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## Charlene's Journey

*AboutFace recently interviewed Charlene Guenette. She shares her experiences of living with Treacher Collins Syndrome and 10 years of experimentation with Bone Anchored Hearing Aids and ear reconstruction. Charlene is an active member of AboutFace and parent to a 12 year-old daughter, Elodie.*

### Can you tell us about the circumstances surrounding your birth?

I was born 38 years ago in Sudbury, Ontario. My mother took thalidomide during her pregnancy. This drug has been directly related to me being born with a facial difference. They kept me from my mother for three days to protect her from the reality that I had Treacher Collins Syndrome and looked different. When she finally saw me, her attitude was that she got exactly what she wanted, a little girl with lots of dark hair and dark eyes.

### How did the medical community treat you during your early years?

My parents were told that the medical community in Sudbury could not provide the specialized care I required. So, when I was about three years old we moved to Toronto to investigate treatment. Dr. Ian Munroe was my first specialist and started my surgical plan at age 11. This plan has worked-out to include 41 surgeries to date. I was Dr. Munroe's first Treacher Collins patient and we are still in touch today.

### How did growing up with Treacher Collins Syndrome affect your self-image as a child?

From the time I was born, my parents treated me just like my siblings. In fact, it wasn't until age eight that I faced the reality of my facial dif-



*Charlene & daughter Elodie*

ference. I remember standing with my sister in front of a mirror comparing our faces. We were the same, each with two arms, legs and eyes and then I touched the hard bones in her face and realized the difference. I knew I only had one ear, but because I had so much thick black hair I thought no one would notice. But they did and I was often called names and teased at school.

### Were your school years difficult?

My school years were lonely. My sister and brothers were very protective and often stepped in to end the taunts and teasing. But they couldn't stop my isolation. I was absent a lot because of my ongoing surgeries and I missed most of the teenage social interactions. I had to constantly rebuild friendships after being away and during high school I never had a date. No one ever invited me to school dances.

# News from Edward Street

by Anna Pileggi, Executive Director

## NEWSLETTER

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Rickie Anderson

**H**appy New Year! I trust that the official start to the new Millennium began without a hitch! This issue of the newsletter you will notice a few changes and some new columns. These decisions have been made as a result of the Readership Survey held in the Fall. It was wonderful to receive such an overwhelming response to the survey from our readers. We thank you for your time and cooperation in helping us to continue to serve you better.

I want to thank the members of the Publications Committee who volunteer their time and expertise to help AboutFace serve its mandate. Without their dedication, the stories and resources you read about would not happen.

Also, I want to thank all the members of AboutFace who share their stories and ideas with us. By sharing your journey, you help others overcome challenges and discover opportunities. Thank You. Please note that the percentages may not always add up to 100% due to non responses to the question.

Demographics we discovered include:

- 81% Women compared to 15% Male

In terms of age groups, we discovered that:

- 37% of readers are within 20–39
- 33% of readers are within 40–49
- 24% of readers of over 50 years

One age bracket with a noticeable void was the teen group. However, in the comments section, there was an overwhelming response to teen issues in learning to live with a facial difference.

- Geographically, 56% of the readers live in the United States, and 44% in Canada.
- Most readers are based in Urban communities: 42% US compared to 53% Canada. In Rural communities the split is Canada and 31% US

Reasons for their affiliation:

- 45% are members of AboutFace because they are parents of an affected child
- 21% are member because they themselves have a facial difference
- 21% are members because of the profession including medical, dental, psychology, social work, speech language, team member, teacher
- 12% are affiliated because of a friend or family member

Most of our readers are employed:

- 32% are professionals
- 27% are full time and/or run their own business
- 19% work part time

- 14% are stay at home parent
- 9% are unemployed

Although 88% of the readers have access to computers at home or at work, and 85% have Internet access, only 27% would like the choice of receiving the newsletter electronically. An strong 73% want to continue receiving the newsletter via mail.

Who Reads the newsletter in your household?

- 43% Parents of affected children only
- 19% Affected Adults
- 13% Health care Providers
- 16% Lobby, Resource Library or collection
- 8% Parents with their children

In terms of content, it was interesting to see that a majority of our readers enjoy (92%) and want us to increase (83%) the personal stories section. There is a strong support for professional information (84%) and the need for us to increase our coverage of tips for parents and adults in regards to new treatment information, options, and alternatives.

In the survey, we asked readers to prioritize the top 5 areas of interest. These topics were provided to us in no strong showing, but were consistent requests:

- teen issues—coping strategies, group for teens, inspirational stories
- school issues—bullying, teasing, talking to teachers, self esteem for kids
- treatment issues and options for specific syndromes—the teams, new research, prosthesis,
- more inspirational stories
- adult resources—surgery, dealing with doctors, dating
- family dynamics—sibling issues, nutrition and health related to facial differences, cultural differences

Some of the changes you will see now. We will be providing a Canada/USA sections within the newsletter so that we can each talk about what is happening within our respective countries. We have started a Teen Column, which will deal with teen issues and is answered by a group of AboutFace teens from all across North America. Finally, we have used the new topic areas as guides for planning the next four issues of our newsletter. This issue we are addressing some treatment options and prosthesis issues.

As always, we welcome your feedback at anytime and more importantly we would love to receive your story. You can send your story—inspirational, treatment, insurance, book reviews, etc. to your national office. We hope you enjoy the newsletter.

# What is a facial prosthesis and how does it work?

by Todd M. Kubon, BA, MAMS

*Dr. Kubon is an Anaplastologist in the Craniofacial Prosthetics Unit at the Toronto-Sunnybrook Regional Cancer Centre, Toronto. He can be reached at: 416-480-4254*

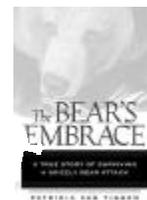
A facial prosthesis is an artificial device used to replace a missing or malformed facial feature. A facial prosthesis can be made to replace an absent ear, nose, or eye with lids. A person in need of a prosthesis may have lost a part of their face due to cancer, trauma, or as a result of a congenital birth anomaly. Facial prosthetics offers an alternative to rehabilitation when surgical reconstruction can not 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 light, which slowly makes it more yellow in color. 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 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 Special Evening with Patricia Van Tighem

Author of *The Bear's Embrace*

When Patricia Van Tighem wrote the *Bear's Embrace*, her story of surviving an attack by a grizzly bear, it was in part an attempt to finally come to terms with her life that had been changed forever.

And, *The Bear's Embrace* has become a national bestseller. Readers have discovered the book and found their own hope in her gripping story of survival and recovery.

On Thursday April 5, 2001 at 7:30 p.m., Patricia, a long-time member of AboutFace, will be speaking in Toronto at the Metro Central YMCA, 20 Grosvenor St., at a special lecture presented by Griot Productions.

*Tickets are \$10 CAD. For more information please contact Griot Productions at (416) 405-8940.*

# Charlene's Journey

*continued from page 1 . . .*

*“Becoming a  
volunteer with  
AboutFace has  
helped me to  
face the world  
and find my  
voice”*

**So your parents and your siblings were very important to your development?**

Yes, and to this day they are my biggest supporters. My parents always treated me equally to their other children and had the same expectations of me, except when I had surgery. During my surgeries, I received special attention. One of my parents would stay with me at all times in the hospital. In fact, I would like to pay special tribute to the memory of my mother. She passed-on in 1993 and is still very much with me today.

**Have these experiences affected the way you raise your daughter?**

Having Treacher Collins has had an impact on both our lives. During my pregnancy, I knew there was a 50 percent chance of passing it on to my baby. When she was born, all I wanted to know was whether she had two ears. The nurses laughed and said, “yes, but most mothers asked about ten fingers and toes.” Elodie is my greatest achievement. I decided to be honest and up front with her about my facial difference right from the start. When some boys in her class started to tease her and laugh at me, it was important to me to confront the situation. I went to her school and presented the AboutFace School Program, Unwrapping The Package. We face the issues and situations that come up together.

**How did you get involved with AboutFace?**

I received a letter from Sunnybrook Hospital about participating in a survey on facial differences and AboutFace. I was very interested to learn more about the organization. Becoming a volunteer with AboutFace has helped me to face the world and find my voice. It was very important to me to be trained on the school program and reach out to children. I get great satisfaction from going to schools, addressing the questions and whispers and seeing kids get my message. No matter what we look like on the outside, we are all the same on the inside.

**Have you had the desire to continue with surgeries to change your appearance?**

As an adult, my biggest concern has been the appearance and functioning of my hearing aid. So in 1991, I had surgery to implant a new Bone Anchored Hearing Aid. At first, I was very excited by the outcome and I could hear everything. Soon however, I began to realize the disadvantages for me. The noise level was so sharp that a sneeze made me jump and I had difficulty sleeping. I also lost some independence, because I couldn't use the telephone without operator assistance. After about two years, I decided the system wasn't adding to my life and had it removed.

**Was that the end of your surgeries?**

I took a bit of a break and it wasn't until 1999 that I felt the desire to look at the situation again. In fact, I was inspired by Paul Stanley's story of living with Microtia and his experiences with reconstructive surgery. I was motivated to go back to Sunnybrook and investigate my options. Dr. James Anderson of the Craniofacial Prosthesis Centre led me through the options: a new Bone Anchored Hearing Aid System, ear canal opening and reconstruction or a prosthesis.

**So you now had the option of choosing to have an ear?**

Yes, and for the first time in my life I considered wearing my hair up without attracting attention and staring. But in the end, I decided that it wasn't that important to me. I wasn't a good candidate for the canal opening procedure because of my facial bone structure. My only viable option was a prosthesis, which would never feel like a part of me. It would always be a foreign object. Plus, I would have to worry about it falling off, losing it, and the high cost of replacing it regularly. Ultimately, I decided that hearing was the biggest concern for me and decided to try the BAHA system again.

**Has this second implant been a positive choice for you?**

It was in the beginning because of the new technology and advances since my implant ten years ago. But soon, I began to experience the same side effects, which had so bothered me the first time. I was not sleeping. I was extremely jumpy and was experiencing discomfort. So after almost 18 months, I have decided to remove the BAHA system and just be me again.

**Do you think that the process of making these decisions has fostered the development of your sense of self-acceptance?**

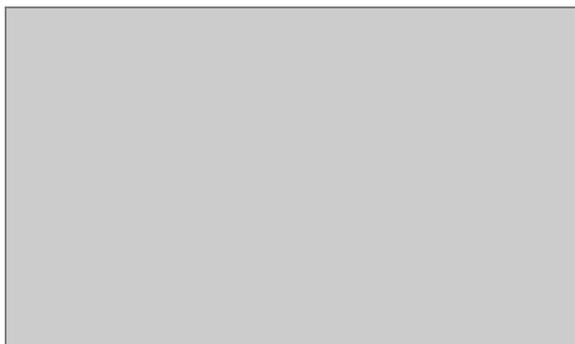
When I turned 18, my parents decided that I was ready to make my own medical decisions. I remember riding the subway on my way to an appointment feeling both overwhelmed and loving the sense of freedom. It really was the begin-

ning of my coming to terms with my appearance. The last 20 years of medical procedures have been a journey for me. A long process, which ultimately helped me to figure out what was right for me personally. I think you reach a point of inner peace when you can feel confident making choices and not look back.

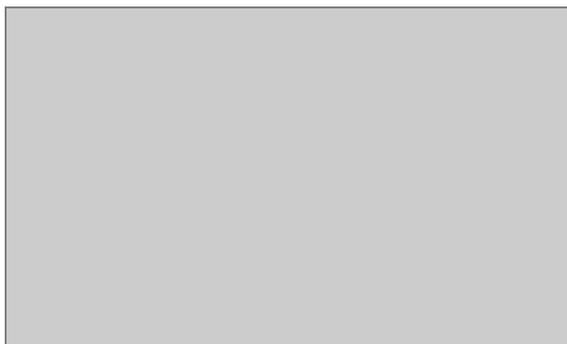
**What would be your advice for others contemplating new technology?**

I think that everyone has to make choices based upon their individual needs. Do some research on the options presented to you, weigh the pros and cons, and then make a decision for yourself. The only one who can truly assess if it works for you is you. Be open to looking at new technology and advances, but don't be afraid to change your mind. There are no mistakes in life only choices.

## Access to Success!



*Carol Brickenden, President of Brickenden Speakers Bureau, kicking off the 14th Annual Access to Success*



*AboutFace Ambassador Karym Joachin addresses the luncheon audience*

The 14th Annual Access To Success was held on December 12, 2000. This executive education forum featured 20 of North America's most esteemed speakers, consultants and musicians. The day was attended by over 400 people and raised in excess of \$50,000 for AboutFace. Special thanks goes out to Carol Brickenden and the staff of the Brickenden Speakers Bureau who generously donate their time and expertise to

host Access. AboutFace would also like to acknowledge Heart Lake Travel-American Express, Jackson-Triggs Vintners, KPMG, Sandals Resorts, Sheraton Centre Toronto and TORYS for their support of Access. We invite you to join us on Tuesday, December 11, 2001 for the 15th Annual Access For Success!

# The Deli Counter

## By Debbie Breslow

*The men behind  
the counter  
seemed to keep  
getting bigger  
and bigger,  
almost like  
giants. But as  
big as they were,  
they seemed to  
be afraid to look  
me in the eye.*

*Narrated by Kenny Breslow  
October 2000*

All we wanted was a bucket of sour pickles. Somehow, it turned into more than that. Somehow, it always does.

Yesterday, Mommy took me, my Papa Paul, my big brother Robbie and my baby brother Danny to our favorite local luncheonette for grilled cheese sandwiches and chips. We placed our order with the waitress and anxiously waited for our lunch to be served. At the booth, there was plenty for me and Robbie to do. There were forks and knives to use as swords. There were sugar packets to flick like hockey pucks and salt shakers filled to the brim to pour on the table for building "sand" castles. Just before things got out of hand, Mom interrupted our fun by saying, "I could really go for some sour pickles". "Me too!" Robbie and I shouted in unison. "I'll go next door to the deli and get some while we wait for our lunch", mom said. "I want to come too!" I exclaimed. "Sure, Kenny", Mom replied, "let's go".

We walked next door to the kosher deli, hand in hand. Mom held the door open and I ran up to the glass counter, eager to place our order. "We want spicy pickles", I yelled to the man behind the glass. The man averted my eyes, ignored my request and said to my mom gruffly, "Can I help you?" "Yes you can", she replied, "we'd like six sour pickles, please". The man behind the counter must have not heard my mom because he did not begin filling a container with pickles. Instead, he bent down and peered through the glass. I thought he was playing a game with me and I started to laugh. I looked at Mom and she wasn't laughing; she looked angry.

Before I could ask her what was wrong, Mom said to the man behind the counter, "it's a birthmark in case you were wondering". The man behind the counter still didn't fill our pickle order. Instead, he bent down again; this time leaning over the three-bean salad dish. He was

attempting to get a closer look at my big, red nose (clinically known as an arteriovenous malformation).

Then he motioned to one of his fellow counter men as if to say, "Hey, take a look at this kid!" The second man behind the counter bent down and looked at my nose. Then the two employees whispered something to each other and began chuckling amongst themselves. "Whad'ya say it was?" the second counter man asked loudly to my mom, "a burn?" "No", Mom replied firmly, "a birthmark".

After that, every time I looked at the men behind the counter, they seemed to keep getting bigger and bigger, almost like giants. But as big as they were, they seemed to be afraid to look me in the eye.

I felt uncomfortable. I wasn't sure if I was upset because of how the deli counter giants were acting or because mom seemed so annoyed. Whatever the reason, I knew there was something about the situation that just wasn't quite right.

I tried once more to gain the attention of the men behind the counter but they wouldn't dare look at me. I wondered what I must have done to make them act in such an unfriendly way.

Mom took the pickles from the man and paid for them at the cashier. We left the deli and returned to the luncheonette where it was "safe".

Mom started the ignition and checked her rear view mirror to make sure we were all buckled in our seats. Just as we began to pull away, Robbie called out, "Mom, wait! We forgot the pickles!"

"That's okay", Mom responded, showing little reaction to Robbie's discovery. And we drove home.

*Debbie Breslow is a mother of three boys. Kenny, her second child, has an arteriovenous malformation (AVM) of the nose, lip and malar region. He is a happy, well-adjusted preschooler and receives ongoing medical treatment.*

# From the Desk of the Executive Director

## by Rickie Anderson

A Board of Directors was elected at the November 2000 board meeting, new by-laws are under consideration and updating of accounting procedures is being established. The Executive Board consists of Dr. Bruce Bauer - President of the Board; David Reisberg - Vice President; Diana Newby - Treasurer; Ann Ross - Secretary. Total board members number eleven and will expand in the coming months. An Advisory Board has six members and are called on when needed. Thank you all for your participation in redefining the needs and planning for a better organization. It has been hard work for the past year. The next board meeting will be held in March.

Thanks to The SmileTrain for the funding needed to offer a toll-free number (888-489-1209) to those that need our assistance. As a result, we are able to serve hundreds of families and individuals seeking support and information. Also, The SmileTrain made funding available to the national office to purchase new computer equipment and programs replacing those stolen last year. We are very appreciative of their ongoing support.

In early January 2000 The Sally Jesse Raphael Show hosted a program and AboutFace USA was invited to participate. Favorable responses are still being received.

Beginning in January, SmithKline Beecham partnered with the USA office to make a 25-cent donation for each hit on our logo on the home page of their Abreva product web site - [www.abreva.com](http://www.abreva.com). Unfortunately, this newsletter might be received after the program is complete, but we want to thank everyone for their help.

If you haven't visited our web site, I invite you to do so now. We have a new domain name [www.aboutfaceusa.org](http://www.aboutfaceusa.org) and served over 1,800 hits in January. Articles and points of interest are

always welcome and considered for this site. Just contact me at the toll free number or write me at our email address of [aboutfaceus@aol.com](mailto:aboutfaceus@aol.com). Twenty plus chapters are listed on the web site as well and many can be contacted directly via an email link.

The 2nd Annual Wine and Cheese Annual Fundraiser for AboutFace USA will take place later in the year. Invitations will be sent to those in the Chicagoland area. If you live outside of the area and want to receive an invitation, please let us know. We are currently soliciting silent auction donations that will be included in the evening events. Please let us know if you have something to donate (products, gift certificates, air miles, trips, condos, appliances, artwork, etc.).

*AboutFace USA is always seeking families and individuals that want to offer their support to others who are undergoing craniofacial medical ordeals. We have a network of individuals to support others via email, phone calls and letters. If you would like to volunteer or need to connect with someone, call our office, toll-free, 888-486-1209 or email at: [aboutfaceus@aol.com](mailto:aboutfaceus@aol.com).*

# Memories—A Cleft Lip & Palate Childhood

by Carolee

**M**y name is Carolee and I was born in December 1957 with a cleft lip and palate. I was the first of four children born to a very young mother.

Thousand of other children are born each year with cleft lip and palate, and that's why I want to tell you, from my heart, about my life.

I didn't really know that I was different until just before starting Kindergarten. The very first thing that I remember is going back and forth to the speech therapist and how he tried to get me to talk by bribing me with a Jack in the Box that I received as a reward if I said a sound or word right. My next memory is going to the doctor's office, then to some place like a dentist office where I had an obturator made every couple of years. An obturator is sort of like a plastic plate that is anchored to the teeth. It covered the cleft in my palate and I was able to eat, drink and speak a little clearer. I hated having one made; it meant several trips to the dentist or who ever he was. There was usually two—three men, two to try to hold me down and one to shove the plates back in my throat to get a proper fit. The plates were metal and they filled them with some nasty tasting, plaster / glue tasting putty. The hard part was trying to get the metal plates to fit my small mouth.

After the first one, I sort of became like a poster child where I went to this big room about the size of a gym and it was filled with doctors. I was on a stage with many people staring at me, my doctor asked me my name, some questions and to blow out a candle. They really didn't pay any attention to me and being very small for my age they looked like giants. But I was well aware that they were talking about me.

My next memory was having an operation, I don't remember what for but I learned from a very young age that I did not like hospitals, shots or being kept in a crib with another crib on top of it so I wouldn't escape. I wasn't in school yet at this time either. I wiggled through the bars of

the crib and somehow found a phone and called home and told my mother to come and get me. She told me to find a room with Jesus and crosses in it and to wait for her. Being young, I thought I was going to finally be going home only to find out that I was



*Carolee*

now tied down in the crib as well. I think experiencing all that at such a young age brought out a survival instinct in me. Through out the rest of my teenage years, in and out of hospitals I fought every inch the way. I'm sure there are plenty of retired nurses who remember me. I wonder if they recognized how truly frightened I was.

The majority of my surgeries didn't start until I was 14 and it got to the point that I was not told that I was even going to the hospital. If I somehow found out I would get sick and start throwing up a good week in advance. I don't know how many operations I've had, but they started when I was in the 8th grade and didn't stop until I was a senior in high school.

The first few operations were to close the roof of my mouth and it took several to close. I don't remember the medical terms but I do know they took tissue from my throat to and stretched it over the cleft in my mouth.

My first surgery is almost comical, this happened in the early '70s when Medical Center and other hospital dramas were on television. I woke up from my first surgery and saw I was hooked up to an IV, having led a very sheltered life my only thought was I was very sick and no one had told me.

When I think back to those television shows I remember only the really sick and dying people were hooked up to IV's so I think its under-

standable while I panicked. Now that I'm older and wiser, I probably would have done a lot better had my parents and doctors prepared me.

After each surgery I was on a liquid diet, followed by a soft food diet, gradually getting back to real food. But once I gained my weight back the next surgery was scheduled. For years my weight yo-yoed up and down from surgery to surgery and as an adult I have suffered a weight problem. Being small, I always looked younger than everyone else my age.

Besides the diet, I wasn't allowed to talk or shower. I had to write everything down and remember my grandmother combing my hair out with cornstarch so it felt clean. I was hyperactive and being kept inside and quiet was bad enough but my dogs were not allowed into my room until I was on the mend. My mother was afraid that I would sneeze because of a piece of dog hair.

Years later, I found out that my sisters and brother were jealous of all the attention I was getting. I guess I never thought what it must have been like for them. It must have looked like I was spoiled.

The operations happened back-to-back and the majority of them are nothing but blurs now with the exception of a few that were bad enough to remember all these years. My very last time in the pediatrics ward was so memorable that every operation after that was traumatic. I had finally grown use to being stuck in the arm with a huge needle, smelling something nasty and going to sleep. So many shots and needles...even as an adult I hate shots.

Like other kids, I was teased and picked on. I really hated school but if I had to do it all over again, I would. Because in the end I think it made me a stronger and better person and so much more compassionate and understanding.

I went through a time when I prayed to God and asked, why, why, why?

My stories of how I dealt with peer pressure I think is more entertaining than this and maybe

I'll try to write them. When a kid looks different other kids can be down right mean and rotten. I think an eye opener for me was taking speech lessons at Easter Seals. I saw kids worse than me.

Tommy was a happy, normal 15-year-old until he crashed into a wall on his motorcycle and was paralyzed from the chest down and also totally blind. He and I became instant friends and accepted each other as we were... he was a real inspiration to me. We would spend many nights talking about what each of us had been through. What's really odd, is the one day I had to go to the hospital for a dislocated shoulder I could see and hear a young man screaming and crying... it was Tommy when he was brought to emergency after his motorcycle accident.

Today, Tommy is happily married and living in Australia. I, too, am very happily married to a wonderful man.

God works in mysterious ways and I feel blessed to have been through everything I have experienced. I like who I am and I know that I am very lucky compared to other people. As a child, when I had no friends I often thought if they just got to know me as a person they would like me. I went through a real shy and I'm ugly phase but I grew into a swan with time. I asked my husband the other day why he married me and besides all the mush and romance he also added that I had a heart of gold. I actually feel sad for the people who are born normal; they go through life as if it's a perfect game and when something bad happens they aren't prepared for it. Growing up, in and out of the hospital, years of speech lessons and so much more, I feel in my heart I'm more adjusted. Things happen all the time, but God in his own way as prepared me in such a way that I feel I can take on the world. What's the worse can happen, I can end up in the hospital and get another shot!

# Youth Connection

## Ways to Connect

• *Get involved*

• *Be confident*

• *Be friendly*

*and open*

• *Be yourself*

• *Teasing*

*happens*

*Welcome to the AboutFace Youth Connection. This new column will be a place for our younger members to discuss issues and topics that are relevant and current to their lives. Each edition will feature a new topic and different points of view from teenage and young adult members of AboutFace. This is a section for you to share ideas, advice and experiences. If you would like to pose a question or participate in providing answers please email us at: [annng@aboutface-international.org](mailto:annng@aboutface-international.org).*

### Question:

"I will be attending high school in the fall and am feeling a little bit overwhelmed and worried about teasing. I wonder if you could give me some advice on how to make the transition easier?"

### CW Responds:

I understand how going to a new high school can be really intimidating. I don't have solutions that will work for everyone, but I will list ideas that I use to make new friends and feel comfortable.

- Get involved with clubs and teams: If there are any extra curricular activities that interest you or you would like to learn try them. It is an easy way to make new friends and hang out with different people while doing something you enjoy.
- Be confident: When you start grade nine there are ice breakers, games and events for big groups of kids to get to know one another. Make sure you go and use it as a way to introduce yourself. When you speak up and become involved, it lets people know who you are and what you are like.
- Be friendly: If you are nice to everyone it is hard for people to be judgmental about you. This applies to your teachers too. If you get along with teachers they will often help you out.
- Be yourself: It never works out in the long run to try to be something you're not to fit in. People will most likely figure it out and then you are BUSTED. Be yourself from the beginning.

We're always told to ignore teasing, and I know how hard it is, but once you realize how unimportant the people making the rude comments are, it becomes easier. Fighting back usually leads to more problems. Once people know that they can annoy you, they will continue. Showing confidence and strong body language will let bullies know they aren't bothering you. Talking to a teacher or other adult can also help by making you feel

that you aren't alone. I try not to let things bug me and to talk easily about my difference. That way it is out in the open and makes me feel a lot more comfortable. Usually once people know about my difference they can't say anything rude anymore and so often they say nothing. Ultimately, we all have to find our own way to deal with teasing and questions.

### RP Responds:

The transition into high school can be a difficult time. Junior high schools are usually much smaller and you will probably know a lot more people. The first day of high school can be very intimidating. You will find yourself in a strange place surrounded by thousands of unfamiliar faces. But the hardest part will be trying to find your classes. As for how to deal with this situation, there are several strategies that can be employed.

Your biggest fear will be that people will take one look at you and think that you are not normal. Well, every person has his or her own unique qualities. Your high school will offer lots of extra-curricular activities such as sports teams, councils, musical ensembles and plays. Get Involved! Take part in every opportunity that presents itself to you. These extra-curricular activities force people to get to know each other and work together regardless of their differences. This will make first impressions easier and people will get to know you for who you really are.

You must keep in mind that no matter whom you are, where you're from, or what you look like you will get teased for something. People will make comments if someone is short, fat, balding, wears glasses, wears braces or has acne. Everyone will get teased for something, so try not to take it too personally if someone makes fun of your difference.

There is no such thing as having a face that looks the same as everybody else. Except for identical twins, every face on this planet is unique. You will find that the reason most people make rude comments is because they are not sensitive enough to understand about your difference. So you can choose not to be offended.

Another method to make the transition into high school easier is not to go to a huge school. It's obviously easier to make first impressions in a smaller community, for the simple fact that you have to make less of them. Unfortunately, you might not always have the option to choose what school you will go to. My advice is to get involved with every aspect of the community in which you live.

## Shavon Ellis' Story

My mom and dad tied the knot sometime in October of 1981. Then nine months later I was born seven lbs., 14 oz. The doctors took me right from birth because my ears hadn't formed properly. They had to run a whole bunch of tests on me to see if my internal organs had formed or not. I was then diagnosed with Bilateral Microtia, which in English means 'little or no ears'. I was born with a 65-decibel hearing loss. I had many specialist appointments in Toronto at the Hospital for Sick Children until I was three. That's when I had my first reconstructive surgery with Dr. Thompson. At the same time my parents were getting divorced and I had Bob and Claire coming to my house weekly to teach my mom how to teach me. I started going to school at the age of three. I attended Central Public until I was ten, then I went to Marlborough Public. When I attended Central I had to learn sign language so that I could communicate with my peers. Speaking of communication I never had a speech impediment. 25 surgeries later my ears have been reconstructed.

The E.N.T. doctor had told me to wait two years for a more advanced way to hear. Finally in 1998, Dr. Thompson referred me to Dr. Papsin and an E.N.T. doctor. He then informed my mom and I of the procedures involved with the BAHA. I was a perfect candidate for this procedure because I had the inner ear. I lack the middle ear and the opening. The procedure started just after I turned 16 years old. I was the seventh one in Canada to receive the BAHA. It took many trips to and from Toronto to finally have the BAHA turned on. The BAHA allows me to hear from the centre of my head and true sounds rather than muffled, mechanically transmitted sounds that my bone conductor did.

Having a hearing loss never controlled my life or my attitude. Most people wouldn't even know I'm hearing impaired unless I told them. The BAHA allows me to live comfortably with no hearing loss. The only time I know I'm hearing

impaired is when my BAHA is broken. I've had my BAHA for about two and a half years and have had to have it repaired twice. The first time it broke I panicked because no one in Windsor even knew what a BAHA was. The second time was just a few weeks ago and I panicked again but know I'll get through it again!

There are many people who have influenced me and believed in me so much. It's made me the person I am today. I want to thank Dr. Thompson for giving me ears; Dr. Papsin for making them work; and Gord Renaud from the Knights of Columbus in McGregor for financing many of the trips. I'm so grateful for all that everyone has done for me.

I want to especially thank my mom and my aunt Penny because after every surgery I'd wake up to see their faces. They were always looking out for me. They always made sure I was taken care of. For that I will always love them. My mom is my best friend who has given me the strength to have such a positive attitude. She was there for me unconditionally. Now I'm nearly 19 and I'm growing up to realize that my life has just now begun. One thing I've learned though is that I'll never take anything for granted because you never know when it'll be gone.

### Microtia Booklet

Aboutface releases an information booklet on microtia this spring. Call your national office to order your book now. First copy is free!

# Be In the Loop!

## Join in the 7th Annual Hoops!



**WHAT:** Bay Street Hoops is an annual fundraising basketball tournament whereby teams from the legal, financial and corporate communities in Toronto get together for a five on five tournament.

**WHY:** These "corporate" hoopsters love to play basketball, so they created this special league to raise money for The Raptors Foundation and AboutFace. This year we hope to raise \$125,000.

**WHEN:** Thursday, March 29 (6:00 pm–9:30 pm); Friday, March 30 (6:00 pm–10:30 pm); and Saturday, March 31 (9:00 am–6:00 pm).

**WHERE:** The University of Toronto Athletic Centre, 55 Harbord Street (Southeast corner of Spadina and Harbord).

*For more information or to register, please contact Tim Costigan at 416-922-8611 or [tcostig@interlog.com](mailto:tcostig@interlog.com)*

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