

# Victorian Birth Defects Bulletin

No. 8 December 2009

Welcome to the eighth edition of the Victorian Birth Defects Bulletin. Pages 1-3 present information on orofacial clefts, and on page 4 we summarise the most recent data for 2007 on birth outcomes, plus a brief explanation of operational changes to the BDR.

Special thanks to Dr Heather Cleland, Director, Department of Plastic & Maxillofacial Surgery, Royal Children's Hospital (RCH) and Ms Pru Hamilton, Cleft and Craniofacial Clinic, RCH, for their help with this Bulletin.

## Orofacial clefts

"A cleft is a "split" or "separation" which can occur anywhere in the body, but in these children occurs at the lip, nose or along the roof of the mouth. We do not know exactly why clefts occur but they do run in families to some extent.

Orofacial clefts are the most common craniofacial birth defect affecting approximately 1 in 581 births in Victoria in 2007. The overall prevalence of orofacial clefts from 2002-2007 was 1 in 531 births. Although these are not anomalies with high mortality rates, and can be corrected with surgery, children who are affected may have residual problems, including speech, hearing and dental problems which may require further treatment during childhood and into adulthood. Some children may also experience psychosocial difficulties related to facial differences and/or associated conditions.

From 2002-2007, 45.6% of clefts involved the palate only (CP), 20.2% involved the lip only (CL) and 34.1% involved both the lip and the palate (CLP). CP usually occurs each year as one of the ten most common birth defects.



Cleft lip and cleft palate in the newborn

Orofacial clefts can occur as isolated anomalies or in association with other defects or syndromes.

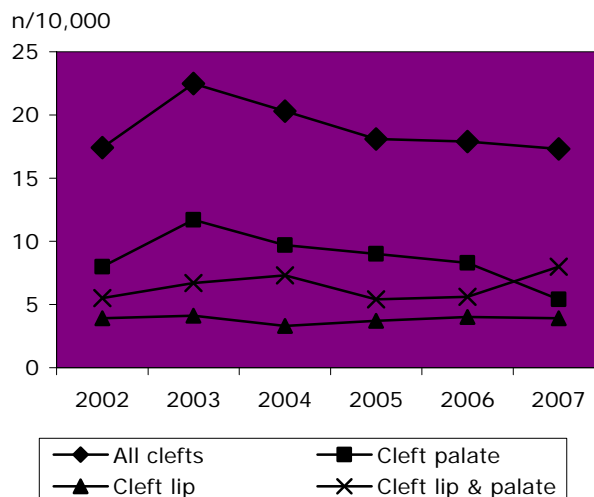
## Proportion of orofacial cleft types as isolated defects or with other defects, 2007

	Per cent (%)		
	CP	CL	CLP
Isolated	56.4	82.0	67.2
Chromosomal	12.8	7.1	13.8
Syndromic	12.8	0	0
Other same system	0	0	0
Other multiple systems	17.9	10.7	19.0

The number of babies with an orofacial cleft has remained stable over the past 6 years ranging from 110 to 150 cases per year.

Overall prevalence refers to the total number of cases occurring over a specified time period and is important to help us understand the number of pregnancies actually affected by the condition.

## Overall prevalence of orofacial clefts, 2002-2007



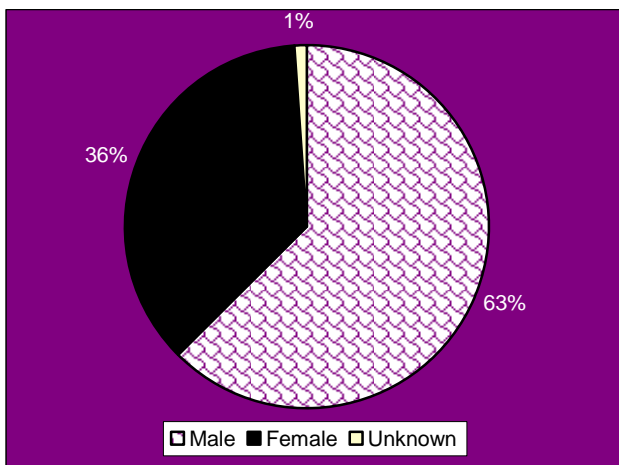
Livebirth prevalence refers to the number of liveborn babies affected by the condition and is useful for service planning and provision.

## Prevalence of orofacial clefts, 2007

n/10,000	Overall prevalence	Livebirth prevalence
CP	5.4	5
CL	3.9	3.5
CLP	8.0	5.7

## Epidemiology of Orofacial clefts in Victoria, 2007

- CP is usually the most common of the three orofacial clefts. However in 2007, for the first time since the BDR began, the most prevalent orofacial cleft was CLP with an overall prevalence of 1 in 1,250 births; CP was 1 in 1,851 births and CL was 1 in 2,564 births.
- Orofacial clefts are not lethal, with 93% of isolated cases surviving beyond 28 days after birth. 46% of cases associated with chromosomal anomalies or syndromes were either terminated before 20 weeks gestation or resulted in a perinatal death.
- CLP more commonly affects males than females. There were the same proportion of males and females affected by CP and CL.



## Proportion of male to female babies with cleft lip and palate, 2002-2007

- There were no significant maternal age associations for any of the orofacial clefts for either 2007 or for combined data from 2002-2007.
- The 2002-2007 prevalence rate of cleft palate was higher in babies born to women from Middle Eastern countries than Australian-born, Asian-born and United Kingdom-born women.

For more information please contact the Victorian Birth Defects Register, Clinical Councils' Unit Department of Health on 1300 858 505 or by email on [perinatal.data@dhs.vic.gov.au](mailto:perinatal.data@dhs.vic.gov.au)

## Studies on orofacial clefts utilising data from the Victorian Birth Defects Register

1. Dr Tiong Yang Tan, Clinical Geneticist, Genetic Health Services Victoria, undertook a PhD on reviewing birth defects and syndromes associated with cleft lip and/or cleft palate in children born from 2000-2002 in Victoria, Australia.

Tan Tiong Yang, Amor David J, Riley Merylyn, Halliday Jane, Kilpatrick Nicky, Simms Katrina and White Susan M, *Registry- and clinic-based analyses of birth defects and syndromes associated with cleft lip/palate in Victoria, Australia*, **Cleft Palate-Craniofacial Journal** (accepted for publication 2009)

2. Dr Linda Vallino-Napoli, Head, Craniofacial Outcomes Research Laboratory, Alfred I. DuPont Hospital for Children, Wilmington, Delaware, worked with staff from the VBDR looking at the epidemiological characteristics of both isolated orofacial clefts, and other birth defects associated with orofacial clefts.

Vallino-Napoli, L., Riley M, & Halliday J., *An Epidemiologic Study of Isolated Cleft Lip, Palate or Both in Victoria, Australia From, 1983-2000*, **Cleft Palate-Craniofacial Journal**, Vol.41 No.2 (March 2004):185-194

Vallino-Napoli, L., Riley M, & Halliday J., *An Epidemiologic Study of Orofacial Clefts with Other Birth Defects in Victoria, Australia*, **Cleft Palate-Craniofacial Journal**, Vol.43 No.5 (September 2006):571-576.

3. The International Clearing House for Birth Defects Surveillance and Research (ICH) received WHO funding in 2000 to undertake **International Collaborative Research on Craniofacial anomalies project** with an aim to "reduce duplication of efforts and achieve broader coverage of priority research needs by bringing together international researchers through collaborative partnerships, and to develop global consensus on CFA research and common research protocols" <http://www.who.int/genomics/anomalies/en>.

The VBDR has contributed data to this project and has been involved in interpretation and reporting of results.

# Victorian Birth Defects Bulletin

No.8 December 2009

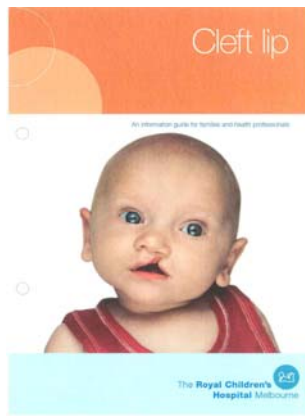
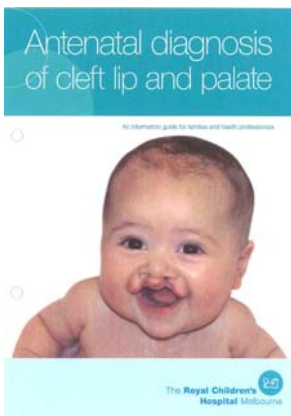
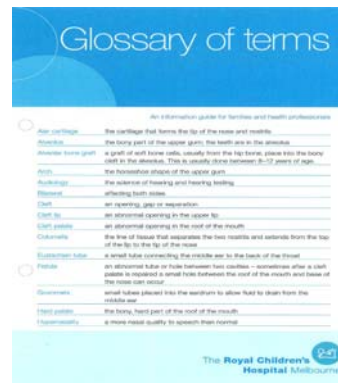
## Cleft and Craniofacial Services at The Royal Children's Hospital

The plastics and maxillofacial department at the Royal Children's Hospital are currently producing a series of booklets to assist and educate parents and other health professionals about cleft lips and palates. We appreciate all the time and effort from numerous departments that has gone into the project and thanks to the families of cleft children for being so willing to provide photos.

Our cleft lip and palate clinic at the Royal Children's Hospital has a large and experienced group of specialists - plastic surgeons, oral and maxillofacial surgeons, ENT (ear, nose and throat) surgeons, audiologists, paedodontists, speech pathologists, orthodontists, otolaryngologists, social workers, and nurses - who combine to form the cleft lip and palate clinic.

These clinics cater for children from birth and follow them through until they have completed their cleft care or are able to be transitioned to an adult hospital.

[www.rch.org.au/plastic/units.cfm](http://www.rch.org.au/plastic/units.cfm)



## CleftPALS

The Cleft Palate and Lip Society (CleftPALS) was established in 1974 to provide support, reassurance, and knowledge to parents and their families of a child born with a cleft condition. This was the vision when the support group seed was planted. The seed has grown over the years with branches in most states around Australia.

CleftPALS Victoria is a group of volunteers, mostly parents of cleft-affected children or cleft affected adults, that can provide advice on a wide range of issues.

Further information can be obtained from their website: [www.cleftpalsvic.com](http://www.cleftpalsvic.com).



# Victorian Birth Defects Bulletin

No.8 December 2009

## 2007 Birth defect data - prevalence and birth outcome

- In 2007 there were 2,863 babies born after 20 weeks or more gestation with a birth defect. There were another 363 identified as terminations of pregnancy before 20 weeks gestation for a birth defect. This gives an **overall birth defect prevalence rate of 44/1,000 or 4.4%**.
- The **livebirth birth defect prevalence rate** in 2007 was 36.8/1,000 livebirths or 3.7%.
- 11.2% of all pregnancies with birth defects were terminated before 20 weeks gestation, and another 5.7% of birth defects were terminated at 20 weeks or later.
- Of babies with a birth defect born at 20 weeks or later, excluding terminations, 39 (1.4%) were stillborn and 58 (2.0%) were neonatal deaths.

## Review of the Consultative Council on Obstetric and Paediatric Mortality and Morbidity (CCOPMM) – its impact for the VBDR

Under the Health Act (1958) one of the functions of CCOPMM is to conduct a perinatal data collection for a number of reasons

including...“to maintain a register of congenital abnormalities”.

Earlier this year the roles and functions of CCOPMM were formally reviewed and the final report was completed in June. As a result of this review there were a number of recommendations which impact on the VBDR.

First, it was recommended that the Birth Defects Subcommittee be replaced by a committee based on ‘a community of practice’. It is expected that those who were involved in the previous subcommittee will be invited to submit an expression of interest to be involved in the new ‘community of practice’, when it is established.

Therefore, we wish to formally acknowledge our appreciation to the following members who have served on the committee over the past few years: Dr Donna Henderson (Chair), Professor Agnes Banker (retired Chair), Associate Professor Robin Bell, Ms Anne Colahan, Dr Sharon Goldfeld, Associate Professor Jane Halliday, Ms Leah Lonsdale, Mrs Tony McDonald, Dr Catherine Rose, Dr Karen Stewart, Ms Marita Walsh.

Second, the review recommended, “the operational practices of the BDR are subject to ongoing reform, particularly in relation to the potential to ‘outsource’ ongoing management in accordance with department practice in relation to other registries”. Therefore a tender process to outsource the VBDR is underway.

## Prevalence of birth defects by outcome, 2002-2007

