

INSIDE

3

*Ask the Professional  
Acquiring a Facial  
Difference*

6

*The Team  
at B.C.'s Children's  
Hospital*

7

*Focus on Funders  
Bay Street Hoops*

9

*Youth Connection*

10

*Making and Fighting  
Medical Claims*

# Life is Worth Living

By Judy Maus

My story begins, almost 20 months ago. On May 2, 1999, I was spending a day in the country with a friend. We were biking down a country road near Caledon, Ontario. Although it was only my second time on a mountain bike, I was having a wonderful time and felt comfortable with the ride.

We had been out for a few hours and were making our way home. I have no idea what happened next, but whatever it was, it changed my life dramatically. We were allowing our bikes to coast down a gravel country road with a slight incline. My friend was ahead of me, but always looking back to make sure I was doing OK. I don't know exactly what happened because I don't remember. The thought is: I must have tried to gear down. Instead, I hit the front break by accident. I was thrown, violently over the handlebars. I had no way to break my fall and ploughed face first into the gravel road.

*...as much as my story concerns doctors and their skills... it is also a story of profound cultural shock.*

I was knocked unconscious and lay on the gravel, bleeding. When my friend turned around to check on me, to his horror, he saw me lying part way down the hill, on my back, with the left side of my face gone. He told me afterwards, he thought I was dead or dying.

I suffered lacerations and abrasions to my arms and knees but the most extensive injuries were to my head, face and neck. I was wearing



*Judy Maus one year after the accident*

sport sunglasses that had been purchased specifically for high-risk use, on the understanding that they were shatterproof. Instead, the lenses on impact exploded into several long pointed shards, and acted like a lethal razor blade. My left eye was badly mutilated by the shards of glass from the sunglasses. The eyebrow was detached. The lower eyelid was sliced away with most of the tissue lost, exposing my eyeball.

My nose was broken and badly sliced open from the inside the left nostril to the upper lip. As well the lower teeth tore up the inside lip.

The cheek was burned off by the gravel road, and something, a rock left a gapping hole the size of a coin on the left side of my mouth, again exposing the bone and teeth. Thank goodness my front teeth were not destroyed, only two broken molars on the right side of my mouth. There was

# News from Edward Street

by Anna Pileggi, Executive Director

## Recognizing our Best

Last year, the Board of Directors decided that AboutFace needed to formally recognize and publicly acknowledge individuals who help make this organization what it is. From that spirit came our new Volunteer Recognition Awards Program. Every year, AboutFace will honor key volunteers of our organization who have shared with us their time, expertise and vision. As a tribute to former members who exemplified a special dedication to our cause, AboutFace created two Service Awards in their honor. This year, at our annual Gala, AboutFace was delighted to present the awards to its first recipients.

### The Betty Bednar Community Service Award

This award is presented to an individual who has dedicated him/her self to supporting and serving the AboutFace mission through their work in the community and with those touched by facial differences. This year's recipient is Ms. F. Rebecca Thomson (loving known to many as Becky).



*Ms. F. Rebecca (Becky) Thomson*

In 1988, Becky lost her nose to cancer. While in hospital, she heard a radio interview on the Andy Barrie Show that changed her life forever. Becky decided to become a volunteer for AboutFace and with that she began a 15 year journey of supporting others, talking to schools, listening to fellow members, and sharing her story publicly. Today, Becky continues to work on behalf of AboutFace visiting other cancer patients and speaking publicly to audiences to help educate the general population. Her "Recipe for Life", an article she wrote for AboutFace some years ago, continues to inspire many and her own positive attitude and outlook gives hope and joy as well. We are very fortunate to have Becky on our team.

### The Dr. Richard Ten Cate Professional-Community Service Award

This award is presented to a health care professional from any discipline who dedicates him/her self to supporting the work of AboutFace and encouraging community involvement and outreach on our behalf. This year's recipient is Dr. Norman Levine.



*Dr. Norman Levine*

Dr. Norman Levine, pediatric dentist and Dean at the Faculty of Dentistry, University of Toronto, made himself available to AboutFace as a director and officer of the Board. Although a humble and quiet person, Dr. Levine has had a strong influence in all of us. His insight and thoughtful opinions have helped to direct and guide AboutFace.

In the community, Dr. Levine uncovered opportunities to enhance our visibility as an important community organization. He connected AboutFace to other dental professional organizations and to the students so that they may understand our cause and support our mission. Dr. Levine gave AboutFace a voice at the U of T Interdisciplinary Forum for over 600 Health Science students and faculty. Dr. Levine has enriched our organization in many wonderful ways.

## NEWSLETTER

Published by AboutFace International

ISSN 1191-5595

**AboutFace International**  
123 Edward Street, Ste 1003  
Toronto, ON M5G 1E2  
tel. 416-597-2229  
or 1-800-665-FACE  
fax 416-597-8494  
info@aboutfaceinternational.org  
www.aboutfaceinternational.org

**Charitable Registration**  
#12676 1410 RR0001

Executive Director  
Anna Pileggi

**AboutFace U.S.A.**  
P.O. Box 458  
Crystal Lake, IL 60014  
tel. 1-888-486-1209  
fax 630-665-8945  
aboutface2000@aol.com  
www.aboutface2000.org

**Charitable Organization**  
501(C)(3)  
AboutFace U.S.A. Director  
Rickie Anderson

# Acquiring a Facial Difference

by James D. Anderson, BSc, DDS, MScD & Todd M. Kubon, BA, MAMS

## Early days

When one acquires a facial difference, it is usually sudden and unexpected. A rapid series of events follows, that likely includes many medical consultations and surgeries. Decisions must be made rapidly, and commitments are acted upon with little time for reflection. It may be a life changing time filled with high anxiety. Nevertheless, people are swept along by events, leaving little opportunity to adjust. People can and do adjust, often at different rates, but the resiliency of people dealing with a new facial difference is remarkable. This adjustment is characterized by many of the following features.

The first type of problem facing patients who have an acquired a facial difference relates to the cause of the loss. If the loss was caused by some particularly traumatic event, there may also be symptoms of post-traumatic anxiety, such as sleep disturbances and nightmares. If a feared disease like cancer caused the loss, there is lingering concern about recurrence. In either case, the individual will be faced with the challenge of accepting the loss and continuing a normal healthy life.

## Loss

A person with an acquired facial difference has different issues to deal with than one who has a congenital difference. People who acquire a difference have to deal with issues of loss. Loss is a state of being without something one has had and valued (Peretz, 1970). Loss can be a very traumatic and painful experience. This triggers a set of emotions similar to the grieving process of having lost a loved one. It is normal for a person who is grieving their loss to go through stages of denial, anger and bargaining, depression and acceptance. The stages of this process may precede or follow the surgical/prosthetic rehabilitation. Depending on where one is in the rehabilitation process, these stages of grieving can affect how well one is able to cope with and accept the results of the rehabilitation process.

## Denial

Denial is often the first stage of the grieving process. A person uses denial as an unconscious defense mechanism so as not to have to deal with the pain of their loss. However, refusal to acknowledge painful realities, thoughts, or feelings can be detrimental to a person's psychological well-being. There are feelings about changes in identity, and how one will relate to

family and friends in the future and in turn how they will relate to the affected person. The facial difference has the potential to affect the social functioning of the person. Not surprisingly, this is the basis for anxiety about future relationships.

## Anger

Anger is the second stage of the grieving process. Anger is a strong emotion of displeasure for what we regard as a wrong toward ourselves. The anger is often shown toward family and caregivers that are trying to help, which seems inappropriate. However, an understanding of the process prevents this from becoming problematic during the care process. However, it can have an impact on the acceptance of the finished result of treatment if the affected person is still angry.

Coping mechanisms include developing an "attitude" that defies the problem. This takes considerable energy; so support mechanisms are important for the affected person. In addition, the person's previous social adjustment may help adjusting to the new situation.

## Bargaining

At this stage, the individual seems to accept the inevitability of the loss, but still looks for ways to diminish the impact of it. People seek ways to escape the reality if even for a short time, to delay the prospect of having to do the work in facing the reality. For example, people may choose to defer definitive rehabilitation treatment for what seems like poorly defined reasons. Under these circumstances, this choice is entirely reasonable. It's just that more time is needed to adjust.

## Depression

Facing the reality of a loss is hard work and it seems to be "uphill" all the way. It is not surprising then that a person may become depressed. Depression can be characterized by an inability to concentrate, insomnia, and feelings of extreme sadness, dejection, and hopelessness. It can last a short time, or it can persist for months. A person who has acquired a facial difference can feel hopeless about the future, and powerless to change it. These feelings need not go on indefinitely. Time and support can help an individual to come to terms with their loss.

*continued on page 8 . . .*

## Judy's Story

*continued from page 1 . . .*

also a deep slice to my collarbone and a broken vertebra in my neck.

I was taken by ambulance to the local hospital. They assessed the injuries, and in their wisdom they moved me by air ambulance to Sunnybrook Medical Center in Toronto. An emergency team of conventional and reconstructive surgeons worked on my face for three hours to try and put everything back in the right place. It is now obvious that they did a wonderful job, considering what they had to work with. But I can tell you, when I finally took a look in the mirror (weeks later) I was horrified at my appearance.

*While in medical terms, my injuries were not classified as “life-threatening”, to me, they couldn’t have been more so.*

While in medical terms, my injuries were not classified as “life-threatening”, to me, they couldn’t have been more so. I was despondent. The face in the mirror looking back at me was someone I didn’t know, and didn’t want to know. The major concern was my left eye—with extensive muscle and nerve damage as well as enormous amounts of tissue lost from the lower lid. The eyebrow had been successfully re-attached and my mouth re-sewn from the inside out. After a week in Sunnybrook, I was told it would be sometime before reconstructive surgery could commence on my missing eyelid.

I was sent home with bandages covering my eye and cheek, with the permanent damage yet to be assessed.

Two weeks later the bandages were removed from my eye and to my horror my injured eye had migrated inward towards my nose. The damaged outer muscles of the left eye could no longer hold their own against the muscles on the inside. As well the bottom of my eyeball was exposed. I was mortified and just couldn’t hold back the river of tears.

With the eyeball locked into the inside corner, the only way I could see or function was to keep the injured eye patched. Un-patched, my vision was double. I was told by the attending Ophthalmologist at Sunnybrook that nerve damage may recover, but it takes time, at least six months—maybe a year. Should the nerves not recover prism glasses would help me to see again or surgery could cut the muscles and straighten the eye but with some peripheral vision being lost.

I was referred to Dr. Hector McDonald as ocular plastic surgeon who for the next year would not only rebuild my eyelid but also nurture my spirit. What followed were six major operations. The rebuilding began and the process was slow. Being an Aries, patience is not one of my strong attributes, but Dr. McDonald’s quiet reminders that my progress would be one small step at a time (as healing had to take place) helped me along. The next eight months saw skin graft after skin graft. Cartilage from my ear to support the new structure, shunts in the eye duck to help the tearing and lots of hand-holding.

The surgical patches that covered my eye after the hospital stay were replaced by the pharmacy-bought patches. And later by fancy colorful patches made by a special girlfriend who is in the fashion business and believed if I had to wear a patch than I might as well have fun with it. All the eye patches now matched my outfits. This really helped my self-esteem. For a year I was monocular.

The nerves in my eye did not recover. So one year to the day after the accident, Dr. Steven Kraft of the Toronto Western Hospital, operated on the damaged eye. He cut the inner muscles, centered the eyeball, and reconnected everything. My double vision was gone. I no longer had to wear my eye patch to function. He told me that it would take a week or two to see normally.

So dark indoor glasses replaced the eye patches, as I was still undergoing surgeries to repair my eyelid. I have no feeling at all on the right side of my face and the pigmentation in the new tissue is considerably different in color than my normal complexion. So I use makeup to blend my new two-toned skin.

With more surgeries, and a little luck, I began to look much like I did before the accident. However, I will never be the same person again on the inside. For as much as my story concerns doctors and their skills or physical and emotional pain, it is, also a story of profound cultural shock. To me, that will be the ugliest scar and, ultimately, the most wonderful healer I will take from this experience.

For the last year, I have lived in the world of being facially different. I have experienced life from a different view and have learned, painfully, how the general public deals with those of us who look different. I now know how precious true

friends and their support can be. I know how hurtful and defeating negative reactions of others can be.

My first realization that my life had changed occurred when I was finally shown my face. During the first few weeks, I was simply too immobilized by my other injuries to do anything but convalesce. The only people around me were family and my closest friends. All were attentive, hugely supportive and very upbeat.

For a time, I was spared from the prospect of dealing with others, business associates, and strangers. While it was always on my mind, in a practical sense, I did not confront it. As time went on, I found my anxiety increasing and, as I said earlier, a desire to hide from the world forever overwhelmed me. In private, and sometimes, not so privately, I wept.

I had to venture out into my new world. My best friends recognized that and, in my heart of hearts, I knew it too. However, I was not ready to face the world. Friends called, sent cards and asked to visit. I wanted to see them but I was apprehensive about their reaction to my appearance. I had this deep-seated perception that my personal appearance was a condition of their friendship.

Recognizing this situation for the danger it held, all my strongest supporters began a program to help me overcome these feelings. They convinced me that the world would overlook my difference and treat me as the person I was in spite of my injuries. I wish I could say that my friends were right.

I finally got up the courage and strength to venture out. What I found, I have come to learn, confronts nearly all people with facial differences. People do react to unusual appearances in a wide range of ways. Some of them are not pleasant. A few are deeply humiliating and plainly unacceptable.

Unfortunately, we live in a world that is obsessed with physical appearances. We are constantly reminded that our worth is based on how we look. Great time and huge sums of money are spent trying to improve the looks that Mother Nature and our bad habits have given us. Advertisements, popular culture and what we see in our everyday life enforce this perception that the world belongs to the young, fit and beautiful.

There is nothing that is more the object of judgment in the physical assessment of each person than his or her face. More than any other part of the human body, it is taken as the measure of a person's self and intellect. I was a complete captive of

that mentality. However, I have now come to appreciate how much of my prior life, both personally and professionally was predicated on my personal appearance. I now know about the obstacles and prejudices with which people with facial differences must contend, and how challenging it can be.

People need to feel good about themselves and their lives. It's called a sense of self worth. Psychologists believe it is one of the most basic components in the makeup of the human psyche. People have to believe that they are wanted, valued and accepted by others. Most importantly, we have to feel wanted, valued and loved by ourselves.

*People have to believe they are wanted, valued and accepted by others.*

I know how important the positive support of all my family and friends was to my recovery, and all the emotional help I received added to my recovery, but there are so many who don't have the circle around them. AboutFace can help.

In the depths of feeling down, depressed and so sorry for myself, though I tried not to show these feelings, my Mother, would send me, at just the right moments, small messages of inspiration, to lift my spirits. Messages that made me feel: Yes, I will journey on! Yes, life is worth living! And yes, I will be complete again, not just physically but emotionally.

A special thanks to my medical team. A special "I love you" to three amazing families. They cried with me, they laughed with me, they encouraged me; they were always there for me—the Lawrie family, Maus family, and Stursberg family.

I know my journey is coming to an end. There are so many, the journey will never end, they are my heroes...

If you wish to share your personal story in our newsletter, please call 1-800-665-3223 or write [info@aboutfaceinternational.org](mailto:info@aboutfaceinternational.org)

# The Team at B.C.'s Children's Hospital

Its spring in Vancouver, British Columbia, the tulips and cherry blossoms are in bloom. Folks have been playing tennis and golf since Christmas. Vancouverites are boating during the day and skiing at night, enjoying warm sunshine and soft rain. What more could anyone want?

In this beautiful setting, the B.C.'s Children's Hospital serves the province at the tertiary level for pediatric care. The hospital provides 250 beds for in-patient care and over 70 ambulatory programs for outpatient care. The Cleft Palate/Craniofacial Program is one of these programs.

The team came together just over 30 years ago in response to increasing demands from B.C. communities for expert evaluation and treatment for children born with a cleft lip and/or palate or a craniofacial birth defect. In the early years, the first clinics were held in a small corner of an old house adjacent to the Vancouver General Hospital. The team was truly ahead of its time in its "multi-disciplinary" compliment of staff. Team members included (all part-time) a pediatrician, three plastic surgeons, a speech/language pathologist and an audiologist. During the first year of operation, it was soon evident that crucial orthodontic input was missing. Two orthodontists were recruited and actually provided hands-on orthodontic treatment in the basement during the clinic.

The program has grown and expanded over the past 30 years to become the second largest in Canada. Our team provides services for the approximately 2,200 patients in the province. There are 1,200 in active treatment and/or follow-up and the program receives approximately 200 referrals/yearly. The core team today is 18 members strong and includes a nurse/coordinator, pediatrician, speech/language pathologist, audiologist, social worker, four plastic surgeons, one oral surgeon, four orthodontists, and two ENT surgeons. Providing much needed clerical support is a full time secretary and a part time data manager. In addition, the team consults and partners with psychology, dietitians, physiotherapy, occupational therapy, neuro-surgery, ophthalmology, dentistry and orthopedics for more complex patients.

Geography can be a challenge for the families in B.C.. Many patients travel many hundreds of kilometers to access our team. With approximately 90 newborns and 700 clinic visits/year, our team is kept busy. Team evaluation begins at birth. Each child's care plan is individualized and mapped to ensure regular assessment. Delivering services "closer to home"



*BACK (Left to Right): Joyce Ternes, Psychologist; Doug Courtemanche, Plastic Surgeon; Mark Reichman, Oral Surgeon; Gary Derkson, Dentistry; Fred Kozak, ENT; Paul Moxham, ENT; Robin Jackson, Orthodontist; MIDDLE: Marilou Carillo, SLP; Keith Riding, ENT; Judi Haddy, Data Manager; FRONT: Sharon Vance, Secretary; Leonie Adler, Social Worker; Lorine Scott, RN; Cindy Verchere, Plastic Surgeon; Angie Loo, Orthodontist; MISSING: Lynn Tissington, SLP; Kathy Barker, Audiologist; Paul Pocock, Orthodontist; Carol Wishart, Orthodontist; Dorothy Sonya, Orthodontist; Christine Loock, Pediatrician; Graham Matheson, Prosthodontist; Don Fitzpatrick, Plastic Surgeon; Kevin Bush, Plastic Surgeon; Jeff Ludeman, ENT*

in the child's home community is essential. All team members work closely with community caregivers to provide ongoing speech therapy, orthodontic & dental care and audiology follow-up in the home community wherever possible. Good communication is key in making this work!

Parents are definitely our partners! Our program is proud to share our visit assessments and treatment plans with families and to involve them in the process. In addition we offer four parents support/education evenings per year providing a variety of educational opportunities for our families. Our newborn family network is active with families who have volunteered to provide family support to new families. We are proud to be able to offer our families two excellent resources for the issue of teasing. The first is "Teasing and How to Stop It" a video and workbook program developed here at BCCH by Dr. J. Ternes. This program is designed for older children and teens to learn techniques to deal with the teaser. Secondly, we are very happy with the success of "Unwrapping the Package" workshops developed by AboutFace. Since last year the workshop has been delivered to our parent group, and five classrooms in the Vancouver area.

*continued on page 8 . . .*

## Bay Street Suits Show Their Softer (and Sweatier) Side

By Jessica Witt, PR Intern

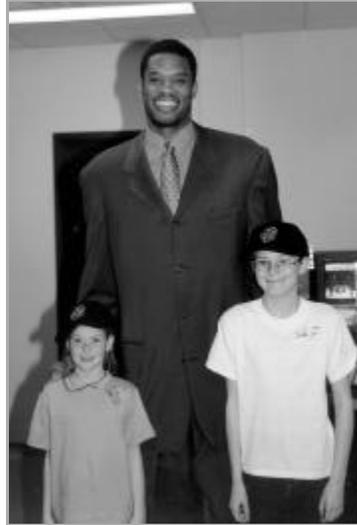
The Bay Street Hoops basketball tournament keeps getting better every year and this year was no exception. A sold-out event with 56 teams representing Toronto's finest law firms, corporations and financial institutions battled it out on the courts March 29–31 at the University of Toronto Athletic Centre. Over 750 Bay Street "suits" raised \$125,000 for AboutFace.

Not only was the tournament hugely successful in raising money and tons of fun for the players, volunteers and kids, but it was also a great opportunity to raise awareness in the Toronto-area about facial differences. Newspapers and television stations covered both the games and the kid's clinic getting the word out concerning AboutFace.

AboutFace members had the chance to take part in the tournament on the court and off. The kids got to play with at the Kid's Clinic. Members volunteered their time and worked like a well-oiled machine under Consuelo's direction and the AboutFace men and women's teams displayed their skills against some of the best Bay Street had to offer. A very special thanks to our volunteer players!

The Kid's Clinic on Saturday afternoon was definitely a highlight for everyone. The Raptor's mascot and star player, Antonio Davis had the kids (and parents) pumped. Over 100 children participated in the exercise drills and shooting practice, followed by an autograph and photo session with the big man, Antonio himself.

Nothing could have topped the three-day tournament better than a party at the Madison Pub for the players and volunteers. Food, drink, live auctions, and awards topped off the weekend of events that, like some of our teams, were truly unbeatable.



*Top: Antonio Davis of the Toronto Raptors teaching kids at Bay Street Hoops; Left: Antonio Davis with Nicole and Danielle; Below: the Raptor with the AboutFace kids*



## A Winning Combination

A very special thanks to Mr. Antonio Davis, The Raptors Foundation, and Pizza Pizza for hosting the Double D Triple Point event this year during the regular Toronto Raptor Basketball Season. For every DD scored by Mr. Davis, \$990 was donated to AboutFace. In addition, our name and logo was announced at every game and on the Mediatron! At the last game, Mr. Davis hosted a Pizza Pizza party for our

AboutFace families! Fun was had by all! A cheque in the amount of \$31,200 was presented to AboutFace on Center court April 17.

Thank you again Pizza Pizza, The Raptors Foundation, and of course Mr. Antonio Davis for a tremendous season and for your generosity and kindness!

## Acquiring a Facial Difference

*continued from page 1 . . .*

### Acceptance and support

Acceptance is the mental attitude that allows an individual to come to terms with their loss. Acceptance of the loss is an important last step for an individual with a facial difference to continue to function normally and happily in every day life situations. The facial difference is a challenge that must be met like any other challenge in life. A more positive approach to family, friends and work becomes evident, and one wants to get on with life, leaving the unhappy events behind. At this point affected people are much more receptive to the results of treatment, and more successfully adapt to any changes in routine required by the new circumstances.

### Conclusion

Normally, people are remarkably resilient and adapt amazingly well to treatment for facial differences. But it is recognized that this resilience relates not just to surgical or prosthetic treatment. The social and emotional side of treatment is just as important, and often needs just as intensive care as the surgical side. When this is done with a well-integrated multidisciplinary craniofacial team, very favorable results can be expected.

## The Team at B.C.'s Children's Hospital

*continued from page 6 . . .*

The B.C. families with children with Apert's Syndrome got together last fall for an afternoon of socializing. This was a very successful day for our patients and their families. The oldest was a young woman who is graduating from High School at age 17 years (she's off to university next year) and the youngest just an infant. The older members assisted the younger ones in making wonderfully creative arts and crafts, while parents chatted and exchanged stories. Folks left energized and enriched with a vow to make this an annual event.

To promote collaboration and community excellence our team is really excited to be able to provide an educational symposium this fall for community professionals involved the care of children with clefts. The symposium is titled "Cleft Lip and/or Palate: The Community's Frequently Asked Questions." The date is set for October 18-19, 2001. The symposium will target nurses, speech pathologists, family doctors, pediatricians, dentists, orthodontists, and audiologists. The

It is difficult however, for an individual to reach the stage of acceptance without support. Having support during a difficult and trying time can make all of the difference. Help is needed from family members and friends who can relate to their needs on a personal level. Family members provide for a sense of belonging at a time when the person can feel most isolated. Patient support groups, such as About Face, provide a network of individuals with common experiences and concerns who can provide emotional and moral support for one another. It's all part of the process.

Since it is well understood that these feelings are a part of the overall problem, psychologists and social workers are often included on the treatment team. They provide support for affected people in their relationships with their family, friends, and members of the health care team. They also help with the practical problems of navigating through the sometimes-complicated health care system. This kind of help has a strong effect on the overall success of the surgical or prosthetic treatments.

two-day event will offer an overview of clefting, team functioning, and genetics, a case study followed by breakout sessions and a social event.

We are busy throughout the year providing educational opportunities for medical, dental and nursing students. As well, we welcome professionals from all disciplines to observe on our clinic day. We have also hosted visiting orthodontists from China for a three-month experience in 1999 and 2000. This was a wonderful opportunity for us to share our knowledge and develop a better understanding of the treatment options in China.

The team at B.C.'s Children's Hospital Cleft Palate/Craniofacial Program is proud to work with AboutFace and to actively work to improve the health and well being of the children and families we follow. Watching children grow from infancy to adulthood is the best reward for any practitioner.

## Making Decisions About Treatment & Surgeries

Welcome to the AboutFace Youth Connection. This section will be a place for young people to share and explore issues and topics. Each month we will feature a new topic and different points of view from teenagers and young adults. 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 [anng@aboutfaceinternational.org](mailto:anng@aboutfaceinternational.org)

### Question:

“I have just decided that I am ready to make my own decisions regarding treatment and future surgeries. Do you have any advice on how to manage the process and make choices?”

### Khrista Boylan Responds:

Deciding whether to have more surgery is a tough decision. Some days you think that it could make you look better, and other days, you wonder if it's just too much trouble.

*I wanted to feel the way I used to feel when I looked in the mirror*

The decision is the hardest part. When I was younger, my parents and my doctors made the decision to have surgery for me so that my jaw would close better or my eyes would be more the same size. In my early twenties, I struggled with the decision for almost three years until the time came when I could no longer ignore the fact that I knew I could look better with surgery. It had nothing to do with my physical health, it was only for me.

I wrote stories and poems. I talked with friends who have had surgery and those who knew nothing about it. Many of them were shocked that I wanted to do something so drastic. Having had surgeries before, it didn't seem like such a big deal.

They thought that I looked fine. I knew that I could look better. I wanted to feel the way I used to feel when I looked in the mirror. And that is important because it's not just our reflection that we see.

To make myself comfortable with the risk of surgery, I learned as much as I could about the procedure, the recovery and the planned time I would need to be away from school. I tried to prepare my family and friends and include them in every step of the preparations. They were quite worried and felt they had done something wrong.

*Try to connect with someone your own age that has had surgery*

If you are worried about how you might look after your surgery, your surgeon can often make a computer-generated image and that can be reassuring. Another good idea is to try to connect with someone your age that has had facial surgery because even if it's not the same procedure, our feelings and worries are usually the same. Having someone to be honest with can be really helpful.

The bottom line is that it takes courage to make such a big decision. Regardless of how the surgery changes your appearance, the most rewarding part is that you make a decision to help yourself. Just remember to prepare yourself by becoming informed before you rush off to the surgeon. It is better to delay the decision until you feel ready and that could take years.

## Networking With AboutFace

Our networking program, links individuals and families to offer emotional support and to share experiences and information. If you would like to become part of the AboutFace Network please call us at 1-800-665-3223 or e-mail [info@aboutfaceinternational.org](mailto:info@aboutfaceinternational.org)

## Filing and Fighting Medical Claims

By Barbara S. Winer  
Claim Recovery Services, Highland Park, IL

You pay your premiums (high as they are!) and assume when the medical bills roll in, you'll be covered. No doubt most of you already know that this is one of the great American myths!!! So, let's start at the beginning and determine what you, an individual with or caring for someone with facial differences, need to do to get those bills paid by your insurance company.

1. Be familiar with your particular medical and dental insurance policies. Pay particular attention to definitions of congenital birth defect/deformity, cosmetic surgery, and the various therapies and other specific terms that apply to your individual situation.

2. You *must* get a benefits booklet from the insurance company or your employer.

*You must make your situation real to them so that they can understand what they and you are really facing*

3. Understand the benefits provided and exclusions defined within the policy. While much of the policy language may seem confusing, you have the right to demand that your questions be answered in plain English, understandable to the lay person. This may mean a phone call to Customer Service at your insurance company's office or details from your Human Resources person at work.

4. Find out the actual coding of each procedure being considered from your doctor and have that information available when you talk to others about this issue. While no insurance company will provide promises of coverage before bills are presented, you have the right to know what types of procedures are generally covered under each definition.

5. Make certain when you ask and receive information of any kind that you make a note of the conversation, including the date, time, the full name of the individual to whom you spoke and the number you called to reach them. Request a direct-line phone and fax number so you can contact that particular individual again even if they were not helpful. Demand to speak to a supervisor if you are not satisfied with the information you were given. If the answers were case-spe-

cific and helpful to you, write a letter to the person you spoke to confirming what he said and ask him to respond within ten days if your summary of the conversation was incorrect.

6. Other than routine claim filings, I send all correspondence to insurance companies Certified Mail, Return Receipt Requested. This frequently prevents them from throwing the mail away and leaves them dumbfounded when they deny they ever received it! This happens often, and I take great delight in letting them know who signed for the document!

7. Another preemptive step you should take when facing extensive and expensive procedures is asking your doctor what his experience has been in getting a particular procedure covered by insurance. While benefits vary from one policy to another, most specialists are familiar with insurance coverage problems. They can let you know what type of success they have had getting procedures covered and whether their charges are considered by most insurers to be over the "usual and customary (U&C)" for the area. Remember, doctors want to get paid, too, and working cooperatively on this issue helps you both. Sometimes if they have been successful with one or two insurance companies in getting significant payment, you will be able to convince your company to do the same for identical procedures unless they are specifically excluded from your policy.

8. Issues people with facial differences specifically must confront and overcome when playing the coverage game are the rarity of their conditions and the rarity of their specialists and the procedures they perform. Unfortunately, you will have to be responsible—again along with your doctors—for educating your insurance company about your medical condition. The people processing your claim are looking at a list of codes with definitions which determine whether your procedures are covered or not, whether they are congenital defects or cosmetic surgery, whether the therapy is mandated by your condition or not, and whether the charges are U&C or not. There are no gray areas—only black (not covered: over U&C) and white (covered: within U&C). You must make your situation real to them so they can understand what they and you really are facing.

9. Once a claim has been denied or underpaid, immediately write a letter to the insurance company advising them that you are planning to appeal the decision and will provide them with additional information to support your contention

that they were wrong. This is an important step since you usually only have 30–60 days to appeal a denial or U&C issue, and it must be done in writing. Remember, Certified Mail, RRR.

10. Now the research starts. First, read your Explanation of Benefits to determine the exact reason for the denial. If it is not stated there, write the insurance company demanding it. Refer back to your policy benefits booklet (you certainly have one by now!) to read more about the reason and to get a sense of what you need to do to show them they are wrong. Pay close attention to definitions, particularly “congenital,” “cosmetic,” and “reconstructive,” (although I hate to admit it, sometimes they may be right, and then you need to talk to your doctor about negotiating the bill.)

11. If you believe you were denied coverage unjustly, contact your doctor to discuss how he can support your position and if he is willing to do so, such as writing a letter to the insurance company and by providing medical records, including pictures and surgery reports, etc.

### *Find out what arguments have worked for others in the same situation*

12. Get referrals to medical journals, articles and other specialists in the field from your doctor, from medical libraries, off the Internet, from friends, etc. Contact the other doctors and enlist their support... if you win, they will find it easier to get payment the next time. Frequently they will review your files (for free or for a small fee) and write a supporting letter. Find out what arguments have worked for others in the same situation. Networking with ABOUT FACE members may provide assistance with this type of research.

13. Write your appeal letter outlining the reasons you believe the denial was unjustified using the actual language from the policy whenever possible to refute the basis of the denial and back it up with tons of supporting documentation: letters, journal articles, pictures, etc. If other insurance companies have paid for this procedure, let your insurer know that. These appeals are reviewed by more sophisticated people than the ones doing the initial processing, but they still need to be educated about your specific situation, so give them plenty to consider.

14. When you have a problem with underpayment due to medical charges over “usual and customary,” ask your doctor if other patients have gotten the procedures covered without that

problem (differentiate between in-network and out-of-network providers here since payments vary greatly for each). Get the specific procedure code numbers and names of other specialists who do the procedure. Contact these other doctors and ask what they charge for the procedure. Most are willing to provide that information, particularly when it is a rare procedure or condition. Find out what the AMA and your local medical association billing guidelines are for the procedure. Compare these with your doctor’s, and if his charges are within a reasonable range of what your research uncovered, write your insurance company and provide them with that information asking them to reconsider their findings. If the charges are way out of line, your doctor might be persuaded by this data to reduce his fee or accept the payment of the insurance company as full reimbursement. Remember, charges in your area will not be the same as other parts of the county or even of your state. The Internet is particularly helpful for this type of research.

I know this seems like a lot of work at a time when your hands are full with other problems and stresses—and it is. But the insurance companies count on you giving up. Saying “no” costs them nothing and reaps them big monetary gains if you do not persist in fighting for your rightful benefits. Just remember those big premiums and be persistent.

*Barbara S. Winer, was a litigation attorney before starting Claim Recovery Services in 1988. Located in Highland Park, Illinois, Claim Recovery Services represents individuals, estates, trusts and companies nationwide in handling medical and disability claim issues. Ms. Winer is certified by the Alliance of Claims Assistant Professionals and is committed to serving her clients with competence, professionalism and personal attention. She has the insurance, legal and medical expertise to maximize and expedite the benefits from all health and disability insurance policies. Contact Claim Recovery Services via phone - (847) 432-8290, snail mail PO Box 1218, Highland Park, IL 60035 or fax - (847) 432-7059.*

# Dates to Remember

**Family Day 2001: Understanding the Journey**  
**Saturday, October 13, 2001**  
**Toronto, Ontario**

This one-day forum is for parents and children affected by facial differences (newborn to 12 years old). The day provides hands on workshops, networking opportunities, and lots of fun. For more information or to register, please call AboutFace at: 1-800-665-3223.

**Cleft Lip and/or Palate: The Community's  
Frequently Asked Questions Symposium**  
**October 18-19, 2001**

**B.C. Children's Hospital, Vancouver, B.C.**

To promote collaboration and community excellence the B.C. team is providing an educational symposium for community professionals involved in the care of children with clefts. For more information call Lorine at: 604-875-3146.

**Access to Success 2001**  
**Tuesday, December 11, 2001**  
**Toronto, Ontario**

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: [www.brickenden.com](http://www.brickenden.com).

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