 live births and fetal deaths.

Table 2.24.2: Number and the estimated rate of cystic kidney by outcome, four Australian states[a], 2002–2003

	2002		2003		2002–2003	
Outcome	Number	Rate	Number	Rate	Number	Rate
Live births[b]	78	4.1	65	3.4	143	3.8
Fetal deaths[c]	17	134.5	19	138.2	36	136.4
All births[d]	95	5.0	84	4.4	179	4.7
Births and TOP[e]	108	5.6	95	4.9	203	5.3

(a) Includes data for New South Wales, Victoria, Western Australia and South Australia.

(b) For live births, the rate is per 10,000 live births.

(c) For fetal deaths, the rate is per 10,000 fetal deaths.

(d) For all births, the rate is per 10,000 live births and fetal deaths.

(e) Includes TOP at less than 20 weeks gestation and all births with at least 20 weeks of gestation or at least 400 grams birthweight.

Baby characteristics

Table 2.24.3: Births[(a)] with cystic kidney by baby characteristics, Australia, 2002–2003

Characteristic	Number	Per cent	Rate per 10,000 births
Sex			
Male	134	58.5	5.2
Female	90	39.3	3.7
Indeterminate/ Not stated	5	2.2	..
Gestational age (weeks)			
Less than 25	35	15.2	141.8
25–36	53	23.0	14.3
37+	139	60.4	3.0
Unknown	3	1.3	..
Birthweight (grams)			
Less than 1500	49	21.4	65.4
1500 –2499	28	12.2	10.5
2,500+	149	65.1	3.2
Unknown	3	1.3	..

(a) Includes all births with at least 20 weeks of gestation or at least 400 grams birthweight.

Maternal characteristics

Table 2.24.4: Number of women who gave birth to babies with cystic kidney, Australia, 2002–2003

	2002		2003		2002–2003	
	Number	Rate(a)	Number	Rate(a)	Number	Rate(a)
Women who gave birth	113	4.6	109	4.4	222	4.5

(a) The rate is per 10,000 women who gave birth.

Table 2.24.5: Reported number of pregnancies affected with cystic kidney and the estimated rate, four Australian states[(a)], 2002–2003

	2002		2003		2002–2003	
	Number	Rate(b)	Number	Rate(b)	Number	Rate(b)
Women who gave birth(c)	90	4.8	82	4.3	172	4.6
Women who gave birth or had a TOP(d)	103	5.5	93	4.9	196	5.2

(a) Includes data for New South Wales, Victoria, Western Australia and South Australia.

(b) The rate is per 10,000 women who gave birth.

(c) Includes women who gave birth to a baby with at least 20 weeks of gestation or at least 400 grams birthweight.

(d) Includes TOP at less than 20 weeks gestation and all births with at least 20 weeks of gestation or at least 400 grams birthweight.

Table 2.24.6: Maternal characteristics of births[(a)] affected with cystic kidney, Australia, 2002–2003

Characteristic	Number	Per cent	Rate[(e)]	Confidence intervals
Maternal age group				
Less than 20	8	3.7	3.5	1.5 – 7.0
20–24	38	17.4	5.2	3.6 – 7.1
25–29	68	31.1	4.9	3.8 – 6.2
30–34	67	30.6	4.0	3.1 – 5.1
35–39	26	11.9	3.4	2.2 – 5.0
40 and over	11	5.1	7.0	3.5 – 12.6
Indigenous status [(b)]				
Indigenous	3	1.4	2.0	0.4 – 5.9
Non-Indigenous	212	96.8	4.5	3.9 – 5.2
Not stated	4	1.8	..	..
Remoteness Area				
Major cities	163	74.8	4.8	4.1 – 5.6
Regional	51	23.4	3.5	2.6 – 4.6
Remote	4	1.8	3.1	0.8 – 8.0
Country of birth [(c)]				
Australia	148	66.7	3.9	3.2 – 4.6
United Kingdom	6	2.7	3.7	1.4 – 8.0
Europe	7	3.2	5.3	2.2 – 11.0
Middle East and North Africa	5	2.3	4.4	1.4 – 10.3
Asia	13	5.9	3.3	1.7 – 5.6
South Central America/Caribbean	3	1.4	10.3	2.1 – 30.1
Africa (excluding North Africa)	3	1.4	5.2	1.1 – 15.3
Other countries	6	2.7	..	..
Not stated	31	14.0	..	..
Parity [(d)]				
Primiparous	82	45.6	6.3	5.0 – 7.8
Multiparous	97	53.9	5.2	4.3 – 6.4
Plurality				
Singleton	209	94.6	4.3	3.7 – 4.9
Multiple	12	5.4	14.3	7.4 – 24.9

(a) Includes all births with at least 20 weeks of gestation or at least 400 grams birthweight.

(b) Excludes data from Tasmania.

(c) Mother's country of birth was classified using ASCCSS system. If the number of women affected was less than three in any country, those women were included under 'Other countries' category.

(d) Excludes data from New South Wales and Tasmania.

(e) The rate is per 10,000 women who gave birth.

25 Bladder exstrophy

Description: A complex anomaly characterised by a defect in the closure of the lower abdominal wall and the bladder. The bladder opens in the ventral wall of the abdomen between the umbilicus and the symphysis pubis. It is often associated with epispadias and structural anomalies of the pubic bones.

ICD-9-BPA codes: 753.5 ICD-10-AM codes: Q64.1

Only a small number of births with bladder exstrophy were reported during 2002–2003, for an overall birth rate of 0.3 per 10,000 births. Very few fetal deaths or terminations of pregnancy were reported (Table 2.25.1).

More females than males had this condition. More than two-thirds (69.2%) of those affected were born at term (Table 2.25.3).

Women aged 40 years or older had the highest rate of affected pregnancies. No Indigenous women had births with bladder exstrophy. There have been no births reported with this anomaly from remote areas since 1998. The rates did not differ by women's areas of residence, parity or plurality (Table 2.25.6).

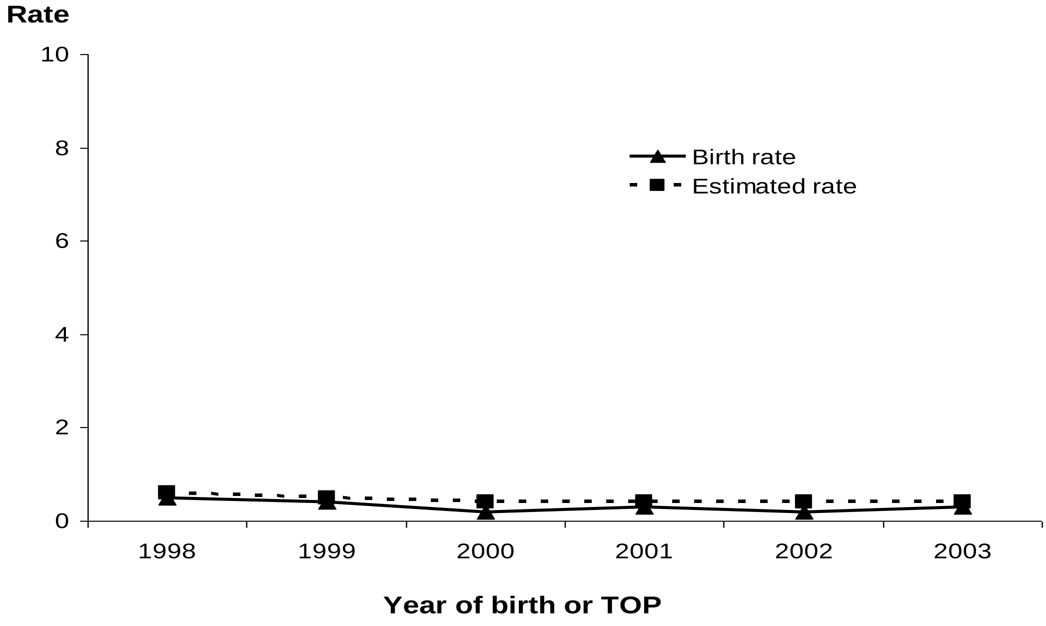

Figure 25: Rate of bladder exstrophy among all births[(a)] and estimated rate[(b)], 1998–2003

(a) Birth rate includes all bladder exstrophy among live births and fetal deaths in Australia per 10,000 live births and fetal deaths.

(b) Estimated rate includes all bladder exstrophy among fetal deaths, live births and TOP before 20 weeks reported by New South Wales, Victoria, Western Australia and South Australia per 10,000 live births and fetal deaths.

Reported rates of bladder exstrophy

Table 2.25.1: Number and rate of bladder exstrophy by outcome[a], Australia, 2002–2003

	2002		2003		2002–2003	
Outcome	**Number**	**Rate**	**Number**	**Rate**	**Number**	**Rate**
Live births(b)	6	0.2	6	0.2	12	0.2
Fetal deaths(c)	0	0.0	1	5.6	1	2.9
All births(d)	6	0.2	7	0.3	13	0.3

(a) Includes all births with at least 20 weeks of gestational age or at least 400 grams birthweight.

(b) For live births, the rate is per 10,000 live births.

(c) For fetal deaths, the rate is per 10,000 fetal deaths.

(d) For all births, the rate is per 10,000 live births and fetal deaths.

Table 2.25.2: Number and the estimated rate of bladder exstrophy by outcome, four Australian states[a], 2002–2003

	2002		2003		2002–2003	
Outcome	**Number**	**Rate**	**Number**	**Rate**	**Number**	**Rate**
Live births(b)	5	0.3	5	0.3	10	0.3
Fetal deaths(c)	0	0.0	1	7.3	1	3.8
All births(d)	5	0.3	6	0.31	11	0.3
Births and TOP(e)	8	0.4	7	0.4	15	0.4

(a) Includes data for New South Wales, Victoria, Western Australia and South Australia.

(b) For live births, the rate is per 10,000 live births.

(c) For fetal deaths, the rate is per 10,000 fetal deaths.

(d) For all births, the rate is per 10,000 live births and fetal deaths.

(e) Includes TOP at less than 20 weeks gestation and all births with at least 20 weeks of gestation or at least 400 grams birthweight.

Baby characteristics

Table 2.25.3: Births[a] with bladder exstrophy by baby characteristics, Australia, 2002–2003

Characteristic	Number	Per cent	Rate per 10,000 births
Sex			
Male	6	46.2	0.2
Female	7	53.9	0.3
Gestational age (weeks)			
Less than 25	2	15.4	8.1
25–36	2	15.4	0.5
37+	9	69.2	0.2
Birthweight (grams)			
Less than 1500	2	15.4	2.7
1500 –2499	2	15.4	0.8
2,500+	9	69.2	0.2

(a) Includes all births with at least 20 weeks of gestation or at least 400 grams birthweight.

Maternal characteristics

Table 2.25.4: Number of women who gave birth to babies with bladder exstrophy, Australia, 2002–2003

	2002		2003		2002–2003	
	Number	Rate[a]	Number	Rate[a]	Number	Rate[a]
Women who gave birth	6	0.2	7	0.3	13	0.3

(a) The rate is per 10,000 women who gave birth.

Table 2.25.5: Reported number of pregnancies affected with bladder exstrophy and the estimated rate, four Australian states[a], 2002–2003

	2002		2003		2002–2003	
	Number	Rate[b]	Number	Rate[b]	Number	Rate[b]
Women who gave birth[c]	5	0.3	6	0.3	11	0.3
Women who gave birth or had a TOP[d]	8	0.4	7	0.4	15	0.4

(a) Includes data for New South Wales, Victoria, Western Australia and South Australia.

(b) The rate is per 10,000 women who gave birth.

(c) Includes women who gave birth to a baby with at least 20 weeks of gestation or at least 400 grams birthweight.

(d) Includes TOP at less than 20 weeks gestation and all births with at least 20 weeks of gestation or at least 400 grams birthweight.

Table 2.25.6: Maternal characteristics of births[(a)] affected with bladder exstrophy, Australia, 2002–2003

Characteristic	Number	Per cent	Rate[(e)]	Confidence intervals
Maternal age group				
Less than 20	0	0.0	0.0	..
20–24	1	7.7	0.1	0.0–0.8
25–29	4	30.8	0.3	0.1–0.7
30–34	1	7.7	0.1	0.0–0.3
35–39	5	38.5	0.7	0.2–1.5
40 and over	2	15.4	1.3	0.2–4.6
Indigenous status [(b)]				
Indigenous	0	0.0	0.0	..
Non-Indigenous	13	100.0	0.3	0.1–0.5
Remoteness Area				
Major cities	9	69.2	0.3	0.1–0.5
Regional	4	30.8	0.3	0.1–0.7
Remote	0	0.0	..	..
Country of birth [(c)]				
Australia	9	69.2	0.2	0.1–0.5
Other countries	4	30.8	..	..
Parity [(d)]				
Primiparous	2	18.2	0.2	0.0–0.6
Multiparous	9	81.8	0.5	0.2–0.9
Plurality				
Singleton	12	92.3	0.3	0.1–0.4
Multiple	1	7.7	1.2	0.0–6.6

(a) Includes all births with at least 20 weeks of gestation or at least 400 grams birthweight.

(b) Excludes data from Tasmania.

(c) Mother's country of birth was classified using ASCCSS system. If the number of women affected was less than three in any country, those women were included under 'Other countries' category.

(d) Excludes data from New South Wales and Tasmania.

(e) The rate is per 10,000 women who gave birth.

26 Polydactyly

Description: Extra digit(s) on the upper limb or the lower limb. It can affect the hand, the foot, or both.

ICD-9-BPA codes: 755.00–755.09 ICD-10-AM codes: QQ69.0-Q69.2, Q69.9

Polydactyly was reported in 8.9 per 10,000 births during 2002–2003. There were few fetal deaths or terminations reported with this anomaly and all of them had other associated anomalies. The rate estimated from the four states providing TOP data was 9.7 per 10,000 pregnancies. This rate was constant since 1998 (Figure 26).
More males than females had this anomaly (58.2%). Most babies (85.3%) were born at term with birthweights of 2,500 grams or more (Table 2.26.3).

Women younger than 20 years had the lowest rate of affected pregnancies and there were no differences among other age groups. Indigenous women had a significantly higher rate of births with polydactyly than the non-Indigenous women (PR=1.8, CI 1.2–2.8). Multiple births had a significantly higher rate than singleton births (PR=1.9, CI 1.1–3.2). The rate did not differ by women's areas of residence or parity (Table 2.26.6).

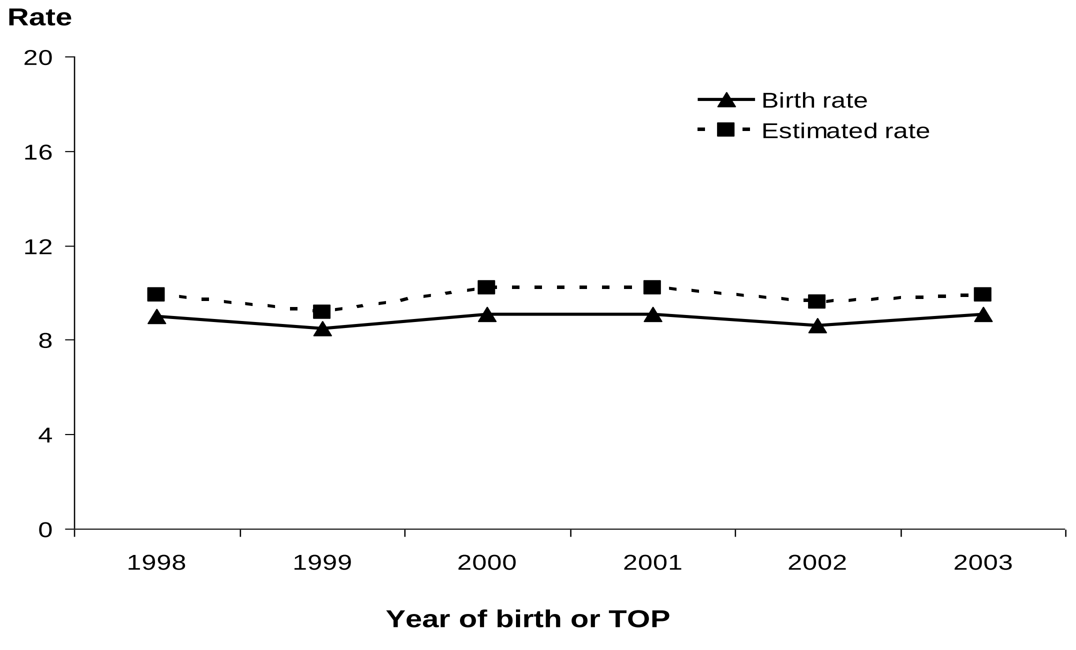

Figure 26: Rate of polydactyly among all births[(a)] and estimated rate[(b)], 1998–2003

(a) Birth rate includes all polydactyly among live births and fetal deaths in Australia per 10,000 live births and fetal deaths.

(b) Estimated rate includes all polydactyly among fetal deaths, live births and TOP before 20 weeks reported by New South Wales, Victoria, Western Australia and South Australia per 10,000 live births and fetal deaths.

Reported rates of polydactyly

Table 2.26.1: Number and rate of polydactyly by outcome[(a)], Australia, 2002–2003

	2002		2003		2002–2003	
Outcome	**Number**	**Rate**	**Number**	**Rate**	**Number**	**Rate**
Live births(b)	211	8.5	219	8.7	430	8.6
Fetal deaths(c)	6	35.8	12	67.2	18	52.0
All births(d)	217	8.6	231	9.1	448	8.9

(a) Includes all births with at least 20 weeks of gestational age or at least 400 grams birthweight.

(b) For live births, the rate is per 10,000 live births.

(c) For fetal deaths, the rate is per 10,000 fetal deaths.

(d) For all births, the rate is per 10,000 live births and fetal deaths.

Table 2.26.2: Number and the estimated rate of polydactyly by outcome, four Australian states[(a)], 2002–2003

	2002		2003		2002–2003	
Outcome	**Number**	**Rate**	**Number**	**Rate**	**Number**	**Rate**
Live births(b)	166	8.7	171	9.0	337	8.8
Fetal deaths(c)	5	39.6	11	80.0	16	60.6
All births(d)	171	8.9	182	9.5	353	9.2
Births and TOP(e)	184	9.6	190	9.9	374	9.7

(a) Includes data for New South Wales, Victoria, Western Australia and South Australia.

(b) For live births, the rate is per 10,000 live births.

(c) For fetal deaths, the rate is per 10,000 fetal deaths.

(d) For all births, the rate is per 10,000 live births and fetal deaths.

(e) Includes TOP at less than 20 weeks gestation and all births with at least 20 weeks of gestation or at least 400 grams birthweight.

Baby characteristics

Table 2.26.3: Births[a] with polydactyly by baby characteristics, Australia, 2002–2003

Characteristic	Number	Per cent	Rate per 10,000 births
Sex			
Male	260	58.2	10.0
Female	187	41.8	7.6
Gestational age (weeks)			
Less than 25	14	3.1	56.7
25–36	51	11.4	13.8
37+	382	85.3	8.2
Unknown	1	0.2	..
Birthweight (grams)			
Less than 1500	23	5.2	30.7
1500 –2499	32	7.2	11.9
2,500+	392	87.7	8.3

(a) Includes all births with at least 20 weeks of gestation or at least 400 grams birthweight.

Maternal characteristics

Table 2.26.4: Number of women who gave birth to babies with polydactyly, Australia, 2002–2003

	2002		2003		2002–2003	
	Number	Rate[a]	Number	Rate[a]	Number	Rate[a]
Women who gave birth	212	8.6	230	9.2	442	8.9

(a) The rate is per 10,000 women who gave birth.

Table 2.26.5: Reported number of pregnancies affected with polydactyly and the estimated rate, four Australian states[a], 2002–2003

	2002		2003		2002–2003	
	Number	Rate[b]	Number	Rate[b]	Number	Rate[b]
Women who gave birth[c]	166	8.8	181	9.6	347	9.2
Women who gave birth or had a TOP[d]	179	9.5	189	10.0	368	9.7

(a) Includes data for New South Wales, Victoria, Western Australia and South Australia.

(b) The rate is per 10,000 women who gave birth.

(c) Includes women who gave birth to a baby with at least 20 weeks of gestation or at least 400 grams birthweight.

(d) Includes TOP at less than 20 weeks gestation and all births with at least 20 weeks of gestation or at least 400 grams birthweight.

Table 2.26.6: Maternal characteristics of births[(a)] affected with polydactyly, Australia, 2002–2003

Characteristic	Number	Per cent	Rate[(e)]	Confidence intervals
Maternal age group				
Less than 20	12	2.7	5.3	2.7–9.3
20–24	67	15.2	9.1	7.0–11.5
25–29	132	29.9	9.4	7.9–11.2
30–34	130	29.5	7.8	6.5–9.2
35–39	81	18.4	10.6	8.4–13.1
40 and over	18	4.1	11.5	6.8–18.2
Indigenous status [(b)]				
Indigenous	24	5.5	16.1	10.3–24.0
Non-Indigenous	411	94.3	8.8	7.9–9.6
Remoteness Area				
Major cities	306	70.1	9.1	8.1–10.2
Regional	123	28.2	8.4	7.0–10.0
Remote	7	1.6	5.5	2.2–11.2
Country of birth [(c)]				
Australia	300	67.9	7.8	7.0–8.8
New Zealand	4	0.9	3.2	0.9–8.1
United Kingdom	15	3.4	9.2	5.2–15.2
Europe	6	1.5	4.6	1.7–9.9
Middle East and North Africa	11	2.5	9.7	4.9–17.4
Asia	54	12.2	13.6	10.2–17.7
North America	3	0.7	10.3	2.1–30.1
South Central America/ Caribbean	4	0.9	13.8	3.8–35.3
Africa (excluding North Africa)	6	1.4	10.5	3.9–22.9
Other countries	6	1.4	..	..
Not stated	33	7.5	..	..
Parity [(d)]				
Primiparous	115	41.1	8.8	7.3–10.6
Multiparous	161	58.9	8.7	7.4–10.2
Plurality				
Singleton	427	96.8	8.8	7.9–9.6
Multiple	14	3.2	16.6	9.1–27.9

(a) Includes all births with at least 20 weeks of gestation or at least 400 grams birthweight.

(b) Excludes data from Tasmania.

(c) Mother's country of birth was classified using ASCCSS system. If the number of women affected was less than three in any country, those women were included under 'Other countries' category.

(d) Excludes data from New South Wales and Tasmania.

(e) The rate is per 10,000 women who gave birth.

27 Limb reduction defects

Description: A congenital anomaly characterised by total or partial absence or severe hypoplasia of skeletal structures of the limbs. This anomaly includes femoral hypoplasia. Exclusion criteria include mild hypoplasia with normal shape of skeletal parts, brachydactyly, finger or toe reduction directly associated with syndactyly, general skeletal dysplasia and sirenomelia.

ICD-9-BPA codes: 755.20–755.49

ICD-10-AM codes: Q71.0–Q71.9, Q72.0–Q72.9, Q73.0, Q73.1, Q73.8

Limb reduction defects were seen in 3.6 per 10,000 births during the period of 2002–2003 (Table 2.27.1). The estimated rate for births and terminations of pregnancy from the four states providing TOP data was 4.5 per 10,000 pregnancies (Table 2.27.2). However the rate shows a gradual decline over the period 1998–2003 (Figure 27). About 41.9% of affected pregnancies were fetal deaths or terminations of pregnancy. About 60.0% of early terminations were performed at 17–19 weeks of gestation.

Of the affected births 53.6% were males. Two-thirds of the births with limb reduction defects were born at term and had birthweights of 2,500 grams or more (Table 2.27.3).

The highest rate of limb reduction defects was seen among babies born to women aged 40 years or older. Women born in Asia had the highest rate of pregnancies affected with these defects. The rates did not differ by women's areas of residence, plurality or parity (Table 2.27.6).

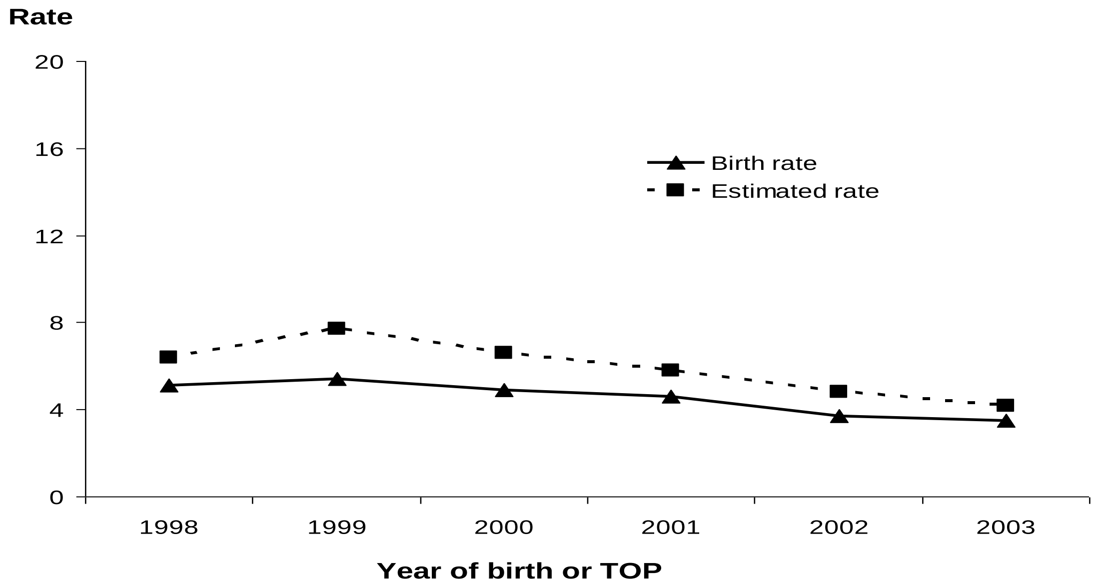

Figure 27: Rate of limb reduction defects among all births[(a)] and estimated rate[(b)], 1998–2003

(a) Birth rate includes all limb reduction defects among live births and fetal deaths in Australia per 10,000 live births and fetal deaths.

(b) Estimated rate includes all limb reduction defects among fetal deaths, live births and TOP before 20 weeks reported by New South Wales, Victoria, Western Australia and South Australia per 10,000 live births and fetal deaths.

Reported rates of limb reduction defects

Table 2.27.1: Number and rate of limb reduction defects by outcome[(a)], Australia, 2002–2003

	2002		2003		2002–2003	
Outcome	**Number**	**Rate**	**Number**	**Rate**	**Number**	**Rate**
Live births[(b)]	78	3.1	74	2.9	152	3.0
Fetal deaths[(c)]	16	95.4	15	84.0	31	89.5
All births[(d)]	94	3.7	89	3.5	183	3.6

(a) Includes all births with at least 20 weeks of gestational age or at least 400 grams birthweight.

(b) For live births, the rate is per 10,000 live births.

(c) For fetal deaths, the rate is per 10,000 fetal deaths.

(d) For all births, the rate is per 10,000 live births and fetal deaths.

Table 2.27.2: Number and the estimated rate of limb reduction defects by outcome, four Australian states[(a)], 2002–2003

	2002		2003		2002–2003	
Outcome	**Number**	**Rate**	**Number**	**Rate**	**Number**	**Rate**
Live births[(b)]	50	2.6	50	2.6	100	2.6
Fetal deaths[(c)]	14	110.8	13	94.5	27	102.3
All births[(d)]	64	3.3	63	3.3	127	3.3
Births and TOP[(e)]	92	4.8	80	4.2	172	4.5

(a) Includes data for New South Wales, Victoria, Western Australia and South Australia.

(b) For live births, the rate is per 10,000 live births.

(c) For fetal deaths, the rate is per 10,000 fetal deaths.

(d) For all births, the rate is per 10,000 live births and fetal deaths.

(e) Includes TOP at less than 20 weeks gestation and all births with at least 20 weeks of gestation or at least 400 grams birthweight.

Baby characteristics

Table 2.27.3: Births[(a)] with limb reduction defects by baby characteristics, Australia, 2002–2003

Characteristic	Number	Per cent	Rate per 10,000 births
Sex			
Male	98	53.6	3.8
Female	84	45.9	3.4
Indeterminate/ Not stated	1	0.6	..
Gestational age (weeks)			
Less than 25	30	16.4	121.6
25–36	27	14.8	7.3
37+	125	68.3	2.7
Unknown	1	0.6	..
Birthweight (grams)			
Less than 1500	38	20.8	50.7
1500 –2499	26	14.2	9.7
2,500+	118	64.5	2.5
Unknown	1	0.6	..

(a) Includes all births with at least 20 weeks of gestation or at least 400 grams birthweight.

Maternal characteristics

Table 2.27.4: Number of women who gave birth to babies with limb reduction defects, Australia, 2002–2003

	2002		2003		2002–2003	
	Number	Rate(a)	Number	Rate(a)	Number	Rate(a)
Women who gave birth	93	3.8	88	3.5	181	3.7

(a) The rate is per 10,000 women who gave birth.

Table 2.27.5: Reported number of pregnancies affected with limb reduction defects and the estimated rate, four Australian states[(a)], 2002–2003

	2002		2003		2002–2003	
	Number	Rate(b)	Number	Rate(b)	Number	Rate(b)
Women who gave birth(c)	63	3.3	62	3.3	125	3.3
Women who gave birth or had a TOP(d)	91	4.8	79	4.2	170	4.5

(a) Includes data for New South Wales, Victoria, Western Australia and South Australia.

(b) The rate is per 10,000 women who gave birth.

(c) Includes women who gave birth to a baby with at least 20 weeks of gestation or at least 400 grams birthweight.

(d) Includes TOP at less than 20 weeks gestation and all births with at least 20 weeks of gestation or at least 400 grams birthweight.

Table 2.27.6: Maternal characteristics of births[(a)] affected with limb reduction defects, Australia, 2002–2003

Characteristic	Number	Per cent	Rate[(e)]	Confidence intervals
Maternal age group				
Less than 20	10	5.5	4.4	2.1–8.1
20–24	34	18.8	4.6	3.2–6.4
25–29	58	32.0	4.1	3.1–5.4
30–34	43	23.8	2.6	1.9–3.5
35–39	24	13.3	3.1	2.0–4.7
40 and over	11	6.1	7.0	3.5–12.6
Indigenous status (b)				
Indigenous	6	3.3	4.0	1.5–8.8
Non-Indigenous	174	96.7	3.7	3.2–4.3
Remoteness Area				
Major cities	115	63.9	3.4	2.8–4.1
Regional	58	32.2	4.0	3.0–5.1
Remote	7	3.9	5.5	2.2–11.2
Country of birth (c)				
Australia	133	73.5	3.5	2.9–4.1
United Kingdom	5	2.8	3.1	1.0–7.1
Europe	3	1.7	2.3	0.5–6.7
Middle East and North Africa	3	1.7	2.7	0.6–7.8
Asia	17	9.4	4.3	2.5–6.8
Other countries	4	2.2	..	..
Not stated	16	8.8	..	..
Parity (d)				
Primiparous	71	50.0	5.4	4.2–6.9
Multiparous	68	47.9	3.7	2.9–4.7
Not stated	3	2.1	..	..
Plurality				
Singleton	177	97.8	3.6	3.1–4.2
Multiple	4	2.2	4.8	1.3–12.2

(a) Includes all births with at least 20 weeks of gestation or at least 400 grams birthweight.

(b) Excludes data from Tasmania.

(c) Mother's country of birth was classified using ASCCSS system. If the number of women affected was less than three in any country, those women were included under 'Other countries' category.

(d) Excludes data from New South Wales and Tasmania.

(e) The rate is per 10,000 women who gave birth.

28 Diaphragmatic hernia

Description: A congenital anomaly characterised by herniation into the thorax of abdominal contents through a defect of the diaphragm. Excludes: hiatus hernia, eventration and phrenic palsy.

ICD-9-BPA codes: 756.61 ICD-10-AM codes: Q79.0

Diaphragmatic hernia was reported in 2.5 per 10,000 births during the period of 2002–2003 (Table 2.28.1). This rate has been stable since 2001 (Figure 28). Of the pregnancies affected by diaphragmatic hernia, 27.4% were ended in fetal deaths or terminations of pregnancy (Table 2.28.2).

More males (71.7%) than females were born with this defect. Among babies born before 25 weeks of gestation, 53 per 10,000 babies were affected with diaphragmatic hernia. More than two-thirds of the births were at term and had birthweights of 2,500 grams or more (Table 2.28.3).

There were no significant differences among age groups of women, Indigenous status, areas of residence, parity or plurality of the women who had given birth to babies affected with diaphragmatic hernias (Table 2.28.6).

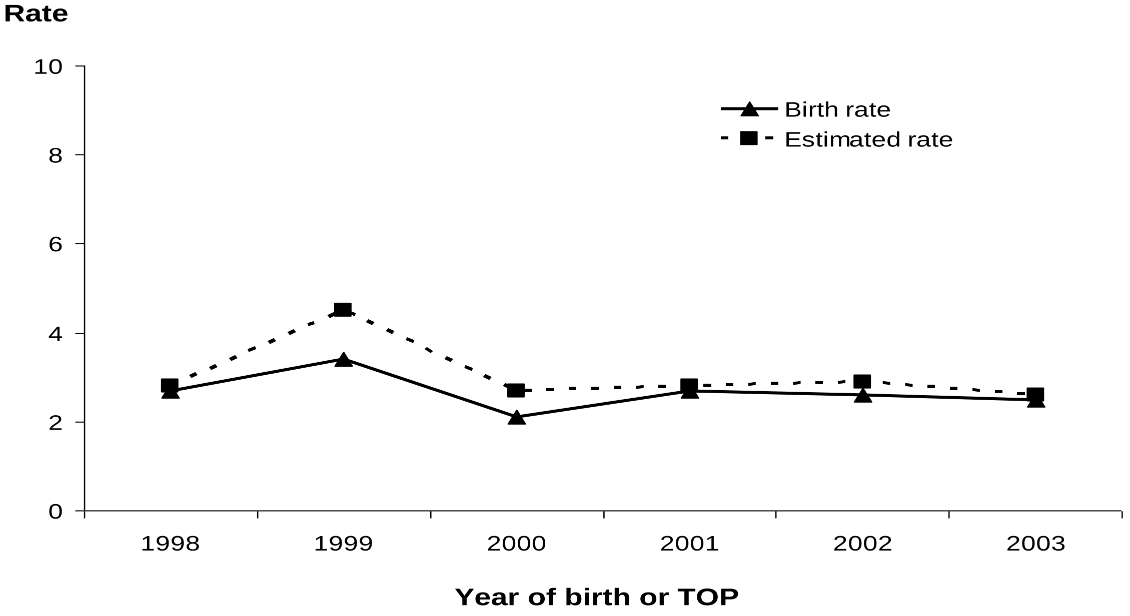

Figure 28: Rate of diaphragmatic hernia among all births[(a)] and estimated rate[(b)], 1998–2003

(a) Birth rate includes all diaphragmatic hernia among live births and fetal deaths in Australia per 10,000 live births and fetal deaths.

(b) Estimated rate includes all diaphragmatic hernia among fetal deaths, live births and TOP before 20 weeks reported by New South Wales, Victoria, Western Australia and South Australia per 10,000 live births and fetal deaths.

Reported rates of diaphragmatic hernia

Table 2.28.1: Number and rate of diaphragmatic hernia by outcome[a], Australia, 2002–2003

	2002		2003		2002–2003	
Outcome	**Number**	**Rate**	**Number**	**Rate**	**Number**	**Rate**
Live births[b]	57	2.3	50	2.0	107	2.1
Fetal deaths[c]	8	47.8	12	67.2	20	57.8
All births[d]	65	2.6	62	2. 5	127	2.5

(a) Includes all births with at least 20 weeks of gestational age or at least 400 grams birthweight.

(b) For live births, the rate is per 10,000 live births.

(c) For fetal deaths, the rate is per 10,000 fetal deaths.

(d) For all births, the rate is per 10,000 live births and fetal deaths.

Table 2.28.2: Number and the estimated rate of diaphragmatic hernia by outcome, four Australian states[a], 2002–2003

	2002		2003		2002–2003	
Outcome	**Number**	**Rate**	**Number**	**Rate**	**Number**	**Rate**
Live births[b]	43	2.3	34	1.8	77	2.0
Fetal deaths[c]	8	63.3	12	87.3	20	75.8
All births[d]	51	2.7	46	2.4	97	2.5
Births and TOP[e]	56	2.9	50	2.6	106	2.8

(a) Includes data for New South Wales, Victoria, Western Australia and South Australia.

(b) For live births, the rate is per 10,000 live births.

(c) For fetal deaths, the rate is per 10,000 fetal deaths.

(d) For all births, the rate is per 10,000 live births and fetal deaths.

(e) Includes TOP at less than 20 weeks gestation and all births with at least 20 weeks of gestation or at least 400 grams birthweight.

Baby characteristics

Table 2.28.3: Births[a] with diaphragmatic hernia by baby characteristics, Australia, 2002–2003

Characteristic	Number	Per cent	Rate per 10,000 births
Sex			
Male	91	71.7	3.5
Female	36	28.4	1.5
Gestational age (weeks)			
Less than 25	14	11.0	56.7
25–36	26	20.5	7.0
37+	87	68.5	1.9
Birthweight (grams)			
Less than 1500	20	15.8	26.7
1500 –2499	24	18.9	9.0
2,500+	82	64.6	1.7
Unknown	1	0.8	..

(a) Includes all births with at least 20 weeks of gestation or at least 400 grams birthweight.

Maternal characteristics

Table 2.28.4: Number of women who gave birth to babies with diaphragmatic hernia, Australia, 2002–2003

	2002		2003		2002–2003	
	Number	Rate(a)	Number	Rate(a)	Number	Rate(a)
Women who gave birth	65	2.6	62	2.5	127	2.6

(a) The rate is per 10,000 women who gave birth.

Table 2.28.5: Reported number of pregnancies affected with diaphragmatic hernia and the estimated rate, four Australian states[a], 2002–2003

	2002		2003		2002–2003	
	Number	Rate(b)	Number	Rate(b)	Number	Rate(b)
Women who gave birth(c)	51	2.7	46	2.4	97	2.6
Women who gave birth or had a TOP (d)	56	3.0	50	2.6	106	2.8

(a) Includes data for New South Wales, Victoria, Western Australia and South Australia.

(b) The rate is per 10,000 women who gave birth.

(c) Includes women who gave birth to a baby with at least 20 weeks of gestation or at least 400 grams birthweight.

(d) Includes TOP at less than 20 weeks gestation and all births with at least 20 weeks of gestation or at least 400 grams birthweight.

Table 2.28.6: Maternal characteristics of births[(a)] affected with diaphragmatic hernia, Australia, 2002–2003

Characteristic	Number	Per cent	Rate[(e)]	Confidence intervals
Maternal age group				
Less than 20	6	4.7	2.7	1.0–5.8
20–24	16	12.6	2.2	1.2–3.5
25–29	36	28.4	2.6	1.8–3.6
30–34	35	27. 6	2.1	1.5–2.9
35–39	29	22.8	3.8	2.5–5.4
40 and over	5	3.9	3.2	1.0–7.5
Indigenous status [(b)]				
Indigenous	4	3.2	2.7	0.7–6.9
Non-Indigenous	122	96.1	2.6	2.2–3.1
Not stated	1	0.8	..	..
Remoteness Area				
Major cities	79	62.2	2.6	2.1–3.2
Regional	42	33.1	1.8	0.4–5.4
Remote	6	4.7	2.0	0.9–4.0
Country of birth [(c)]				
Australia	101	79.5	2.6	2.1–3.2
United Kingdom	3	2.4	1.8	0.4–5.3
Asia	8	6.3	2.0	0.9–3.9
Other countries	7	5.5	..	..
Not stated	8	6.3	..	..
Parity [(d)]				
Primiparous	33	36.7	2.5	1.7–3.5
Multiparous	57	63.3	3.1	2.3–4.0
Plurality				
Singleton	125	98.4	2.6	2.1–3.1
Multiple	2	1.6	2.4	0.3–8.6

(a) Includes all births with at least 20 weeks of gestation or at least 400 grams birthweight.

(b) Excludes data from Tasmania.

(c) Mother's country of birth was classified using ASCCSS system. If the number of women affected was less than three in any country, those women were included under 'Other countries' category.

(d) Excludes data from New South Wales and Tasmania.

(e) The rate is per 10,000 women who gave birth.

29 Exomphalos

Description: A congenital anomaly characterised by herniation of abdominal contents through the umbilical insertion and covered by a membrane which may or may not be intact. The anomaly excludes gastroschisis, hypoplasia of abdominal muscles and skin covered umbilical hernia.

ICD-9-BPA codes: 756.70 ICD-10-AM codes: Q79.2

There were 2.1 per 10,000 births with exomphalos in the period of 2002–2003 (Table 2.29.1). This is a slight increase in the rate compared with the period 1998–2001 (Figure 29). There was nearly a two-fold increase in the estimated rate when the TOP data from the four states were included indicating early identification and termination of affected pregnancies (Table 2.29.2). Data from the four states show that 63.7% of the exomphalos affected pregnancies ended in terminations of pregnancy or fetal deaths. The majority of termination of pregnancy occurred in less than 20 weeks of gestation.

More males than females had this anomaly. More than half (53.8%) of affected babies were born preterm (Table 2.29.3).

A significantly higher rate of births with exomphalos was seen in women who had multiple births than in women who had singletons (PR=3.4, CI 1.5–7.7). The rates did not differ by women's age, areas of residence, Indigenous status or parity (Table 2.29.6).

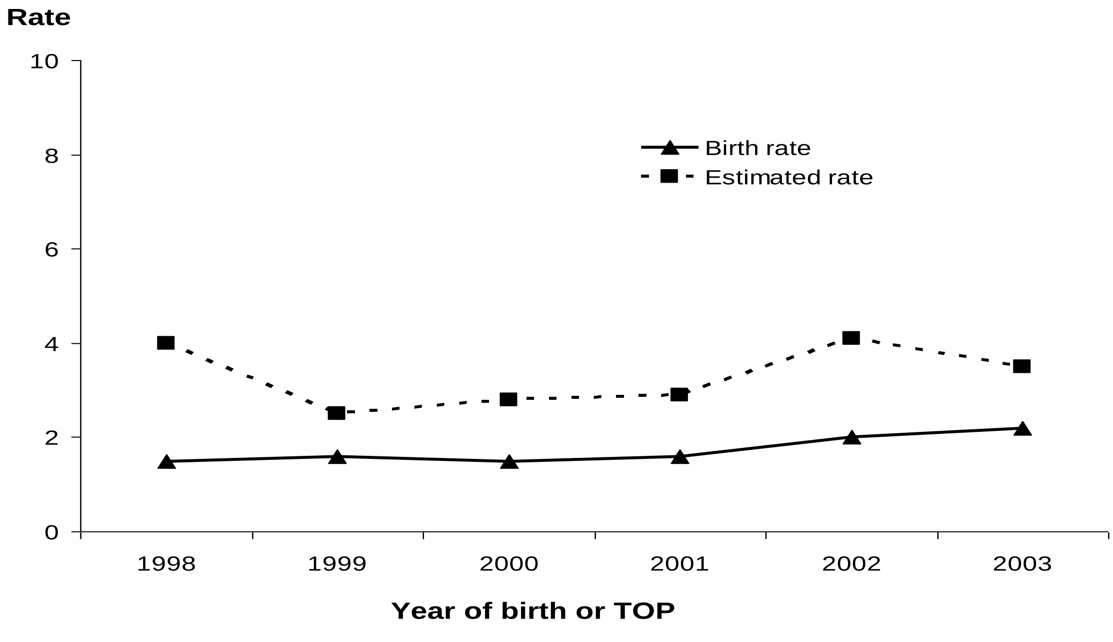

Figure 29: Rate of exomphalos among all births[(a)] and estimated rate[(b)], 1998–2003

(a) Birth rate includes all exomphalos among live births and fetal deaths in Australia per 10,000 live births and fetal deaths.

(b) Estimated rate includes all exomphalos among fetal deaths, live births and TOP before 20 weeks reported by New South Wales, Victoria, Western Australia and South Australia per 10,000 live births and fetal deaths.

Reported rates of exomphalos

Table 2.29.1: Number and rate of exomphalos by outcome[(a)], Australia, 2002–2003

	2002		2003		2002–2003	
Outcome	**Number**	**Rate**	**Number**	**Rate**	**Number**	**Rate**
Live births(b)	33	1.3	38	1.5	71	1.4
Fetal deaths(c)	17	101.4	18	100.8	35	101.1
All births(d)	50	2.0	56	2.2	106	2.1

(a) Includes all births with at least 20 weeks of gestational age or at least 400 grams birthweight.

(b) For live births, the rate is per 10,000 live births.

(c) For fetal deaths, the rate is per 10,000 fetal deaths.

(d) For all births, the rate is per 10,000 live births and fetal deaths.

Table 2.29.2: Number and the estimated rate of exomphalos by outcome, four Australian states[(a)], 2002–2003

	2002		2003		2002–2003	
Outcome	**Number**	**Rate**	**Number**	**Rate**	**Number**	**Rate**
Live births(b)	26	1.4	27	1.4	53	1.4
Fetal deaths(c)	16	126.6	12	87.3	28	106.1
All births(d)	42	2.2	39	2.0	81	2.1
Births and TOP(e)	78	4.1	68	3.5	146	3.8

(a) Includes data for New South Wales, Victoria, Western Australia and South Australia.

(b) For live births, the rate is per 10,000 live births.

(c) For fetal deaths, the rate is per 10,000 fetal deaths.

(d) For all births, the rate is per 10,000 live births and fetal deaths.

(e) Includes TOP at less than 20 weeks gestation and all births with at least 20 weeks of gestation or at least 400 grams birthweight.

Baby characteristics

Table 2.29.3: Births[(a)] with exomphalos by baby characteristics, Australia, 2002–2003

Characteristic	Number	Per cent	Rate per 10,000 births
Sex			
Male	61	58.1	2.4
Female	42	40.0	1.7
Indeterminate	2	1.9	..
Gestational age (weeks)			
Less than 25	21	19.8	85.1
25–36	36	34.0	9.7
37+	48	45.3	1.0
Unknown	1	0.9	..
Birthweight (grams)			
Less than 1500	34	32.4	45.4
1500 –2499	21	20.0	7.8
2,500+	47	44.8	1.0
Unknown	3	2.9	..

(a) Includes all births with at least 20 weeks of gestation or at least 400 grams birthweight.

Maternal characteristics

Table 2.29.4: Number of women who gave birth to babies with exomphalos, Australia, 2002–2003

	2002		2003		2002–2003	
	Number	Rate[(a)]	Number	Rate[(a)]	Number	Rate[(a)]
Women who gave birth	50	2.0	53	2.1	103	2.1

(a) The rate is per 10,000 women who gave birth.

Table 2.29.5: Reported number of pregnancies affected with exomphalos and the estimated rate, four Australian states[(a)], 2002–2003

	2002		2003		2002–2003	
	Number	Rate[(b)]	Number	Rate[(b)]	Number	Rate[(b)]
Women who gave birth[(c)]	42	2.2	36	1.9	78	2.1
Women who gave birth or had a TOP[(d)]	78	4.1	65	3.4	143	3.8

(a) Includes data for New South Wales, Victoria, Western Australia and South Australia.

(b) The rate is per 10,000 women who gave birth.

(c) Includes women who gave birth to a baby with at least 20 weeks of gestation or at least 400 grams birthweight.

(d) Includes TOP at less than 20 weeks gestation and all births with at least 20 weeks of gestation or at least 400 grams birthweight.

Table 2.29.6: Maternal characteristics of births[(a)] affected with exomphalos, Australia, 2002–2003

Characteristic	Number	Per cent	Rate[(e)]	Confidence intervals
Maternal age group				
Less than 20	5	5.0	2.2	0.7–5.2
20–24	19	18.8	2.6	1.6–4.0
25–29	23	22.8	1.6	1.0–2.5
30–34	29	28.7	1.7	1.2–2.5
35–39	19	18.8	2.5	1.5–3.9
40 and over	6	5.9	3.8	1.4–8.3
Indigenous status [(b)]				
Indigenous	4	4.1	2.7	0.7–6.9
Non-Indigenous	93	95.9	2.0	1.6–2.4
Remoteness Area				
Major cities	66	68.8	2.0	1.5–2.5
Regional	26	27.1	1.8	1.2–2.6
Remote	4	4.2	3.1	0.8–8.0
Country of birth [(c)]				
Australia	75	72.8	2.0	1.5–2.5
Asia	6	5.8	1.5	0.6–3.3
Other countries	8	7.8	..	..
Not stated	14	13.6	..	..
Parity [(d)]				
Primiparous	32	45.7	2.5	1.7–3.5
Multiparous	38	54.3	2.1	1.5–2.8
Plurality				
Singleton	96	94.1	2.1	1.6–2.4
Multiple	6	5.9	7.1	2.6–15.5

(a) Includes all births with at least 20 weeks of gestation or at least 400 grams birthweight.

(b) Excludes data from Tasmania.

(c) Mother's country of birth was classified using ASCCSS system. If the number of women affected was less than three in any country, those women were included under 'Other countries' category.

(d) Excludes data from New South Wales and Tasmania.

(e) The rate is per 10,000 women who gave birth.

30 Gastroschisis

Description: A congenital anomaly characterised by visceral herniation through a right side abdominal wall defect with an intact umbilical cord and not covered by a membrane. This anomaly excludes hypoplasia of abdominal muscles, skin covered umbilical hernia and exomphalos.

ICD-9-BPA codes: 756.71 ICD-10-AM codes: Q79.3

Gastroschisis was reported in 2.6 per 10,000 births during 2002–2003. Few fetal deaths or terminations of pregnancy were reported from the four states providing TOP data. The estimated rate is similar to the rate at birth, indicating a low rate of early terminations (Table 2.30.1 and Table 2.30.2).

There were similar proportions of males and females with this anomaly. Half of the affected pregnant women delivered preterm (Table 2.30.3).

These data show a significant decreasing risk of affected pregnancies with advancing maternal age. Young women less than 30 years of age had eight times higher risk of gastroschisis affected births than the older women aged 30 years or more (PR=8.0, CI 4.7-13.4). There were no births with gastroschisis notified in women older than 39 years for 2002 and 2003. Primiparous women had a significantly higher rate of births with this anomaly (PR=3.2, CI 2.1–4.9). Indigenous women had a significantly higher rate of affected births than non-Indigenous women (PR=2.4, CI 1.2–4.8). There was no significant difference between affected multiplebirths and singletons (Table 2.30.6).

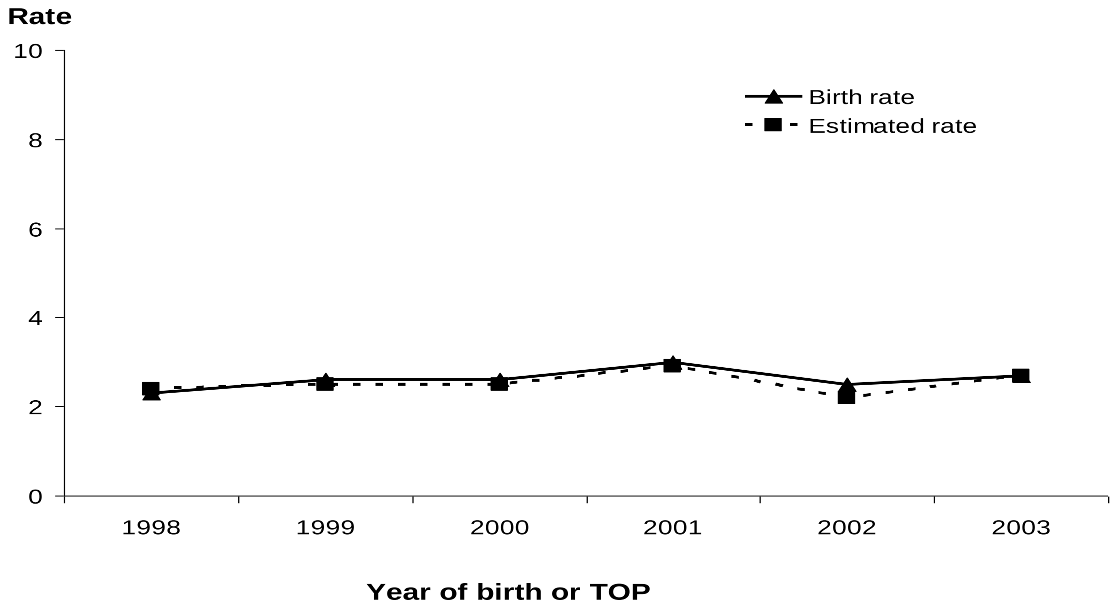

Figure 30: Rate of gastroschisis among all births[(a)] and estimated rate[(b)], 1998–2003

(a) Birth rate includes all gastroschisis among live births and fetal deaths in Australia per 10,000 live births and fetal deaths.

(b) Estimated rate includes all gastroschisis among fetal deaths, live births and TOP before 20 weeks reported by New South Wales, Victoria, Western Australia and South Australia per 10,000 live births and fetal deaths.

Reported rates of gastroschisis

Table 2.30.1: Number and rate of gastroschisis by outcome[a], Australia, 2002–2003

	2002		2003		2002–2003	
Outcome	**Number**	**Rate**	**Number**	**Rate**	**Number**	**Rate**
Live births[b]	59	2.4	63	2.5	122	2.4
Fetal deaths[c]	4	2.4	6	3.4	10	2.9
All births[d]	63	2.5	69	2.7	132	2.6

(a) Includes all births with at least 20 weeks of gestational age or at least 400 grams birthweight.

(b) For live births, the rate is per 10,000 live births.

(c) For fetal deaths, the rate is per 10,000 fetal deaths.

(d) For all births, the rate is per 10,000 live births and fetal deaths.

Table 2.30.2: Number and the estimated rate of gastroschisis by outcome, four Australian states[a], 2002–2003

	2002		2003		2002–2003	
Outcome	**Number**	**Rate**	**Number**	**Rate**	**Number**	**Rate**
Live births[b]	36	1.9	39	2.0	75	2.0
Fetal deaths[c]	4	31.6	6	43.7	10	37.9
All births[d]	40	2.1	45	2.3	85	2.2
Births and TOP[e]	43	2.2	51	2.7	94	2.5

(a) Includes data for New South Wales, Victoria, Western Australia and South Australia.

(b) For live births, the rate is per 10,000 live births.

(c) For fetal deaths, the rate is per 10,000 fetal deaths.

(d) For all births, the rate is per 10,000 live births and fetal deaths.

(e) Includes TOP at less than 20 weeks gestation and all births with at least 20 weeks of gestation or at least 400 grams birthweight.

Baby characteristics

Table 2.30.3: Births[(a)] with gastroschisis by baby characteristics, Australia, 2002–2003

Characteristic	Number	Per cent	Rate per 10,000 births
Sex			
Male	67	50.8	2.6
Female	65	49.2	2.7
Gestational age (weeks)			
Less than 25	6	4.6	24.3
25–36	61	46.2	16.5
37+	65	49.2	1.4
Birthweight (grams)			
Less than 1500	12	9.1	16.0
1500 –2499	47	35.6	17.5
2,500+	72	54.6	1.5
Unknown	1	0.8	..

(a) Includes all births with at least 20 weeks of gestation or at least 400 grams birthweight.

Maternal characteristics

Table 2.30.4: Number of women who gave birth to babies with gastroschisis, Australia, 2002–2003

	2002		2003		2002–2003	
	Number	Rate(a)	Number	Rate(a)	Number	Rate(a)
Women who gave birth	63	2.6	69	2.8	132	2.7

(a) The rate is per 10,000 women who gave birth.

Table 2.30.5: Reported number of pregnancies affected with gastroschisis and the estimated rate, four Australian states[(a)], 2002–2003

	2002		2003		2002–2003	
	Number	Rate(b)	Number	Rate(b)	Number	Rate(b)
Women who gave birth(c)	40	2.1	45	2.4	85	2.3
Women who gave birth or had a TOP(d)	43	2.28	51	2.7	94	2.5

(a) Includes data for New South Wales, Victoria, Western Australia and South Australia.

(b) The rate is per 10,000 women who gave birth.

(c) Includes women who gave birth to a baby with at least 20 weeks of gestation or at least 400 grams birthweight.

(d) Includes TOP at less than 20 weeks gestation and all births with at least 20 weeks of gestation or at least 400 grams birthweight.

Table 2.30.6: Maternal characteristics of births[(a)] affected with gastroschisis, Australia, 2002–2003

Characteristic	Number	Per cent	Rate[(e)]	Confidence Intervals
Maternal age group				
Less than 20	32	24.2	14.2	9.7–20.0
20–24	51	38.6	6.9	5.1–9.1
25–29	33	25.0	2.4	1.6–3.3
30–34	14	10.6	0.8	0.5–1.4
35–39	2	1.5	0.3	0.0–0.9
Indigenous status [(b)]				
Indigenous	9	6.8	6.1	2.8–11.5
Non-Indigenous	119	90.2	2.5	2.1–3.0
Not stated	4	3.0	..	..
Remoteness Area				
Major cities	74	56.5	2.2	1.7–2.8
Regional	48	36.6	3.3	2.4–4.3
Remote	5	3.8	3.9	1.3–9.1
Not stated	4	3.1	..	..
Country of birth [(c)]				
Australia	102	77.3	2.7	2.2–3.2
New Zealand	4	3.0	3.2	0.9–8.1
United Kingdom	3	2.3	1.8	0.4–5.4
Asia	6	4.6	1.5	0.6–3.3
Other countries	4	3.0	..	..
Not stated	13	9.9	..	..
Parity [(d)]				
Primiparous	67	69.8	5.1	4.0–6.5
Multiparous	29	30.2	1.6	1.1–2.3
Plurality				
Singleton	131	99.2	2.7	2.2–3.2
Multiple	1	0.8	1.2	0.0–6.6

(a) Includes all births with at least 20 weeks of gestation or at least 400 grams birthweight.

(b) Excludes data from Tasmania.

(c) Mother’s country of birth was classified using ASCCSS system. If the number of women affected was less than three in any country, those women were included under ‘Other countries’ category.

(d) Excludes data from New South Wales and Tasmania.

(e) The rate is per 10,000 women who gave birth.

31 Trisomy 13

Description: A congenital chromosomal malformation syndrome associated with extra chromosome 13 material. This anomaly includes translocation and mosaic trisomy 13.

ICD-9-BPA codes: 758.10–758.19 ICD-10-AM codes: Q91.4-Q91.7

The overall rate of trisomy 13 was 0.6 per 10,000 births (Table 2.31.1). The estimated rate of births and TOP for trisomy 13 from the four states providing TOP data was 2.6 per 10,000 pregnancies indicating a high rate of early terminations (Table 2.31.2). These data show that 72% of trisomy 13 affected pregnancies were ended in fetal deaths or TOPs.

The proportion of males and females with trisomy 13 was almost equal. More than three-quarters (77.4%) of the babies with trisomy 13 were born preterm, and only 11.3% had a birthweight of 2,500 grams or more (Table 2.31.3).

The highest rate of trisomy 13 affected births was seen in women aged 40 years or older. All women who had an affected pregnancy were non-Indigenous and none of the women who had multiple births reported to have pregnancies affected with trisomy 13. No women from remote areas were reported to have babies with this anomaly (Table 2.31.6).

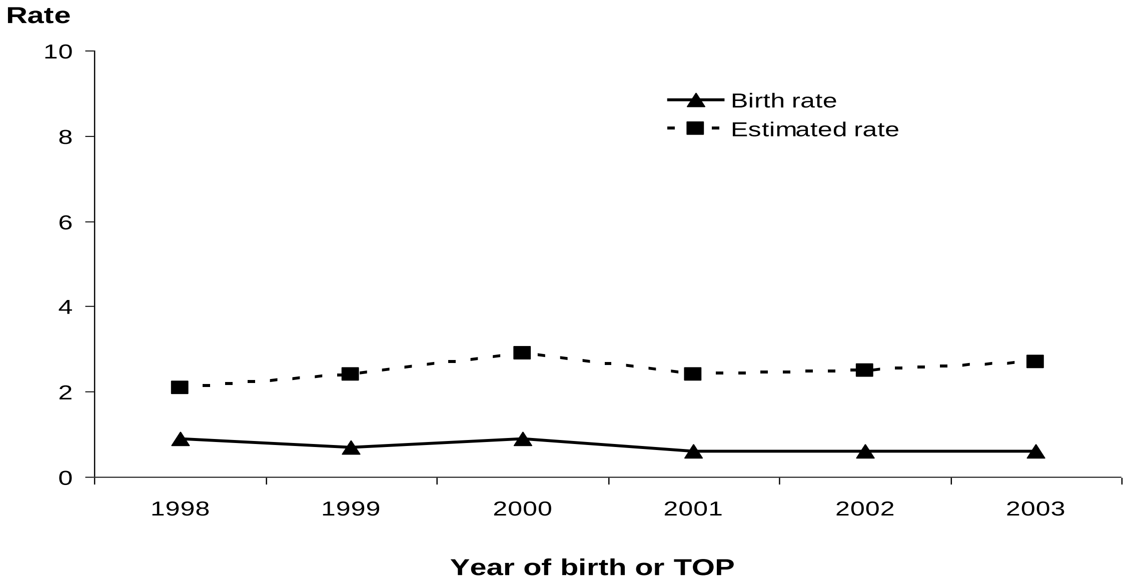

Figure 31: Rate of trisomy 13 among all births[(a)] and estimated rate[(b)], 1998–2003

(a) Birth rate includes all trisomy 13 among live births and fetal deaths in Australia per 10,000 live births and fetal deaths.

(b) Estimated rate includes all trisomy 13 among fetal deaths, live births and TOP before 20 weeks reported by New South Wales, Victoria, Western Australia and South Australia per 10,000 live births and fetal deaths.

Reported rates of trisomy 13

Table 2.31.1: Number and rate of trisomy 13 by outcome[(a)], Australia, 2002–2003

	2002		2003		2002–2003	
Outcome	**Number**	**Rate**	**Number**	**Rate**	**Number**	**Rate**
Live births[(b)]	7	0.3	6	0.2	13	0.3
Fetal deaths[(c)]	8	47.8	10	56.0	18	52.0
All births[(d)]	15	0.6	16	0.6	31	0.6

(a) Includes all births with at least 20 weeks of gestational age or at least 400 grams birthweight.

(b) For live births, the rate is per 10,000 live births.

(c) For fetal deaths, the rate is per 10,000 fetal deaths.

(d) For all births, the rate is per 10,000 live births and fetal deaths.

Table 2.31.2: Number and the estimated rate of trisomy 13 by outcome, four Australian states[(a)], 2002–2003

	2002		2003		2002–2003	
Outcome	**Number**	**Rate**	**Number**	**Rate**	**Number**	**Rate**
Live births[(b)]	5	0.3	5	0.3	10	0.3
Fetal deaths[(c)]	8	63.3	10	72.7	18	68.2
All births[(d)]	13	0.7	15	0.8	28	0.7
Births and TOP[(e)]	48	2.5	52	2.7	100	2.6

(a) Includes data for New South Wales, Victoria, Western Australia and South Australia.

(b) For live births, the rate is per 10,000 live births.

(c) For fetal deaths, the rate is per 10,000 fetal deaths.

(d) For all births, the rate is per 10,000 live births and fetal deaths.

(e) Includes TOP at less than 20 weeks gestation and all births with at least 20 weeks of gestation or at least 400 grams birthweight.

Baby characteristics

Table 2.31.3: Births[(a)] with trisomy 13 by baby characteristics, Australia, 2002–2003

Characteristic	Number	Per cent	Rate per 10,000 births
Sex			
Male	16	51.6	0.62
Female	15	48.4	0.61
Gestational age (weeks)			
Less than 25	15	48.4	60.78
25–36	9	29.0	2.43
37+	7	22.6	0.15
Birthweight (grams)			
Less than 1500	21	33.9	28.01
1500 –2499	3	4.8	1.12
2,500+	7	11.3	0.15
Unknown	31	50.0	..

(a) Includes all births with at least 20 weeks of gestation or at least 400 grams birthweight.

Maternal characteristics

Table 2.31.4: Number of women who gave birth to babies with trisomy 13, Australia, 2002–2003

	2002		2003		2002–2003	
	Number	Rate(a)	Number	Rate(a)	Number	Rate(a)
Women who gave birth	15	0.6	16	0.6	31	0.6

(a) The rate is per 10,000 women who gave birth.

Table 2.31.5: Reported number of pregnancies affected with trisomy 13 and the estimated rate, four Australian states[(a)], 2002–2003

	2002		2003		2002–2003	
	Number	Rate(b)	Number	Rate(b)	Number	Rate(b)
Women who gave birth(c)	13	0.7	15	0.8	28	0.7
Women who gave birth or had a TOP(d)	48	2.6	52	2.8	100	2.7

(a) Includes data for New South Wales, Victoria, Western Australia and South Australia.

(b) The rate is per 10,000 women who gave birth.

(c) Includes women who gave birth to a baby with at least 20 weeks of gestation or at least 400 grams birthweight.

(d) Includes TOP at less than 20 weeks gestation and all births with at least 20 weeks of gestation age or at least 400 grams birthweight.

Table 2.31.6: Maternal characteristics of births[(a)] affected with trisomy 13, Australia, 2002–2003

Characteristic	Number	Per cent	Rate[(e)]	Confidence intervals
Maternal age group				
Less than 20	1	3.3	0.4	0.0–2.5
20–24	5	16.7	0.7	0.2–1.6
25–29	6	20.0	0.4	0.2–0.9
30–34	8	26.7	0.5	0.2–0.9
35–39	8	26.7	1.0	0.4–2.1
40 and over	2	6.7	1.3	0.2–4.6
Indigenous status [(b)]				
Indigenous	0	0.0	..	..
Non-Indigenous	30	100.0	0.6	0.4–0.9
Remoteness Area				
Major cities	17	56.7	0.5	0.3–0.8
Regional	13	43.3	0.9	0.5–1.5
Remote	0	0.0	..	..
Not stated	1		..	..
Country of birth [(c)]				
Australia	20	64.5	0.5	0.3–0.8
Other countries	7	22.6	..	..
Not stated	4	12.9	..	..
Parity [(d)]				
Primiparous	8	44.4	0.6	0.3–1.2
Multiparous	10	55.6	0.5	0.3–1.0
Plurality				
Singleton	31	100.0	0.6	0.4–0.9
Multiple	0	0.0	..	..

(a) Includes all births with at least 20 weeks of gestation or at least 400 grams birthweight.

(b) Excludes data from Tasmania.

(c) Mother’s country of birth was classified using ASCCSS system. If the number of women affected was less than three in any country, those women were included under ‘Other countries’ category.

(d) Excludes data from New South Wales and Tasmania.

(e) The rate is per 10,000 women who gave birth.

32 Trisomy 18

Description: A congenital chromosomal malformation syndrome associated with extra chromosome 18. Includes: translocation and mosaic trisomy 18.

ICD-9-BPA codes: 758.20–758.29 ICD-10-AM codes: Q91.0–91.3

The reported rate of trisomy 18 at birth was 2.0 per 10,000 births (Table 2.32.1). Information from the four states providing TOP data shows that the estimated rate of trisomy 18 was 3.5 times the rate at birth indicating a high rate of terminations (7.1 per 10,000 births). The estimated rate was higher in 2003 than in 2002. About 68.6% of pregnancies affected by trisomy 18 were terminated early in pregnancy or were stillbirths (Figure 32, Table 2.32.2).

More females (62.1%) than males had trisomy 18. The rate of Trisomy 18 among babies born before 25 weeks gestation was 146 per 10,000 births. About 70% births were preterm and 87.4% had a birthweight of less than 2,500 grams (Table 2.32.3).

Women aged 40 years or older had a significantly higher rate of pregnancies with trisomy 18 than younger women (Table 2.32.6). Women born in Africa had the highest rate of affected births. The rates did not differ by Indigenous status, women's areas of residence parity or plurality (Table 2.32.6).

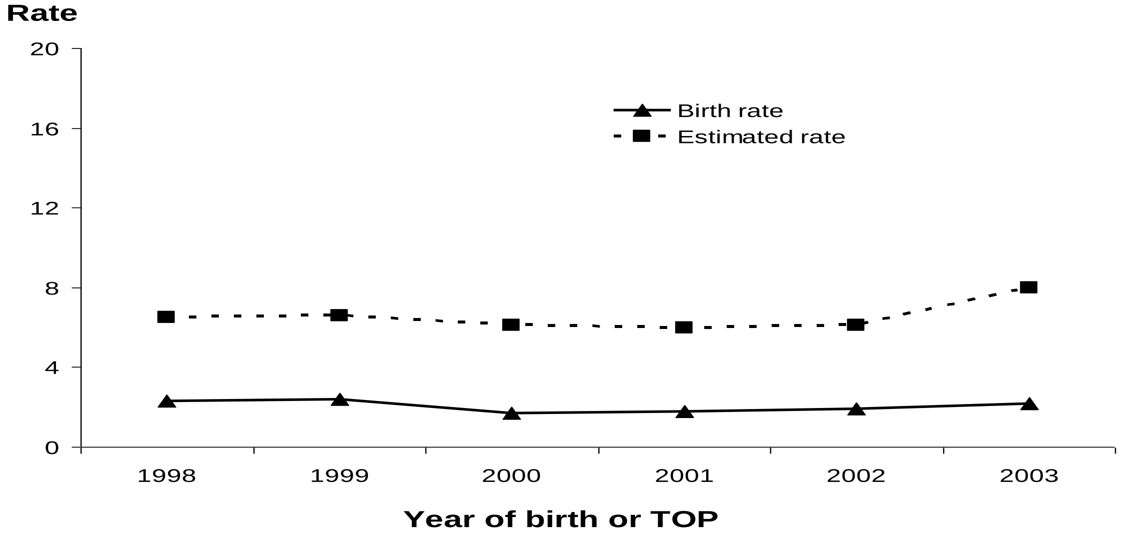

Figure 32: Rate of trisomy 18 among all births[(a)] and estimated rate[(b)], 1998–2003

(a) Birth rate includes all trisomy 18 among live births and fetal deaths in Australia per 10,000 live births and fetal deaths.

(b) Estimated rate includes all trisomy 18 among fetal deaths, live births and TOP before 20 weeks reported by New South Wales, Victoria, Western Australia and South Australia per 10,000 live births and fetal deaths.

Reported rates of trisomy 18

Table 2.32.1: Number and rate of trisomy 18 by outcome[a], Australia, 2002–2003

	2002		2003		2002–2003	
Outcome	**Number**	**Rate**	**Number**	**Rate**	**Number**	**Rate**
Live births[b]	20	0.8	20	0.8	40	0.8
Fetal deaths[c]	28	167	35	196.2	63	182.0
All births[d]	48	1.9	55	2.2	103	2.0

(a) Includes all births with at least 20 weeks of gestational age or at least 400 grams birthweight.

(b) For live births, the rate is per 10,000 live births.

(c) For fetal deaths, the rate is per 10,000 fetal deaths.

(d) For all births, the rate is per 10,000 live births and fetal deaths.

Table 2.32.2: Number and the estimated rate of trisomy 18 by outcome, four Australian states[a], 2002–2003

	2002		2003		2002–2003	
Outcome	**Number**	**Rate**	**Number**	**Rate**	**Number**	**Rate**
Live births[b]	16	0.8	17	0.9	33	0.9
Fetal deaths[c]	24	189.9	28	203.6	52	197.0
All births[d]	40	2.1	45	2.3	85	2.2
Births and TOP[e]	117	6.1	154	8.0	271	7.1

(a) Includes data for New South Wales, Victoria, Western Australia and South Australia.

(b) For live births, the rate is per 10,000 live births.

(c) For fetal deaths, the rate is per 10,000 fetal deaths.

(d) For all births, the rate is per 10,000 live births and fetal deaths.

(e) Includes TOP at less than 20 weeks gestation and all births with at least 20 weeks of gestational age or at least 400 grams birthweight.

Baby characteristics

Table 2.32.3: Births[a] with trisomy 18 by baby characteristics, Australia, 2002–2003

Characteristic	Number	Per cent	Rate per 10,000 births
Sex			
Male	38	36.9	1.5
Female	64	62.1	2.6
Not stated	1	1.0	..
Gestational age (weeks)			
Less than 25	36	35.0	145.9
25–36	36	35.0	9.7
37+	30	29.1	0.7
Unknown	1	1.0	..
Birthweight (grams)			
Less than 1500	67	65.1	89.4
1500 –2499	23	22.3	8.6
2,500+	8	7.8	0.2
Unknown	5	4.9	..

(a) Includes all births with at least 20 weeks of gestation or at least 400 grams birthweight.

Maternal characteristics

Table 2.32.4: Number of women who gave birth to babies with trisomy 18, Australia, 2002–2003

	2002		2003		2002–2003	
	Number	Rate[a]	Number	Rate[a]	Number	Rate[a]
Women who gave birth	46	1.9	55	2.2	101	2.0

(a) The rate is per 10,000 women who gave birth.

Table 2.32.5: Reported number of pregnancies affected with trisomy 18 and the estimated rate, four Australian states[a], 2002–2003

	2002		2003		2002–2003	
	Number	Rate[b]	Number	Rate[b]	Number	Rate[b]
Women who gave birth[c]	38	2.0	45	2.4	83	2.2
Women who gave birth or had a TOP[d]	115	6.1	154	8.1	269	7.1

(a) Includes data for New South Wales, Victoria, Western Australia and South Australia.

(b) The rate is per 10,000 women who gave birth.

(c) Includes women who gave birth to a baby with at least 20 weeks of gestation or at least 400 grams birthweight.

(d) Includes TOP at less than 20 weeks gestation and all births with at least 20 weeks of gestational age or at least 400 grams birthweight.

Table 2.32.6: Maternal characteristics of births[(a)] affected with trisomy 18, Australia, 2002–2003

Characteristic	Number	Per cent	Rate[(e)]	Confidence intervals
Maternal age group				
Less than 20	2	2.0	0.9	0.1–3.2
20–24	11	11.1	1.5	0.7–2.7
25–29	19	19.2	1.4	0.8–2.1
30–34	22	22.2	1.3	0.8–2.0
35–39	27	27.3	3.5	2.3–5.1
40 and over	18	18.2	11.5	6.8–18.2
Indigenous status (b)				
Indigenous	1	1.0	0.7	0.0–3.7
Non-Indigenous	98	97.0	2.1	1.7–2.5
Not stated	2	2.0	..	..
Remoteness Area				
Major cities	73	72.3	2.2	1.7–2.7
Regional	26	25.7	1.8	1.2–2.6
Remote	3	3.0	2.3	0.5–6.8
Not stated	1	1.0	..	..
Country of birth (c)				
Australia	55	54.5	1.4	1.1–1.9
Europe	3	3.0	2.3	0.5–6.7
Middle East and North Africa	3	3.0	2.7	0.6–7.8
Asia	17	16.8	4.3	2.5–6.8
Africa (excluding North Africa)	5	5.0	8.7	2.8–20.4
Other countries	8	7.9	..	..
Not stated	10	9.9	..	..
Parity (d)				
Primiparous	19	29.7	1.5	0.9–2.3
Multiparous	45	70.3	2.4	1.8–3.3
Plurality				
Singleton	99	98.0	2.0	1.7–2.5
Multiple	2	2.0	2.4	0.3–8.6

(a) Includes all births with at least 20 weeks of gestation or at least 400 grams birthweight.

(b) Excludes data from Tasmania.

(c) Mother's country of birth was classified using ASCCSS system. If the number of women affected was less than three in any country, those women were included under 'Other countries' category.

(d) Excludes data from New South Wales and Tasmania.

(e) The rate is per 10,000 women who gave birth.

33 Trisomy 21

Description: A congenital chromosomal malformation syndrome characterised by a well known pattern of minor and major anomalies and associated with excess chromosomal 21 material. The anomaly includes, trisomy mosaicism and translocations of chromosome 21.

ICD-9-BPA codes: 758.00–758.09 ICD-10-AM codes: Q90.0–Q90.2, Q90.9

The overall rate of trisomy 21 for 2002–2003 was 11.1 per 10,000 births. The information provided by the four states that include TOP data shows that 26.3 per 10,000 pregnancies were affected by this anomaly. The estimated rate was increased in 2002–2003 compared with 1998 (Figure 33). A large proportion (63.6%) of women with trisomy 21 affected pregnancies had fetal deaths or early terminations of pregnancy (Table 2.32.2).

More males (54.4%) than females had trisomy 21. Among babies born before 25 weeks of gestation, the rate of trisomy affected births was 219 per 10,000 births. More than two-thirds (66.2%) of the births were at term and had birthweights of 2,500 grams or more (Table 2.33.3).

The rate of births affected with trisomy 21 increased with the advancing maternal age. This rate was significantly higher for women aged 35 years or older than for women younger than 35 years (PR=3.0, CI 2.5–3.6). The highest rate was seen among women aged 40 years and older. The trisomy 21 birth rate was significantly higher for women who had multiple births than for those who had singleton births (PR=2.0, CI 1.3–3.2) and for multiparous women compared with primiparous women (PR=1.7, CI 1.3–2.1). Women's areas of residence and Indigenous status were not significantly different (Table 2.33.6).

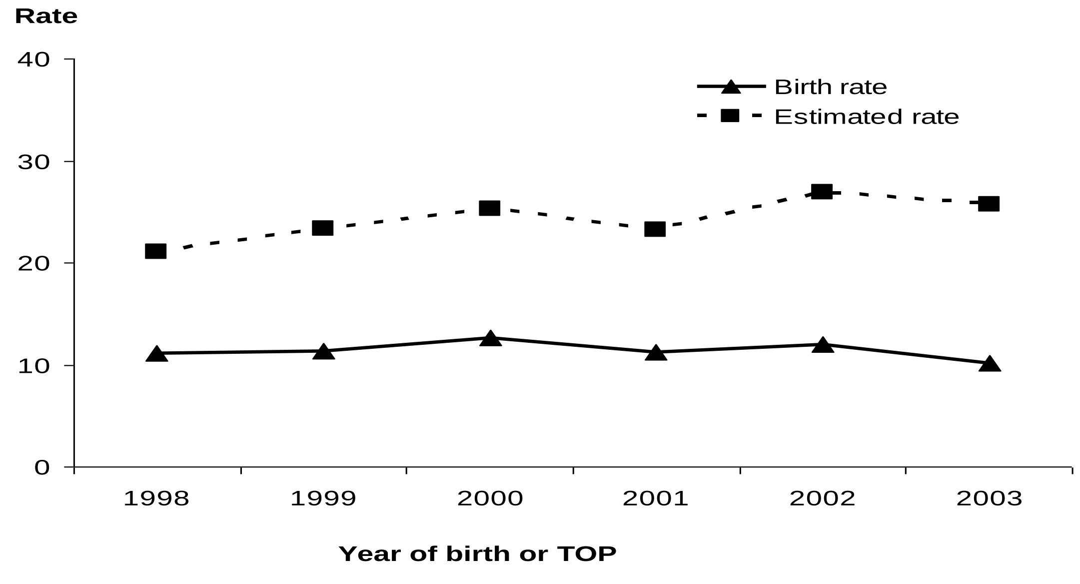

Figure 33: Rate of trisomy 21 among all births(a) and estimated rate(b), 1998–2003

(a) Birth rate includes all trisomy 21 among live births and fetal deaths in Australia per 10,000 live births and fetal deaths.

(b) Estimated rate includes all trisomy 21 among fetal deaths, live births and TOP before 20 weeks reported by New South Wales, Victoria, Western Australia and South Australia per 10,000 live births and fetal deaths.

Reported rates of trisomy 21

Table 2.33.1: Number and rate of trisomy 21 by outcome[a], Australia, 2002–2003

	2002		2003		2002–2003	
Outcome	**Number**	**Rate**	**Number**	**Rate**	**Number**	**Rate**
Live births[b]	267	10.7	229	9.1	496	9.9
Fetal deaths[c]	35	208.7	28	156.9	63	182.0
All births[d]	302	12.0	257	10.2	559	11.1

(a) Includes all births with at least 20 weeks of gestational age or at least 400 grams birthweight.

(b) For live births, the rate is per 10,000 live births.

(c) For fetal deaths, the rate is per 10,000 fetal deaths.

(d) For all births, the rate is per 10,000 live births and fetal deaths.

Table 2.33.2: Number and the estimated rate of trisomy 21 by outcome, four Australian states[a], 2002–2003

	2002		2003		2002–2003	
Outcome	**Number**	**Rate**	**Number**	**Rate**	**Number**	**Rate**
Live births[b]	199	10.5	169	8.8	368	9.7
Fetal deaths[c]	25	197. 8	24	174.5	49	185.7
All births[d]	224	11.7	193	10.0	417	10.9
Births and TOP[e]	516	26.9	495	25.7	1011	26.3

(a) Includes data for New South Wales, Victoria, Western Australia and South Australia.

(b) For live births, the rate is per 10,000 live births.

(c) For fetal deaths, the rate is per 10,000 fetal deaths.

(d) For all births, the rate is per 10,000 live births and fetal deaths.

(e) Includes TOP at less than 20 weeks gestation and all births with at least 20 weeks of gestation or at least 400 grams birthweight.

Baby characteristics

Table 2.33.3: Births[(a)] with trisomy 21 by baby characteristics, Australia, 2002–2003

Characteristic	Number	Per cent	Rate per 10,000 births
Sex			
Male	304	54.4	11.7
Female	254	45.4	10.4
Indeterminate/ Not stated	1	0.2	..
Gestational age (weeks)			
Less than 25	54	9.7	218.8
25–36	110	19.7	29.7
37+	370	66.2	8.0
Unknown	25	4.5	..
Birthweight (grams)			
Less than 1500	69	12.3	92.0
1500 –2499	84	15.0	31.3
2,500+	373	66.7	7.9
Unknown	33	5.9	..

(a) Includes all births with at least 20 weeks of gestation or at least 400 grams birthweight.

Maternal characteristics

Table 2.33.4: Number of women who gave birth to babies with trisomy 21, Australia, 2002–2003

	2002		2003		2002–2003	
	Number	Rate(a)	Number	Rate(a)	Number	Rate(a)
Women who gave birth	302	12.2	256	10.3	558	11.3

(a) The rate is per 10,000 women who gave birth.

Table 2.33.5: Reported number of pregnancies affected with trisomy 21 and the estimated rate, four Australian states[(a)], 2002–2003

	2002		2003		2002–2003	
	Number	Rate(b)	Number	Rate(b)	Number	Rate(b)
Women who gave birth(c)	224	11.9	192	10.2	416	11.0
Women who gave birth or had a TOP(d)	516	27.4	494	26.1	1010	26.7

(a) Includes data for New South Wales, Victoria, Western Australia and South Australia.

(b) The rate is per 10,000 women who gave birth.

(c) Includes women who gave birth to a baby with at least 20 weeks of gestation or at least 400 grams birthweight.

(d) Includes TOP at less than 20 weeks gestation and all births with at least 20 weeks of gestation or at least 400 grams birthweight.

Table 2.33.6: Maternal characteristics of births[(a)] affected with trisomy 21, Australia, 2002–2003

Characteristic	Number	Per cent	Rate[(e)]	Confidence Intervals
Maternal age group				
Less than 20	13	2.5	5.8	3.1–9.8
20–24	50	9.6	6. 8	5.0–8.9
25–29	107	20.5	7.6	6.3–9.2
30–34	137	26.3	8.2	6.9–9.7
35–39	128	24.6	16.7	13.9–19.8
40 and over	85	16.3	54.3	43.4–67.1
Indigenous status [(b)]				
Indigenous	20	3.6	13.5	8.2–20.8
Non-Indigenous	493	88.8	10.5	9.6–11.5
Not stated	42	7.6	..	..
Remoteness Area				
Major cities	371	67.1	11.0	9.9–12.2
Regional	166	30.0	11.3	9.7–13.2
Remote	15	2.7	11.7	6.5–19.3
Country of birth [(c)]				
Australia	349	62.5	9.1	8.2–10.1
United Kingdom	19	3.4	11.7	7.0–18.2
Europe	11	2.0	8.4	4.2–15.0
Middle East and North Africa	13	2.3	11.5	6.1–19.7
Asia	56	10.0	14.1	10.6–18.3
North America	4	0.7	13.7	3.7–35.1
South Central America/ Caribbean	7	1.3	24.1	9.7–49.6
Africa (excluding North Africa)	11	2.0	19.3	9.6–34.5
Other countries	10	1.8	..	..
Not stated	77	13.8	..	..
Parity [(d)]				
Primiparous	105	30.0	8.0	6.6–9.7
Multiparous	245	70.0	13.2	11.7–15.0
Plurality				
Singleton	539	96.6	11.1	10.1–12.0
Multiple	19	3.4	22.6	13.6–35.2

(a) Includes all births with at least 20 weeks of gestation or at least 400 grams birthweight.

(b) Excludes data from Tasmania.

(c) Mother's country of birth was classified using ASCCSS system. If the number of women affected was less than three in any country, those women were included under 'Other countries' category.

(d) Excludes data from New South Wales and Tasmania.

(e) The rate is per 10,000 women who gave birth.

4 Future directions

National Minimum Data Set for congenital anomalies

The AIHW National Perinatal Statistics Unit (NPSU) has received Australian Health Minister's Advisory Council (AHMAC) funding through the Statistical Information Management Committee (SIMC) to work towards developing a National Minimum Data Set (NMDS) for congenital anomalies.

A NMDS is a core set of data elements agreed to by the SIMC and endorsed by the National Health Information Management Principal Committee (NHIMPC) for mandatory collection and reporting at a national level. An NMDS depends on national agreement to collect uniform data and to supply it as part of a national collection (HDSC 2006). The standards make data collection activities more efficient by standardising core data items and so reducing duplication of effort; more effective by ensuring that information to be collected is relevant and appropriate to its purpose; and more comparable and consistent for reporting purposes. An NMDS includes agreement on specified data elements (discrete items of information or variables) and supporting data element concepts as well as the application of those data elements and the statistical units for collection. Definitions of all data elements that are included in National Minimum Data Sets are included in the AIHW's online metadata registry, 'METeOR'.

The development of a NMDS for congenital anomalies will involve developing and agreeing on:

- a definition for congenital anomalies
- the scope of the NMDS, including the conditions to be included, the period of notification and the data elements to be included
- the data element definitions
- a classification for congenital anomalies
- a timeframe for implementation
- integration with the perinatal NMDS.

Some jurisdictions use ICD-9-BPA to code congenital anomalies and others use ICD-10-AM. The jurisdictions using ICD-9-BPA have not moved to ICD-10-AM because it lacks specificity for some congenital anomalies. Following the review of the National Congenital Malformations and Birth Defects Data Collection, the National Congenital Anomalies Steering Committee (NCASC) agreed that a single classification should be developed for use in Australia and that this should be based on ICD-10-AM. Currently the NPSU is working with the National Centre for Classification in Health (NCCH) to develop a classification for congenital anomalies based on the sixth edition of ICD-10-AM and the ICD-9-BPA.

The NCCH in collaboration with the NPSU has already completed developing maps from ICD-9-BPA to ICD-10-AM, so that the data can be presented in a single classification in national reports. This will enable time series analyses to be undertaken using a single classification. However the maps have not been uniformly adopted by all states and territories.

In addition, a national workshop was held in December 2007 at the NCCH to develop ICD-10-AM classification for chromosomal abnormalities. Experts in the field from all states and territories participated in the workshop. Instead of the existing complex coding system, a new classification with more descriptive coding system that will assist in coding the chromosomal abnormalities without difficulty by all states and territories was successfully completed. However, since there were major changes to the existing system, approval from the WHO to have necessary changes is a requirement. Therefore the new classification will not be used until the approval procedure is completed.

Committees

The NMDS for Congenital anomalies will be developed in consultation with several committees convened by the NPSU – NCASC, the State and Territory Implementation Committee for Congenital Anomalies (STICCA) (See Appendix D) and when relevant, National Perinatal Data Development Committee (NPDDC). Following endorsement by the NCASC and the STICCA, submissions will be made to the Health Data Standards Committee (HDSC) and the SIMC.

Proposed timeframe

The proposed timeframe for the development of the NMDS for congenital anomalies is by December 2008, with implementation from 1 July 2009. The timeframe for the development of the classification for congenital anomalies is by early 2009.

Clinical definitions

For the conditions included in this report, which were defined by the International Clearing house for Birth Defects Surveillance and Research (ICBDSR), the definitions in the report were determined to be inadequate for the Australian context by a working group of the NCASC. A decision was made to use them in the current report but to label them as descriptions rather than definitions. The Australian Paediatric Surveillance Unit (APSU) is currently undertaking a project, in consultation with the NPSU, on developing nationally standardised clinical definitions for selected congenital anomalies that are adequate for the Australian context and will provide more accurate information about the prevalence of these conditions.

National report on neural tube defects

Food Standards Australia and New Zealand (FSANZ) has approved mandatory fortification of food with folic acid to reduce the prevalence of neural tube defects (NTD). An important part of assessing the impact of fortification is the availability of baseline data to compare rates of NTD before and after fortification. A national report on NTD using currently available data is being prepared. It will contain data on births and TOP with NTD occurring in 1998–2005.

Newborn screening

Newborn screening has been undertaken in Australia since the late 1960s. It identifies a range of metabolic disorders in newborn babies for which morbidity, mortality and associated disabilities can be reduced by early intervention (HGSA-RACP 2004). A blood sample is taken from a newborn baby between 48 and 72 hours after birth by pricking the baby’s heel and collecting blood onto absorbent paper (a Guthrie card).

Prenatal screening and diagnosis

The aim of prenatal screening and diagnostic testing is the early detection of congenital anomalies. This enables strategies for prevention and treatment to be developed early on, thus reducing the effect of the disease.

Prenatal screening programs differ from diagnostic testing in that screening programs are conducted at a population level and, in the context of congenital anomalies, are used to identify pregnant women who may be at risk of having a baby with a congenital anomaly.

Screening programs may be targeted at 'high risk' individuals, for example pregnant women aged 37 years and older. Diagnostic testing is conducted at the individual level to diagnose or confirm a birth anomaly. Indications for diagnostic testing include advanced maternal age (37 years and older), abnormal screening results, history of a congenital anomaly and exposure to a teratogen (Muggli & Halliday 2003).

Prenatal screening tests include full blood examinations; first and second trimester maternal serum screening (this is a biochemical test which is usually done in the second trimester, but is being increasingly performed in the first trimester to coincide with the measurement of nuchal translucency conducted by ultrasound); ultrasound including nuchal translucency (this is performed at 8–12 weeks to determine gestational age and at 10–14 weeks to determine the nuchal translucency which can indicate a risk of chromosomal abnormality); and ultrasound performed in the second trimester which can be used to screen for structural congenital anomalies.

Prenatal diagnostic tests include amniocentesis and chorionic villus sampling. Amniocentesis involves the collection of amniotic fluid from the amniotic cavity in the uterus. The cells from the amniotic fluid are grown in culture and chromosomal, biochemical and molecular biological analyses are undertaken to detect various congenital anomalies and certain genetic diseases. This test is performed at 14–18 weeks of pregnancy. Chorionic villus sampling involves collecting tissue from the villi of the chorion (part of the placenta) and testing for congenital anomalies and genetic diseases. This test is performed at 10–12 weeks of pregnancy, so can be performed earlier than amniocentesis.

National reporting of data on newborn screening and prenatal screening/diagnosis

The review of the National Congenital Malformations and Birth Defects Data Collection (Birch et al. 2004) recommended that the NPSU develop collaborations with organisations collecting data on newborn screening and prenatal screening/diagnosis and that data on newborn screening and prenatal screening/diagnosis be included in the revised national report on congenital anomalies.

The NPSU received AHMAC funding through the SIMC to investigate the feasibility of national data collection and reporting on newborn screening and prenatal screening/diagnosis. The scoping study identified a number of issues, which were broadly structural, data ownership issues, and ethical or privacy issues. The NPSU recommended a program of national data development; in the interim a set of summary measures could be reported nationally.

Appendix A: Denominator data

Table A: Total numbers of live births, fetal deaths and all births, Australia, 2002–2003

	2002	2003	Total
Fetal deaths	1,677	1,785	3,462
Live births	249,699	251,478	501,177
All births	251,376	253,263	504,639

Note: Excludes Northern Territory.
Source: NPDC.

Table B: Total numbers of live births and fetal deaths; NSW, Vic, SA and WA only, 2002–2003

	2002	2003	Total
Fetal deaths	1,264	1,375	2,639
Live births	190,403	191,116	381,519
All births	191,667	192,491	384,158

Source: NPDC.

Table C: Total numbers of women who gave births, Australia, 2002–2003

	2002	2003	2002–2003
Women who gave birth	247,084	248,965	496,049

Note: Excludes Northern Territory.

Source: NPDC.

Table D: Total numbers of women who gave births; NSW, Vic, SA and WA only, 2002–2003

	2002	2003	2002–2003
Women who gave birth	188,427	189,234	377,661

Source: NPDC.

Table E: Indigenous status, Australia, 2002–2003

Indigenous status	Number of women
Aboriginal or Torres Strait Islander	14,874
Other	469,959
Not stated	11,216
Total	496,049

Note: Excludes Northern Territory.

Source: NPDC.

Table F: Remoteness Area of usual residence, Australia, 2002–2003

Remoteness area	Number of women
Major cities of Australia	336,445
Total regional	146,599
Total remote	12,843
Not stated	162
Total	496,049

Note: Excludes Northern Territory.

Source: NPDC.

Table G: Parity, Australia, 2002–2003

Parity	Number of women
Primiparous	130,588
Multiparous	184,780
Total	315,368

Note: Excludes Northern Territory, New South Wales and Tasmania.

Source: NPDC.

Table H: Plurality, Australia, 2002–2003

Plurality	Number of women
Singletons	487,625
Multiple births	8,424
Total	496,049

Note: Excludes Northern Territory.

Source: NPDC.

Table I: Mother's country of birth, Australia, 2002–2003

Country of birth	Number of women
Australia	382477
New Zealand	12571
United Kingdom	16261
Europe	13099
Middle East and North Africa	11303
Asia	39772
North America	2915
South Central America/Caribbean	2902
Africa (exclude north Africa)	5696
Other Countries	6217

Note: Excludes Northern Territory.

Source: NPDC.

Table J: Mother's age group, years, Australia, 2002–2003

Age group (years)	Number of women
<20	22,568
20-24	73,771
25-29	139,965
30-34	167,330
35-39	76,771
40+	15,644

Note: Excludes Northern Territory.

Source: NPDC.

Table K: Sex of the baby, 2002–2003

Sex	2002	2003	2002–2003
Males	128,885	130,302	259,187
Females	121,843	122,855	244,698
All births	250,728	253,157	503,885

Note: Excludes Northern Territory.

Source: NPDC.

Table L: Birthweight groups

Birthweight groups (grams)	number
Less than 1500	7,498
1500 –2499	26,807
2500 or more	470,168
Total	504,473

Note: Excludes Northern Territory.

Source: NPDC.

Table M: Gestational age group, 2002–2003

Gestational age group	number
Less than 25 weeks	2,468
25–36 weeks	37,026
37 weeks or more	465,092
Total	504,586

Note: Excludes Northern Territory.

Source: NPDC.

Appendix B: State and territory reports on congenital anomalies

New South Wales

Centre for Epidemiology and Research 2006. New South Wales Mothers and Babies 2005. NSW Public Health Bulletin 15: S-5. Sydney: NSW Department of Health.

Victoria

Riley M & Halliday J 2006. Birth defects in Victoria 2003–2004. Victorian Perinatal Data Collection Unit. Public Health. Melbourne: Department of Human Services.

Muggli E & Halliday J 2006. Report on prenatal diagnostic testing in Victoria 2005. Public Health Genetics, Murdoch Children's Research Institute.

Queensland

Queensland Health 2007. Perinatal statistics Queensland 2005. Brisbane: Queensland Health.

South Australia

Hann E, Chan A, Scott H & van Essen P 2006. 2004 Annual Report of the South Australian Birth Defects Register and incorporating the Annual report of Prenatal Diagnosis in South Australia, 2003, Women's and Children's Hospital Adelaide, South Australia.

Western Australia

Bower, C, Rudy E, Ryan A, Cosgrove P & Callaghan A, 2006. Report of the Birth Defects Registry of Western Australia 1980–2006, King Edward Memorial Hospital, Women's and Children's Health Service, Number 13.

Tasmania

Department of Health and Human Services 2005. Council of Obstetric and Paediatric Mortality and Morbidity, Tasmania: annual report for 2003. Hobart: Department of Health and Human Service.

Australian Capital Territory

Population Health Research Centre, ACT Health 2005. Maternal and perinatal health in the ACT 1997–2001. Canberra: ACT Government.

Appendix C: Data collection contacts for congenital anomalies

New South Wales

Ms Sue Travis
NSW Birth Defects Register
NSW Health Department
Locked Mail Bag 961
North Sydney NSW 2059
Phone: (02) 9391 9000
Fax: (02) 9391 9101
Email: nswhealth@doh.health.nsw.gov.au

Victoria

Ms Merilyn Riley
Victorian Births Defects Register
Victorian Perinatal Data Collection Unit
GPO Box 4003
Melbourne Vic 3001
Phone: (03) 9096 2695 or 1300 858 505
Fax: (03) 9096 2700
Email: perinatal.data@dhs.vic.gov.au

Queensland

Joanne Bunney
Data Services Unit
Health Information Centre
Queensland Department of Health
GPO Box 48
Brisbane Qld 4001
Phone: (07) 3234 1708
Fax: (07) 3234 0279
Email: joanne_bunney@health.qld.gov.au

South Australia

Ms Phillipa van Essen /Ms Heather Scott
The South Australian Birth Defects Register
Women's and Children's Hospital
72 King William Road
North Adelaide, SA 5006
Phone: (08) 8161 7368
Fax: (08) 8161 6088
Email: cywhs.sabdr@cywhs.sa.gov.au

Western Australia

Ms Edwina Rudy
The Western Australia Birth Defects Registry
King Edward Memorial Hospital
Women's and Children's Health Service
374 Bagot Road
Subiaco WA 6008
Phone : (08) 9340 2735
Fax: (08) 9340 2636
Email: Edwina.Rudy@health.wa.gov.au

Tasmania

Ms Helen Galea
Clinical Data Services
Hospitals and Ambulance Service
Department of Health and Human Services
Level 2, 10 Murray Street
Hobart Tas 7000
Phone: (03) 6233 2173
Fax: (03) 6233 3550

Australian Capital Territory

Ms Maureen Bourne
Population Health Research Centre
ACT Health
Building 5, Level 1
The Canberra Hospital
PO Box 11
Woden ACT 2606
Phone: (02) 6205 2612
Fax: (02) 6244 4138

Northern Territory

Acute Care Information Services
Department of Health and Community Services
Building 6, Royal Darwin Hospital
PO Box 41326
Casuarina NT 0810
Phone: (08) 8922 7779
Fax: (08) 8922 7787

Australian Paediatric Surveillance Unit

The Australian Paediatric Surveillance Unit
The Children's Hospital, Westmead
Level 2, Clinical Sciences Building
Locked Bag 4001,
Westmead NSW 2145
Phone: (02) 9845 3005/2200
Fax: (02) 9845 3082
Email: apsu@chw.edu.au

Appendix D:

National Congenital Anomalies Steering Committee

Name	Position/Organisation
Professor Elizabeth Elliott	Chair/ Disciplines of Paediatrics and Child Health, University of Sydney and Director, Australian Paediatric Surveillance Unit
Professor David Tudehope	Deputy Chair/Director, Neonatal Intensive Care Unit, Mater Mother's Hospital, Brisbane
Professor Carol Bower	Head, Division of Population Sciences, The University of Western Australia and Western Australian Birth Defects Register
Associate Professor Elizabeth Sullivan	AIHW, NPSU
Associate Professor Jane Halliday	Epidemiologist/Victorian Birth Defects Register, Head, Public Health Genetics, Murdoch Children's Research Institute
Associate Professor Annabelle Chan	Senior Medical Consultant, Pregnancy Outcome Unit, South Australian Department of Health
Dr Hugh Martin	Paediatric Surgeon, Royal Australasian College of Paediatric Surgeons
Dr Lee Taylor	Manager, Centre for Epidemiology and Research, NSW Department of Health
Ms Sue Cornes	Senior Director, Health Information Centre, Queensland Health

State and Territory Implementation Committee for Congenital Anomalies

Ms Merilyn Riley	Victorian Birth Defects Register
Ms Sue Travis	Birth Defects Register, New South Wales
Ms Edwina Rudy	Western Australian Birth Defects Register
Ms Phillipa van Essen	South Australian Birth Defects Register
Ms Maureen Bourne	Population Health Research Centre, Australian Capital Territory
Mr Peter Mansfield	Clinical Data Services, Department of Health and Human Services, Tasmania
Ms Joanne Bunney	Health Information Centre, Queensland Department of Health

Glossary

Birthweight: the first weight of the baby (stillborn or live born) obtained after birth (usually measured to the nearest 5g and obtained within one hour of birth).

Congenital anomalies: a structural, functional or metabolic abnormality that is present at birth, even if not diagnosed until months or years later.

Fetal death (stillbirth): death prior to the complete expulsion or extraction from its mother of a product of conception of 20 or more completed weeks of gestation or of 400 g or more birthweight. The death is indicated by the fact that after such separation the fetus does not breathe or show any other evidence of life, such as beating of the heart, pulsation of the umbilical cord, or definite movement of voluntary muscles.

Gestational age: the duration of pregnancy in completed weeks calculated from the date of the first day of a woman's last menstrual period and her baby's date of birth, or via ultrasound, or derived from clinical assessment during pregnancy or from examination of the baby after birth.

Induced abortion: Termination of pregnancy before 20 completed weeks of gestation.

Infant death: death of a live born child under 1 year of age. Infant death rates are expressed per 10,000 live births in this report.

Isolated malformation: only one major congenital anomaly is present in the infant or fetus.

Live birth: the complete expulsion or extraction from its mother of a product of conception, irrespective of the duration of the pregnancy, which, after such separation, breathes or shows any other evidence of life, such as beating of the heart, pulsation of the umbilical cord, or definite movement of voluntary muscles, whether or not the umbilical cord has been cut or the placenta is attached; each product of such a birth is considered live birth.

Low birthweight: birthweight of less than 2,500 g.

Major congenital anomaly: congenital anomaly that are either lethal or significantly affect the individual's function or appearance.

Maternal age: mother's age at the birth of her baby.

Multigravida: pregnant woman who has had at least one previous pregnancy.

Multipara: pregnant woman who has had at least one previous pregnancy resulting in a live birth or stillbirth.

Neonatal death: death of a live born baby within 28 days of birth.

Parity: number of previous pregnancies resulting in live births or fetal deaths, excluding the current pregnancy.

Perinatal death: a fetal or neonatal death of at least 20 weeks gestation or at least 400 grams birthweight.

Plurality: the number of births resulting from a pregnancy.

Post-term birth: birth at 42 or more completed weeks of gestation.

Pre-term birth: birth before 37 completed weeks of gestation.

Primipara: pregnant woman who has had no previous pregnancy resulting in a live birth or stillbirth.

Stillbirth: see fetal death.

Termination of pregnancy: termination of pregnancy by medical or mechanical means before 20 weeks of gestation.

References

ABS (Australian Bureau of Statistics) 1990. Australian Standard Classification of Countries for Social Statistics. ABS Cat. no. 1269.0. Canberra: ABS.

ABS 1998. Australian Standard Classification of Countries for Social Statistics. ABS Cat. no. 1269.0. Canberra: ABS.

ABS 2001. Australian Standard Geographical Classification. ABS Cat. no. 1216.0. Canberra: ABS.

Al-Yaman F, Bryant M & Sargeant H 2002. Australia's children: their health and wellbeing. Cat. no. PHE 36. Canberra: AIHW.

Armitage P, Berry G 1994. Statistical Methods in Medical Research, third edition, Oxford: Blackwell Scientific Publications, 118–132.

Birch M-R, Grayson N & Sullivan E 2004. Recommendations for development of a new Australian birth anomalies system: a review of the congenital malformations and birth defects data collection. Cat. no. PER 23. Sydney: AIHW National Perinatal Statistics Unit (Birth Anomalies Series No.1).

Bower C, Ryan A & Rudy E 2001. Ascertainment of pregnancies terminated because of birth defects: effect on completeness of adding a new source of data. Teratology 63(1): 23–5.

BPA (British Paediatric Association) 1979. British Paediatric Association Classification of Diseases. London: BPA.

Food Standards Australia, New Zealand, 2006. Final assessment report. Proposal P295 — Consideration of mandatory fortification with folic acid.

Hurst T, Shafir E, Day P & Lancaster P 1999. Congenital malformations Australia 1995 and 1996. AIHW Cat. No. PER 8. Sydney:AIHW National Perinatal Statistics Unit (Birth Defects Series No.3).

Muggli E & Halliday J 2006. Report on prenatal diagnostic testing in Victoria 2005. Public Health Genetics, Murdoch Children's Research Institute.

NCCH (National Centre for Classification in Health) 1998. The International Statistical Classification of Diseases and Related Health Problems, 10th Revision, Australian Modification (ICD-10-AM), 5th ed. Sydney: University of Sydney.

Riley M & Halliday J 2006. Birth defects in Victoria 2003–2004. Victorian Perinatal Data Collection Unit, Public Health. Melbourne: Department of Human Services.

The International Clearinghouse for Birth Defects Surveillance and Research, Annual report 2006 with data for 2004.

The International Clearinghouse for Birth Defects Surveillance and Research, Annual Report 2005 with data for 2003.

List of Tables

List of Figures