



AboutFace

LEADING THE WAY FOR PEOPLE WITH FACIAL DIFFERENCES

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## Evan—Completing Our Family

*As told by Donna Bantis  
and edited by AboutFace.*

My name is Donna. I have a great husband, Steven and two wonderful children. Tiana is four and Evan is now 18 months. It took Steven and I about two years to get pregnant each time. We wanted two children to complete our family and as fate would have it we got a little more than we expected with our second child, Evan.

When I finally got pregnant with our second baby, we were elated. I was looking forward to the simple things like breastfeeding and cuddling our new baby. I developed toxemia with both of my pregnancies and at 31 weeks had to start regular visits to the hospital. Every week, I had two ultrasounds and fetal monitoring.

Exactly nine days before my scheduled induction, at 37 weeks, I had a routine ultrasound. Immediately following that, the technician told me not to leave the hospital. I knew something was wrong. I was nervous as I paced the room, waiting for my midwife. She was very professional and straightforward as she said, "You're having a healthy baby, but the baby has a cleft lip and possible palate."

*Boom!* Everything shut down for me. In a matter of minutes my existence had changed from one of stability and utter joy to one of deep anxiety and fear. It felt like forever! I knew what a cleft lip and palate could look

like, from books, but I had no concrete knowledge of all it entailed. I imagined the worst-case scenario. I was clearly devastated. All sorts of things went through my head: what will our baby look like; is there anything else wrong with the baby; can I breastfeed; how do I tell my husband, family and friends; will I



*Evan*

want to take pictures, go out in public... the list went on.

Everything sped up for me. I was in shock. I thought about how our society is so absorbed with how "cute" babies are. We all imagine the perfect "Gerber Baby." Now, faced with this new reality, that my baby's difference would be facial, my expectations were completely shattered. So much emphasis is placed on our appearance. I recall imagining my baby's life from infancy to adulthood and wondering what trials and judgments my child and our family would ultimately endure. I realized we were about to have a special needs baby.

I got home and called my husband, Steven. I was distraught and incoherent. He

# News from Edward Street

by Anna Pileggi, Executive Director

Fall is upon us and with the events of last month (September 11) it is hard to predict the state of affairs by the time you receive this newsletter.

Firstly, on behalf of the Board and staff of AboutFace, we wish to extend our heartfelt sympathy and prayers to all the families and members of our organization who have been directly touched by the tragic events of that week. Our thoughts and prayers are with you.

Secondly, I would like to welcome some volunteers who have joined the ranks in our organization. Earlier this year, the Board of Directors approved two new advisory committees who will work with us to help identify and refine our programs and services.

The Health Care Advisory is made up of healthcare professionals from various disciplines working in the craniofacial field from across Canada. As well, we have a Constituency Advisory made of members from various experiences (adults, teens, parents, acquired and congenital differences) again, from across Canada. These two groups will work with the Board and Staff to ensure that AboutFace continues to stay on the leading edge of support and services to the craniofacial community. Welcome to all!

Thirdly, I would like to welcome the new members of our newsletter committee. Our committee will be meeting in December to plan themes for the coming year (2002), should you have any thoughts or suggestions to share on storylines or issues you want to see covered,

please email me at [annap@aboutfaceinternational.org](mailto:annap@aboutfaceinternational.org) or visit our website at [www.aboutfaceinternational.org](http://www.aboutfaceinternational.org)

Finally, I would like to make a correction from the last newsletter. Dr. Levine, recipient of the Dr. Richard Ten Cate Professional Community Service Award, is director emeritus at the University of Toronto, Faculty of Dentistry.

*The Opportunity to practice  
brother/sisterhood presents itself  
every time you meet a human  
being.*

*Jane Wyman*

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## Part I: Alveolar Bone Grafting\*

by David M. Fisher, MD

*See page 6 for Part II: A Kid's View...*

The “alveolus” is that portion of the jaw that holds the teeth. A cleft may extend to involve the alveolus and this portion of the cleft is called an “alveolar cleft”. In many cleft centers, and at the Hospital for Sick Children, the preference is to delay closure of the alveolar cleft to allow for optimum growth of the jaws and teeth. The procedure to close the alveolar cleft is called an “Alveolar Bone Graft”.

The three main goals of alveolar bone grafting are: 1) to join the upper jaw segments to form a single dental arch, 2) to provide bony support for the teeth on either side of the cleft, and 3) to close the communication between the nose and mouth (“nasopalveolar fistula”).

The operation is performed by your Plastic Surgeon, however, the timing of the surgery is decided by your Orthodontist. Generally this will be between the ages of nine and 12 years. It is determined by the stage of dental development. If we know that jaw surgery will be necessary then we may postpone the alveolar bone graft so that only one operation is necessary. (Jaw surgery is usually performed at the end of facial growth—approximately age 15-17 years in girls and age 17-19 in boys.)

To close the bony gap in the upper jaw we borrow some bone from the hip. Not to worry, we do not take it from the hip joint, so activity will not be affected afterwards. We take soft bone from the inside of the “iliac crest”—that part of your hip on which your belt rests. The shape of your hips will not be changed but there will be a small scar (approximately three centimeters long).

By this age most of the kids have had at least one operation. But these were when the child was a baby and so are not remembered. The bone graft is done later

and so the kids have a much greater understanding of the surgery. I think this is why it is the most worrisome. This is only natural. However most who have had the surgery will say it wasn't as bad as they thought it would be. There will be some discomfort from the hip and so we will give you pain medication to control this. There will be some facial swelling but this will go away in



*Before and After Surgery: Alveolar Bone Graft*

about five days. Most kids are walking the day after surgery, home the next day, and back to school in a week.

I think that this is a really good operation because once this is complete, the orthodontist can do wonders with your teeth, and in the end you will have an even brighter smile.

*David M. Fisher MD FRCSC,  
Medical Director, Cleft Lip and Palate Program  
The Hospital for Sick Children  
Toronto, Ontario, Canada*

## Evan's Story

*continued from page 1 . . .*

raced home thinking that I had lost the baby. I told him we were having a baby with a cleft lip and possible palate. I got no reaction from him and then he said he had no idea what a cleft lip was. I tried my best to describe it to him, but it was very difficult for him to conceptualize what I was talking about. After all the talking I did, I couldn't seem to stop, he asked "Is the baby going to be healthy?" "Yes, they think so," I said. "Fine, then we're going to get through this. Its not going to be a problem." Then he gave me a really big hug.

The first couple of days, after finding out about the cleft, were the most difficult. I could not talk about the cleft without crying. I agonized over what our baby might look like and how others and myself would respond. I really struggled with the "physical" aspects of the cleft lip. I was heartbroken over how I thought I might react when I saw my baby for the first time, scared of what I might see and how I would feel. I was terrified of perhaps not feeling that "incredible elation" that a mother experiences when she first lays eyes on her new baby. I knew in that moment, that I didn't want to give birth being so frightened and overwhelmed.

Both Steven and I knew it was imperative that we speak to someone. We really needed to know how others felt and dealt with this issue. We had so many questions and no answers. Our goal was support and information. We went to the library, got on the internet and starting surfing. My first goal was to find pictures of other babies so that we could both have a sense of what we would be dealing with physically. It was a blessing that we choose this route, because we found AboutFace on the internet. It felt awkward calling because I had no idea what services AboutFace offered. I was going out on a limb, but I knew I had to call someone and get the help we needed.

AboutFace introduced us to some really great families. Steven was able to hook up with other fathers, which was incredibly important. I was so relieved to hear from other mothers that they experienced the same or similar feelings and thoughts that I had been going through. It was a relief to understand that what we were experiencing was normal. Of all the people we spoke to, there was one couple in particular who were especially wonderful to us. We were invited to their home before

the birth of our child. They opened their home and hearts to us and we are forever grateful. They showed us pictures and videos of their son. The best part of the visit was being able to share our feelings and get the support we so desperately needed. They helped us to see that in time, everything works out okay.

By the end of the week, we realized that we had to stop focusing on the cleft. In my head I kept thinking about hav-

ing a baby with a cleft instead of a healthy baby who had something extra. We decided that we would not discuss the cleft any more. It was vital that I focus on what was really important. Our second child was on the way! Would it be a boy or girl? I couldn't wait to hold, cuddle and kiss our new baby. Introducing Tiana to her new brother or sister was going to be a joy. Completing our family and loving each other. These were the things that really counted.

The hospital team that was present at birth included my midwife, a doctor and nurses.

Everything happened so fast. The baby was delivered and placed on my chest and we all looked at him. I remember looking at my baby's face and thinking, "well, there it is." It wasn't as bad as I had imagined. In an instant I realized it really didn't matter. I was holding my beautiful new baby boy and my tears were pure joy.

Evan didn't respond immediately like most babies, so they gave him some oxygen in the delivery room and took him to ICU. They tubed him through his nose in preparation for feedings. This was shocking to me. I asked the doctor, "Isn't he healthy?" "Yes of course he is," he assured me. "Then why does he need to be in ICU?" I was puzzled. The doctor told me that cleft lip and palate babies go to ICU. This was hospital protocol. They



*Evan after surgery*

wouldn't let me stay with Evan, which also really surprised me. At this hospital Evan's cleft lip and palate was a big deal. Suddenly, all the old feelings and fears came back.

The nurses at the hospital were untrained to deal with a baby with cleft lip and palate. I knew how to use the bottles and nipples that Evan needed and brought them to the hospital. I had to train each shift of nurses in order for Evan to be fed. They were very receptive to helping once they knew what they were doing. The doctor was unsatisfied with how much Evan was taking in, so the feeding tube remained and was in use. Steven and I felt it was unnecessary and wanted it removed.

After four days of no one listening to me, I became angry and depressed. They had taken away my sense of control. This was not how it was supposed to be. I spent the week before the birth, learning the skills necessary to feed and take care of my own child. I kept asking, "Please take the tube out, he's fine." Days went by, same cycle, same routine. No one wanted to listen to me at the hospital. My midwife was advocating for us to no avail. It was horrible. I was barely allowed to go in and hold him. I felt so distant from Evan and needed to bond with him. They treated Evan like he had a terrible illness and I felt like they were keeping me away from him so that I wouldn't get that attached.

After ten long stressful and exhausting days, I secured a letter from the Cleft Team at The Hospital For Sick Children who recommended the removal of the tube. Unfortunately, neither hospital was able to connect me to someone who could help me to breastfeed Evan. I later spoke to other mothers who had nursed successfully. I was concerned because I developed a bond with my first child while breastfeeding and I thought if I couldn't breastfeed, how was I going to bond with Evan? Soon, I found out that I had bonded with him in other ways that were equally rewarding.

Our family was very supportive, but we still needed to tell our friends. Everyone wanted to hear about the new baby. We decided on a positive statement. Our statement was, "We had a healthy baby boy and he was born with a cleft lip and palate." There was silence at the end of the phone in almost every situation.



*Evan and Tiana*

Now we had to go out in public. Having people see Evan was a great learning experience for our entire family, including Tiana. She was almost four years old at this point and knew what was going on. Before the birth, we showed her pictures of babies with cleft lip and palate. We told her that this is what our baby would look like. We explained that when the baby got bigger we were going to fix it. When Tiana, first saw Evan, she went right up to him and looked at his face. She looked up at us and said, "Is that his boo, mommy?" I said, "Yes that's his boo." That was it. She acted like it was nothing. In her own way, she helped set the stage for how we were going to present Evan to the world.

Most people were nice, others weren't. There was a lot of staring. In a couple instances, people were down right rude. Other parents had warned us to be prepared in public. I decided that I could go out in public in one of two ways: I could be defensive and hostile to people or I could go out and start educating others about cleft lip and palate. Steven and I decided to be educators.

Evan's face was a great conversation starter. We never went out with Evan without having a conversation with someone. It was really a wonderful experience. For us, it was therapeutic. We found out that a lot of people had

*continued on page 6 . . .*

## The Team

The IWK Cleft Palate Team has been in existence since 1972, when the Province of Nova Scotia created a provincial Cleft Lip and Palate Programme under the guidance and strong initiatives of Dr. Downey Grover, the Team's first Pædiatrician. Since that time the Team has grown into an interdisciplinary Team of 12 members with the goal to provide integrated health care for this population of patients. As the only Cleft Team in Maritime Canada registered with the American Cleft Palate Association (ACPA), the Team provides care for patients in Nova Scotia as well as the other two Maritime Provinces, New Brunswick and Prince Edward Island. For patients in New Brunswick and Prince Edward Island, the IWK Cleft Team strives to provide support and any additional care that is needed by the patients beyond what the smaller local teams can provide. Often the majority of the surgical procedures are performed at the IWK Health Centre, as the tertiary pædiatric care centre.

At present, the IWK Cleft Palate Team has 12 members (Audiologist, Clinical Co-ordinator, Craniofacial Surgeon, ENT surgeon, Family Representative, Nurse, Oral and Maxillofacial Surgeon, Orthodontist, Pædiatrician, Pædiatric Dentist, Plastic Surgeon, Speech-Language Pathologist) who participate in the clinic on a weekly basis. Various additional clinical services including genetics, neurology, and ophthalmology, participate in the care of patients through a referral system on an as-needed basis. There are additional clinicians that liaise with the IWK Cleft Palate Team and are involved with the care of the patients in their home communities. On average, the Team sees 25-30 new patients per year and has a recall caseload of over 400 patients with either clefts or craniofacial anomalies. The Team both sees patients and conducts meetings on a weekly basis to review patient progress and treatment plans.

A unique aspect to our Team is the membership of a volunteer, lay-person, family representative as a full-team member. In her capacity, she joins the weekly Team meetings to contribute to the treatment planning of out patients. Our family representative has a son who was born with a unilateral cleft lip and palate and who also was involved with the IWK Cleft Palate Team during his



*From left to right:* Gerri Halfpenny-Franklin, clinic nurse; Dr. Dave Precious, Oral and Maxillofacial Surgeon; Mrs. Farris MacPherson, Family Representative; Dr. Ross Anderson, Pædiatric Dentist; Linda Huntley, Clinic Co-ordinator; Dr. Charlie Cron, ENT; Cindy Dobbelsteyn, Speech Language Pathologist; Dr. Ken Wilson, Plastic Surgeon; Dr. Kathy Russell, Chair and Orthodontist

care. As the family representative, not only is she familiar with aspects of health care for children with facial clefts but also is personally familiar with the specific health centre in which she works. She serves as an additional resource for parents that extends beyond the clinical Team members as well as serving as a resource for the Team members themselves.

The Team is involved with some new initiatives including the creation of a Team database with clinical data dating back to 1972. The foundation for the database is the ACPA database that we have customized for our specific Team. When the database is created, it will serve as a wealth of information to support clinical outcome research and to improve patient care with the clinical evidence to support the specific treatment we provide. With a similar goal in mind, the Team is investigating the ACPA Clinical Outcome Registry to investigate our clinical protocols and outcomes. A second research project involving the Team in the area of the impact of prenatal diagnosis of clefts has just received funding, and will soon be underway.

## Meeting Planners International

Every year, the members of Meeting Planners International, Ottawa Chapter, organize a fundraising event and have, for the last two years, donated the proceeds to the Ottawa Chapter of AboutFace. This year, MIP Ottawa raised \$7,000 to support a regional Family Education Day in the Ottawa area for the Spring 2002. A very special *thank you* to the members and Executive Board of MPI, Ottawa Chapter. Their next event is scheduled for November 13.



*Photo: Anne de Gobeo, liaison for AboutFace, Judy Maus, AboutFace Ambassador, Louise Gervais Chairperson of the MPI fundraising committee*

### Evan's Story

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never seen an open cleft. They would see it after the surgeries, but not before. It dawned on me, that perhaps many parents don't show their baby to others because a cleft lip is so visual. In the beginning, I really had to get up the nerve to go out the door. I was always worried and afraid of how others would react. After the first few weeks, I realized it didn't matter what others thought about Evan. What mattered was what Steven and I felt about Evan. I gave birth to an amazing little boy who completed our family and we loved unconditionally. I loved Evan exactly the way he was.

The next hurdles were the surgeries. Evan had his first surgery to repair his lip at four months. His second surgery was to repair his palate at 14 months. Every mom that I talked to said that I would miss the cleft lip after the first surgery. I thought "No, that's weird. I just want it fixed." As soon as Evan opened his eyes after the surgery, I broke out into tears. It was the only time I cried during his first surgery. I cried because I wanted his other face back. I loved the face he was born with and I didn't want it to change. It felt like I had lost the child that I had given birth to. I was really glad someone told me to expect these feelings of loss.

This first surgery changed the look of his face so profoundly that I was in total shock. I couldn't believe it. He looked adorable, but I wanted his other face back very

badly. Four months later, I had this new baby. Steven experienced the same thing. We got through the first surgery okay. Again, AboutFace was very helpful in providing information and support. We spoke to other parents about the next surgeries and we were as prepared as possible. This made a huge difference in how we survived and dealt with the emotional roller coaster.

Throughout everything my best support was my husband, Steven. We already had a great relationship, but in dealing with this crisis, we reached a new level of intimacy. To share the hopes, fears, joys and sorrow of this experience ultimately made our bond stronger.

Today, Evan is 18 months old. He is a happy, outgoing little toddler who is full of energy and love. He is very affectionate and greets everyone with a huge smile! When I reflect back to his birth, the two surgeries we have gone through, and knowing there are a few still to go, I am comforted by the knowledge that with love and support we can survive whatever comes next.

What have I learned in the last 18 months? I've developed more compassion, empathy and patience. I have learned to be less consumed with the physical. Evan has taught me to live each day as it comes, enjoy the time shared together and look past the outside. Real beauty lives within and shines through in everyone.

## Part II: A Kid's View of Surgery

By Kyle McKenzie

I can't believe three months have passed since I had my surgery! (Alveolar bone graft).

On July 17, 2000, I had my 10-year assessment with the cleft lip and palate team at the Hospital for Sick Children in Toronto. I was at that meeting and we discussed the operation that I would have the following spring.

My plastic surgeon, Dr. Ron Zuker told me he would take bone from my hip and use it to attach the three pieces of my upper palate together. He said that it would be painful. At that time, I asked him "how painful is it going to be? How long will I be in the hospital? How much time will I get off school?"

To prepare for the surgery I started upper arch expansion in September 2000. Dr. Suri did the expansion at the orthodontic clinic. I wore a stainless steel appliance in my mouth that expanded my arch. I had to make frequent trips to the ortho clinic for adjustments (good thing we live so close by).



*Kyle at four months*

The appliance wasn't uncomfortable and it didn't hurt. It affected my speech a little at first then I got used to it. My surgery was scheduled for March 27, 2001. Dr. Suri was pleased with how well the expansion was going. He did a great job.

As the surgery drew closer I started wondering will I have a scar? What would I bring to the hospital? Will people visit me? I dreaded the thought of having to use that awful-tasting mask that they put over my nose and mouth, to put me to sleep, because I hate the artificial flavor. Then my surgery got moved from March 27 to May 2. I was relieved, but at the same time disappointed because I wanted it over with. I even asked: do I really have to have this surgery?

As the new date drew nearer, I experienced all the same feelings I had before. I was also little worried about the operation being so closed to my birthday (which is

May 26) and would there be a television in my room.

On the day of surgery, I was scared. I was full of questions about what was going to happen. At 1:30 pm I walked through the door to the operation room. Then suddenly, I awoke in the recovery room and saw Mom and Dad. My mom stayed in the recovery room with me. I went in and out of sleep. Once when I woke I vomited but didn't feel any pain. I was moved up

to my room by 6:30 pm. I soon fell asleep again. In the night, I got up to go to the bathroom. I tried to stand up (with help) but I felt dizzy, I vomited and my hip hurt, so I got back in bed. The following day I had visitors and I was happy. I went wheel chairing with my cousins and saw Dr. Suri in the hall. It was nice to see him.

On May 4, I was walking a lot and I felt great. I had lots of company that day and I had fun. I was surprised and happy at how pain free I felt. I didn't need any pain medication. Dr. Zuker came to see me that day. It was great to see him and he was pleased to see how well I was doing. He said I could go home the next day. I was looking forward to going home. I got Dr. Zuker to sign my "Plastic Surgery" t-shirt and I named my new stuffed owl Ruker, after him.

### Note:

To Dr. Zuker, the operation team, the nurses on 8c and Dr. Suri, I want to say thank you for taking such excellent care of me—*Kyle*.



*Kyle on a fishing trip last summer*

# Back to School

by Dr. Kathy Kapp-Simon

Fall is here and many school doors are opening for the new year. This is a time of anticipation and excitement for many; apprehension and worry for some. What this experience is like for your child in many ways is out of your control; however, there are ways that you can help your child make a good adjustment.

Before sending your child to school, educate her about her facial difference. This education is best carried out in the context of a childhood where talking about your child's specific facial difference is as natural as talking about the color of her hair or which outfit she will wear to school. In my experience, the common thread seen in families where the child has done well is the family's ability to view the facial difference as one characteristic of the child, which is no more important than any other. A child who can look in the mirror and point to his nose, mouth, cleft lip scar, and hair with equal comfort will be more at ease when faced with a question about his lip from a classmate. Thus the emotional "weight" that is given to discussions of facial difference is critical in influencing the attitude that your child develops regarding her facial characteristics. Feelings of shame or pity have no place when discussing these issues.

All children, regardless of age, need to have a simple reply to the question, "what happened to your face (lip, nose, cheek, etc)?" How children answer that question sets a tone for their interaction with peers. An unself-conscious reply that provides simple but accurate information is the best strategy. Confidence is reflected in your child's ability to make eye contact, his tone of voice, and his ability to convey an appreciation of the other child's interest in him. Educating your child in a matter-of-fact manner about the importance of his being a "teacher" with the other children will help ease his self-consciousness. He should be taught that many children are unfamiliar with his medical condition and questions are often asked out of curiosity, not malice. You also model appropriate responses each time you respond to question from a teacher, an acquaintance, or someone in the supermarket.

Success in school is at least in part related to a child's feeling of social acceptance. A child who has experienced acceptance and respect within her own family is more likely to exhibit self-confidence in social situations. This acceptance starts with a recognition and validation

of your child's feelings even when they are different from your own. If your child is fearful of attending school, you will be most helpful if you acknowledge that fear and communicate that you accept the fear as reasonable. A simple statement such as, "Meeting the new kids at school is kind of scary," validates your child's feelings and lets her know that that you understand where she is coming from. Repeated validation of a child's feelings enhances self-esteem because it allows a child to believe that her perceptions of the world are rational. Feelings of esteem in turn foster self-confidence and enable your child to engage her peers in positive social interactions.

Despite our best efforts most children, whether or not they have a facial difference, encounter some teasing during their school years. A self-confident child will recognize that this teasing occurs because of the other child's needs and weaknesses rather than allow the teasing to impact his own self-esteem. As parents we foster this perception by teaching our child ways of responding to the teasing that both preserve self-worth and increase our child's feelings of confidence. To this end, teach your child that teasers are generally looking for a reaction. They want the teased child to feel bad, to entertain the teasers friends through a reaction, or to behave in a way that gets the teased child in trouble. Your child can deflect the teasing by refusing to give the desired response and instead reacting in an unexpected way. Generally this means teaching your child to look at the teaser directly and letting him know how he feels about the teasing. Body language and tone of voice are very important when delivering a response—often more important than the words that are used. A statement such as "I don't like being called names; I have better things to do than listening to your taunts" delivered in a calm, but firm tone of voice that demands respect and followed by your child's determined movement toward a group of friendly classmates will often deter the teaser. To be effective, children need to practice responding to teasing in a safe environment, either at home or with a trusted teacher or counselor at school.

*Kathy Kapp-Simon, Ph.D. is a pediatric psychologist who currently works with the Northwestern University Cleft and Palate Institute. She has worked with children who have facial differences for 25 years.*

# My New Nose

By Christina Lemmo

I can remember the day earlier this spring when, while driving in my car, that the teasing from a neighboring car and its passengers really stuck in my mind. For some reason, my guard was down so that the comments really hurt. Throughout my life I have always been teased even as an adult, it is part of one's "life experience" when living with a cleft lip and palate. My reaction to that particular episode was not exemplary at all, but it served a purpose by allowing me to seriously consider having more surgery. "More surgery?" Did that thought come from me? Hello! Since when have I "chosen" to have surgery done? Isn't that why I stopped having operations after meeting the requirements for my rehabilitation. Surgeries on my face that started at the age of 6 1/2 weeks and continued to the age of 28. After a ten year hiatus, strange as it may seem, I was "ready" for more.

Luckily for me I already had a particular reconstructive/ plastic surgeon in mind and he came highly recommended. My former reconstructive surgeon had since retired due to medical reasons. Dr. X had been my surgeon since the age of eight. Now I would have to enter into a new relationship with a different surgeon—similar to breaking in a rookie. The surgical skills are his while the face "in his hands" is mine. His results will be the first thing that others see when looking at me. With all this in mind, I still decide to have the consultation and knew exactly what I wanted as results.

When we met, I explained my expectations - reduce the bulk from the tip of my nose; repair a previous cartilage graft which "fell" (literally) in to disrepair. I wanted my nose to be turned up or rotated—just enough to create a good (normal) appearance, without giving me a "Miss Piggy" nose. That we both could agree on this was a good first step.

Unlike the other surgeries that were done in the past, I went into the planning stages of this one basically prepared for the fact that insurance would not pay any of the related costs. "Okay," I gulped, "just how much is this going to cost?" The doctor told me the cost. Expensive, yes, but even so I decided to forge ahead. Then I had to contend with scheduling difficulties but after some negotiations, a new date was established. Much to my

surprise though, my surgeon was able to have the surgery covered. True it was a "nose job" but it was not being done for vanity but rather for approaching a more normal looking nose.

By now I had accomplished the first two P's—plans and price. Now for the dreaded third P—pictures, taken by medical photographers. They should be called medical mug shots. On July 31, I had my final pre-surgery consultation—those mug shots were covered with angles and degrees that would lead to my *third* new nose. He showed me a "before" photo covered by a plastic sheet reflecting the new contours of my nose. It was absolutely remarkable. On the basis of what was shown to me, I became increasingly more excited about the surgery.

Finally the big day arrives and I am prepared for the 4 hour ordeal. My doctors and I spend 15–20 minutes reviewing the plans for one last time. After the surgery and a little bit of time spent "recovering", I was able to go home. It didn't take long to hear what the reactions were from others—people looking at me. Those who looked at me saw the results almost immediately. "Great, I thought but, will the difference be so visible to me?"

As the person behind the nose (so to speak), I would probably be the last one to appreciate any changes that have been made.

I looked in the mirror and around the splint and couldn't believe what was, or more truthfully, wasn't there, which was about half my nose. The "new" me in the mirror had a shorter, thinner nose which was more equally shaped nose. The person in the mirror was me. Unlike the other two times that my appearance was drastically changed through surgery, I could appreciate it almost immediately. In turn, I could hardly wait to point it out to others. At that moment I could see that this new nose really belonged on this face. To me! It was worth every nervous thought and moment I have spent in the last few months while anticipating this surgery. This is my new nose, it fit, looked great on me. Even better than the last two. It is not "perfect" but after a journey of 38 years, it is one of the biggest steps towards "normal" that I have ever taken. Would I do it over again? As the saying goes it's as plain as "the nose on your face".

## Handling Questions After Treatment and Surgery

This column is a place for our younger members to share and explore issues. Each month we feature a new topic and different points of view. If you would like to pose a question or participate in providing answers please email us at [anng@aboutfaceinternational.org](mailto:anng@aboutfaceinternational.org)

### Question:

I am returning to school after having surgery. My appearance has changed and I know that people will be curious. How do I handle the questions and comments?

### Answer by Colleen Wheatley:

The first and most important issue to think about when dealing with these questions is your comfort level. Deal with the questions, as best you can, but don't feel you have to explain more than you want. It is a bit of a confusing time after surgery, because on one level you want there to be a noticeable difference, otherwise surgery would not have been a choice, but on another level change isn't always great and is sometimes hard to deal with.

My strategy to deal with these questions is short, simple and honest answers.

In most cases, you will have to explain to people that yes, you had surgery. Sometimes you may feel comfortable explaining about your surgery - what was done, what it was like to go through and why you had it. But, if you don't feel like going into such detail it's fine to answer: "I felt it was time", "I was ready" or even "I don't want to talk about it right now".

Never feel that you have to justify your reasons for having surgery. It is a personal decision and there is no need to defend yourself to people who have no idea what it's like to go through the process. These questions may seem offensive, but sometimes it could simply be people's curiosity. Try not to get defensive when dealing with questions and try to answer if you can. However, if questions asked by others make you uncomfortable, it's okay not to answer them.

Another important issue to deal with is when you have surgery in the middle of the school year. While it is important not to rush back into things before you are ready, it is also not a good idea to avoid it for too long. It is easy to get nervous about returning to school and see-

ing everyone again, but the longer you stay away from it, the harder it will be to go back.

After going through surgery, it can be a hard time; unfortunately the feelings of anxiety and confusion do not disappear over night. Take your time to recover physically and mentally. It may seem like a long process, but don't rush it. Deal with questions as best you can, but remember that your comfort level is the most important thing. You just did something that not a lot of people have to go through and it takes a lot of guts to do. So be proud and be confident of who you are inside and out.

### Quick Tips

- Give short, simple and honest answers
- It's okay not to answer questions that make you feel uncomfortable
- Take time to recover physically and mentally
- Be proud and confident of who you are inside and out

# Dates to Remember

The Tenth Annual MPI Auction  
Tuesday, November 13, 2001; 5:30-9:00 pm  
National Arts Center, Ottawa

All proceeds to go to AboutFace. For more information, contact Anne de Gobeo at Sam Jakes Inn at: 613-269-3711 x 436 or visit: [www.mpiottawa.org](http://www.mpiottawa.org).

Access to Success 2001  
Tuesday, December 11, 2001  
Toronto

This one day corporate forum introduces a variety of topical and esteemed speakers on current management issues, motivational issues, and training. For more information on this year's itinerary, call 905-713-3222 or visit the website at: [www.brickenden.com](http://www.brickenden.com)

8th Annual Gala—Voices of Children  
Saturday, February 16, 2002  
Fairmont Royal York Hotel, Toronto

Come and enjoy an evening of fun, laughter and great entertainment! The 8th Annual Gala will touch your heart with the *Voices of Children*. For an invitation: please call 800-665-3223 or visit our web site at [www.aboutfaceinternational.org](http://www.aboutfaceinternational.org) special events section.

Bay St. Hoops 2002  
Come join the fun as corporate hoopsters take to the courts in support of AboutFace. If you love to play basketball (men or women) give us a call or email us at: [annap@aboutfaceinternational.org](mailto:annap@aboutfaceinternational.org)

**MOVING?** Please let us know. Send your new address to your national AboutFace office.