



Cleft Connection

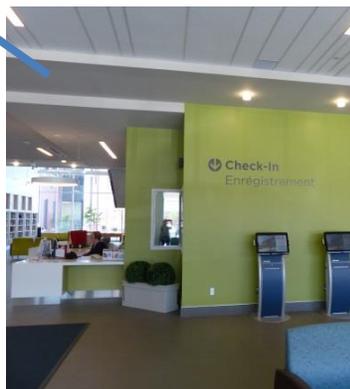
McMaster Children's Hospital Cleft Lip and Palate Team Newsletter

Volume 8 Issue 1

January 2017



RJCHC :)



Have you been to the new **Ron Joyce Children's Health Centre** yet? We have successfully moved our Chedoke services to the new building at 325 Wellington Street North. In fact our first anniversary was in November!

Staff updates

In November 2015, Dr. Robert Tocchio retired after 25 years from his role as the CLP Team orthodontist. He is still active in his orthodontic practice in Brantford and many local families still benefit from his expertise.

Dorothy Ram, Team Secretary retired in December 2014. We benefited from her awesome dedication and efficiency for 8 years.

Dr. Elizabeth Jeney, ENT, attended her last 7 Plus Clinic in December 2016 due to scheduling issues. She will continue to see families in her new office location on Upper James Street in Hamilton. Dr. Jeney has been an enthusiastic and valued member of the team since 1992.

We would like to thank Dr. Tocchio, Dr. Jeney and Dorothy Ram for their many years of dedicated service with the CLP Team.

A Warm Welcome to:

Dr. Allyson Bourke has taken on the orthodontist role on our team. She has an orthodontic practice in Hamilton. We are extremely pleased to be working with her.

Dr. Paul Bhatti has opened an Oral and Maxillofacial Surgery office in Ancaster. He began attending our 7 Plus Clinics in September 2016.

Dr. Bruce Korman and Dr. Jonathan MacLean, ENTs from 3V1 at McMaster will start attending the 7 Plus clinic in January. Many families will already know them from early tube placement at time of palate repair.

Karen Thersidis is our new Business Clerk as of February 2016.

We try to produce the **Cleft Connection** newsletter annually. To submit your story ideas, comments or questions contact: Sue Eastwood at (905) 521-2100 extension 77069, or by email: eastwood@hsc.ca



What is an Alveolar Bone Graft?

The alveolus is the part of the upper jaw where your teeth are. Some people with cleft lip and palate can also have a cleft in this part of the jaw. They may also have a hole called a fistula between their nose and mouth.

An alveolar bone graft is a surgery to fill the cleft or gap in the bone of the upper jaw. To fill this gap, a small amount of bone is often taken from another part of the body, usually the hip bone. After surgery, the new bone in the upper jaw will become hard and strong.

Why is an alveolar bone graft needed?

- The purpose of an alveolar bone graft is to stabilize the bone arch, providing better support for the base of the nose and create new bone for the roots of the developing teeth to grow into.
- Your child may need an alveolar bone graft to allow his or her teeth to develop in the right place.
- Your child may need braces to straighten his or her teeth by moving them into the correct position. However, teeth cannot be moved into a cleft space as they will become loose and can be damaged.
- If your child has a fistula, food and fluid can leak into his or her nose from the mouth. The alveolar bone graft seals the fistula so this cannot happen.

When is the ABG operation done?

The timing of the alveolar bone graft is very important because it must be done as your child begins losing baby teeth, before the permanent teeth come in. The surgery is usually done when the permanent canine or eye teeth are three-quarters formed. This depends on how quickly your child's teeth are developing but normally happens between eight and ten years of age. A series of X-rays are used to work this out so the operation can be best scheduled to allow your child's teeth to develop normally.

Preparing for the alveolar bone graft

Some children need a short period of orthodontic treatment using fixed or removable braces before the operation. This takes six months to a year and aims to improve your child's bite (how the teeth fit together when your child bites on something) and the shape of the cleft.

Other children need some baby teeth removed a few months beforehand so that the gum is fully healed by the time of the operation.

It is very important that you:

1. Arrange a consult with an orthodontist if you aren't already followed by one. Braces may be needed for a short time before the bone graft.
2. Have a consult with an oral surgeon. Your orthodontist can refer you to an oral surgeon.

It is important that your orthodontist and oral surgeon are in communication with one another and have a treatment plan. This needs to be done early.

Understanding the 7 Plus Clinic...

When your child is 7 years old, he or she begins to attend the **7 Plus Clinic**. In the morning you will have pediatric, audiology and speech-language appointments. The Social Worker may also attend. The format is very similar to the 2 to 6 clinic.

In the afternoon, your child will see the:

- Pediatric Dentist
- Orthodontist
- Oral Surgeon
- Prosthodontist
- Plastic Surgeon
- ENT Specialist

A summary report will be written and a copy mailed to you. **It will be important for you to share this report with you local dental specialists.**

Children and young adults return to this clinic as needed. It **may** be needed every 1 to 3 years.

Procedures that may be considered in the 7 to 22 year range:

- **Alveolar bone grafting**
- Orthodontics (braces)
- Pharyngeal flap surgery
- Maxillary advancement
- Prosthetics
- Reconstruction of the nose

Also in the 7 to 22 year range, your child or teen:

- May need hearing assessments
- May need speech therapy. This would be arranged through the school system and provided at the school. The team speech-language pathologist would be available as a resource for the school.
- May attend the VPI Clinic to investigate nasal sounding speech
- May need a review with an ENT specialist in his or her office
- May be referred for a consultation with a geneticist
- May want to go to Camp Trailblazers! →

Expert Consultation

The dental specialists in the 7 Plus Clinic provide expert **consultation only**.

As families come from such a large geographical area, individual care needs to be provided as close to home as possible. This will require visits to your local dentist, orthodontist, oral surgeon and/or prosthodontist for consultation and treatment.

Families local to Hamilton may choose to be followed by our team dental specialists. As in other communities, initial consults and treatment will need to be arranged at their community dental offices.

Numbers/Stats

Diagnosis	2014	2015	2016
CLEFT LIP	9	9	8
CLEFT LIP/PALATE	9	8	10
CLEFT PALATE	8	9	6
PIERRE ROBIN SEQUENCE	7	7	1
HEMIFACIAL MICROSOMIA	2	1	0
SUBMUCOUS CLEFT	0	1	3
Total	35	35	28

This table shows the new referrals to the team in the last three years. Despite fluctuations from year to year, the incidence of cleft lip and palate continues to be stable at about one in every 650 to 700 births. We expect to be busy in 2017.

Camp Trailblazers 2016



“Camp Trailblazers provides a welcome escape for children between the ages of 10 to 18 who are living with a facial difference. It is somewhere they can spend the time together, throwing themselves into a whole range of outdoor activities and challenging their own physical boundaries.”

Here’s what three campers from our team had to say about their camp experience:

Hi, my name is August and I am 13 years old. I have been going to Camp Trailblazers for 4 years now, since I was 10. It is a fun place with lots to do. My favourite activities are swimming, archery, and capture the flag. There are other activities like rock climbing, high ropes, crafts. I have met many new friends. This is a camp where you can just be yourself!!!

by August, Age 13

This summer I went to Camp Trailblazers. At the camp we could swim, fish, rock climb and much more. I met many people but the one that stuck out the most was Leah. She was very kind. Camp Trailblazers was my first time away from home for that many days. I loved being around kids like me. The counsellors were beyond nice and they cared so much for us. The food was yummy too. I can’t wait to go back next year!

by Claire, Age 10



Camp Trailblazers is by far the best place to be because we are all the same so nobody is treated differently. We do all kinds of stuff like swimming, kayaking, fishing, archery, rock climbing, art and we have a camp fire every night. The best part about camp is the food. It’s so good you can taste it before you put it in your mouth. I made lots of friends and can’t wait to go back next year.

by Jonathan, Age 12

Learn more at: <http://www.aboutface.ca/programs/>



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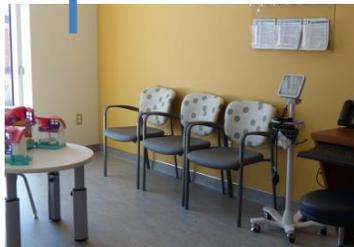
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When you come to the new centre, you'll find the Cleft Lip and Palate Team on the 2nd floor. Our waiting area is just outside the elevators and at the top of the stairs. One stop for audiology, pediatrics, social work, speech-language pathology, and the 7 plus dental clinic.

2 Developmental Pediatrics & Rehabilitation
Audiology
Medical Clinics
Research



Did you know?

We have updated all our education materials. You can access them all at: www.mcmasterchildrenshospital.ca/clp
Just click on Patient Education Material:

- [A Guide for Families of Children with CLP](#)
- An explanation of [Submucous cleft palate](#)
- [Pierre Robin Sequence](#)

Surgical Support

- [Preparing for Your Baby's Lip Surgery](#)
- [Preparing for Your Child's Palate Surgery](#)
- [Preparing for Your Child's Pharyngeal Flap Surgery](#)

The Velopharyngeal Inadequacy Clinic

- [The Velopharyngeal Inadequacy Clinic](#)
- [Pharyngeal Flap Surgery](#)
- [VPI Clinic Physician Referral Form](#)

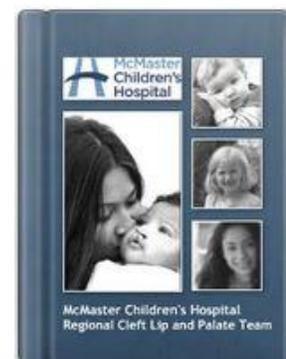
Information about Chromosomes

- [Info for parents about FISH test for 22q11 deletion syndrome](#)
- [Learning About Chromosomes](#)

Specialized Dental Funding

- [Dental funding for Cleft Lip and Palate](#)

We have also upgraded our scrapbook to a photobook. Thank you to all the families who have generously shared their photographs!



Can you find

these items at the **Ron Joyce Children's Health Centre** during your next visit?

