



CleftPALS VICTORIA

PARENT INFORMATION BOOKLET



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1 Introduction

CleftPALS Victoria (Cleft Palate and Lip Society) **is run by a group of volunteers, mostly parents of cleft-affected children or cleft-affected adults.**

It is a non-profit organisation that receives no government funding and is governed by a National group, which is based in Sydney. Branch groups also exist in NSW, Queensland, WA, SA and Tasmania.

CleftPALS was initially established in 1974 in NSW to provide support, reassurance, and knowledge to parents and their families of a child born with a cleft condition.

In Victoria, Joel and Ruth Solomon established CleftPALS Victoria soon after.

2 What CleftPALS does

CleftPALS Victoria is able to assist in a number of ways including:

- 1) Supporting families in obtaining the most appropriate feeding equipment and providing this equipment at a discounted cost.
- 2) Supporting families through the breast-feeding process if this is an option.
- 3) Supporting families through our network of Contact Parents throughout Victoria who can meet with families and young people at different stages of their journeys. Contact Parents are parents who have a child with a cleft and who support others when their child is diagnosed. We have a range of Contact Parents throughout Victoria. The Contact Parents have been through the experiences themselves and can offer a parent's point of view on the journey through cleft treatment and the day to day care of your child.
- 4) Supporting older children and young adults with repaired clefts through Cleftstars, a network of young cleft-affected individuals aged between 10 to 20 years of age. This forum provides young cleft-affected people and their families with the opportunity to share experiences and to provide mentorship and support to one another and to other cleft-affected young people in the community. Cleftstars is a CleftPALS Victoria initiative.
- 5) Discussing a range of surgery and treatment options with families and young people who have had similar experiences.
- 6) Linking families to a range of different professionals including surgeons, feeding specialists, dentists, orthodontists and speech pathologists. Registration with Medicare's Cleft Lip and Palate Scheme is recommended as soon as possible. (Please refer to Section 14 for further details).

CleftPALS runs regular playdates and special events where families can meet other cleft-affected families.

CleftPALS runs informative sessions and conferences for people affected by clefts, which often include key speakers such as surgeons, psychologists, speech pathologists, dentists and so on.

CleftPALS publishes quarterly newsletters filled with member stories, information about surgery and feeding, advice and ideas. This newsletter is circulated to all CleftPALS members.

CleftPALS lobbies government on behalf of cleft-affected families, delivers presentations to medical, nursing and allied health professionals across Victoria, and supports cleft affected children in developing countries.

3 About Clefts

One in every 600 to 700 babies in Australia is born with a cleft. It is one of the most common birth defects. In about one third of families there is a relative also born with a cleft, or an associated syndrome such as Pierre Robin Sequence. In about two thirds of cleft patients there is no family history or associated syndrome.

A cleft occurs when the lip and/or the palate fail to fuse during gestation.

A cleft lip is a split in the upper lip. The lip is formed when two processes of skin unite from the sides of the face with one from the nose. This occurs at around 4 to 6 weeks of gestation, and a failure to fuse results in a cleft lip.

A cleft palate is a split in the roof of the mouth, resulting in an opening between the mouth and the nose. Tissue grows in from the sides of the upper jaw and joins in the middle to form the roof of the mouth (palate), during the first two months of pregnancy. Failure to fuse results in a cleft palate.

Babies can be born with a cleft of the lip OR a cleft of the palate, OR a cleft of the lip and palate. The cleft can affect one side (uni-lateral) or both sides (bi-lateral) of the lip and/or palate.

Many clefts are now being diagnosed by ultrasound. Those that are not detected this way are usually diagnosed at or soon after birth.



NEWBORN WITH UNILATERAL CLEFT LIP AND PALATE AT BIRTH

4 Cleft Associated Conditions

Pierre Robin Sequence (PRS):

PRS is a condition where an infant is born with an underdeveloped lower jaw, a cleft palate and a tongue that is positioned further back in the mouth and may result in an upper respiratory breathing obstruction for some infants. PRS is a cleft associated disorder which is present in 1 in 4700 Victorians. Infants who are diagnosed with PRS may have problems with normal breathing and feeding and require additional surgeries. 65% of infants diagnosed with PRS have underlying conditions including Sticklers Syndrome or Velocard Facial Syndrome which require additional treatment and support.

There are a large number of other cleft associated conditions. In around two thirds of cases, a cleft occurs with no underlying condition and no family history.

5 Emotions

Parents who discover that they have or will have a baby born with a cleft may experience a variety of emotions however it is important to note that babies who are born with clefts do go on to lead normal, happy lives.

If a baby's cleft has been detected through ultrasound, the hospital, doctor or obstetrician may offer information and support. Parents may choose to embark on further testing such as amniocentesis to check for further abnormalities. Most cleft babies do not have genetic or chromosomal problems but a small proportion do.

Speaking to a cleft surgeon can provide a clearer understanding of the journey ahead. Finding the right surgeon, either through the public or private system, is entirely a personal choice. Doctors, obstetricians or the cleft teams at either the Royal Children's Hospital in Melbourne (RCH) or Monash Medical Centre (MMC) can assist with contacts. Both RCH and MMC have experienced, well-resourced and helpful 'Cleft teams'.

Friends and family can often be a great source of support, reassurance and comfort.



CHILD AT 2 YEARS FOLLOWING SURGICAL REPAIR

6 Preparing For The Birth

If a baby's cleft is detected in utero, it is advisable to inform the birthing hospital to ensure they are adequately prepared to cater for the birth including the provision of appropriate feeding equipment.

Talking to CleftPALS about feeding equipment is useful in discussing the various bottle and teat options. As many mothers of cleft-affected babies may not be able to breastfeed, having the appropriate bottles on hand is important. Trying out different feeding equipment before finding one that suits both mother and baby best may take some time. Usually a range of different factors are considered when trialling a particular teat. Do check manufacturers' sterilising instructions for each piece of feeding equipment, as correct sterilisation will prolong the life of all feeding equipment.

7 Feeding and Equipment

Feeding is often the biggest concern when having a baby with a cleft. It is important to note that the severity of the cleft does not necessarily determine the degree of difficulty with feeding.

Babies born with a cleft lip only (intact palate) can sometimes be breastfed. The baby needs to be positioned so that the cleft is filled with breast and a seal is created.

A cleft palate prevents normal suction, thus a baby with a cleft palate is usually unable to breastfeed.

The most common feeding solutions are:

- Expressing breast milk and feeding through a bottle
- Formula feeding through a bottle
- Utilising special bottles and teats such as the Special Needs Feeder (Haberman).
- Breastfeeding with supplementary bottle

CleftPALS has information on bottles and teats and can provide them at a reduced cost for CleftPALS members (see appendix one 'Feeding Equipment' for more details).

For help with feeding, contact:

- The CleftPALS' Feeding Equipment hotline – Ph: 0425 784 136
- Dr Julie Reid, Feeding Consultant & Senior Speech Pathologist (please contact Julie via the Feeding Equipment hotline)
- The birth hospital, paediatrician or a maternal & child health nurse if they are experienced in feeding cleft-affected babies.
- The cleft team at RCH – Ph: 9345 6582
- The speech pathologists in the cleft team at Monash Medical Centre – Ph: 9594 2561
- The Australian Breastfeeding Association (ABA) for advice or to hire breast pumps for expressing – Ph: 9885 0855 (general enquiries) or 9886 9399 (breast pump hire). A booklet is available through the ABA for mothers who wish to breastfeed.
- Breastfeeding Education & Support Services (BESS) – Ph: 9344 3651 or email bess@rwh.org.au

8 Dental

Cleft-affected babies can be seen by a paediatric dentist or orthodontist soon after his/her first teeth appear.

Many cleft-affected babies will have either missing teeth, extra teeth, and/or malformed teeth. It is therefore reasonable to anticipate further treatment later in childhood or during adolescence.

The most important thing to keep in mind is good personal dental hygiene. It is recommended that this routine be instilled at an early age. Oral hygiene may prove to be more challenging for a cleft-affected baby with severely misaligned teeth. Dentists recommend using toothpaste which contains fluoride to further strengthen young teeth and a low-sugar diet to assist in preventing decay.

9 Orthodontics

Cleft-affected babies will usually require orthodontic treatment as part of their journey. A specialist orthodontist will assist in all individualised treatments. As mentioned earlier, registration in Medicare's Cleft Lip and Palate Scheme is highly recommended. Orthodontists and plastic surgeons can assist with this registration process (see Section 14 for further details).

Some babies with more severe clefts may require Nasoalveolar Moulding (NAM). This treatment aims to reposition displaced segments of the cleft and is done prior to lip and palate surgery. In this procedure, a custom orthodontic appliance is designed to assist with the correction or movement of parts of the cleft to support the optimal outcome of plastic surgery. Other alternative techniques for NAM could include the use of special medical tape to position the separated parts near to the cleft.

Jaw growth subsequent to the primary plastic surgery can be assessed as young as 5 years of age, but more usually this will be done at age 7, when records such as study casts (impressions) with accurate head and neck radiographs can be taken to measure and analyse jaw growth and assess jaw relations and teeth positions in both the upper and lower jaws.

Preliminary orthodontic treatment in the mixed or transient dentition period (in the changing of first to second teeth) usually includes wearing dental appliances such as a dental plate which is glued onto the upper teeth to expand the upper arch (around 8 – 12 years of age). This is done to facilitate a bone graft to the maxillary (upper jaw) cleft areas and which oral surgery aims to close any fistulae (holes) persisting between the mouth and nose. An alveolar bone graft also provides the framework for permanent (second) teeth to develop and erupt more normally.

At a later stage (usually during early adolescence), full fixed braces (orthodontic treatment in both jaws) can be done when the permanent teeth are fully erupted and developed.

After adolescence in a significant percentage of patients, further maxillo-facial (orthognathic or jaw straightening) surgery may be needed to correct disproportionate jaw growth.

All cleft treatments are aimed to be minimally invasive and are carried out in regular consultations between the young cleft-affected person, parent/s, specialist orthodontist and oral-maxillofacial surgeon.

10 Speech

Prior to the palate repair operation, a cleft-affected baby's words may sound different and perhaps a little more 'nasal'. Some sounds may be more difficult to say (e.g. "dad-da" may sound like "nan-na" and "bub-bub" like "mum-mum").

However post-palate repair, a cleft-affected baby has better physical capabilities to gradually learn correct speech sounds. Gentle praise and encouragement and good speech role models are essential for a cleft baby's speech development and for the general well-being and happiness of any child.

A cleft child's hearing should be closely monitored and addressed if necessary, as this can impact upon speech development.

Speech and language skills will be assessed by an experienced speech pathologist. Initial speech assessments are usually arranged between 12 to 18 months of age.

Should concerns with speech persist, it is recommended that further consultation occur with a speech pathologist or a referral request made in consultation with the surgeon or cleft coordinator. In some cases, further palate surgery may be required, often at around 5 to 8 years of age.

11 Hearing

The repair of the child's palate is important for the health of the upper air passages (i.e. the nose and throat). However, children who have a cleft palate, even after it has been repaired, are more likely to be troubled with ear, nose and throat problems compared to other children.

In particular, most children with cleft palates tend to have fluid build up behind their eardrums, in the middle ear. This is a condition called "Glue Ear" because of the thick, sticky nature of the fluid. This fluid tends to make the child slightly hard of hearing and may upset general development and schooling. Depending on the level of hearing difficulty as determined by the audiologist and/or ENT surgeon, children with 'glue ears' may have the thick fluid removed usually through the insertion of very small plastic tubes, called 'grommets', into the eardrums to keep a flow of air to the middle ears, preventing further collection of fluid. This procedure may have to be repeated several times throughout the early life of the child.

In some children there may be distortion inside their nasal passages, which may produce blockage resulting in recurring or persistent infection. This distortion may need to be corrected. The adenoids and tonsils can become infected causing tonsillitis. However, the size and position of these glands help some children to speak more proficiently. Therefore, the tonsils and adenoids should not be removed without first asking for specialist opinion.

12 Surgeries

Preparing a child for surgery may be challenging. Here are a few ideas which might assist:

- Prior to surgery, depending on the age of the child, reading books about going to hospital may be a good opportunity for parents to share the next stage of the 'journey'. (e.g. *Going to the Hospital* by Anna Civardi is the story of a little boy having surgery on his ear).
- Often role-play, using a toy doctor's kit, can be a fun way of making the experience and equipment less scary.

The hospital will supply a list of what to bring on the day. Some tips from other parents include:

- Feeding bottles and teats. Ensure they are clearly labelled with baby's name and hospital UR number.
- A favourite toy, blanket or other item.
- Post-operation, loose singlets or t-shirts with loose sleeves are useful especially with splints.
- Baby jellies or custards, as some hospitals do not provide these
- A change of clothes and toiletries for the carer/parent
- Tins of formula (taken in unopened)
- Breast pump; most hospitals will be equipped but it is best to check
- Consider bringing a cup or straw, depending on the age of the child as feeding may be more difficult post-surgery.
- Food for the carer/parent although hospital café food usually suffices.
- Accommodation may need to be considered for the carer/parent particularly if the hospital is some distance away from home.

LIP SURGERY:

The surgeon will often choose to close the cleft and reshape the lip (and the nose if necessary) usually within the first three to four months. In some of the more severely affected babies the assistance from an orthodontist is common. Orthodontic treatment at this stage could include taping, fitting dental plates over the baby's gum pads or using a sucking plate to cover the gap in a baby's palate to assist with feeding.

PALATE REPAIR SURGERY:

Food and liquid may enter the nose because the cleft palate allows connection between the nasal passage and the mouth. This is a source of inconvenience to the child and may lead to infection being carried into the middle ear. Infection of the middle ears may cause discomfort, as well as pain and deafness. The shape and movement of the soft palate are important in assisting with the formation of speech sounds, thus a repair of the soft palate is essential during a baby's early stages of development. Early surgical repair may also assist with the development of other normal functions of the mouth, such as chewing and swallowing, as well as normal breathing through the nose. These functions are very important for stimulating healthy growth of the upper jaw and parts of the face affected by the cleft. Post-palate surgery, babies usually remain in hospitals for an average of 2 to 4 days.

As children with clefts are often more prone to more ear and throat infections, the removal of the child's tonsils and adenoids may be recommended. This can, however, have implications on a child's speech development. A discussion with the surgeon is useful and can provide you with a more accurate perspective on what the best surgical route may be.

13 As Your Child Gets Older

PEER SUPPORT - CLEFTSTARS:

For a young person, being able to speak to another young person who truly understands what he/she is going through is invaluable. Whilst a parent can provide much of the emotional support for a child, the importance of peer support and positive role modelling can never be underestimated. As your child gets older, participation in the Cleftstars group (which is run exclusively by CleftPALS Victoria at this time) is an option. The supportive, encouraging environment in which the group is conducted allows young people aged 10 – 20 years an opportunity to interact with other young people who are on the cleft journey. Cleftstars participate in social activities together and in facilitated discussion forums where they have the opportunity to share and compare experiences and hear from medical and allied health professionals who specialise in working with cleft-affected individuals. Cleftstars has been in operation since early 2009. For more information, please see the committee list attached or visit www.cleftpalsvic.com.

BONE GRAFTING OF THE UPPER JAW (MAXILLARY) CLEFT:

At about the age of 6 or 7 years, most children start to grow some adult teeth. In patients with both a cleft lip and palate there is likely to be a cleft in the gum and jaw bone that often communicates through to the nose (fistula). For these patients, it is common for an orthodontic expansion appliance to be placed to facilitate a bone graft to close the cleft. This is usually undertaken between the ages of 8-12 years and this unites the upper jaw and allows sufficient bone for eruption of the eye-tooth (canine) and also closes the abnormal communication into the nose as well as supporting the part of the nostril base. Generally bone is taken from the inner part of the hip (bone regenerates in this region) and is transferred to the alveolar cleft and the gum is repaired over the top. Patients recover quickly and are only usually in hospital overnight.

There is varied international opinion as to the optimal timing of a necessary alveolar bone graft (ABG) procedure. ABG can be done as early as 6 years of age if developing second teeth (upper laterals) require early bone graft placement and yet, ABG can be done as late as 15 years of age, particularly if medical, psycho-social and orthodontic reasons indicate that it is best carried out later. Severity of the cleft along with prior surgical outcome and medical and dental issues are the determinants in arriving at this decision. ABG could be done at around 10 years of age if the permanent cuspid (corner) teeth require the ABG to allow the full and correct development and eruption of the upper cuspid teeth more favourably.

ORTHOGNATHIC (JAW) SURGERY TO CORRECT THE BITE AND ALIGN THE PROFILE:

Many cleft patients undergo disproportionate jaw growth. This results from both the lack of growth of the upper jaw (associated with the cleft) as well as their inherited growth pattern. A combination of orthodontic alignment to straighten the teeth followed by upper jaw (and often lower jaw) repositioning is usually undertaken when growth is complete. This is usually about 15-16 years old in females and 17-18 years old in males. Advancement of the upper jaw with or without altering the position of the lower jaw is undertaken by surgery inside the mouth and patients are in hospital for 1-2 nights. The recovery period, with a soft diet, is about 3 weeks.

LIP AND NOSE REVISION

When clefts that occur on one side only are repaired by a skilled surgeon, little (if any) additional surgery is required for the child, except perhaps for surgery on the nose in the teens. However, sometimes the original repair of the lip may be improved, and any remaining distortion of the nose may be corrected, especially for those children with bilateral cleft of the lip.

14 Parent Accommodation

There are a range of parent accommodation options for families during the time of surgeries. If the surgery takes place at the Royal Children's Hospital in Melbourne, the options available include:

- Parent accommodation within RCH – priority given to parents of critically ill children and breastfeeding mothers; this cannot be confirmed prior to admission.
- Ronald McDonald House (03) 9345 6300
- Hotels and motels around the hospital

Wards can usually supply a fold down bed for one parent. Some families may be eligible for a subsidy for accommodation and travel costs associated with medical care. Contact the Cleft Coordinator, social worker or DHS for more information.

15 Useful Information

FINANCIAL BENEFITS AVAILABLE TO CLEFT PATIENTS

DENTAL HEALTH CARD: MEDICARE – CLEFT PALATE & LIP SCHEME

All children born with a cleft (of any type) are entitled to this scheme.

This card is in addition to your normal Medicare card and entitles you to a special Medicare rebate (85% of the schedule fee) on some dental and most Orthodontic work your child may require. This covers three dental check ups a year, most x-rays and orthodontic treatment up to the age of 28 years. However, it does not include fillings, crowns, bridges, tooth implants, etc. Treatment must be carried out by a registered practitioner.

A Certification of Cleft Condition form must be completed by a doctor or dentist and submitted to Medicare. A Cleft Lip and Palate Patient Identification Card will then be issued.

Application forms are available from the plastic surgeon, orthodontist, or from Medicare. In order to claim orthodontic treatment under the Medicare Cleft Scheme, the orthodontist must be accredited under this Scheme.

For further information visit the Medicare website:
www.medicareaustralia.gov.au/public/services/cleft-lip.jsp
Or call 132 0111 or 1300 652 492.

ENHANCED PRIMARY CARE (EPC) PROGRAM

This program was designed to improve coordination of care for people (of all ages) with chronic conditions and complex care needs, providing a framework for a multidisciplinary approach to health. This enables eligible families who are being managed by their general practitioner under the EPC plan access to Medicare rebates for allied health services. Cleft-affected families can claim rebates for up to five sessions per year and this could include any combination of allied health services, such as speech pathology. General practitioners can assist with this process.

If a cleft-affected baby has other associated syndromes, then additional benefits may be claimable such as the Victorian Patient Transport Assistance Scheme (VPTAS) and the Carer Allowance through Centrelink.

VICTORIAN PATIENT TRANSPORT ASSISTANCE SCHEME (VPTAS): DEPARTMENT OF HUMAN SERVICES VICTORIA.

This scheme provides financial assistance with travel and accommodation costs to Victorian residents who reside more than 100 kilometres from specialised medical and/or dental treatment. Forms can be obtained from the doctor or regional DHS office.

Certain conditions do apply so it is advisable to contact the nearest DHS regional office for a copy of the guidelines.

This website may be useful: www.disabilityinfo.org.au

Department of Human Services Ph. (03) 9616-7777

CARER ALLOWANCE (CENTRELINK)

The Carer Allowance (child) is a supplementary payment that may be available if you are a parent/carer who provides daily care and attention for a child under 16 years of age with a disability or medical condition. It can be paid in addition to wages or other income support payments such as Age Pension, Carer Payment or Parenting Payment. To find out more details regarding this allowance, eligibility criteria and details as to how to claim, visit:

www.centrelink.gov.au or call 13 27 17

16 CleftPALS Membership

There are a number of benefits to joining CleftPALS Victoria including:

- The CleftPALS Vic newsletter which is issued quarterly (four times annually). It contains interesting and informative articles from a range of relevant professionals, parents and young people affected by the cleft condition. The newsletter contains important dates for key events, such as information seminars, morning teas, family days and Cleftstar dates.
- The opportunity to attend CleftPALS meetings and social events. A range of different professionals, including plastic surgeons, orthodontists, speech therapists and ear nose throat (ENT) specialists, are often invited to deliver informative presentations at CleftPALS forums.
- Access to Contact Parents and/or Cleftstars who can provide support, assistance and guidance.
- Purchasing bottles and teats directly from CleftPALS at a discounted rate.
- Access to the CleftPALS library which contains interesting and informative articles relating to the cleft condition.
- Actively helping CleftPALS to continue supporting other families who are affected by cleft condition.

Note: to download a membership form, please visit www.cleftpalsvic.com

17 Other Useful Resources

ACLAPA	<p>ACLAPA is the primary resource for treating cleft professionals in Australia, New Zealand and Oceania and the means by which specialists keep themselves up to date with international trends in research and treatment of patients with orofacial clefts. www.cleft.org.au</p> <p>Changing Faces is a UK organisation offering information and support to children and adults who have facial disfigurement. Some excellent guides for helping your child</p>
CLAPA	CLAPA is the UK Cleft Lip and Palate Association. This site has lots of good information including lots of publications and discussion forums
CleftPALS	Australia National Group has information and links to CleftPALS in other Australian states
Cleft Palate Foundation	Cleft Palate Foundation is a US organisation offering information to parents of babies born with clefts and other craniofacial anomalies and to health care professionals who are involved in the care of affected infants
Cleft Clinic	Cleft Clinic, Royal Children's Hospital has lots of resources, information and links
Cleftworld.com	Cleftworld.com is a website which hopes to be a comprehensive resource for the global cleft community, allowing members to discuss cleft-related issues via the forum, offering information and listing current cleft-related news from around the globe. Membership is free and though registration is recommended, it is not necessary to access most of the site.
Southern Health (Monash Medical Centre)	Southern Health (Monash Medical Centre) has lots of resources, information and links. Monash Medical Centre also has family support units.
The Cleft Club	The Cleft Club is an interactive US club for people affected by cleft lip/palate. There are different forums where messages can be read and posted.
Face Forward	Face Forward is a UK site with discussion forums and online chat rooms for parents and cleft affected adults
Genetic Support Network Victoria	Genetic Support Network Victoria aims to facilitate an information, support and advocacy network that empowers people to identify and / or overcome genetic challenges
Australian Orthodontic Institute	Australian Orthodontic Institute is a not-for-profit Australasian organisation helping cleft-affected persons in Indochina. Their key focus is to assist disadvantaged families and the provision of ongoing tertiary training of multi-disciplinary cleft clinicians in our region (Project Boomerang). www.AustOrthInst.org.au
Operation Cleft	Operation Cleft is an Australian based charity helping cleft affected families in Bangladesh
Operation Smile	Operation Smile is a volunteer organisation repairing clefts and advocating sustainable healthcare systems for children around the world
Speech Pathology Australia	Speech Pathology Australia is the professional body for speech pathologists. Includes information for the public about speech pathology and referrals
Speech Pathology	Speech Pathology at the RCH is an informative site with lots of information and links
Wide Smiles	Wide Smiles is a USA organisation with resources about cleft lip and palate

18 Contacts

Royal Children's Hospital Cleft Coordinator

Phone: (03) 9345 6582

RCH Department of Plastic and Maxillofacial Surgery

Phone: (03) 9345 5391

Monash Medical Centre Cleft Clinic

Phone: 9594 2380

Pierre Robin Australia Information Support & Education

Phone: 8751 1174

Mobile: 0418 55 33 80

email: info@pierrerobin.org.au or visit

website: www.pierrerobin.org.au

19 Acknowledgements

ROYAL CHILDREN'S HOSPITAL

The Department of Plastic and Maxillofacial Surgery

Dr Andrew Heggie

Dr Heather Cleland

Associate Professor Nicky Kilpatrick

Pru Hamilton

MONASH MEDICAL CENTRE

Cleft & Facial Anomalies Clinic

Michael Snow

Janella Christie

Dr Julie Reid, private speech pathologist and cleft feeding specialist

The parents and young people who contributed personal stories to this booklet

Booklet Design – Annalis Pepe

Final Editing – Brooke Harding

Book Printing – Melbourne Office Supplies

APPENDIX ONE TREATMENT TIMELINE

The treatment timeline will vary depending on each individual child's requirements, the surgeon, and general treatment practices and philosophies between different hospitals.

Regular E.N.T., audiology and dental checks from birth and resulting appropriate treatment as required.

TREATMENT PATHWAY (Andrew Heggie, RCH)	
Lip closure	3 – 6 months
Palate closure	9 – 15 month
Paediatric dental assessment	Eruption of baby teeth
Speech assessment	
Audiology (ENT)	18 months – 6 years
Pharyngoplasty	
Orthodontic Assessment	6 – 8 years
Upper arch expansion	6 – 8 years
Alveolar bone graft	8 – 12 years
Orthodontic assessment	Eruption of permanent teeth
Surgically-assisted RME	Pre-orthodontic Rx
Interim maxillary distraction ?	
Orthodontic surgery	
Septo-rhinoplasty/lip revision	Completion growth
Tooth replacement	

APPENDIX TWO PERSONAL STORIES

ALIDA'S STORY

JARRAH'S STORY – The Arrival

PER'S STORY

OLIVER'S STORY

ALYSSA'S STORY

JENNIFER'S STORY

SAM'S 'TOP TIPS'

NATASHA'S STORY

BRENDAN'S STORY

JARROD'S STORY

AN ADVENTURE WITH PIERRE
ROBIN SEQUENCE

ALIDA'S STORY

At the time these diary extracts were written, Alida was very pregnant and expecting their first child.

6.15am, Monday, 23rd March, 2009

"Oh my G-d. Oh my G-d!!!!" were the first words out of my mouth as I inspected the faintest, second line on my fifth pregnancy test in 5 days. Grin ear to ear, I called my husband Daniel. "Daniel..." I started, "Oh my G-d. Oh my G-d!!!!" was his response. Wow. I was pregnant after our first efforts at trying to make a baby. We could not have been more excited if we tried – we called each other innumerable times throughout the day, just to let some of our exhilaration spill over as it was our little secret. I booked an appointment with the obstetrician, and couldn't wait to meet him.

In the weeks following, I suffered no nausea or morning sickness, with the exception of the smell of garlic which was banned from use in our house until such a time I could stomach the smell once more. Nobody picked that I was pregnant; I didn't take a day off work, and was in a constant state of delightedness. Daniel and I chose to tell immediate family and friends, but decided to keep our surprise from the 'general public' until after the 12 week ultrasound.

11.30am, Tuesday 21st April, 2009

First appointment with the obstetrician, and a lovelier specialist we couldn't have asked for. Daniel and I opted to have an early ultrasound, even though we were told that all we would see was a teeny flickering grain-of-rice-shaped speck on the screen. Who cared – we just wanted to have a peek! Off we went, and were told that the heartbeat was good and that everything was in the right place. I was incredulous that the little white dot on the screen was one day going to be a baby.

4.45pm, Tuesday 26th May, 2009

12 week ultrasound. Daniel held my hand as the ultrasonographer applied gel to my belly and brought up the first images of our little one, fondly nicknamed 'Teeny.' It was one of the most memorable and exhilarating days of my life – Teeny measured up perfectly, had 10 fingers and 10 toes, the nuchal translucency measurement with my blood test results were great, and our hearts were filled with bliss watching this wriggly little jelly bean bounce around the screen. The next day, Daniel and I shared our joyous news with extended family and workmates, and were on cloud nine.

3.45pm, Tuesday 21st July, 2009

20 week ultrasound. We were even more eager this time around to see Teeny on the screen to see how Teeny was growing. "He's practicing sucking, look!" I said, as I noticed Teeny's mouth was puckered up. The ultrasonographer showed us Teeny's hands, feet, spine and organs, measured the femur to make sure standard growth was occurring, and then concentrated carefully on Teeny's face. I saw that the pucker was still in Teeny's lips, and commented again, and



this was when the ultrasonographer gently told us that Teeny had a cleft. "It's unilateral," he began, "And I can't be sure, but I think it's a cleft lip and palate..." Everything had been so normal and so perfect; in that instant, it felt like the world had come crashing down around me. "Is that like a harelip?" asked Daniel. Before the ultrasonographer could answer, in a dazed voice I replied "Yeah, sort of, but that's the lip only and that's the colloquial term." I am a self confessed 'medophile' and had done some internet research on birth defects, and had a pretty good understanding of what a cleft lip and palate were. I think the ultrasonographer was a little surprised, but continued explaining in more detail what it meant to Daniel, and also called the obstetrician to let him know what was going on. My thoughts drifted, and all I could think about was that this little person inside me who was NOT PERFECT, and could not believe this had happened to us.

We had an appointment booked with the obstetrician immediately after the ultrasound, luckily in the building next door. I managed to hold back my feelings until we left the ultrasound clinic, but as soon as I stepped outside, I couldn't keep them in any longer. The obstetrician was waiting for us at the entry to his rooms, and ushered us in. Amid my tears, Daniel and I asked question after question for an hour; the obstetrician was ever so patient as he answered us, and slowly, slowly, it started to sink in. My emotions were running wild; I was scared, nervous, grieving the loss of my 'perfect' baby, apprehensive, stressed that something else was going to go wrong and angry at the world, but at the same time relieved that it was 'just' a cleft lip and palate, and still truly thrilled that Daniel and I were going to have a little baby in another 20 weeks. At the end of the appointment, Daniel and I thought that we'd like something else relating

ALIDA'S STORY *continued*

to the baby to think about, made the decision to find out if the ultrasonographer had noted the baby's sex – the obstetrician placed a quick phone call, turned to us and said "Congratulations, you're going to have a little boy."

I took the next day off work as I slept poorly that night with thoughts continuing to race around my head, and my nerves were like a train wreck. I woke up already crying at 6am, and called Daniel who was already at work. "Come home, I need you..." I pleaded. "OK, I'll just finish up what I'm doing at work, and I'll be right there." I called him back 5 minutes later, after calming myself down, and told him I would be OK. He asked if I was sure and said he could be home soon, but I pulled myself together and said that I was alright, but would call him if I changed my mind. I lay in bed for a while, then threw the covers off and started my day. "Right," I thought, "I'm going to allow myself to be upset about this, but I'm also going to be productive." I jumped on the internet and started researching. We had been told that the cleft was unilateral, and was approximately 5mm wide at that point. I must have looked at hundreds of pictures of cleft lips and palates, unilateral, bilateral, cleft lip only, cleft palate only, syndromes with clefts and clefts as part of other craniofacial deformities. Then I searched for before and after photos, and was amazed at how incredible the results were. I called a friend of mine who is a GP, and asked if she could recommend anybody. She had done a round at the Royal Children's in the cleft lip and palate team, and recommended a surgeon to us. I called the rooms, and was unduly frustrated as I could not make an appointment there and then because their reception doesn't operate on Wednesdays. I would have to wait for that one. I then researched treatment plans, different methods of surgery, and feeding approaches. I read blogs belonging to parents of cleft children and absorbed as much information as I could. I also called the CleftPALS hotline and spoke with the genial Fran, who recommended that I meet a family with a child who had a cleft lip and palate, that she had a family in mind, and would get back to me. All the while, I tried to stay focused that we were going to soon have a baby boy to look after, and that he would be his own little person who happened to have a cleft, who would require our love and care and attention the same way a 'cleftless' baby would!

The next day, I received a phone call from Fran with the phone number of someone near me named Evelyn, who would be happy to meet me and introduce me to her family. I called Evelyn and she invited Daniel and me to visit her home later that week. That same day, I called the Royal Children's, spoke extensively to their fabulous cleft lip and palate co-ordinator, and finally, called the surgeon's rooms and booked in a consultation.

4.00pm, Sunday 26th July, 2009

We knocked on the door of Evelyn's home and stood on the front step, nervous to meet brand new people and talk about something of a personal and delicate nature, but also curious to see what a cleft lip and palate kid looked like after surgery, as we had never known anybody personally with a cleft lip or palate. Evelyn and her husband Nick were extremely hospitable, and made us welcome with fresh coffee, Tim Tams and Doritos. We met their very cute children; their

daughter Yasmin, and son Jarrah. Evelyn told us that Jarrah was born with quite a large, unilateral cleft lip and palate, but unless we paid extra attention to his face, would not have noticed the faint scar on his top lip. Evelyn and Nick took us through their experiences, trials and tribulations and joys with the aid of a photo album and kindly answered our zillions of questions. Meeting Jarrah put our minds at ease – there, before our very eyes, was a 3 year old boy like any other.

11.00am, Monday 17th August, 2009

Finding parking was painful, but we managed to make it to the surgeon's office on time. The surgeon took us through stages of possible surgeries from age 0 – 20 of the life of the cleft lip and palate child. The technology is astounding, and the results extremely encouraging. We became aware that there was a long road ahead of us, but as the surgeon said, over a 20 year period, in treating a cleft lip and palate, a child will generally spend under two weeks total in hospital for the various surgeries which may be required. This really put things into perspective for us; he showed us his before and after photos, and had an aura of general calm and sensibility which ensured Daniel and I were far more comfortable with the future of our son than we had previously been.

12.30pm, Thursday 15th October, 2009

Seven weeks and one day until my due date. We have come to terms with the fact that we are going to have a son who has a cleft lip and palate. There are some days where I still get angry about this, but mostly I am just excited to meet this little man who is hogging so much of my stomach space.

We have braced ourselves for the challenges of being new parents, with the added knowledge that our path will likely be a little more difficult at times due to the cleft; however with the support of family, friends and of course CleftPALS, we know that we won't be facing these challenges alone. Ultimately, Daniel and I are very much looking forward to cuddling our son and being the best parents we can possibly be when he arrives.



JARRAH'S STORY – The Arrival

Jarrah is the vivacious 4-year-old son of Evelyn, author of this article. Jarrah was born with a severe unilateral cleft lip and palate. Evelyn is currently co-running Cleftstars and secretary of CleftPALS Victoria.

The day of our 20-week ultrasound scan started out like any other. In fact, I had planned social engagements for the rest of the day. Anticipating that this scan would be as 'uncomplicated' as that of our 3-year-old daughter, my husband and I could not have predicted what was to unfold over the next couple of hours. After what seemed to be an unusually lengthy scan, our sonographer paused before delivering the news that our unborn baby had a cleft lip and palate. He continued to say that our unborn baby had several choroid plexus on his brain and that this is often indicative of further complications, including severe intellectual (and physical) abnormalities. We were subsequently informed that in some cases, babies may not survive the pregnancy. We were devastated by the mere possibility that we may never meet our baby.

After careful consideration and discussion with our sonographer, we opted to take his advice undertaking an amniocentesis. As this took place over the Easter period, we had no option but to wait almost two weeks for the test results to become available. This was probably the most anxious two weeks we have ever experienced, as different scenarios circulated in our minds. We tried our best to stay positive under the circumstances. When the test results came back negative, we felt overwhelmingly relieved knowing that we could now focus on developing our knowledge of clefts and accessing necessary supports. We were positive that nothing at this point was insurmountable.

During this period, we met with Tony Holmes, plastic surgeon, who was referred to us via our obstetrician. Although we knew that Tony had had this same conversation with many other couples before us, we were deeply appreciative of the time he spent talking to us. It was obvious to us in an instant how truly passionate he was about his 'art'. This marked the beginning of our journey.

My first instinct was to contact CleftPALS. I was immediately referred to a Contact Parent. Following this, I spent time talking to CleftPALS' feeding equipment coordinator. Both conversations were very valuable and gave us increased confidence that we would be okay. I found that the most beneficial information came from the personal stories which were included in the CleftPALS parent information pack. These stories were honest and heartfelt.



We subsequently informed our immediate family and close friends in person. We chose to communicate via email to all others. This proved to be beneficial to us in so many ways. All our family and friends were incredibly supportive and were keen to find out more about the cleft condition from my husband and myself. We felt empowered knowing that the road ahead would be a process of discovery and challenges but we were ready.

On the 9th August after a long labour, Jarrah was born. My first natural response was, "Isn't he cute!" and I genuinely meant that. His wide cleft was not my primary focal point but rather his beautiful big inquisitive eyes. After months of anticipation and preparation for this day, I was thrilled to finally meet our baby.

Four years on and Jarrah has undergone a lip repair and rhinoplasty operation, taping, a soft and hard palate repair operation, a grommet procedure, regular hearing tests and a few months of speech therapy, but all is great!

PER'S STORY

Per's story was written by actress and writer, Tania Lacy. Per is now four years old and ready to conquer the world!

Our son Per was born on December 29 2005. When my water broke at three in the morning, I woke my husband Ole, crazy with excitement and nerves. We were finally going to meet our baby! But as I noticed the colour drain from Ole's face I wondered if he'd ever considered that this baby did have to come out at some point. As we drove to the hospital my mind flashed back to a moment two weeks prior when in a shopping mall, and travelling down an escalator, my mother asked me if she felt my baby had ED. ED is short for Ectodermal dysplasia, a genetic disorder that has affected my brother and his daughter, and that had a one in four chance of affecting our child. While it had been a big concern for my husband and I, we were willing to take the risk based on the fact that my brother and his daughter enjoyed an excellent quality of life despite the challenges of their ED. So I remember saying to my mother, 'I don't think he has ED but I feel like there is something wrong.' It was just a feeling, an uneasiness, but I felt it.

And so back to the birth. My 'this is so exciting' vibe soon gave way to screams of 'bring me the head of the mid-wife who suggested aroma-therapy oils and relaxation music!' Anyway, long story short - After a good seven hours of pushing it became apparent to the doctor that Per was stuck and a forceps birth was going to be necessary. I was rushed off to theatre (operating, not Shakespeare), husband in tow. By now he was as white as the sterile suit they had put him in. A spinal epidural, a couple of pushes later and Per arrived. Suddenly he was on my chest and I looked at him, my baby!

A rush of emotions - joy, excitement, relief, love and then he was whisked away. 'Hang on, did I just see a Hare Lip?' I asked myself. (And yes, I remember very clearly I said 'Hare Lip'.) No, it was just the way the blood was smeared on his face I told myself. But then Ole was called over by the doctor. I could see them chatting quietly. What was going on? Why wouldn't anyone tell me? Was my baby okay? Whose legs are they in the stirrups? Oh mine! Ole arrived back at my side and I still think of this moment with the greatest adoration for my husband. He had this funny, weird half-smile on his face. He looked so vulnerable. He had something to tell me and he was nervous. But when it came down to it, he told me what I already knew - Per had a cleft lip. In fact it turned out Per had a unilateral incomplete cleft lip and incomplete palate - to be precise.

As I lay in recovery waiting for the feeling to return to my legs, dozens of questions ran through my mind. How did this happen? Was this my fault? Had I somehow failed everyone - my husband, my parents, who were all expecting a "perfect child". Of course, my fears proved to be completely unfounded. When I was taken to the ward, my husband and family were nothing but supportive. 'He's got a cleft,' I said, almost as an



apology, as they wheeled me into the ward. 'It doesn't matter,' came the swift response from everyone, 'He's beautiful.' And he was. But we all had a little ways to go yet before we could all come to grips with what was going on, what the future held for Per and how we would all come to deal with this situation.

My first hurdle arrived on the second day after Per's birth. I was in my ward, listening to other parents talk excitedly about their baby's perfect nose, or cupid's bow lips or any other number of perfect baby features. I found myself, suddenly, once again, overwhelmed with this sense of failure - and I wept. I wept that I was continually apologising to people about Per's condition. I realised every person I spoke to, I started the conversation with an explanation so that they wouldn't be shocked when they saw him and more importantly, they wouldn't blame me. I wept because I couldn't talk about my baby's perfect face like the couple next to me. I wept that I couldn't breast feed Per, an experience I had been looking forward to. I wept because I was worried about what people would think.

And then I realised, this wasn't about me. It would be the first and last time I would indulge myself in relation to Per's condition because ultimately this was about Per and the life he was going to lead, the future he was to have, and right now that future was in my hands. If I was going to be of any service to my beautiful gorgeous baby boy, I needed to get my sorry-ass out of his way and do all I could for this child and his self esteem. And as far as I was concerned that was going to start right now, in the hospital, on his second day of life.

Don't get me wrong. I wasn't making a pact with myself to become cold and heartless about all this, I was making a decision to not be the victim. That wasn't going to help Per, it would only serve to keep us all in a cycle of defeat. And trust me, I have cried since that day - the surgeries were hard, and we've all been there, some of us more than others. No parent likes to see their child suffer and I cried when I saw Per suffer pain. But I have not, and will not, ever cry because Per's situation is hard for me.

Why is this so important? What is the difference between crying for my son's suffering or crying for my son's situation. I believe there's a big difference. The first sends a message that says 'I love you so much but it's hard to see you suffer', the second says 'your condition is the reason why I suffer' and that's the one that's not fair - on any child and it's definitely not the message I wanted to send to my son. Having a good blub in the hospital two days after giving birth was possibly the best thing I could have done for myself and for Per. I left feeling strong, understanding that there were more hurdles to face, but I knew where I stood in all of this. Yes, I was the parent of a baby who was born with a cleft lip and palate, but ultimately I was a parent of a beautiful baby boy - and this was a time to celebrate.

OLIVER'S STORY – PART ONE

Oliver is the gorgeous son of the author of this story, Alison. Oliver was born with a unilateral cleft lip and palate.

Oliver's unilateral cleft lip and palate was detected at our 20 week scan. The sonographer reassured us that 'if we were going to have a problem, then this was the one to have - as its all fixable'. We were fine about it at the time and thankful it wasn't a developmental problem. However, it was still an unknown world we were entering and the first thing I did when I got home was to 'google' cleft lips!! That's how I found CleftPALS, as well as lots and lots of other websites that kept me reading for ages. In the next little while, I did have some sad days worrying about what my baby would have to go through, the severity of it, and the reaction of others – though I hate to admit it!

When Oliver was born on April 23rd, we couldn't believe how beautiful he was.

He arrived all wide eyed and calm and was taking in the world around him from the first minute. We didn't even really notice his lip as it was just all part of this beautiful little boy. We couldn't wait to show him off to everyone!!

Dr David Chong came to see us that night in hospital. His care and concern for children shines through and he helped us to feel very calm about Oliver's lip and palate and confident that it could be treated all in good time. Breastfeeding didn't really work, so I expressed milk and started using the Haberman Feeder. Oliver fed well from the start. Tony and I had more trouble with his feeding equipment trying to put all the bits together so it wouldn't leak, and trying to get the squeeze motion right. Sometimes the teat was on too tight and the milk wouldn't flow. It took quite a few weeks before we felt like it was working properly all of the time. It was a bit frustrating, especially when we had a hungry baby to deal with!

I contacted CleftPALS again as soon as I knew exactly what Oliver's cleft condition was. They put me in contact with Evelyn Culnane, and Evelyn and her little boy Jarrah came over to visit when Oliver was only 2 weeks old. It was so generous of the Contact Parents to give up their time. It meant so much to Tony and I to be able to speak to Evelyn and to see her photographic record of Jarrah's progress. This again helped to ease our mind and concerns about what Oliver would need to go through and what sort of results we could expect.

We had a visit to the orthodontist in the first month. He took an imprint of Oliver's mouth and photographs of his face from different angles. He showed us how to apply Steristrips to Oliver's lip to try and encourage the lip muscles to grow together as much as possible before the operation. We also visited an audiologist who advised us that Oliver had a mild hearing loss in both ears.



Oliver had his lip repair operation at the Mercy Private Hospital on August 20th when he was 16 1/2 weeks old. He recovered from the general anaesthetic well and was feeding about three hours after the operation ended. When I first saw him, I felt that I almost had to bond again with his new little face. He stayed in hospital overnight, and the next morning after learning how to put his arm splints on and practising bathing him, we went home. He wasn't quite himself for a few days but he gradually returned to his usual happy self. I also had to clean his wound daily with saline and a cotton bud and apply antiseptic ointment. He didn't mind that too much but he couldn't work out why his hands wouldn't go in his mouth for the first few days! As soon as the splints were off twelve days later, his fingers went straight back into his mouth!

Five days after the operation we went to the Royal Children's Hospital where Oliver's stitches were removed under general anaesthetic. He wore plastic stents in his nose that were kept in place with tape. The stents kept falling out the first night and I wondered how I was going to do this for the recommended 4 to 6 months. I felt a bit down that my beautiful boy would still have to be taped up when I just wanted him to shine through like all of the other babies in my mothers' group. It just didn't seem fair.

OLIVER'S STORY – PART TWO

Oliver's cleft palate was repaired in February 2009 when he was almost 10 months old.

I think that the hardest part of the day of the surgery was the fasting! Imagine trying to keep food and drink from a very hungry, boisterous, crawling boy for 5 hours! His dad did a great job in the hospital keeping him distracted with toys.

I went into the theatre with Oliver. It was a little daunting seeing him go under general anaesthetic but I was glad to be there for him. The operation took just over two hours. In recovery, he looked like he had just done a round with Mike Tyson as he had residual blood around his nose and mouth. When he awoke from his anaesthetic that evening, the pain relief started and we attempted to give him some milk which he took carefully but gratefully! He also had a little bit of fruit gel. He also had to have the dreaded arm splints on again – Mummy's favourite! Not!



That first night, he woke up regularly to catch up on his milk but the next day he stopped taking the fruit gel and wouldn't even eat custard (his favourite) so it was a milk-only diet. We could have gone home then but I decided to stay another night just to make sure he was monitored and for the nurses to administer extra pain relief if required. I was very glad I did stay because we had a very upset little boy for the whole of the following week at home. I think initially he was uncomfortable with pain and the new sensations in his mouth, but as he had stopped eating solid food, he became hungry all of the time. It was back to almost four-hourly feeds.

After seven days, I decided to cut back on the pain relief and I was desperate to try and get some extra nourishment into him. I started giving him runny rice cereal in a syringe and when he got the taste for that, he would sometimes even take the spoon. It was a very, very gradual process getting him back on track with his eating.

When I look at Oliver's palate, it seemed so raw and there seemed to be a huge gap on the left hand side of his palate and at the front. I was so concerned that I eventually rang the surgeon. He assured me that it would look pretty bad and unless Oliver seemed unwell, it was probably all okay. After eight days upon my request, the surgeon examined Oliver's palate and said that the palate repair did seem to have come away slightly at the front but that it was still okay. It did take a long time for the palate to heal. After a few more weeks, the hole in Oliver's palate still looked like it hadn't completely healed over and he still had some food coming out of his mouth. It turned out that he did have a small fistula (hole) in his palate, which is quite common. His teeth appeared in this area around this time too which may have affected the healing tissue.

Six months after the operation, food rarely came out of his nose. We were advised to wait and see what if the fistula would heal over naturally in time. I wanted to be sure, however, that Oliver had no problems resulting from this by the time he started school.

ALYSSA'S STORY

Alyssa is currently 16 years old and a 'Cleftstar', supporting other young people affected by the cleft condition.

Heya everyone, my name is Alyssa.♥ I turned 16 this year in January. My friends threw me a surprise party and I was very surprised. Ooo! I just got my L's! I am in year 11 in Wodonga studying English, Japanese, Mathematical Methods, Chemistry, Biology and Religion and Society units 3 & 4 - it is sooo much work! I was born with a bilateral cleft lip and palate - Keith Mutimer is my plastic sugeon, Tim Probert is my maxillofacial surgeon, John Robinson is my orthodontist and Joyce Alley is my speech pathologist. I have no idea of the number of surgeries I've had but I know it's a lot!

Out of school I like to swim, dance ballet, sometimes play the piano, walk and ride my bike. I swim three to four mornings for an hour and a half before school with the Wodonga swim club. I do ballet on Mondays and Fridays after school. I am up to grade 4 AMEB syllabus for piano but I just play at home now.

I am going to Japan for two weeks as part of the school exchange program and I'm very excited. I have been learning Japanese since I was 5 years old, that's 11 years this year.

My subjects are quite time demanding. I think I have at least three hours of homework a night and many people ask me how I do that, my extra curricular activities and manage to have a social life. All I can tell them is I have good time management skills. I like school and actually enjoy my subjects despite the work that is involved and most importantly I love my friends. They mean the world to me and are always there for me as I am for them. I am known for being the 'cheerer upperer' and for always being bright and bubbly!

Living in Wodonga means there are many restrictions as opposed to living in the city. All my specialists are in the city because no one in the country specialises with people who have this particular birth defect. Because of this I come down to Melbourne every 6 weeks on a Friday to see my orthodontist. I have to catch up on a lot of schoolwork just for a 5-minute appointment in Melbourne.

Hospital is a different matter altogether. Because recovery takes too long for my liking, I am often away from school for lengthy periods of time and people don't see me for ages until all the swelling has gone down and I can talk properly and regained some body weight. I believe that if you want to lose weight fairly quickly, these operations are the way to do it!

When I chose the subjects that I wanted to study for year 11, my course counsellor said to me "Wow! And what is the potential outcome for all this hard work?" My long term goal is to become a paediatrician. I have the next few years of my life planned out already. I am going to finish year 12 with the ENTER that I want and go and enrol in James Cook University's Bachelor of Medicine and Surgery. JCU is in



Townsville and I decided I wanted to go there because it is far, far away from Wodonga. I feel Wodonga is limiting my personal growth for what I want so I decided I wanted out, and nothing is going to change that. After I complete my university degree I want to travel to Paris, Greece, Spain, Barcelona, America, Italy, Perth and Darwin. I want to go to every Disneyland in the world.

The best day of my life is yet to come, I don't know when or what will happen but I will know when that day is. Alice Walker once said "Expect nothing, live frugally on surprise."

The worst day of my life would have to have been when I nearly died when I was 10. I felt like I had a stomach ache and it eventually got worse. I was constantly tired and I couldn't keep food or liquid down. The pain was horrible and not one doctor could tell me what was going on. It got to a point where mum decided to take me to one last doctor. Luckily this doctor knew and told us that when I was sleeping during the day I was actually falling in and out of consciousness and that it was likely that I had peritonitis. Peritonitis is a life threatening emergency that requires urgent medical attention. The infection stops the normal movements of the intestines (peristalsis). The body quickly becomes dehydrated, and important chemicals called electrolytes are dangerously disturbed. The internal organs- such as lungs, kidneys and liver- may fail. A person with untreated peritonitis can die within a few days. Fortunately I was rushed to hospital and they removed my appendix which was close to bursting.

The last movie I saw was '17 again' - Zac Efron is so hot in that movie. You should see it. It's really funny. On my last shopping trip, I bought my first pair of Connies (Converse shoes), they are white with small black hearts and blue butterflies all over them. I am a chocoholic, shopaholic teenager who loves living life and living my dreams.

Think about this question:

If you were any colour of the rainbow what colour would you be and why?

JENNIFER'S STORY

Jennifer is the mother of 10-year-old Cleftstar, Sam. This is an excerpt from Jennifer's presentation at the 2009 Cleftpals Information Seminar

Sam came into the world in a big hurry (unlike his older brother), on July 10, 1998. We had decided to try to find out the sex of our second child, as we had inadvertently discovered this with our first child (by the presence of an erection on both scans), but Sam had other ideas and they were unable to clearly tell...so it was a delightful surprise to discover we had another lovely, health baby boy!

I do remember clearly however asking at the 18 week scan for them to check that the baby didn't have a cleft lip/palate, as an old school friend had recently just given birth to her baby who had a cleft lip/palate, so it had been on my mind. I was told that all was fine and that there were no problems. So you can expect that we had some shock when told that our beautiful baby boy had a "birth defect" by the medical staff.

Initially, somehow the words "birth defect" frightened and immobilised me, and got in the way of me seeing the rest of my beautiful baby. At first I was too scared to look into his mouth as I did not know what to expect – Sam had been born with a "unilateral incomplete cleft lip and palate", which meant he had a cleft lip and a partial cleft of his palate (soft) – although we have later learned that he has cysts along the cleft line in his hard palate, where bone is missing.

This was definitely not part of the plan with my second child – and I had so many anxious questions I needed answers for. The obstetrician and paediatrician in hospital on the first day gave me some initial and very brief information about being referred to a Plastic Surgeon, but I had difficulty taking it all in...Would I be able to breastfeed as I had done for my first child, what surgery would he have to have, would he be ok in the world, and how was I going to deal with all of this? The worries started to slowly disappear as I watched my 2 ½ year child Nik smothering Sam's face with kisses as he didn't notice or see any "birth defect"...

I felt much sadness about not being able to breastfeed in the way I had with my first child, so decided that I needed to focus on the fact that I could still provide Sam with breast milk, but it would just be delivered in a different way...having said this, I could not bring myself to use the word "bottle fed" and so insisted that everyone around me just call Sam's bottle his "milk", so that I could be reminded that he was being "breast-milk fed".

This was a very personal decision and in no way was a judgement on other ways of feeding choices that other people made – it just reflected my sense of importance in providing the very best for Sam and giving him the same love and care that his brother had had... Everyone around me was extremely obliging and from then on it was referred to as "Sam's milkies". I am very grateful of the extraordinary support we received from family and friends during this time, which enabled me to breast milk feed Sam (via expressing 8 times a day), until post his palate repair when he was 9 months old.

I was very fortunate that in my first few days in hospital I was visited by a lovely person from Cleftpals, with her 12 month old baby boy, who also had a cleft lip/palate. She was able to answer many of my questions and provide important unbiased information about the choices and options for us a family, in relation to hospitals (public vs private, and Monash vs RCH), different plastic surgeons, and what to expect over the next few months. I also received a card from my old school friend, in which she told me I would probably have a few "why me?" days – and that I could ring her any time to talk. I remember this as an overwhelming time on many levels, but having the connections of people that understood was incredibly helpful.

I decided to join the Cleftpals committee when Sam was about 12 months old and was fortunate to meet some very remarkable people. The importance of having other babies for Sam to "grow up" with, who were like him, has been an invaluable part of the journey. We have also had the immense benefit of being able to discuss upcoming surgical procedures with other parents, and now that Sam is 11 years old and facing orthodontic work including a bone graft, it has been very important for him to be able to ask the other children he knows through Cleftpals, about what experiences were like from their perspective.

Sam had noticed that he didn't know many "grown-ups with a joined up lip" (as Sam refers to it), and was the only one at school with a cleft lip/palate. Through Cleftstars we have met Jarrod who is 30 and Sam sees an Osteopath called Marnie, both of whom were also born with a cleft lip/palate. We are lucky to also know Josh's dad Tim, and Sam is interested in knowing about Wendy Harmer, so he is very fortunate to have different adults in his life and world who are terrific positive role models.

JENNIFER'S STORY *continued*

Sam's cleft related experiences over the 11 years of his life have been influential in shaping him profoundly as a young person, filling him full of energy, enthusiasm and joy for life, significant courage and resilience, and a sense of wisdom and sensitivity often beyond his years. Sam smiled for the first time this year in his school photo, and will now talk to anyone about anything – including the time they “took fat from his bum to put in his throat to help him talk better” (otherwise known as a fat augmentation pharyngoplasty)! Sam developed his own list of “tips” for dealing with a “joined up lip” which he was happy to share with other kids like him.

From my perspective, we have been taken on an extraordinary journey - from the moment of giving birth, we went on a voyage that hadn't been planned, expected or even wanted...we stopped at lots of different destinations, experienced some unusual terrain, and had a few bumps and shocks – but also had the privilege of some unexpected and joyful surprises along the way...I experienced a broadening of my views and opinions about life and the world, although sometimes it felt like I was learning a new language of medical terms, surgical and orthodontic procedures...to the unexpected benefits of meeting some remarkable people that I would otherwise have never met, and learning new aspects about myself (some not so pleasant!) - but most of all learning from Sam and my other child Nik that nothing can ever be the same or “equal”, and gradually accepting and embracing that it is just different for us all...

SAM'S 'TOP TIPS'

Sam is a 10-year-old Cleftstar

1. You might look a bit different/funny with your lip, but it's the person inside that is important.
2. Sometimes you do feel a bit self conscious about your lip (Sam notices his lip a bit more than others do), but usually people are just a bit curious about why your lip looks different.
3. Your scar on your lip gets better as you get older...
4. Your friends get used to you sounding a bit different.
5. You get used to having to be a bit more brave and this helps in getting to know lots of people.
6. Never be shy of telling someone about your lip – and if people are teasing you, always talk to a grownup.
7. Dealing with problems with lots of snot – best if you keep on top of it (by being a good nose blower), because if you are on top of it, you can hear better and won't get a burst eardrum.
8. You need to remember that you have lots of courage, lots of operations and are pretty tough because of it all.
9. You will probably have a bit of funny teeth, but these are just teeth and can always be fixed.
10. There are a lot of people with "joined up lips", so don't think you are the only one.
11. Don't ever feel left out because you are exactly the same as everyone else – you can do everything the same as everyone else, it's just that your lip and teeth, and maybe snot that are just different.
12. People will help you a lot if you ask for help.
13. There's always a solution to things – you will always have a joined up lip but it is just a small scar compared to the rest of your body.



NATASHA'S STORY

Natasha is 17 years old and sister to 10-year-old Callum who was born with a bilateral cleft lip and palate.

Hi, my name is Natasha and I am 17 years old. I was 10 when my brother Callum was born with a Bi-lateral Cleft Lip & Palate. My brother Liam (who was 7 at the time of Callum's birth) and I were very shocked and surprised on his arrival. We obviously didn't know what this condition was and either did our parents. With us seeing this confusion, it worried us to the severity of Callum's problems. However shortly after his birth we were informed about the condition itself, what applied to Callum directly and anything else that was associated with it both mentally & physically. Throughout the first few years of Callum's life, it was easy to see the struggle my parents had feeding him, as he had to wear the tape constantly to push back his pre-maxilla, which made Callum uncomfortable and it caused rashes & scratches on his face. To see him in pain and to have deal with all these struggles, it was very hard because you feel helpless. During Callum's lip being repaired and the build up towards it, I felt anxious, mainly due to the unknown and these situations being so new. These feelings don't change with every upcoming surgery, my brother and I still feel nervous and sad for Callum, however it's not now as daunting, especially as he is getting older and understanding more.



BRENDAN'S STORY

Brendan is a 19-year-old Cleftstar and currently completing his first year medical degree at Monash University.

Hi, my name is Brendan Flanders and I was born on the 11th of May 1990, with a unilateral cleft lip and palate. This is my personal story.

I was born at the Mercy Hospital in East Melbourne. There was no known family history of clefts in either of my mum or dad's family and the cleft condition was not picked during normal prenatal ultrasound scans. My mum and dad tell me it came as quite a shock to them when I was born. The next day, the hospital organised for CleftPALS to contact us. The initial shock to my parents was eased after finding out how common the condition was, and the medical procedures that were available to repair my cleft were explained to them.

In hospital, I was firstly fed with a Rosti bottle, which was common at the time but did not work very well for me as it was very time consuming and messy. CleftPals introduced my parents to the Chu-Chu teat, and, although this was against the nursing staff's orders, this worked much better and I thrived. The president of CleftPals at the time was Robyn McKerlie, who happened to live in the next suburb. This was very handy for getting replacement bottles, teats and support when needed. Mum and dad owe a lot to Robyn in those early months.

At 3 months old I had my first of 10 operations at last count. Professor Wayne Morrison, who we later discovered is a world-renowned plastic surgeon, repaired my lip at the Mercy Hospital.

Professor Morrison repaired my palate when I was 10 months old and at the same time grommets were put in both ears because of persistent ear infections. The ear grommets were replaced in another minor procedure when I was 2 years old. With my lip and palate repaired, I was no different to any other kid. However, due to the fact that I had a fistula, I was able to do a few party tricks that other kids couldn't do. I can make liquid come out of my nose voluntarily although when younger, I had no control over this. I had another small lip revision done by Professor Morrison when I was about 4 years old.

In 1996 I started school at Heany Park Primary School. This is my sister and I on my first day of school. During my early school years I had constant bouts of tonsillitis so I had my tonsils removed when I was 6 years old. I also started to follow Collingwood along with the rest of my family and I am now as one-eyed as all Collingwood supporters.



When I was 8 years old I was referred by our local orthodontist to the cleft program at the Royal Children's Hospital. There, I was looked after by Nicky Kilpatrick, Michael Robinson, Adam Rose and their teams who manage my dental and orthodontic work. I continue to see Adam Rose privately for normal orthodontic work. The work at the Royal Children's Hospital firstly involved removing extra teeth and widening the gap in my hard palate to prepare for the bone graft. When I was 11 years old I had a bone graft with bone taken from my hip. The pain in my hip seemed to be a lot worse than that in my mouth. I remember returning to school and having to explain to my friends why I was limping around as well as having a sore mouth. Luckily they were all very supportive and understanding and they made things a lot better.

Being born with a cleft lip and palate never stopped me being able to do anything. Throughout primary school, I played soccer for Boronia Junior soccer club and was captain for 4 years, winning the best and fairest in 2000. I also was a member of the Knox under 12 boys 4X200m relay team, which won the state championship at Olympic Park in 2001. In 2002 I was elected school captain of my primary school. In the same year I had my braces put on. I had these for the next 5 years.

BRENDAN'S STORY *continued*

In 2003, I got a scholarship to Caulfield Grammar School in Wheelers Hill and started secondary school. At school I played football, soccer and tennis and represented the school in athletics. When I was 15, I had a replacement tooth put on a bridge to fill the gap that I had. This was something that worried me as I didn't know if the tooth was going to match with the rest and I thought it might be something that people would easily notice. Luckily, the tooth was perfect and no one can even notice it's not real.

At the end of 2007 between year 11 and 12, I had an optional revision on my lip after advice. Dr Andrew Greensmith at Cabrini Hospital did the surgery. This was by far the most worrying surgery as I had to have a bandage over my lip for 6 weeks, and as I was 17, I was quite self-conscious about what other people my age were going to think. Although a few people asked about it, I was never teased and my friends were very supportive about the operation.

In 2008, I completed my VCE after a long and hard year. After much deliberating, I put down Medicine at Monash University as my first preference at university. I had my doubts about whether or not I was going to get in, so when I was accepted I was very surprised. After a couple of stressful first weeks I am now enjoying the course although it is hard work at times. I will now spend the next 5 years at university studying to become a doctor. I hope in the future to perhaps become a surgeon and be able to help out people in need just like doctors did in the past for me.

I also have a part time job at Bunnings, which keeps me busy in any spare time that I have.

I have recently joined Cleftstars and congratulate Evelyn and Jarrod on their initiative in getting this up and running. I think it is a great idea and believe that the children can get a lot out of talking to other people who have the same type of problems.

That basically brings me to the end of my 19 years. It has been an interesting journey so far and I am excited about the future. I think what I'd most like to convey is that having a cleft lip and palate is not something that has to stop you doing anything in life. It certainly hasn't affected me in any way and I definitely would not consider having a cleft as a disability in any way. Also, I think the most important thing that helped me growing up as a child was having very supportive family and friends that were there when I needed them. I am thankful for the help that CleftPALS volunteers, my many doctors and nursing staff and the team at the Royal Children's Hospital have given me as I'm sure they will continue to help others with cleft conditions like mine.

JARROD'S STORY

Jarrold currently co-runs Cleftstars, a support group of young people aged between 10 and 20 affected by the cleft condition.

My name is Jarrod Morrison and I am a new CleftPALS Committee Member. I was born with a unilateral cleft lip and palate and I feel I have an indelible link to CleftPALS and its mission. Having a cleft palate has had a major impact on my life, far-reaching from the surgeries, recovery and speech pathology of my formative years. Throughout the medical, surgical and emotional journey (endured by most born with a cleft palate) I know I gained an inner strength that I've been able to bring to other aspects of my life.

As most born with a cleft palate know, taking time out for surgery and recovery at different ages and stages of life meant I needed to make choices (sacrifices) that saw me miss out on opportunities and experiences my friends were enjoying (horrible to do as a child or teenager). Accepting these choices, being able to find the up-side to the operations, and staying positive after every (well almost every) doctor's appointment and specialist visit has been a mind set I've used to help me achieve other goals in my life so far, including finishing university, succeeding at work, and travelling overseas.

A bit of my back story (not so cleft-specific)... I am 29 years old and I am a qualified Mechanical Engineer. I loved my time at university and now enjoy living in the heart of Melbourne and working as a Project Engineer in the Oil and Gas industry. Before this, I enjoyed a working holiday overseas that saw me work in the midlands and then London (amongst other things driving tanks in the hills of England) before I grabbed my backpack for a "trains, planes and automobiles" trek around Europe (eastern and western) and South America. Again I drew on the inner strength and positive attitude I'd developed along the cleft palate journey from birth, through adolescence to early adulthood to help assure me I'd survive alone, away from home, for so long. Travelling alone, working in a foreign county and always pushing myself to take up new experiences definitely helped me mature. A highlight of this time away was a cruise to Antarctica. So amazing, so inspiring, and so vastly different to life in suburban Melbourne, I have to consider it "life changing".

Returning home after this time abroad, I decided I wanted to help others born with a cleft palate understand that although there are a lot of tough times, there is a lot to look forward to once you're free of the doctors, specialists, orthodontists and braces. In joining CleftPALS I hope to share this optimistic outlook. My parents made use of CleftPALS' support and advice when I was born and I feel with my personal experience of the doctors, emotions and surgeries I can offer a valuable perspective for parents and children.



I was born at a time when specialists were emerging with new and improved reconstructive surgeries for the cleft palate so I definitely saw my fair share of hospital wards and doctor's waiting rooms. Throughout these times the constant support of my family was paramount. Coping with surgery, speech pathology and self esteem issues so early in life is tough for a cleft patient. I strongly believe that family support be it at your bedside when recovering from a major surgery, making you laugh, even when it hurts, or lending an ear when you are feeling a bit low is important for a patient's swift recovery from surgery and to ensure the patient has the courage to go through the next surgical/orthodontic/dental procedure when they are scared/tired/low.

I fully appreciated just how valuable my family's support was to my recovery just after I'd gone through adolescence, with many major surgeries, recoveries and puberty behind me. I had to face up to completing my final four surgeries, just when I was supposed to be enjoying my last few teenage years. Committing to another four major surgeries was a big step however; the support of my family (with advice, comfort and jokes) helped me to see my long term goals and to tackle the surgeries/recoveries, one at a time. The time passed and I now remember mostly the fun times in hospital and recovering at home, not the stitches or the swelling.

Although the cause is close to my heart through personal experience, I am also passionate about CleftPALS because I realise that many in society have a limited understanding of a cleft lip, or cleft palate and how it affects those born with it. CleftPALS is also not just about education for parents, it also helps cleft patients better understand how to cope with both the medical and emotional scars left by the surgeries and the self esteem battering a patient takes from a condition affecting their personal appearance and speech. I've talked with many cleft patients of varying ages that have struggled with the psychological and emotional issues that accompany this condition. Any steps I can take to increase community awareness and educate people that while a cleft lip or palate is a condition some are born with, it does not stop them achieving their life goals and living a happy, active life.

Some quotes I've found strength in as a cleft palate patient:

"Life is not a dress rehearsal", Michael Caine

"Major surgery is any surgery that involves you, minor surgery happens to other people." Kerry Packer

My own quotes you might find strength/amusement in:

"Never take eating solid foods for granted."

"Dissolvable stitches are the best invention ever"

AN ADVENTURE WITH PIERRE ROBIN SEQUENCE

Balin is the son of Mick and Jacinta Cannon, who are the founders of Pierre Robin Australia Information Support and Education. A video of Balin's Story can be found at www.pierrerobin.org.au or on [YouTube.com](https://www.youtube.com).

What I have discovered for myself and wish to share with you is a lesson 3 years in the making. Our story "Balin's Story", like so many others is a journey of adversity and triumph. I believe that the most challenging aspect of parenting a child with special needs is the continuous bi-polar psychological experience between devastating heart ache and overwhelming joy.

Over the passage of time we have learnt not to look too far into the future, to face challenges as they arise, but to also make dam sure that we as a family and as a community take time to celebrate the many, many milestones that our very special kids overcome. All too often between feeding challenges, genetic testing, surgeries, speech therapy, reviews and follow up appointments we get distracted from enjoying the things that our children can do!

Not long after Balin was born a very kind nurse handed Jacinta a story titled "Welcome to Holland". At the time due to my own fears and anxiety, I did not appreciate the metaphors that the author discussed. However, now looking back over everything we have endured, I cannot help but to feel connected with the message in the story. I hope that by sharing a small window of our experience with you that you too can one day see that having a child with a special condition whether it be a cleft or cleft related disorder will enrich your life in more ways than you could ever understand.



This is Balin's Story...

During our pregnancy Balin was diagnosed with an underdeveloped lower jaw, horseshoe kidneys and a possible cleft palate. We were told that these observations were evident in a range of moderate to severe physical and intellectual disabilities and were advised to consider termination. Our world fell apart. Despite the odds we loved our baby and wanted to give him every possible chance of survival.

Balin came into the world on September 26th, 2006. He was born in severe respiratory distress. Due to his small jaw, Balin's oral tissues blocked his airway and were preventing him from breathing. He was then rushed to the neonatal intensive care unit. We didn't expect him to survive. After what had seemed like an eternity, Balin was finally intubated. He was unable to make a sound. His face turned red, as he gasped for his first breath of air. A lone solitary tear fell from his eye. He had made it!

Balin was diagnosed with Pierre Robin Sequence. Due to his impaired airway and cleft condition, he was unable to breathe or feed normally and required medical intervention to do so. It is now widely published that children with PRS are developmentally delayed. They are often severely underweight and labelled as "failure to thrive". At 18 months, Balin's cleft palate was repaired and ear grommets were inserted. Although this gave him some hearing, Balin is yet to acquire spoken language and relies on Auslan to communicate. Though we believe that his hearing has improved Balin prefers to sign and is learning new signs every day. Balin was also recently been diagnosed with Chronic Infant Obstructive Sleep Apnoea and underwent Jaw Distraction surgery in June 2009. The benefit of this procedure that is as the jaw becomes longer, the oral cavity gets larger opening the airway and elevating the breathing obstruction. Although Balin's surgery didn't quite go to plan, he is now a happy and gorgeous 3 year old little boy who loves swimming, chocolate, bikes, books and Bear in the Big Blue House. Balin attends day care 3 days a week and benefits from the socialisation and interaction with children his own age.

Due to the overwhelming support we have received from the team at CleftPALS, The Royal Children's Hospital, Melbourne, Anglicare and the team at Pierre Robin Australia, I no longer see Balin's condition as a disability. I see it as an opportunity! An opportunity to create a better world for others like him and like us, the parents. The support we have received from CleftPALS VIC has assisted us to create PRAISE which does just that. What I didn't realise until recently was how being a member of this very passionate and dynamic team has helped me.

Good luck with your journey.

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