

# AboutFace Magazine

*A community of support for people with facial differences*

Volume 1, Number 1  
Fall 2012



Photo of Samantha Seadon at Camp Trailblazers Manitoba

# AboutFace Magazine

2012- 2013 AboutFace Board of Directors

## Executive Officers

Sharon Fitzpatrick, *Chairperson*

Margaret Waddell, *Secretary*

Scott Galbraith, *Chair, FR and Strategic Partnerships*

Bobbi Jean White, *Treasurer*

Nicholas C. Bader

Robert Pielsticker

## Directors

Dr. John O'Keefe, Dr. Lonny Ross, Bob Pielsticker, Dr. Kathy Russell, Matthew Milne-Smith, Bob Elliott

## Honorary Directors

Donald Triggs, *Founding Director*

Paul Stanley, *Celebrity Spokesperson*

Elisabeth Ross, *Founder*

## Staff

Anna Pileggi, *Executive Director*

Jessica Fitzpatrick, *Manager, Marketing & Outreach*

Emily Tye, *Office Administrator*

Colleen Wheatley, *Manager, Programs & Services*

Vivian Curl, *Manager, Corporate Sponsorships & Partnerships*

Jennifer Labach, *Grants Officer*

## What's in this issue?

Fall 2012 • Vol. 1, No. 1



	Page
Unmasked - A Story by Patrycja Domurad	3-4
What is a Facial Prosthesis and How Does it Work?	5
The Importance of Volunteering	6
Feature Volunteer: Linda Huntley	6
John Balogh – AboutFace Volunteer	7
Camp Trailblazers	8-9
Experiential Programming	10
My Experience at Camp Trailblazers – Two Perspectives	11
Hannah's Story	12
Oral Feeding Babies with a Cleft Lip and/or Cleft Palate	13
Tyler's Story	14
AboutFace Resources	15

## Note from THE EDITOR:



We are delighted to introduce our newest communications tool, *AboutFace Magazine*. We hope you enjoy the fresh look and content. The *AboutFace Magazine* is where we can tell your amazing stories and keep everyone informed of AboutFace's programs and services. We are looking for inspiring stories from people affected by facial differences, so if you think others could benefit from your story, send it along. We also publish a bi-monthly e-newsletter to share upcoming events and stories on a regular basis. To share your

story, or suggest something you think we should feature in the magazine, or ask to receive the e-newsletter, please send an e-mail to [info@aboutface.ca](mailto:info@aboutface.ca).

Happy reading!

Emily Tye, *Managing Editor* 🌟

## Notes from EDWARD STREET

In the bestseller trilogy, *The Hunger Games*; also a blockbuster movie, the 17-year-old heroine—with her resourcefulness, skill, determination, compassion, friendship and love—brings down the “Capitol” in a futuristic world. With her valuable archery skills, she is undefeated with her bow and arrows. When I saw the photo of Samantha (Sam) from our Camp Trailblazers Manitoba program, I was instantly reminded of Katniss, the heroine of *The Hunger Games*.



Our cover photo is a power image. Sam projects confidence, focus, determination and skill. She exemplifies everything we aim to achieve with our AboutFace youth programs. Encouraging and empowering children and adults with a facial difference is the essence of what we expect our programs and services to achieve. Sam embodies all the strength and courage that we work to nurture and promote.

The school years, from kindergarten to high school, can be some of the toughest to endure. Children search to understand who they are; try to discover what they can offer; and long to find a place where they belong. Add to that a visible difference, whatever it might be, and suddenly you stand out too much; you are too different to belong; you are vulnerable and an easy target. Taunting, bullying and isolation are common experiences for children and teens with facial differences. How then can we prepare and effectively equip our youth to go out into the world and not just survive, but thrive?

As parents, educators and healthcare professionals working with this unique group, our responsibility and obligation is to be mindful of the messages we impart to them every day. We can help our children and youth find their inner strength, embrace courage, develop determination, and inspire them to succeed. Every child is able to achieve their full potential with the proper support. How can we accomplish this? Start with helping them to look deeper into themselves. Help them see beyond physical appearances and differences in both themselves and others. In finding ways to tap into their heart, mind and soul to discover their talents, abilities, compassion, imagination, kindness, enthusiasm, sympathy, humour, creativity, passion, friendship and love, we allow them to discover their true selves, and notice the potential good in others.

*I hope you will enjoy this magazine and be inspired by its stories and guidance through the experiences of others.*

Anna Pileggi, *Executive Director* 🌟

## UNMASKED

### - A Story by Patrycja Domurad

My new life began on  
March 10, 2003.

by Patrycja Domurad



Patrycja Domurad and Michael Makarczyk – March 2011

**I WAS 14 AND IN GRADE NINE.** During March Break, my sister, three other friends and I piled into a car with snowboards on our laps and skis laid horizontally inside the car for the ski trip just north of Toronto. After our driver missed a few stop signs, his luck ran out and we got hit by a truck. The skis collided with my face upon impact and I sustained massive trauma to the bones of my face; bones were crushed and my right eye, ejected from its socket at the time of the blow, was severed. Before my second major craniofacial reconstructive surgery, a team of doctors working on piecing together the fragments of my face tried to explain my future to me: heavy scarring, muscle and nerve damage, metal screws and plates in my face, and enucleation—the removal of my right eye.

Life was hard for a long time after my accident. I was in constant pain and nightmares plagued me. Painkillers numbed my world. Sleep seemed to consume me. Doctors, therapists, sympathetic visitors, endless cards, stuffed animals, gift baskets—even from strangers; the love and support was a blessing. When I finally came home from the hospital, I began to realize that my life had changed for good. I went from being an independent teenager, to having to rely on my mother to bathe me. Swollen from my injuries, my face was unrecognizable to most; my good eye swollen shut, I was unable to see the extent of my injuries. I had to rely on my family and friends for care, support, kindness and courage at a time when I was left blind and helpless.

Slowly, it all began to sink in; anger and fear of the permanence of my injuries, frustration at the constant pain or grogginess from pain killers, and the unknown factor of the extent of the damage. My face was still too swollen for me to see in the mirror. I would wake at night in pain, touch my raw scars and try to recognize the feel of my puffed-up face, all with a sense of disconnect. My sister, also injured with two broken ribs and a fractured pelvis, was back to her regular life.

My other friends were back at school and I was still in pain, the future still unknown. One night, when my vision was clearing up from the ointments used on my facial wounds, I sneaked out of bed and made my way to the bathroom. I sat on the toilet, gaining courage; stalled at the sink, making sure not to get my hand bandages wet, and finally looked up at my face for the first time in over two months, and the first time since my accident.

The first thought was—Frankenstein. I stood dumbfounded by my reflection. Gone was the pretty girl, the aspiring young model; gone was the girl who loved to read, and go to school, who had a quirky sense of humour and loved to laugh. Even the unknowing girl who had laughed just that afternoon with visiting friends had faded away. I could not find myself in the mirror's reflection. A stranger looked back at me, moon-faced and pale with matted blonde hair, greasy from the ointment on the scar running ear-to-ear across my scalp. My cheeks so swollen they were level with my nose, small in its blue cast. My eye, barely open, stared out from a thin red opening, sunken into the socket and disfigured from the scar. My eye had changed its shape and size—and this was the “good” eye. A large, angry red scar carved my face cruelly, running beneath my left eye, cutting up the inner corner, across the middle of my eyebrow and then across my right eyelid, from under which a cold blue glass eye stared into nothing. Who was this monster? How was I supposed to live?

The period that followed was a dark time in my life. It hit me harder than the ski that hit my face in that collision. It was unbearably difficult to accept. Soon, sleep was my solace and I began to love the numbness the pain killers gave, and found that two, three, four pills weren't enough. I still saw visitors, but kept my eyes closed, pretending I still couldn't open them. I would never look at anyone in my room and I would pretend they couldn't see me either.

One day my mother dropped a bag onto my bed

---

*“Who was this monster? How was I supposed to live?”*

---



Patrycja before the accident taken in 2001, age 13

---

*“My resilience in life comes not from what I have been through, but from who I have stepped up to become.”*

---



Patrycja about three months after the accident in 2003, age 14

and told me to open it. Inside were a dozen pairs of sunglasses, all different shapes, colours, designers. Her friend who owned an optical store had lent out the best selection for me to try. One pair particularly struck my mom and sister and I glanced in the mirror. It worked—they were large, opaque black and covered every abnormality on my face, save for the slight swelling and scar between my brows. I felt an incredible sense of relief. I think that day saved my life.

I was happy to be alive, of course. I was told of the miracle of my situation—the skis hitting at just the right angle; a few inches lower and decapitation was certain, one inch higher and instant death. The damage to my muscles and bones should have left my face paralyzed and I should have been unable to move my face naturally, but aside from facial numbness, my smile remained. But all that aside, the miracle was accounted to something else: still being completely me even with the force of the blow to my head. The comparison made by my surgeons was of a bulldozer smashing through a brick wall and leaving the dry wall beneath unscathed—the dry wall was my brain. It was virtually impossible for me to not have brain damage. But all of this was of little comfort to a girl whose face was unrecognizably disfigured, even with my quick wit intact.

I began to rely on the sunglasses. I wore them everywhere. I wore them to hide, but no one questioned my motives. They allowed me to blend in, and to accept myself. I returned to school, always in sunglasses. I went on dates, in sunglasses. I saw family, in sunglasses. I suffered from depression and isolation, in sunglasses. While they allowed me to heal in peace, and to deal with what my life had become at my own pace, they eventually held me back. The sunglasses became a mask that I was unwilling to let go of. The sunglasses, supported by everyone in my life with the best of intentions, made me fear who I was beneath them.

I wore them through high school and my first two years at university. I overcame depression in them, learned to deal with who I was in them, and eventually became confident, capable and wise, despite them. I outgrew them long before I would admit to myself that my victim mentality wasn't productive to who I was becoming in my life.

My resilience in life comes not from what I have been through, but from who I have stepped up to become. I see my experiences as an opportunity and I can now recognize that my story isn't one of ruin, but of a gift that created the opportunity to become who I am today. I continue to search for answers in my life and I am fully accountable for who I am.

When you experience discomfort and pain in your life, you are actually moments away from having a breakthrough in realizing how you can shift your perspective on the world around you. There is nothing about a facial difference that demands that I have to be a victim. There is nothing I cannot do. There is no experience I am excluded from in life. There is no amount of happiness, joy, self-acceptance and connection that I limits me. If I am unhappy, you better believe that I will find a way to look at life differently and count my blessings, because my facial difference does not dictate my mood—I do. This is one lesson I can pass on to others.

Everyone has scars. Mine just happen to be on the outside. People with facial differences have our vulnerabilities on display; that doesn't make us vulnerable, it makes us powerful. There is grace in being comfortable in your own skin that is universally recognizable and can inspire others. I was terrified of facing others, of getting rid of my mask of sunglasses and what it would mean. It was a horrible, frightening time right before I made a leap of faith and did it. It was incredible and all of the positive experiences and blessings in my life today come from the courage to be who I am, scars and all.

Be who you are. Love who you are. You may just realize that all your problems, all your isolation and disconnect will disappear when you first accept yourself and connect to your heart, and open yourself to the world. Lead a life that inspires you.

Follow Patrycja at her blog [inspiredgreatness.tumblr.com](http://inspiredgreatness.tumblr.com) or connect to her via email. [patrycja.domurad@gmail.com](mailto:patrycja.domurad@gmail.com)

## What is a facial prosthesis AND HOW DOES IT WORK?

by Todd M. Kubon B.A., M.A.M.S.

A **FACIAL PROSTHESIS** is an artificial device used to replace a missing or malformed facial feature. A facial prosthesis can be made to replace an absent ear, nose, or eye with lids. A person in need of a prosthesis may have lost a part of their face due to cancer, trauma, or as a result of a congenital birth anomaly. Facial prosthetics offers an alternative to rehabilitation when surgical reconstruction cannot be achieved, or is preferred by the patient. The prostheses are created by an Anaplastologist who is part of a craniofacial rehabilitation team. The Anaplastologist has special training in art, anatomy and dental technology. Facial prostheses offer various advantages and disadvantages compared to surgical rehabilitation that should be discussed with the craniofacial team.

A facial prosthesis can be easily thought of in the same way as movie make-up that is used to enhance or change the appearance of a movie star. A facial prosthesis is first sculpted and then molded to custom fit the individual's tissue site. Anatomical landmarks, facial proportion, and symmetry are all taken into account to create a convincing, life-like facial feature. Facial prostheses are most commonly cast out of a silicone rubber that can be tinted to match the pigmentation of the individual.

Although a facial prosthesis can often achieve a very realistic look, there are limitations to its use. Facial prostheses are made to fool the casual observer in everyday social encounters such as walking down the street, riding the bus, or shopping at the grocery market. A facial prosthesis can often help to ease the anxiety associated with a casual social encounter, but may be detectable under close observation. The practice of making facial prosthetics incorporates as much art as science. Therefore the esthetic results are dependent on the skills of the Anaplastologist. A facial prosthesis degrades over time and loses some of its esthetic value. This is caused by several factors, such as pollution and ultraviolet lights, which slowly makes it more yellow in colour. Typically, a facial prosthesis needs to be remade every two years.

A facial prosthesis is most commonly secured in place by one of two methods. The first method requires the individual to apply a medical grade adhesive to the back of the prosthesis to hold it in place. This is the same method used to secure masks and camouflage make-up in the movies. The prosthesis has to be removed at night and cleaned, along with the underlying skin on a daily basis. Certain situations, such as high humidity, oily skin or profuse sweating can cause



*A facial prosthesis*

the prosthesis to come off at an inopportune moment. The possibility that this might happen can undermine the individual's confidence in the prosthesis. A more secure method for retaining a facial prosthesis is through the use of bone integrated implants. This process, known as osseointegration, usually requires two minor surgeries. The first surgery consists of implanting little titanium fixtures into the bone. The implants are left alone for a period of at least three months while the bone grows around them to hold them in place. The second surgery is utilized to extend the implants above the skin surface by using an intermediate titanium extension called an abutment. The abutments can then be used to hold a gold bar so that the prosthesis can be clipped into place. Magnets can also be used. Osseointegration greatly enhances the retention of a prosthesis and enables the Anaplastologist to achieve better esthetic results. The prosthesis still needs to be removed overnight and cleaned along with the skin on a daily basis. Unfortunately, not every individual in need of a facial prosthesis is a candidate for osseointegration. The treatment options should be discussed with an experienced craniofacial rehabilitation team. 📍

---

*A facial prosthesis can be easily thought of in the same way as movie make-up*

---



*Becky Thomson wearing her prosthetic nose*

## The Importance of VOLUNTEERING

VOLUNTEERS are one of the most important assets a not-for-profit organization has. They generously dedicate their spare time to a cause they are passionate about, and in turn give back to their community to enrich the lives of others. Being a volunteer does not only affect the lives of the people you help; it also enriches your own life, through developing lifelong friendships, learning new skills, gaining valuable experience for the future, as well as giving you the rewarding feeling that you are making a difference in the world.

Volunteering with AboutFace is a great way to give back to your community. Any little thing you do to help can have an impact, whether it is for a few hours a week, a month or even a year. At AboutFace, there are various ways to volunteer which may include:

- Being a Camp Trailblazers counselor
- Hosting our parent, adult, or acquired facial difference group support calls
- Volunteering at one of our events
- Hosting your own fundraising event for AboutFace
- Bringing awareness and resources to schools in your area
- Helping out in the office

AboutFace has launched its online volunteer training program thanks to the financial support of the Ontario Trillium Foundation (OTF)—an agency of the Government of Ontario. OTF is one of the largest grant-makers in Canada, awarding approximately 1,500 grants each year to community-based not-for-profits and charitable organizations in the arts, recreation, environment and human and social services sectors. Thanks to OTF, AboutFace has been able to create an online standardized training program, which gives the volunteer a better knowledge of AboutFace as an organization as well as educating them on things related to facial differences.

Is AboutFace an organization you would love help? Go to the Get Involved section of our website to see how you can become a volunteer. 🌟



## Feature Volunteer: LINDA HUNTLEY

### When volunteering becomes a passion

by Linda Huntley



**I FIRST HEARD OF** AboutFace six years ago from a parent in my clinic whose son was born with a cleft lip. I learned more about the organization on their website and ordered whatever books, pamphlets and educational information that I thought would be beneficial to families at the Izaak Walton Killam Health Centre (IWK) in Halifax, Nova Scotia.

I began volunteering with AboutFace because I knew we could provide families with additional support by linking them with the organization. It has opened doors for families of IWK by connecting them with one another. AboutFace has also provided our clinic with additional teaching tools to help families. I hope to make a difference for the families we serve at the IWK Health Centre. Getting the word out about AboutFace to patients and their families as well as other healthcare professionals and communities have had a powerful effect on me. I have worked in the Cleft Lip and Palate Clinic for over 16 years, but I really feel that the past few years have been the most rewarding for me because of my involvement with AboutFace.

Volunteering for AboutFace has been a new experience for me and it feels great. My family and friends have been very supportive and have helped me put together baseball tournaments, BBQs and 50/50 tickets. To date we have raised over \$4,000 for AboutFace. I got the idea that I could raise funds by doing small events after having lunch in Halifax with Jessica Fitzpatrick, AboutFace's Manager of Marketing and Outreach. She said that even small fundraisers can have great impact. Randy Pielsticker, AboutFace's Camp Director has met with families in my clinic to discuss AboutFace programs for children of all ages. My current goal is to get a corporate sponsor in Nova Scotia in support of Camp Trailblazers. I really believe fundraising promotes awareness.

I really want all children born with facial differences to have every opportunity to achieve happiness, success and make friendships for life. When a new family arrives in our clinic they are provided with information on the programs and services AboutFace has to offer. Being involved with AboutFace has made me feel that I have made a big difference in the world. I love volunteering at Camp Trailblazers and watching the children building confidence and lifelong friendships. For example, we had a child at the IWK Health Centre who never spoke a word or never made eye contact with anyone. He visited again in January 2012 after going to Camp Trailblazers the previous fall and when he walked in he made eye contact with everyone he spoke to and had a great conversation with me about his time at camp. I was so moved by his newly-developed confidence. This year is our fifth for Camp Trailblazers in Nova Scotia and the number of campers grows every year. Thank you, AboutFace for all you do for the families in Nova Scotia. I am proud to be part of this fantastic team.

I am so passionate about my work at the IWK Health Centre. Volunteering for AboutFace has been rewarding and awesome for me. I have learned that you do not need to focus on big fundraisers to make a difference—even the small ones are important, because every dollar raised makes a difference in someone's life. 🌟

## JOHN BALOGH – AboutFace Volunteer

Finding personal benefits  
through helping others

by John Balogh

**IT WAS AN 11-YEAR-OLD** boy from Vietnam who helped me to discover AboutFace. I was watching the CBC news when I saw Son Phenh, and his sponsors struggling to get him treatment for a significant vascular deformity. I got involved in Son's hunt for treatment, but more importantly for me, it was really the first time in my life that I had any direct relationship with another person with a facial difference.

I'm almost 50. I've lived a good life with a great wife and two crazy, wonderful kids and a successful career. That said, it wasn't until I met Son and found myself being interviewed on national TV about what it is like to live with a facial difference, that I really felt a connection to my community—the community of us folks who live the challenging and rewarding reality of having a facial difference. From Son, I got involved in AboutFace's Camp Trailblazers in BC and have had the honour of facilitating calls with other adults with facial differences.

I have loved finding our community. For years I was almost afraid of finding other folks who look like me, worrying that the toolbox I'd built to make my way in the world would unravel if I was face to face with myself. To my wonderful surprise, I have discovered a world of people whom I can talk to, laugh with, struggle with, and trade ideas with and who, for the first time in my life, share something fundamental with me—looking different.

Like so many of us, I have had my struggles with looking different and have even found myself battling depression at times. I have also discovered the joys and advantages of facing these challenges and making it one of the central parts of myself that brings me strength. For me, that has meant putting simple things into practice, like holding my head up and looking people in the eye, knowing that there is strength and confidence that comes from the ability



John Balogh (centre) with Randy Pielsticker and a child at Camp Trailblazers



John Balogh

to reach out to others to put them at ease and create a quick entry into a deeper conversation. It has also meant taking on the bigger challenge of learning to esteem and accept myself, even when I don't feel so good about going out into the world.

I wouldn't change the way I look (well, maybe I'd take being 10 years younger). I'm reminded of that every time I play with my crazy daughters. I also know that my life has become fuller since I've met so many new friends through AboutFace.

I hope you'll join me sometime on one of our AboutFace calls, to share a little about our lives, share ideas about what is in our toolboxes to navigate through the world and make some new friends.

*John is one of our hosts of the Adult Workshop Conference Call which takes place once a month. We also hold an Acquired Facial Difference Call and Parent Call. For more information on all of the Workshop Calls, please check our website under the events section. [www.aboutface.ca](http://www.aboutface.ca)*

---

*“For years I was almost afraid of finding other folks who look like me . . . ”*

---



# A Camp For Kids With

*"I cannot wait until next year!"*



*"At camp, I was never afraid to share my experiences or stories, and I always loved hearing other peoples' experiences and getting advice on how to handle what I'm going through."*



**CAMP**  
**TRAILBLAZERS**  
AN EXPERIENCE







# h Facial Differences

*"I had more fun in three days, than I do in a year."*

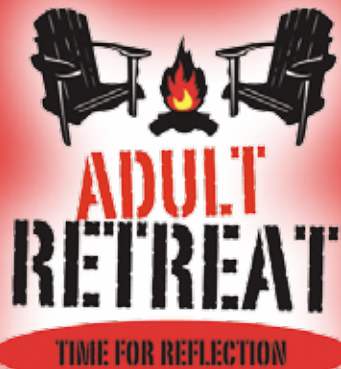


*"Nobody at camp is judgmental and everybody was a good listener and supporter."*





Camp Trailblazers is a camping retreat for AboutFace youth ages 10 to 18 who have a facial difference. Together we spend a weekend participating in outdoor activities, challenging our own physical boundaries and sharing thoughts, feelings and ideas. Every year, we welcome new campers and look forward to our reunion with returning participants. Our goal is to create a network of friends who stay connected and learn from each other as an ongoing community of support. Join us for the experience of a lifetime! 📍



The Adult Retreat is for adults 25+ who have a facial difference. It is a weekend getaway in which participants will have the opportunity to interact and socialize with other adults who also have facial differences, to share ideas, thoughts and stories, and to enjoy the natural wonders of Muskoka. During the weekend there is the opportunity to participate in workshops as well as just enjoy each other's company and relax! 📍



The Leadership Expedition is a week long wilderness experience where youth 19-24 will learn practical canoeing and camping skills for the first two days and then use their new skills as they head into the heart of Algonquin Park for a backcountry paddling and portaging trip. It is an opportunity to interact and socialize with other young adults who also have facial differences, to share ideas, thoughts and stories with like-minded individuals, to make some new friends, reunite with old friends, to have some fun, and to enjoy some of the world's most pristine lakes and rivers. This excursion is also the first step in becoming a volunteer counselor for Camp Trailblazers. 📍



Family Camp is a new concept that AboutFace is trying to implement. It will consist of getting families who have a child with a facial difference together to be able to connect with each other as well as participate in workshops geared towards the whole family. There will be some for parents, children with the facial difference, as well as for their siblings and everyone together. Details around Family Camp are still not finalized so stay tuned and keep checking our website for updates! 📍

## My Experience at CAMP TRAILBLAZERS – Two Perspectives

by Nick Barnes and Kathy Barnes

### Nick, age 12

**WHEN I FIRST ARRIVED** at the mall in Toronto, I was nervous and a bit scared. I knew no one. Randy came over first and told me who he was and then I was happy I was there. After that Amanda came and talked to me, and off we went on the bus. On the way to Camp Trailblazers on the bus everybody was so nice, so cheery, and so happy and made me feel welcome. We sang and got to know each other. We thought we had arrived at the camp, but discovered we had missed a turn, so we turned around and zoomed back to the camp. That was so funny! When we finally arrived there the first thing I thought was that this camp is going to be amazing. I made some friends and started to explore all the things that we were able to do. I remember the first thing we did was find our cabins. I was with Randy, Andrew, Gage, Kirk and two other people but I don't recall their names. By then I knew it was going to be fun.

The first day was amazing; bacon and eggs for breakfast then our group went on the rock wall. It was scary at first but then I zoomed to the top. After, we did some group games really made us think and took us a while but we finally did it. This is where I realized that my new friends go through some of the same surgeries I have and they have the same doctors as me. I thought that was cool. When the sun went down the whole camp gathered around the campfire. We started to sing songs and do skits and some of the girls volunteered to come up on stage and sing. The next and final day was the absolute best; we went canoeing—a thing I have always wanted to do. I got soaked but it was awesome. Then Kirk and I went back to play on the trampoline; they were really bouncy trampolines. After that dinner was served, it was so good and yummy. Then we had the final campfire which was the best. It was so fun, we all did songs, skits and I remember one person doing the worm—it was cool.

On the way home I got some friends' numbers to stay in touch and when I got off the bus I was a little sad to see my friends leave but I knew I would see them next year for another amazing time. Camp Trailblazers was my first camp experience and was the best camp I ever had in my entire life!

### Kathy

**FROM A MOM'S** perspective, I am glad that we have AboutFace as part of our lives. The camp experience Nick had with AboutFace was an amazing experience for him to have. It proved that he can be with other kids and have fun and not worry about what he looks like or if they couldn't understand him because of his speech problem. He gained some self confidence and was able to come out of his shell a bit. For the first time in his life, Nick felt like he belonged, not like an outsider.

As he is getting older, I see some of the challenges that he has endured like other kids judging him, and I know when he came home from camp he started to show self confidence and talk more about his cleft lip and palate. All along he thought he was alone, but after camp he was thrilled to have shared the same experiences with the other kids. He felt like a part of a special group for the first time in his life.

When he went to Disney (with the Dreams Take Flight program) with his friend Gage from Camp Trailblazers, he was so excited. The two of them never left each other's side. The friendship that they have is incredible and if it wasn't for Camp Trailblazers, they would never have met.

AboutFace and all of the staff have made a positive impact on my son's life and we are very grateful that the hospital gave us your brochure. With all of you beside him, and giving him experiences and challenges to overcome, Nick can now look in the mirror at himself and... SMILE! 🌟



Nick and his friend Gage with Dreams Take Flight at Disney World



Nick at Camp Trailblazers Ontario



Nick Being silly



Nick at Camp Trailblazers Ontario

## HANNAH'S Story

What an emotional time for our whole family!

by Nancy Brown

**MY HUSBAND ROB AND I** live in Gander, NL, with our 2½-year-old daughter, Hannah. Both Rob and Hannah were born with bilateral cleft lips and cleft palates. My husband had numerous surgeries as a small child to repair his and remembers bits and pieces of some of the treatments received as an older child.

Before attempting to conceive a child together, we asked our physician about the chances of our child having a cleft lip/palate. We were told that it was not genetic and we had nothing to worry about. During my sixth month of pregnancy, we were referred for a detailed ultrasound to find out if our baby had a cleft lip (a cleft palate would not be detectable on an ultrasound). Due to the positioning of the baby, they were unable to get a 3D view of baby's face. However, we were reassured that the baby did not have a cleft lip based on the views that they were successful in getting.

Hannah was born at 41 weeks gestation weighing 8 lb 3½ oz. She was perfectly healthy and had a bilateral cleft lip and cleft palate just like her daddy. We were surprised to say the least but it was not something foreign to us. We both coped quite well with the surprise. Hannah had to travel on a plane at five days old to visit the provincial children's hospital for an assessment. While there, she was fitted with a palatal obturator which she wore from the age of one week until her palate repair surgery at 15 months of age. The obturator had to be removed once daily for cleaning and was secured in her mouth with PolyGrip, a denture adhesive. Hannah was fed with a special cleft/lip palate squeeze bottle. It was a little different to use from a regular baby bottle but we quickly adapted to it. However, it was always a challenge when leaving her with anyone because they were not familiar with feeding her.

Hannah had her bilateral lip repair at five months old. What an emotional time for our whole family! There were many tears shed when she returned from the OR—all tears of joy of course. Her surgeon did an amazing job and we were beyond pleased. She remained in the hospital for four days and came home with arm restraints for four weeks. That was quite a challenge. Hannah adapted quite well to eating solid foods but had some minor troubles with textures. It was a challenge for quite some time.

At 11 months, Hannah had another trip to the OR to have t-tubes inserted in her ears due to recurrent ear infections. This is common in cleft palate children due to the anatomy of the ear and the inability of fluid to properly drain from her ears. Hannah had to be weaned from her bottle before her palate surgery at 15 months. She did very well transitioning to a sippy cup and was actually drinking all of her milk/formula from her cup by 12 months.

Her palate repair surgery happened at 15 months. This surgery was more extensive than her lip repair and she was in the hospital for six days. She developed some post-operative complications unrelated to her palate. Again, she came home with arm restraints in place for four weeks. This was to prevent her from putting things in her mouth that could pose damage to her newly repaired palate. Since her last surgery, Hannah has done great. Her speech was slow to develop at first, but she has improved 150 percent in the last few months. Her speech therapists are so pleased with her progress. Hannah is like any other 2½-year-old. She is very sociable, curious, and sometimes a handful. We are very pleased with her progress

in all areas and are so thankful for her wonderful physicians/nurses for their phenomenal care. We only hope she continues to thrive and that she will be proud to share her experiences with others when she gets older. 🌟



*Hannah before her cleft lip repair*



*Hannah, age 2*

## ORAL FEEDING BABIES with a Cleft Lip and/or Cleft Palate

by Sharon Samaan, MSc(OT), OT Reg. (Ont.) Occupational Therapist, Cleft Lip and Palate Program, The Hospital for Sick Children, Toronto



Mead Johnson Cleft Lip/Palate Nurser®

**PARENTS OF AN INFANT** with a cleft lip and/or palate may be concerned about whether their baby will have problems with feeding. Overall, babies who are born with a cleft lip and/or cleft palate in isolation will be able to orally feed with the appropriate feeding support. The type of feeding (breastfeeding versus bottle feeding) that will be possible is dependent on the type of cleft a baby is born with.

### What if my baby has a cleft lip?

Babies with a cleft lip can generally breastfeed or bottle feed similar to children without a cleft lip. The cleft lip generally does not impact an infant's ability to orally feed.

### What if my baby has a cleft lip *and* a cleft of the alveolus (gum line)?

Both breastfeeding and bottle feeding are often possible when a baby presents with this type of cleft. The one exception may be if your baby presents with a cleft that is very wide, as there may be difficulty with their latch. Therefore, if oral feeding difficulties are noted, a referral to both the feeding expert on your Cleft Lip and Palate Program and a Lactation Consultant is strongly recommended.

### What if my baby has a cleft palate (which may or may not include a cleft lip)?

When a baby breastfeeds or bottle feeds, adequate suction must be created to efficiently transfer milk. To create suction, a baby must be able to completely seal their oral cavity. A baby who is born with a cleft palate is unable to completely seal their oral cavity as the cleft palate produces an air leak that impairs the creation of suction. Therefore, babies with a cleft palate will require a specially designed bottle. Two recommended bottles are the Medela Special Needs ®Feeder (also referred to as the Haberman feeder) or the Mead Johnson Cleft Lip/Palate Nurser® (see below for descriptions). Both the Special Needs Feeder and the Mead Johnson Cleft Lip/Palate Nurser eliminate a baby's need to create suction, and allow babies to successfully bottle feed. When a baby has a cleft palate, a referral to the feeding expert on your Cleft Lip and Palate Program is required to

ensure you have the appropriate education and support with oral feeding.

Many parents ask about breastfeeding their baby with a cleft palate. Although exclusive breast feeding is not possible when a baby has a cleft palate due to the baby's inability to create adequate suction and obtain enough volumes to grow, if a mother wishes to incorporate breastfeeding, there are ways to do so. For mothers who wish to give their babies breast milk, expressing breast milk is encouraged. In addition, mothers can also offer breastfeeding after a bottle feed which can enhance attachment between mother and baby and provide direct skin-to-skin contact. A referral to a Lactation Consultant is highly recommended to further provide this support to mothers.

### Medela Special Needs ®Feeder

The Medela Special Needs Feeder offers a variable flow rate controlled by the feeder and the baby; you and baby are in control of the flow of milk, leading to a more natural feeding experience. It has a one-way valve and comes with a Mini-SpecialNeeds teat. This innovative design rewards the weakest suck, and it also prevents flooding so baby is never overwhelmed with too much milk. It is BPA/DEHP free and is in sterile packaging.

### Mead Johnson Cleft Lip/Palate Nurser®

Mead Johnson Bottle is a soft squeeze bottle with long cross-cut nipple. Mead Johnson Bottle is designed to be "pulse" squeezed with baby's suck and swallowing. Longer nipple allows milk to be directed past the cleft and cross-cut allows increase flow with squeezing. NUK and premie nipples also work well on this bottle. The holes on the nipples of the Mead Johnson Bottle may need to be made larger to allow milk to flow faster.

### In Conclusion

Overall, no two babies are alike and babies can have differences in how they feed, even if they have the same type of cleft. At any point in time, if you have concerns that your baby is not feeding well, regardless of the type of cleft that your baby has, you should contact the feeding expert on your Cleft Lip and Palate Program for further assessment and support. 🍌



Medela Special Needs ®Feeder

## TYLER'S Story

Not knowing what is wrong with your baby is the scariest place to be.

by Jannick Theriault

**TYLER WAS BORN EARLY**, at 35 weeks, in October 2010. My water broke spontaneously in the middle of the night. We weren't expecting the arrival of our first baby so soon and were definitely not ready for his condition when he was born. When I delivered Tyler, the doctors noticed he was swollen on one side of his face and had some excess skin under his chin. He was placed in a nursery incubator because he was having difficulty breathing. The doctors didn't know what was wrong with Tyler and decided to wait a day to see if the swelling was due to the delivery. I remember not wanting to see Tyler because I was so afraid to get attached to him in case he wasn't going to pull through. I was also scared of what he would look like since I had only been able to catch a glimpse of him after his birth.

After a few days and still no progress with the swelling they then realized that we were dealing with a more permanent condition. To further diagnose his problem, Tyler was in need of an ultrasound/MRI. The doctors had a pretty good idea of what his diagnosis could be but the ultrasound technicians did not feel confident enough to make a proper diagnosis following the results. Tyler was then flown to the Izaak Walton Killam Health Centre (IWK) in Halifax where they had specialists able to diagnose the problem.

As the days passed, it was hard. We were dealing with the early arrival of our baby boy plus the surprise of a health condition. It was an emotional roller coaster. As a new mother, I had feelings that I didn't know I could have. They ranged from anger to fear, sadness to spite, happiness to guilt and everything in between.

Once we got the diagnosis, things started to calm down and it's like we began to breathe. Tyler was diagnosed with Cervical Lymphangioma, a rare congenital veno-lymphatic malformation that causes benign cyst-like formations. Tyler's condition affects the right side of his face, more so in the neck and cheek area. Tyler has both microcystic and macrocystic cysts, an even rarer type of lymphangioma. This type is harder to treat due to the fact that the microscopic cysts are harder to drain. Tyler was also born with a separate condition that caused breathing and eating issues. The team of doctors at the IWK were spectacular and they made sure we understood the conditions and everything that came with it.

After three weeks in various hospitals, we were able to bring Tyler home. That's when reality set in, you begin to ask yourself questions of how will you react when people look at him and notice he is different. How will you answer? Will you be able to accept that he is different? Will he be teased at school? Will you be able to protect him? The uncertainties and questioning went on and on. We decided we were going to be honest about his diagnosis and explain that he may look different but it's not a life threatening condition. Tyler has such a great personality that now people hardly notice his facial difference.

I am glad I was made aware of AboutFace from a social worker at a hospital, and happy to have found such a great organization. The information provided was helpful and made us feel less alone in the journey we were travelling.

At three months old, Tyler had an operation (sclerotherapy) to drain some of the cysts. The procedure was a success and shrunk most of the cysts located under his chin. Now, 16 months, Tyler is thriving everyday. We cannot wait for what is to come and fully love and accept Tyler as he is. We are ready to conquer anything and know Tyler can as well. 🍌



Tyler at 15 months



Tyler at 5 months

## AboutFace RESOURCES



*Facing it Together* is a workbook and DVD to provide support, insight and effective strategies to deal with some of the major issues that parents face during the first few years of your child's life. *Facing it Together* is free for parents of children under the age of five with a facial difference. It is available in English and Spanish.



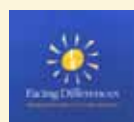
*Making Faces: Logan's Cleft Lip and Palate Story* is a picture story book that documents the cleft treatment process from birth to young adulthood through the personal journey of Logan Bristow. The story touches on many of the issues families face when their child is born with a cleft.



*Jessie's Blessing* is a picture storybook and interactive CD for kids ages 3-7 and teaches about differences and acceptance. The book is available in English and French; the CD is available in English only.



*Building Bridges Across Difference and Disability: A Resource Guide For Health Care Providers* is for professionals who have direct contact with people living with facial differences and disabilities.



*Facing Differences* is an interactive educational resource (in-class video and program guide) for children ages 8-12. The independent format provides teachers the accessibility and flexibility to direct learning on diversity issues within their classroom.



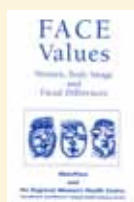
*Talking About Body Image, Identity, Disability and Difference: A Facilitators Manual* is designed for professionals who want to implement workshops to help explore, develop and strengthen the social skills of individuals with facial differences and disabilities.



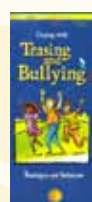
*You, Your Child and the Craniofacial Team* is a guide for parents to help understand and become effective participants in the "team approach" to medical treatment of craniofacial conditions. It is available in English and French.



*My Baby Has A Facial Difference* is a guide addressing common medical, social and emotional issues for new parents as they begin the journey of raising a child born with a facial difference. It is available in English and French.



*Face Values* is a collection of personal stories providing insight into the feelings, attitudes and self image of women living with facial differences.



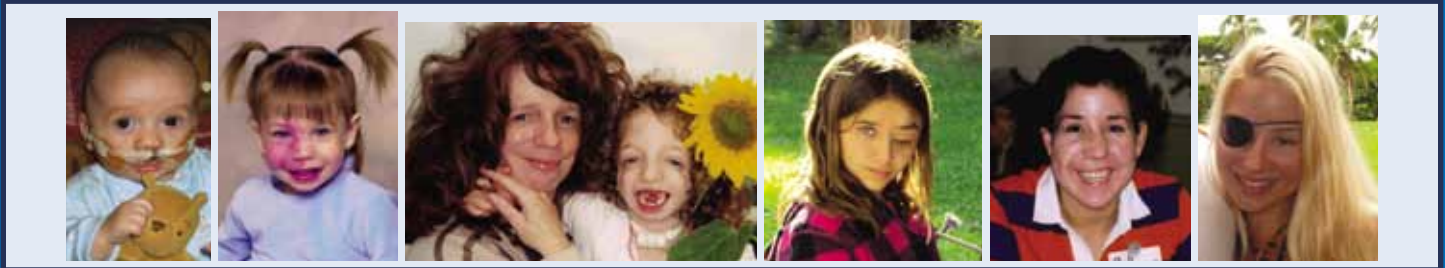
*Coping With Teasing and Bullying* provides strategies and practical solutions to help kids deal and respond to these situations.

SEPTEMBER  
IS



## AboutFace National Facial Differences Awareness Month

*"A facial difference is what I have; it's not who I am." – Client*



September was AboutFace National Facial Differences Awareness Month—a first for our charity.

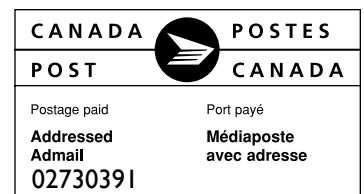
Across Canada, AboutFace families, friends, volunteers and healthcare clinics will be asked to do what they can to raise awareness about individuals with Facial Differences. As one client states, "A facial difference is what I have, it's not who I am." This year the focus of is on cleft lip and palate—just one of many issues that results in a facial difference.

In September we opened a section on our website focusing on ways to raise awareness and funds for AboutFace. Check it out for ways that you can participate.



AboutFace

123 Edward St.  
Suite 1003  
Toronto, ON M5G 1E2



Would you like to receive our bi-monthly e-newsletter to keep up with what we are up to? Sign up on our website [www.aboutface.ca](http://www.aboutface.ca). Moving? Please let us know. Send your new address to AboutFace by mail or to [info@aboutface.ca](mailto:info@aboutface.ca).