the blue book

cleft new zealand

Te Manatōpū Ngutu Riwha o Aotearoa

Blue Book II: Age One to Adult

Below is a list of all the specialists contributing to Blue Book II

Megan Sanders Cleft Nurse Specialist
megan.sanders@middlemore.co.nz

Maeve Morrison Speech Language Therapy
maeve.morrison@middlemore.co.nz

Louise Ayrey Cleft Research
l.ayrey@auckland.ac.nz

Samuel Greig ENT
samuel.greig@cdhb.health.nz

John Perry Orthodontics
john.perry@cdhb.health.nz

Arun Natarajan Oral Health
arun.natarajan@cdhb.health.nz

Arthur Yang Cleft Surgery
arthur.yang@waikatodhb.health.nz

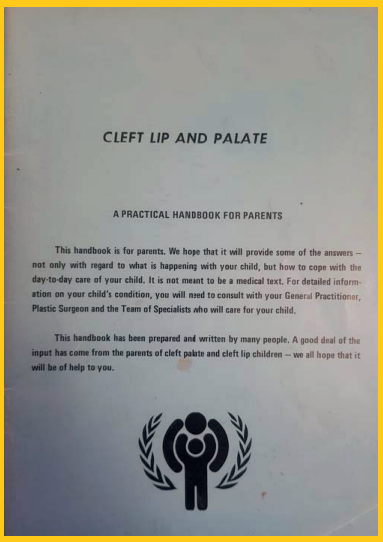
Cleft Book I

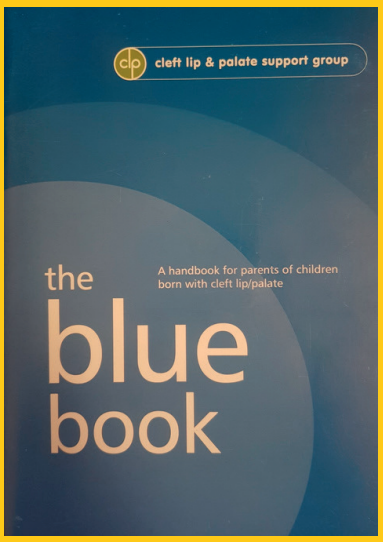
A parent handbook for the antenatal period and up to age one (usually first operations on lip/palate) to help guide parents through what to expect and understand what is happening.

Cleft Book II

Information on what to expect after the first year through to adulthood on your cleft journey. Written for both parents and those going through the procedures.

PREVIOUS EDITIONS OF THE BLUE BOOK





CONTENTS

INTRODUCTION

This book is about the journey children with cleft lip and palate experience and the specialists they may encounter as they grow.

When you read this book, it may feel like a lot is happening, and it can be overwhelming but do remember that every child is different and their journeys vary depending on what they need. Not all children will require every specialty or procedure mentioned.

You may feel like you will see your cleft team a lot, but also remember, whilst your child has a cleft, it should not define them. It is only a part of who they are, they will be able to do the same as other children and they will lead a full and happy life.

ABOUT CLEFT NEW ZEALAND INC. SUPPORT GROUP

Cleft New Zealand (Cleft NZ) provides support for parents whose baby has been diagnosed with a cleft. We have a website with extensive information on cleft lip and/or palate to inform parents and health professionals, **www.cleft.org.nz**. Cleft NZ brings together parents of children, teenagers, young people and adults who are cleft affected. It also provides training for health professionals that may need to support cleft affected families. We want to make it easier for your family to cope with and to be involved in your child's or your own care. We also work as an advocate on your behalf for improvements to the services available in New Zealand.

We have a closed Facebook group where parents can support each other and ask questions in a safe space. Talking to other parents who have experienced what you are going through can help ease your anxiety and can provide the same support to young adults going through treatment. Cleft NZ also holds coffee mornings so you can meet with other parents.

To become a member of Cleft NZ, visit our website **www.cleft.org.nz**. You can also get in touch with us via email (**info@cleft.org.nz**), phone (0800 425 338), or the contact forms on our website.

We also have an app to download. Information on how to do so is available from our website.

SECTION ONE:

INFORMATION FOR PARENTS

Oliver's mum

I believe every experience adds to the people we become each day. I'm full of gratitude for the experiences being born with a facial difference has offered my son, myself, my husband and his brother. Of course, we would rather not have had this particular journey for our boy, but reflecting on the past 18 years, I can now see the gems this has offered us too.

Oliver is strong, kind, compassionate, self-reliant, independent, very funny and resilient. He has built amazing communication skills, knows what he wants and is unafraid to advocate for himself and others. He has formed deep meaningful friendships with people who see all of what makes him Oliver. He knows who he is and confidently shows up in the world. He has a deep conviction to a core value that recognises the innate worth in every human. It has motivated him to succeed, provided inspiration for him to be his own person and follow his own path. Maybe this would still be who he is today, but those things that looked like insurmountable struggles at one time, have now given him the knowledge that he can overcome everything that comes with living life. A lesson some of us never learn. His experiences have given him a depth of character, a pragmatic understanding of life that we as his parents, are very proud of.

I've learnt a lot about myself too – what is important, where my boundaries are, to believe in my intuition and gut feelings. I've met amazing people that I never would have, been given opportunities I had never imagined, and been given the push to address those things about myself I needed to change. I've learnt to advocate with respect, persevere for change, and understand what true empowerment means without getting it confused with my own need to bolster my sense of self-worth. This journey uncovered my purpose in life, ensuring patient and whanau experience is heard and counted. That our hard-won insights are valued and shape the health and wellbeing services for others moving forward. It brought us closer together as a couple and a family. I wouldn't change one moment of it.

Remember in those tough times, that this too will pass. This moment will offer you and your family future-selves the gems that will add to the depth of your unique character. Great things take time, and our kids become truly amazing human beings.

Oliver is now 19 and is studying to be a doctor at Otago University.

AFTER THE FIRST YEAR

Once your child has had their cleft and/or palate repaired, they will have a follow-up with their cleft team, usually each year. This is a time for the surgeon and speech language therapist to assess how your child's speech is developing. Children with cleft lip may only have appointments every two years or so.

This is a time for your cleft team to check on hearing, speech, dental development and other health issues that may affect your child related to their cleft.

MONITORING SPEECH AND LANGUAGE DEVELOPMENT

Children with cleft palates will vary in their speech development and can have some degree of speech difficulty and language delay. The severity (size) of the cleft does not always indicate how your child's speech will develop. Many children have no problems, some find certain sounds difficult to make, and others may experience language delays.

For those with issues following surgery, they may have a fistula (a hole in the palate after repair) which can cause difficulty with the production of some sounds made at the front of their mouth (t, d, s) or they may have a palate disorder known as velopharyngeal insufficiency (VPI), where the palate is not closing properly at the back of the throat, causing nasal speech. VPI can also cause air to leak out of the nose on some speech sounds (p b t d s sh). Because they have difficulty getting oral pressure, they may develop a different way to produce those sounds. Your speech language therapist (SLT) will assess your child's speech and work with you to determine the need for speech therapy and/or further surgery. Further on in this book there is information on surgical procedures for VPI.

The important thing in the preschool years is to provide your child with lots of opportunities to hear you modelling gentle production of these front pressure sounds (p b t d). This can be done through natural conversation and sound play. Your child does not have to copy you to learn the sounds. When they are ready, they will start to use those sounds.

Whilst your child will be monitored and supported by the cleft SLT, they may also receive support and therapy for a period of time from a local SLT from the Child Development Team or Ministry of Education. The cleft team SLT will work closely with the local SLT to provide any specific advice on what to include in the child's therapy programme.

During SLT therapy sessions, it may appear that the therapist is simply playing with your child, but this is an excellent way to assess and provide therapy. You should be involved in the process of helping your child. You can take part during therapy sessions and continue the work at home.

Important information to remember:

- Not every child with a cleft lip and/or palate experiences a speech problem.
- Some speech problems may not be related to the cleft.
- Children with any cleft are at risk of speech and language delay.

EAR HEALTH AND MONITORING HEARING

Children with cleft lip have no more ear problems than the average population, but children born with a cleft palate have a higher chance of having ear problems. This is because the small tube between the throat and ears (eustachian tube) does not open and close properly. As a result, fluid present in the middle ear may not drain out; it becomes a thick mucus like fluid causing “glue ear” or otitis media with effusion (OME).

This thickened fluid can block sound by stopping the vibration of the ear drum and the three tiny bones inside the middle ear, which means that your child’s hearing can be affected.

There is also the potential for acute ear infections, where the middle ear fluid becomes infected and the ear drum could burst. Signs of ear infections are pain in the ear, your child will be upset, may have a fever and young children may appear irritable and have disturbed sleep. If you have concerns that your child may have an ear infection, see your family doctor. If your child has ongoing ear infections, or you are concerned, contact your cleft team who can refer your child to an Ear, Nose and Throat (ENT) Specialist.

The treatment for chronic glue ear is to insert a tiny ventilating tube, called a grommet, into the ear drum. This is a minor operation that takes a few minutes, requiring a general anaesthetic and is done as a day stay procedure. Some children who have only had a few infections may be reviewed after their palate surgery to check their ear health, as repairing the palate can improve their ear health, avoiding the need for grommets.

After grommet surgery, hearing should return to normal. Grommets gradually grow out of the ear drums after about 6-18 months. Some children require multiple sets of grommets – your ENT specialist will advise you on the best course of treatment.

Remember every child is different. If you have questions or concerns, contact your cleft team.

Important information to remember:

- Hearing issues affect speech and language development. The sooner these issues are identified the better for your child.
- Hearing tests can be performed with children of all ages, even babies – it is especially important to have a hearing test if there is a concern that babies or children do not react to loud noise, do not seem to hear conversations or have delayed speech development.
- It is desirable that all children with cleft palate have regular audiology testing and ear examinations.
- Chronic fluid in the middle ear (called glue ear) may be difficult to recognize without audiology and ear examination.
- Acute ear infection (acute otitis media) usually presents in the same way as it does with non-cleft children and would be suspected if the child has apparent ear pain or fussiness, disturbed sleep associated with fever, or if there is discharge from the ear.

Other ear, nose or throat problems in children with cleft palate may include infected or enlarged tonsils and adenoids. Some children may require removal of their tonsils if sore throats or tonsillitis are an ongoing problem. They may also need to be removed if excessive enlargement of the tonsils causes airway obstruction and affects breathing.

The adenoids sit at the back of the throat and help the body fight infections. Sometimes they become enlarged and can cause problems with snoring and breathing. Removal of the adenoids can help with breathing, but can have a detrimental affect on speech, causing VPI. Any recommendations for tonsil and adenoid surgery should be discussed with your cleft team prior to removal.

CARING FOR YOUR CHILDREN'S TEETH

The health of your child's teeth and gums is extremely important. Healthy teeth and gums are essential for good eating, good speech and a good appearance.

For children with cleft lip and/or alveolus, you might notice that their baby and/or adult teeth may be crooked, they may be missing teeth, have too many teeth, or have teeth erupting in different places in the gum.

As your child gets older, they will develop their adult teeth. It is at this stage that they will be seen by the orthodontist associated with your cleft team. The timing for this can be variable but most commonly occurs when the child is close to having all of their permanent teeth.

Successful orthodontic treatment needs good healthy teeth and gums to start with. Tooth decay is common and preventable and what you do at the very start of a child's life, has a big effect on the overall health of their teeth.

Babies get teeth at around 6 months old. These teeth need cleaning with a baby toothbrush and a tiny smear of toothpaste with fluoride. The best time is often after the bath, it helps you remember and often the baby is relaxed.

Giving a baby a bottle to take to bed to sip during the night can cause tooth decay very fast. This is because even plain milk has natural sugars, and if the sugars are always around the baby's teeth, then bacteria starts breaking down the dental enamel.

Juice is a problem too as it is very sweet and acidic, and has a lot of calories. It can make babies and toddlers refuse their formula and food just when they need a variety of food to grow. Our advice is to give babies, toddlers and anyone in the family tap water if they are thirsty.

For snacks for toddlers, think a sandwich rather than a biscuit, or vegetables and yoghurt rather than muesli bars or raisins. Small pieces of cheese or cooked sausage are an example of other types of snacks.

Don't fret about occasional sweet things at parties and outings. Their teeth will be fine if they have good food, and a good regime for cleaning their teeth at home.

Children born in the main hospitals in the area of the ADHB are automatically registered with ARDS, the Auckland Regional Dental Service which provides free dental services from 0-17 years old. They usually send an appointment when the baby is one year old. If your baby is born at any other place in New Zealand or overseas, you may need to phone 0800 TALK TEETH (0800 825 583) to register your child for the free service.

Talk to your child positively about visits to the dentist. Children need your support, and remember: having healthy teeth begins at home.

Important information to remember:

- Enrol your child with your local school dental therapist when their teeth start to erupt and ensure they are seen regularly.
- Clean their teeth twice a day with a suitable toothbrush and toothpaste.
- Encourage a healthy diet, avoid regular use of sweet and fizzy drinks, and try to keep sweets for special occasions.
- Encourage your child to drink water or milk.
- Use a good fitting mouth guard for contact sports.
- Start flossing when two teeth are touching together.

Application of fissure sealants and topical fluorides should be considered by your dental health provider.

It is important to protect your child from tooth decay and gum disease. As your child may have some poorly formed teeth, the rest must be kept in very good condition as future treatment may be needed to straighten them. Children with clefts are more susceptible to poor enamel and tooth decay.

PREPARING YOUR CHILD FOR SURGERY

Having to go to hospital with a child or young person can be challenging for parents and families. There is a lot of support for children in hospital, so if you have any concerns about your child's stay in hospital, please talk with your cleft team.

Some helpful tips provided by KidsHealth.org.nz:

- As a parent or caregiver, you are the best source of support for your child or young person – you know what frightens them, how they cope in stressful situations and how they like to be comforted.
- It is important to give children information simply and truthfully, in words they understand.

The younger child:

- Younger children cope with the hospital experience better if they have a parent or loved one stay with them.
- Bring in familiar items from home – blanket, cuddly toy, their bottle/teat, favourite soft foods and snacks.
- Explain things in words that are familiar to them.

- Be honest about when and why they are having surgery.
- If you have other children at home, explaining things to them too can help them feel informed and prepared for family members spending time in hospital.
- Encourage your child to go to the play room on the ward.
- Let your child know that it is ok to have feelings about going to hospital, listen to them and help them talk about their feelings.

For school age or older children:

- Bring familiar items from home, such as pyjamas, blanket/pillow, activities such as books, music, art.
- Have a plan for someone to stay with your child as much as possible.
- Be honest about why they are having surgery and what is involved.
- Encourage your child to participate in their health care by asking questions and being included in discussions about their treatment.
- Encourage your child to keep a diary/memory book about their journey.
- For many young children, fear of the unknown and fear of pain are common anxieties. Be honest with them about what to expect and how they may feel.
- Encourage contact with friends from school, especially if recovering at home for a long period of time.

- If you have questions contact your cleft team who can support you.

Tips for helping your child or young person manage tests and procedures:

- Find out about the procedure and explain to your child why they need the procedure and how long it will take. There may be patient information pamphlets available so talk with your cleft team.
- Encourage your child to ask questions and to express any concerns or worries they may have.
- Where possible, use simple language and explain the meaning of unfamiliar terms they may hear such as “anaesthetic”.
- Help your child manage their pain or discomfort. Encourage your child to take their pain relief medication when given, and utilise techniques like distraction, deep breathing, songs, iPad etc. depending on your child’s age.
- Afterwards, comfort your child in whatever way is soothing and reassuring for them.
- Ask for help from play therapists, nurses and other health team members to support you and your child through their hospital experiences.

LATER SURGERIES

Because each child's cleft is different, it is not possible to predict exactly what surgery will be necessary. Each child is regularly seen in the clinic and assessed by your team of specialists. As a child grows and develops, cleft related problems may arise that will need further surgery. These operations range from very small procedures to fairly major adjustments.

It could be a small procedure, such as a small adjustment to the lip before they start school, or other procedures could be fistula repairs or further surgery for speech.

FISTULA INFORMATION AND REPAIR

Occasionally for various reasons, the repair of the palate does not heal over the whole length of the repair. A hole of varying size can appear on the suture line, connecting the nose with the mouth. This is called a palatal fistula. You may notice that food or fluid begin to leak from your child's nose again after palatal surgery – this can be a sign of a small fistula.

Often these will heal upon their own over time, but sometimes the surgeon may need to repair this with another smaller procedure. This does not need to be done immediately, and your surgeon will advise the best time to do this.

Another type of fistula that could be mentioned at your clinic appointment is an anterior fistula - a gap that remains after primary surgery where the gum joins the hard palate, common in children who have had a unilateral or bilateral complete cleft lip and palate. The fistula is repaired at the time of bone graft surgery.

SPEECH SURGERY FOR VELOPHARYNGEAL INSUFFICIENCY (VPI)

What is VPI?

Velopharyngeal insufficiency (VPI) occurs when the soft palate (velum) and the back wall of the throat (pharynx) cannot close properly during speech.

Some children who have had their cleft repair may need further surgery if velopharyngeal insufficiency (VPI) persists. Symptoms of VPI include nasal sounding speech and often air leaking out of the nose on certain sounds. If VPI is suspected, then your cleft team will arrange to carry out further investigations. The two most common investigations to assess VPI are videofluoroscopy and nasendoscopy.

Videofluoroscopy is an investigation that assesses palate movements during speech using x-rays. Your child has to be able to sit still, and repeat some words and short sentences. The movement of the palate can be seen on the x-ray and recorded for later analysis by the cleft team surgeon and SLT. The procedure is carried out by the cleft team SLT together with a radiographer in the x-ray department of the hospital. The child can usually manage this procedure from about the age of three years.

Nasendoscopy is a procedure where a fiberoptic tube with a tiny telescope is inserted into the child's nose to view the palate movement from above. The child will have their nostril numbed to make it easier for the tube to slide into the nose. This is usually carried out by the cleft team plastic surgeon but in some cleft centres it may be the ENT. The cleft team SLT is also present. The child is asked to repeat some words and sentences, and the palate movement is observed on a screen. This test can be carried out from about the age of six years.

Information from the videofluoroscopy or nasendoscopy, together with a detailed speech assessment, can help the cleft team determine whether further surgery may be needed to improve speech.

The surgical procedure will depend on the structural problem and the surgeon will tailor the surgery to your child's problem. There are several different surgical options. The surgeon may want to lengthen the soft palate or build up the back wall of the throat. The purpose of treating VPI is so that your child can create pressure in their mouth which allows them to make stronger sounds.

The surgeon will discuss the surgery and post operative care with you in the clinic and provide more detail. After surgery, speech should sound less nasally and your child should be able to get better pressure to make speech sounds, but sometimes it takes weeks or months for the surgery to take effect.

Your child may need speech language therapy to capitalise on the surgical procedure. Your child is usually reviewed by the cleft team three to six weeks after surgery and speech language therapy can continue after that. Many children need to relearn how to make the sounds if they have developed different ways to produce speech sounds because of the VPI. The SLT will give you ways to work on your child’s speech.

Sometimes a small amount of nasality is still present after treatment, but perhaps not enough for most people to notice.

LIP REVISION SURGERY

Sometimes the lip scars will stretch or change with growth. If it is felt that the shape or look of the lip could be improved, then lip revision surgery may be discussed. Surgery such as lip revisions can be done at any age but are often done prior to starting school.

Lip revision surgery for young children often involves a one night stay, dissolvable sutures and they can eat and drink as normal after surgery. They may need a few days off kindergarten or school to recover.

Any surgery will involve a scar, so you need to take into consideration that the scar will need time to settle and improve in appearance.

ORTHODONTICS

Orthodontics is a specialty of dentistry that corrects the position of teeth. Orthodontists correct crooked teeth by using orthodontic appliances. The most commonly used orthodontic appliances are 'fixed appliances' (braces) and plates. These appliances help to straighten the teeth and fix the bite.

Orthodontic care may be provided by your cleft service for free depending on the severity of the cleft and if your child is a New Zealand resident. There are some limitations as to what can be provided for adults.

The type of orthodontic treatment your child will need depends largely on whether or not their cleft affects the alveolus. The alveolus is the part of the upper jaw where the teeth and gums grow.

Children born with a cleft that goes through the alveolus will usually need more extensive orthodontic treatment. A cleft can cause a gap in the gum and bone of the upper jaw (the alveolus). This means some front teeth come into the mouth twisted, in the wrong position, or don't appear at all.

Some children will have sufficient bone present in the deficit area to allow for their secondary teeth to erupt through so they may only require braces to help straighten their teeth. Your cleft team will review your child as they grow and determine if a bone graft is required.

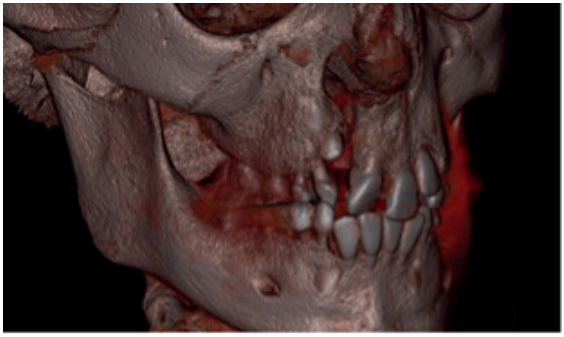
ALVEOLAR BONE GRAFTS

The alveolar bone graft places bone in the cleft area of the upper jaw to make sure the adult teeth grow as best they can.
The bone graft provides support for the teeth to avoid them being lost. The alveolar bone graft can also seal off any remaining holes (fistula) in the gum.

When will my child need the alveolar bone graft operation?

The operation works best before the upper canine (eye) teeth erupt. This is normally between eight and eleven years of age, depending on how quickly your child's teeth are growing. At this time, your child will come under the care of the orthodontists and will see the plastic surgeon again when it is time to plan the bone graft surgery. If you have any concerns about other aspects of your child's care during this time, please contact your cleft team.

Your orthodontist and surgeon, together, use x-rays to tell when it is time for your child to have a graft. An x-ray is the best way to tell whether the teeth have grown enough to begin.



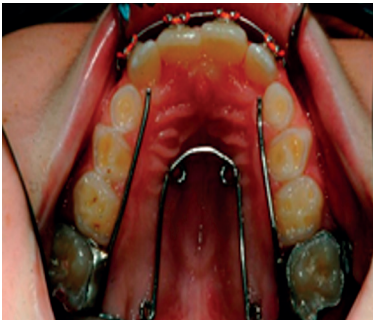
Preparation for the alveolar bone graft

A short course of orthodontic treatment may be needed to help set the teeth up with braces or a plate before the bone graft. If so, regular trips to the orthodontist will be required.

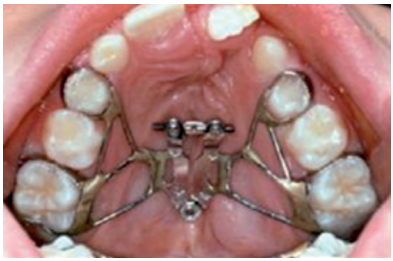
Encourage your child to clean their teeth regularly before surgery. Good oral hygiene will help prevent infection post operation.

Some children need orthodontic treatment using an expander/quadhelix to prepare the area for a bone graft. A quadhelix is a slow expansion device attached to the upper teeth to make room if the teeth are crowded as the surgeon needs room to place bone in the space of the cleft. The appliance is shaped like a W and it is springy. It is cemented to the back tooth on each side. Another appliance that can be used is called a fan expander *(see pictures below).*

The appliance is left on the teeth until it is removed in the dental department before surgery.



Quadhelix appliance before bone graft



Fan expander before bone graft

What is involved in caring for the quadhelix?

Once the quadhelix is in place, the expansion of the upper teeth begins. This can be tight at the beginning but will settle down after a few days.

There is the potential for food to become caught in the quadhelix. Good oral hygiene such as cleaning teeth twice a day and mouthwashes are a good way of ensuring the appliance and teeth are clean.

Regular trips to the orthodontist to check the quadhelix is doing its job are necessary. It is important to contact your hospital and specialist dentistry department if you cannot make an appointment so another time can be arranged.

What does the bone graft operation involve?

This surgery will take place under a general anaesthetic so your child is fully asleep. Bone is taken (usually from the hip) and used to build up the gum in the upper jaw to help the teeth erupt. These small pieces of bone are used to repair the alveolar cleft. An incision is made at the cleft site on the gum line and these bone fragments are packed into the gap. The gum is then closed over the bone graft. These small pieces of bone act like a 'bridge' for new bone to grow and develop across the cleft site. Over time, your child's adult teeth will then be able to erupt through the new bone.

To take bone from the hip, a small cut around 5cm long is made low down on the hip in an area that is usually covered by swimwear. This scar will fade considerably with time. The bone will eventually grow back and the hip will be good as new.

After the operation children are normally able to go home the next day after a night on the hospital ward. Your child will be able to walk after a few hours but the hip may be sore for a few days after the procedure. Your child will need to avoid sports and physical exercise for four to six weeks to allow for the initial phases of healing.

Helping your child to clean their teeth well each day in the morning and before bed increases the success of the bone graft and helps prevent infection.

After bone graft surgery, your child will have a clinic appointment where an x-ray will be taken to check that the bone has healed in the cleft gap.

After this, your child will be under the care of the orthodontist. This may mean that you won't be in contact with the cleft team as often, which can be a cause of concern for some parents. If you are not sure when your child is next due for an appointment with the plastic surgeon, or if you have any concerns call your cleft team.

MANAGING SELF-ESTEEM, CONFIDENCE AND SOCIAL SITUATIONS

As parents, it is not uncommon to worry about whether your child's cleft might affect their self-esteem and self-confidence. Your child's physical appearance may form a part of the way they see themselves. At times, their cleft might cause them to see themselves in a negative light. You can support them by acknowledging their feelings and talking about their condition in a positive way. It can help to explain your child's cleft to them in a way that they can understand and explain to others if they need to. As a family, see if you can talk about physical appearance, in general, in a positive and non-judgmental way.

It can be helpful to think of building your child's self-esteem and self-confidence a bit like baking a cake. Just as a good cake is made of many different ingredients; self-esteem and self-confidence are made up of many things too. You can build your child up by focusing on the whole person – such as their personality, values, hobbies and things they are good at.

It's also important to remember that self-esteem and self-confidence are not the sort of things that we either have or don't have. They fluctuate throughout life and this is a normal part of everyone's development.

You might also wonder whether your child might face social challenges as a result of their cleft and how you can support them. It is possible that you or your child may be asked questions about their cleft. Often people are just looking for information to help them understand. You can model helpful and appropriate responses for your child by answering questions calmly and clearly with brief information about your child's cleft. You can also get your child to practice responding to questions with you so that they are prepared if the situation arises.

Unfortunately, it is possible for some children to experience teasing or bullying about their cleft from their peers. You can help your child face these situations by identifying how they can respond. They can practice statements with you that they can use in these situations. Practicing in advance can help your child feel more prepared to respond in a difficult moment. You can also encourage them to walk away and find someone who can help, such as a teacher if at school. But remember, bullying is not an issue that your child should be expected to deal with on their own. If teasing or bullying is an issue at school, you may find that you have to advocate for your child with their school so that the school is aware of the issue and has a plan in place to support your child.

Speaking with their teacher is a good place to start. See if you can stay connected with supports such as Cleft NZ – there you can find others who have been through difficult situations and might be able to help you if you need it.

SECTION TWO:

FOR TEENAGERS AND YOUNG ADULTS

This section is written for our teenagers and young adults. Support your child by encouraging them to read this section, ask questions and participate in their ongoing care.

Henry

Dear parents and any kids out there with a cleft, my name is Henry and I'm 13, I'm the youngest of three kids. I don't remember much from my surgeries early on. The last one I can remember was the bone graft where they took a little bit of my hip and put it in my gum line (it sounds worse than it is). I'm looking forward to the end of my journey with surgery.

One out of every 565 babies are born with a cleft lip and/or palate, and in my case and for many others, I was born with both. Sometimes this can make me upset but mostly it makes me feel unique. My advice is to simply accept it and be okay with it because you were born to stand out for a reason. My cleft hasn't affected me in making friends and I've got a good group of loyal friends, including lots that I've known almost my whole life.

Sure, some people have tried to bring me down with bad things to say about my face but there is nothing wrong with the person being made fun of, it's the person doing the bullying who has something wrong with them. Some of the stuff people can say gets under my skin sometimes but doing something I love makes me feel a lot better. Find something you love, even better if it is something you are really good at.

Sometimes I even feel cool because of my face. Yes, there are the curious comments but people say some good things too, like some think my scar is cool, some think the un-symmetrical part of my face is cool too.

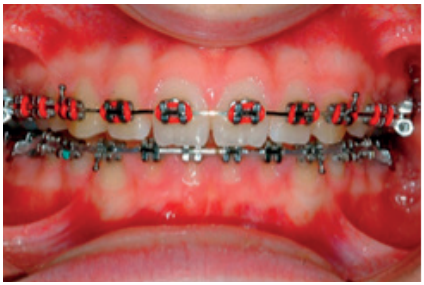
Occasionally I compare myself to others and it makes me a bit upset at how I don't look like lots of other people, but I've come to like the fact that my face is different and there's not much I can do about it, so I love it instead.

The information here is a general guide only because everyone is unique and treatment pathways vary for each person.

ORTHODONTIC TREATMENT AS A TEENAGER

Just like your friends, many children with clefts require orthodontic treatment to straighten their teeth in their teenage years. Braces are usually placed when all of your permanent teeth are close to being present (11-15 years of age). Orthodontic treatment usually takes about two years with adjustments needed every four to eight weeks.

Good tooth brushing, a healthy diet and regular dental check-ups are required before orthodontic treatment can start.



When you were a child, your parents will have made decisions about your treatment together with cleft specialists. As you get older, you will want to be more involved with your own care and treatment pathway. We encourage you to ask questions, so you feel comfortable about anything to do with your cleft or treatment.

If you are under 16, your cleft team will want your parents to be involved so they can support you with any treatment, but you may be unsure if further treatment is what you want. Or you may have concerns about your appearance and you want something to be done. This is completely natural, and your team are happy to discuss options with you.

Your cleft team may have a health psychologist available who you can talk with to help you with important decisions like whether to undergo further treatment or surgery. It's okay to be unsure about whether to have further surgeries or not, just make sure you have all the information you need before making a decision. Ultimately it is up to you.

When you are 16-20+ years old, and your treatment pathway is completed, you may be at the end of your cleft journey. You may be discharged from the cleft team. For some, their treatment pathway continues. Every cleft is different so it's important to talk to your specialists to know more about what you can expect over your teenage years. It is also important to know that you can still have further treatment at any time in the future if there's anything else you think would be beneficial to you – get your GP to refer you to your local cleft service.

Time goes slowly when you are waiting to be fully grown, so it might be a good time to talk to your cleft team psychologist to look at strategies to cope with or deal with those annoying questions you get asked. It can be helpful to talk to other young people about their experiences – ask your cleft team to connect you with others who have had this surgery.

If you have ongoing concerns or are worried about a delay in treatment, you can call your cleft service and they will be able to discuss with you where you are on your cleft journey.

The treatment you may need as a teenager/young adult may include some of the following depending on your unique concerns and needs:

- Orthodontic care (e.g. braces)
- Revision surgery for your lip and/or nose
- Orthognathic (jaw) surgery
- Ongoing dental care
- Advice about your speech and accessing therapy if needed
- Appointments with a psychologist to talk through any problems or worries you are having and to support you in making decisions about further treatment
- Discussions with a clinical geneticist if you are curious about whether any children you may have in the future are likely to be born with a cleft

As part of your treatment plan, you may want to have surgery to revise something you aren't happy with. This surgery may be aesthetic (meaning it aims to change something about the way you look) or it can be functional (for example, helping you breathe easier or speak more clearly).

It is important to know what is involved in the surgery, but also the recovery time after surgery so you know how long you may need off school, study, sports or activities.

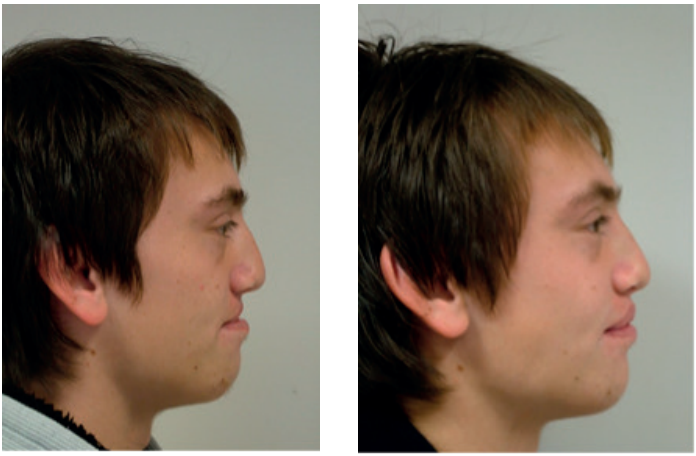
JAW (ORTHOGNATHIC) SURGERY

Jaw surgery (also called '*orthognathic* surgery') is a procedure to change the position of the jaw to improve the way the jaw looks, and to get a better bite.

Why might your child be offered jaw surgery?

Not everyone needs this surgery, but some young people and adults with a cleft have an upper jaw (maxilla) which is relatively smaller than their lower jaw (mandible). This can make the upper lip and nose look a bit flat and make the top teeth sit behind the bottom teeth (an underbite).

Surgery, in combination with orthodontics, can bring the top teeth and upper jaw forward to line up better with the lower jaw and teeth. The middle part of the face can be made to come forward and appear less flat. This can change the appearance of the face a lot, especially from the side. It can also help with problems with chewing and eating as it will change how your teeth fit together. Surgery is usually only performed once the growth of the face has slowed down, which is around 16-18 years old.



Before and after upper jaw surgery

Planning and preparation

Your orthodontist works together with your surgeon to plan jaw surgery. Braces are put on the teeth to move them into different positions so that when the jaw is moved, the teeth will fit together comfortably.

Additional speech testing may be required prior to jaw surgery to ensure the movement of the jaws does not impact on your speech.

Surgery

The surgery is mostly done from inside the mouth. Sometimes only the upper or lower jaw needs to be moved, but sometimes both jaws need to be moved. Once the jaws are moved, they will be held in place by tiny metal plates and screws.

Recovery

At least two weeks off school or work and a bit more time away from sporting activities is required after jaw surgery. There will be some swelling and numbness and a liquid/soft diet until the jaw has fully healed is required.

Summary of orthodontic treatment that may be offered to your child

1. Early treatment with a plate before lip surgery (see Cleft Book I)
2. Orthodontic treatment before alveolar bone graft
3. Orthodontic treatment for a nice smile in your teenage years
4. Later orthodontic treatment and jaw surgery when fully grown

If you have any questions about orthodontic treatment, please ask your cleft coordinator or orthodontist.

SPEECH SURGERY

Sometimes after your jaw surgery, your speech may sound worse. Moving your upper jaw forward, can cause a gap between your palate and the back wall of your throat, causing more air to escape out of your nose when you speak, called hypernasal speech.

There are various options for speech surgery that can be performed to improve your affected speech. Your surgeon and speech therapist will assess your speech and discuss the best treatment with you.

RHINOPLASTY

If you need jaw surgery, the best time to do a rhinoplasty is after jaw surgery. If your orthodontist and surgeon have said you do not need jaw surgery, but you have concerns about your nose function or shape, you can discuss options for surgery and the best time to do so at any time.

Your nose changes as you grow, and can begin to look different as you become a young adult. You may notice that it can be difficult to breath from one or both nostrils, this can be due to a bend in the nasal septum (central portion of your nose) which is common with people who have had a cleft lip and palate.

Rhinoplasty surgery may be able to change different features of your nose, for example, the width, profile and projection (how much it sticks out), the shape and the straightness of your nasal septum.

But not every issue can be solved with surgery, so it is important to discuss your issues and expectations with your cleft surgeon.

LIP REVISION SURGERY

You may wish to discuss having some surgery to your lip – for example, the scar may be too wide or your upper lip might be too short. There are several different surgical options that your surgeon can discuss with you, depending on your individual needs. You should feel free to raise any issues you have with your cleft team.

GROWING UP

Emotional ups and downs are a part of growing up. This is normal for everyone. There are lots of new experiences, such as starting a new school, making new friends and adjusting to changes in our bodies. For some people, living with a cleft doesn't seem like it has too much of an effect on other parts of their life. But some people find that living with a cleft presents situations and challenges that their mates don't have to go through. For one, you might have had more medical appointments and surgeries than others. You might also have a visible physical difference, like a scar.

For some people, this can lead to difficulties with the way they see themselves, their mood, worries or relationships with other people. When you're feeling down, it can be easy to compare yourself to other people and think they're better than you in some way, or to not see the things that are good about yourself. It can be helpful for your overall wellbeing to remind yourself of the things that make you awesome. See if you can look after yourself by doing things that make you feel happy and fulfilled. And remember that you don't have to do it alone – sharing how you're feeling is usually a good way to manage how you're feeling. You can try talking to friends or family, your school counselor, or asking your GP about psychology support options in your area. You can also connect with other people living with a cleft through Cleft NZ.

As you get older, you might want to start being more involved in your cleft treatment. When you were younger, your parents or caregivers may have done all the talking and decision-making in your cleft appointments. If you're ready, you can talk to your parents/caregivers about them taking a back seat during your appointments. To prepare for appointments, you can try writing a list of things you want to talk about or ask your cleft team. At the appointment, you can be the one answering the team's questions.

When it comes to making decisions about treatment, it can help to think about the pros and cons of your options so you can make the best choice for you. It can still be helpful to talk through your options with your parents/caregivers to clarify your thoughts.

SECTION THREE:

FURTHER INFORMATION

Asher & Jarvis' mum

I am a mum of three. Bella, 13, Jarvis, 11 and Asher 8. Jarvis was born with a unilateral cleft lip and palate and Asher was born with a bilateral cleft lip and palate. We are a fair way along the cleft journey, but I still remember the anatomy scan and the surprise and shock of hearing the words "I suspect your baby has a cleft lip/palate". We have learnt so much since then and I want to share some of what I have learnt.

Most importantly, learn to accept your questions and thoughts. It is absolutely normal to feel sad, disappointed and even grief. It is really ok to be worried and anxious, but know that when your baby arrives he/she will be so perfect (in their very unique way) that most of the worries will evaporate. My hardest thought was 'Will I love this baby as much?', I knew it was crazy, and as soon as I met Jarvis, the moment he was in my arms that worry completely disappeared.

Another worry I had was other people's reactions, and my reaction to these. I knew my baby would and did look different, and yes, very occasionally we struck people who didn't know what to say, but most were just curious. I was very conscious of not judging people's first reactions as most people were so kind...even with the very typical 'it's amazing what they can do these days'. I found most people were surprised (as we were) at how all the lip was there, just not connected in the right place. Most people who met our babies in person were usually won over by their unusual but gorgeous smile and expressions.

It is also important to trust the cleft team. We have found the team to be incredible, professional, skillful and clever but most of all approachable and caring. More than likely these are the people you will hand your baby over to for surgeries and other care, and that is not easy. Take time to get to know them and always, always ask! If you have any questions, doubts or are just curious, ask. They do this for their job. Things like feeding, weird tooth placement/growth, unusual holes and spaces, are 'different' and a little bit scary for us, but most of the time the team have seen it before and will know how to fix it. In fact, I often ask "is that normal for cleft?" I have never had anyone answer 'no' yet... sometimes the 'thing' is rare but still normal.

Enjoy life when you have no appointments or surgeries looming. That first year can be especially overwhelming, Having a baby is generally full on, but having one with extras is even busier.

Make sure you do have downtime, don't compare yourself to other families, ask and accept practical help and forgive yourself if you do feel overwhelmed and exhausted. Be okay with the 'why us question?' but try not to dwell on it. You might even feel resentful of others with their 'easier' babies. This is all okay, and it is also okay to ask for help if you are struggling. Recognise how amazing you are doing and how much you have had to learn and get through.

Most of all enjoy your baby. Remember, while you are pregnant that you are having a baby, not a cleft. Your baby will do and want all the normal baby things, he/she will feed, poop cry, giggle, have that delicious new baby smell and smile (oh that smile!). I remember when we told Bella that the new baby would also have a cleft she asked 'will the baby have the biggest smile in the world like Jarvis?' With this statement I remembered how gorgeous our babies are (and cried)! He/she will want to play with toys, have cuddles and be talked to. They will turn into demanding (but gorgeous) toddlers, curious preschoolers, busy children and moody (sorry) but mostly lovely teenagers.

I always have in my mind that the journey belongs to my children. It is my job to help them cope with all the appointments, surgeries and all that comes with having a cleft and set them up to know that they are incredibly strong people who are better for their experiences. They know they are who they are meant to be.

As my son said in a recent speech for school, a cleft is just a gap.
He is mostly right, but my goodness it is a space that creates a whole lot. It creates children who don't just accept differences in themselves and others but they embrace it. It creates children with an awareness and empathy for others well beyond their age, stepping in to help, when most children simply wouldn't see the need. It creates an ability to ask for help and advocate for your children. It creates an ability to put things into perspective. But most importantly of all it creates the most incredible babies and children, who grow into people that inspire their parents, grandparents, teachers and anyone who is lucky enough to know them. I am incredibly proud of my children and feel that although it comes with some big challenges, cleft has been a gift.

GENETICS

The likelihood of having another child with a cleft lip and palate depends on a few factors:

- If there is a cleft and other abnormalities, then genetic testing and/or a referral to the clinical genetics service may be warranted. There may be a chromosome or syndrome diagnosis that can impact on chances of clefting happening again in another pregnancy.
- If there is a strong family history of clefting then this can affect the chances of having another affected child. Families with a strong family history of clefting can have a discussion with the genetics service for possible assessment and risk advice.
- If there is isolated clefting (with no suggestion of any other features and no family history): see the attached table for risks of affected children.

Frequency of oral clefts in relatives based on probands phenotype i.e. cleft lip alone (CL), cleft lip with cleft palate (CL/P) or cleft palate alone (CP).

Relative	CL %	CL/P %	CP %
Sibling	2.5	3.9	3.3
Half sibling	1.0	0.5	1.0
Parent	2.5	2.5	2.5
Offspring	3.5	4.1	4.2
Niece/nephew	0.9	0.8	1.1
Aunt/uncle	0.6	1.1	0.6
First cousin	0.3	0.5	0.4

RELATED CONDITIONS AND SYNDROMES

A syndrome is when a group of different symptoms occur together. There are over 300 syndromes where cleft lip and/or palate are listed as part of the condition, although some are extremely rare.

It is estimated that 15-30% of people born with a cleft are affected by one of these conditions or syndromes. **Having a cleft alone does not mean that an individual has a syndrome.** Most people born with a cleft are "non syndromic".

Most of the syndromes and conditions affect people to various degrees. Syndromes or conditions such as velocardiofacial syndrome (22q11 deletion), Sticklers and Van der Woude are most commonly seen in cleft centres, and your cleft team will be aware of this. They will liaise with your paediatrican or other health specialists when planning treatment.

BENEFITS AND ENTITLEMENTS

In New Zealand, we are very fortunate that the public health authorities fund the treatment and repair of cleft lip/palate. You should not have to pay for any outpatient fees, time spent in hospital, orthodontic equipment, surgeries and revisions.

To receive public health funding you must be a permanent resident of New Zealand or have New Zealand nationality.

RESEARCH IN NZ - THE UNIVERSITY OF AUCKLAND

The University of Auckland Department of Paediatrics: Child & Youth Health and Department of Obstetrics and Gynaecology have been involved in Cleft Research since 2014 after a successful grant application to the New Zealand Health Research Council (HRC) worth $1,005,314. Associate Professor, John Thompson has led a team throughout the research. He was successful again in 2017 and the second HRC grant ($1,198,687), and the project began in October of the same year. Associate Professor Thompson intends to continue submitting funding applications for ongoing research in this area of paediatric health.

New Zealand has not seen this sort of investment in Cleft Research previously. There is other research taking place within cleft teams and health professionals. Here, we are covering research carried out by The University of Auckland.

Quality of care and outcomes in children with cleft lip and/or palate in NZ

John Thompson, Peter Stone, Nicola Austin, Peter Fowler, Glenn Bartlett, Maeve Morrison, David Gillett, David Fitzsimmons, Jonathan Sandy

This study had two main objectives in relation to cleft lip and palate (CLP). Firstly, it aimed at investigating the health care delivery from the time of diagnosis to surgery for children with a cleft lip and/or palate and their families. Secondly, it has provided the first consistently collected outcome data in relation to cleft lip and palate in New Zealand. *(Published papers listed below in appendix).*

Closing the knowledge gap: what factors may affect cleft lip and/or palate?

John Thompson, Peter Stone, Clare Wall, Andrew Shelling, Peter Fowler, Juliet Taylor Pauline Koopu, Jonathan Sandy, Gemma Sharp, Kaye Roberts-Thomson, Loc Do

Cleft is a common birth anomaly and often requires long-term treatment. Cleft occurs in higher numbers in New Zealand (1 in 565 babies) than generally quoted rates (1 in 700 babies). There has been little progress in understanding environmental or genetic factors that may lead to a cleft. We seek to identify the factors and interactions associated with cleft. The project has the potential to identify factors which could lead to public health interventions and potentially prevention of cleft. At the time of writing, this project is ongoing and your participation is welcome.

FINAL WORDS

Your journey with your child who is cleft affected may seem daunting at times but there are many ways to get help. Cleft NZ are here to support you. Please join as a member to benefit from our experience and resources, and feel free to visit the website or our Facebook page, as there is a lot of information availabe for you.

www.cleft.org.nz/
www.facebook.com/groups/faceitcleftnz

Donations

Cleft New Zealand Inc is a registered charity. As such, we rely on fundraising and donations to fund the support we provide, such as the breast pumps, the Blue books and training health professionals.

If you have found this book useful, found an answer to your questions on our website or are looking to the future for you and your child, then you may want to help us financially.

Your donation will make a difference. Your help will ensure the group continues to support all those going through the cleft journey, and help us to expand the services we can offer you and your child into the future.

Every donation to Cleft NZ makes an enormous difference. As a registered charity we depend on the generosity of our supporters to finance our work.

Through our website you will find different options on how to donate and if this is not possible, here are some suggestions on how to help support us:

- Join our Facebook page. It is a great way to promote Cleft NZ to your networks
- Volunteer your time and expertise
- Help us spread the word and raise public awareness of cleft
- One-off gifts
- Ongoing monthly contributions
- Bequests

With your help, we continue to support families, children and adults, with realistic information and positivity and with a real sense of hope for the future. Because we think the future looks great.

Websites

For up to date information on website links, resources and support available please go to the Cleft NZ website:

www.cleft.org.nz/support/information-links/

ACKNOWLEDGEMENTS

Megan Sanders - Cleft Nurse Specialist
megan.sanders@middlemore.co.nz

Maeve Morrison - Speech and Language
maeve.morrison@middlemore.co.nz

Louise Ayrey - Cleft Research
l.ayrey@auckland.ac.nz

Samuel Greig - ENT
samuel.greig@cdhb.health.nz

John Perry - Orthodontics
john.perry@cdhb.health.nz

Arun Natarajan - Oral Health
arun.natarajan@cdhb.health.nz

Arthur Yang - Cleft Surgeries
arthur.yang@waikatodhb.health.nz

APPENDIX

Previous editions

Sharryn Nicholson - conception of original Blue book, 1979, Glenn Bartlett and Tristan de Chalain (plastic surgeons), Heather Keall and Peter Fowler (orthodontists), Ian Esson (special needs dentist), Lesley Salkeld, Anthony Cecire (otolaryngology (ENT) surgeons), Maeve Morrison and Marilyn Heine (speech language therapists), Salim Aftimos (paediatric geneticist), Richard Davis (radiologist), Megan Sanders, Susan Reay, Ruth Berry, and Jane Widdowson (cleft team co-ordinators).

Published NZ research from University of Auckland (2019-2021)

1. Children with orofacial cleft at 5 and 10 years of age. Cleft Palate Craniofacial Jou Morrison M, Mason NT, Forde BL, Stone PR, Fowler PV, Thompson JMD. Speech outcomes of a national cohort of rnal 2021 (in press).
2. Fowler PV, Ayrey SL, Stone PR, Thompson JMD. A nationwide survey of oral health related quality of life of children with orofacial cleft in New Zealand. Cleft Palate Craniofac J. 2020 Dec 16:1055665620980239. doi: 10.1177/1055665620980239.
3. Thompson JMD, Slykerman RF, Ayrey SL, Stone PR, Fowler PV. Behavioural outcomes in children with orofacial cleft in a national study. Cleft Palate Craniofac J. 2020 Nov 25:1055665620972862. doi: 10.1177/1055665620972862.
4. Thompson JMD, Ayrey SL, Slykerman RF, Stone PR, Fowler PV. Quality of Life Using General Population Validated questionnaires in Children With Cleft Lip and/or Palate in New Zealand Cleft Palate Craniofac J. 2021 Jun;58(6):779-786. doi: 10.1177/1055665620962371.Epub 2020 Sep 30.
5. Fowler PV, Corbett A, Lee M, Thompson JMD. A retrospective nationwide study of the dental caries experience of New Zealand children with orofacial cleft. Community Dent Oral Epidemiol. 2020 Feb;48(1):42-48. doi: 10.1111/cdoe.12499.

6. Thompson JMD, Stone PR, Williams K III, Sanders M, Mason N, Pope R, Fowler PV. Nasolabial outcomes in a nationwide study of oro-facial cleft in New Zealand. Orthodontics and Craniofacial Research 2019 Aug;22(3):194-200. doi: 10.1111/ocr.12310.

7. Fowler PV, Al-Ani AH, Thompson JMD. Bone infill following secondary alveolar bone grafting in New Zealand for children with cleft. Orthodontics and Craniofacial Research 2019 (in press, online Feb 25, 2019). doi: 10.1111/ocr.12305.

8. Fowler PV, Keall H, Kennedy D, Healy D, Thompson JMD. Dental arch relationship outcomes for children with complete unilateral and complete bilateral cleft lip and palate in New Zealand. Orthodontics and Craniofacial Research 2019 (in press, online Feb 11, 2019). doi. org/10.1111/ocr.12300.

9. Fowler PV, Wholley C, Perry J, Thompson JMD. Craniofacial morphology and soft tissue profile outcomes for complete unilateral and complete bilateral cleft lip and palate in New Zealand. Orthodontics and Craniofacial Research 2019 online Feb 8 2019). doi.org/10.1111/ocr.12294.

10. Fowler PV, Bellardie H, Shaw B, Eyres P, Semb G, Thompson JMD. Reliability of a categorical scale (GOSLON) and a continuous scale (10-cm visual analogue scale) for assessing dental arch relationships using conventional plaster and 3D digital orthodontic study models of children with complete unilateral cleft lip and palate. Cleft Palate Craniofac J. 2019 Feb;56(1):84-89. doi: 10.1177/1055665618770054.

11. Fowler PV, Azza AH, Thompson JMD. Comparison of reliability of categorical and continuous scales for radiographic assessments of bone infill following secondary alveolar bone grafting. The Cleft Palate-Craniofacial Journal. doi.org/10.1177/1055665617723922

12. Thompson JMD, Stone PR, Sanders M, Van der Zee H, Borman B, Fowler PV. The incidence of Orofacial Cleft in live births in New Zealand. NZMJ 19 August 2016; vol 129, no 1440.

NOTES

NOTES

cleft new zealand

Te Manatōpū Ngutu Riwha o Aotearoa