

LEADING THE WAY FOR PEOPLE WITH FACIAL DIFFERENCES

INSIDE

4
Ask The Professional
Types of Maloclusion

Being Different: Fueling my passion, my understanding, my dreams

By Amy Urbonavicius

Life Skills
Live Your Life

8
For Men
A Man's Point of View

9 Break Out & Have Fun

10 Smile at that Special

Resources
Nutrition After Oral
Surgery

I was born 21 years ago with a Unilateral Cleft Lip and Palate. Since then I have undergone many surgeries to correct this. People always ask me if it was hard and scary for a little girl to have undergone so much. My response is always no, it wasn't hard at all, I did what I had to. I knew no different so I never questioned or wondered what

would be like if I didn't have to have another surgery. When I was a teenager I would wonder why me, but I never once thought of the surgeries as a burden (actually, I got out of writing some final exams because of surgery!). The only thing I can remember hating about the surgeries was going to sleep feeling fine and then waking up feeling like my face didn't belong to me due to bruising and swelling. I did go through with it because I trusted that Dr. Zucker, Dr. Phillips, Cindy, the amazing nurses and the rest of the cleft team would have me back to normal in no time.



Amy circa 1985

the rest, and which was a life changing one was my jaw surgery. At my grade 8 graduation, I became very aware of how different my profile was from my peers when we decorated the gym walls for the ceremony with silhouettes of our profiles. I changed mine so that it was more like the others. I always tried to make sure that pictures were not taken of my profile after that. I was very self-conscious of it. When I was 14 years old, I was asked to speak on a panel for a conference that AboutFace was holding for teens with facial differ-

One surgery I had that sticks out from

ences. After the session was over, a girl named Kathryn approached Instantly, we became inseparable. We wrote back and forth, visited each other during holidays, for the first time I was proud of having a cleft lip and palate because I was no longer alone and I knew we under-



Amy and friend Kathyrn, 1999

Continued on page 3

Summer 2003 Volume 18 Number 3

News from Edward Street

by Anna Pileggi, Executive Director

Summer is upon us, and unlike most Canadians who wind down to enjoy the warm weather, AboutFace is winding up! This summer plans to be one of our busiest ever! In August, we will be launching a new fundraising event, releasing a new publication for clients, and a special manual for health care professionals.

On August 18th, AboutFace will host its inaugural golf classic at the Royal Woodbine Golf Club in Toronto. This new event is helping to generate new core-operating funds and to build community awareness. If you love golf, this is a wonderful way to support AboutFace and have fun! Space is limited, so book your foursome today!

As well, AboutFace is delighted to announce the release of two special resources.

Talking About Body Image, Identity, Disability, and Difference: A Facilitator's Manual is the second part of our Building Bridges Project. Drawing on our experience in conducting workshops, we wrote this manual to make it possible for others to implement similar programs. We have incorporated what we learned designing, organizing, facilitating, and supervising our workshops, and more importantly, what we learned from the women and men who have participated in the workshops. If you are a health care professional in Canada, you can order the manual for \$30.00 plus shipping and handling. For international orders (USA and abroad), the cost is \$50.00 (USD), plus shipping and handling.

Acquiring a Facial Difference: Skin Cancer is the newest booklet in our series. The booklet outlines key characteristics of various types of skin cancer; it outlines different treatment options, introduces the cancer team and provides some insight into the psychological process of acquiring a facial difference. You can order the book by going on line or contacting the office.

Finally, I would like to invite you to nominate someone for the AboutFace Volunteer Recognition Awards Program. We would love your input as to whom you feel is deserving of recognition for the work they do in the area of facial difference. The Volunteer Community Service Awards were established to recognize individuals who make a difference in the lives of others and in their community. Awards are presented to both an affected individual or parent, and a health care professional every year at the annual Gala (February). If you know someone who you think is deserving of one of these awards, please fill out a nomination form and send it to AboutFace, before October 31. For details on the program and a nominations form, please go online to www.aboutface.ca or contact the office.

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Charitable Organization 501(C)(3)

U.S.A. Director Rickie Anderson

Continued from page 1

stood each other completely.

We arranged to have our orthodontist appointments together at Sick Kids and we would joke around with each other and I'd try to get Kathryn in trouble with the orthodontist each month. We soon learned that we would be both having Jaw Surgery and the cleft team arranged it so that they both happened on the same day. It was an absolute dream come true! I had someone to talk to about my anxieties, my worries, and my progress afterwards. To prepare for surgery, I had to get pictures taken of my face as sort of "before" shots at the hospital. For my own records, I also asked my mother to take pictures of my profile too, which was a big step for me since I usually avoided this at all cost.

We both went in the same day, I went in first and when I woke up in the recovery room I asked the nurse where Kathryn was and I could see her feet poking from the bed across from mine. I was more swollen after this surgery than any other, I didn't have my jaw wired shut, but I was still very uncomfortable. All that mattered and what made the world of a difference to me was that Kathryn was there, that we didn't have to do it alone anymore.

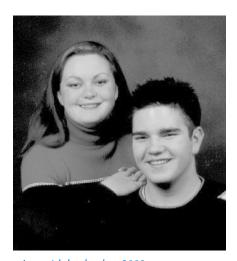
A year later, I had school pictures taken and when I got them back I couldn't believe the difference! It wasn't until then that my family and I could see the change the surgery had made in my appearance, and the confidence it gave me was amazing!

If you asked me when I was 12

years old would I have chosen to have a cleft lip if given the choice, without thinking I would have said I would choose not to. Today, if you ask me, after much thought and learning through this experience, I would definitely say that I would do it again. I believe that being different has made me the person I am today; it has given me my passion, my understanding, my dreams and has shaped the individual I am. I am currently going to school to become a nurse. I will use the gift I have been given to help others, and that is the only way to look at it. The process has been long but worth it.



Before surgery



Amy with her brother, 2003



After surgery

Continue on page 4

Types of malocclusion and their management

by John Daskalogiannakis, DDS, MSc, FRCD(C)
Orthodontist, The Hospital for Sick Children, and Bloorview-MacMillan Children's Centre,
Toronto, Canada

Malocclusion is a problem in the way the upper and lower teeth fit together in biting or chewing. In modern orthodontic thinking, any deviation from the ideal occlusion (fit of teeth) is a malocclusion. This includes situations ranging from plain old "crooked teeth" (where the fit of the jaws and back teeth is reasonably good), to severe skeletal malrelationships, that are mainly caused by poor fit between the upper and lower jaws.

Three main types of malocclusion exist (Angle Classification):

Class I, in which the upper and lower back teeth fit normally but the anterior teeth are crooked or misaligned (fig. 1);

Class II, in which the lower teeth (or the entire lower jaw) are too far back and/or the upper teeth (or the entire upper jaw) are too far forward (fig. 2); and

Class III, in which the lower teeth (or the entire lower jaw) are too far forward and/or the upper teeth (or the entire upper jaw) are too far back (fig. 3).

The above can be combined with one or more other features of malocclusion such as crowding, where there is inadequate space to accommodate the teeth within the dental arch; spacing, where there is too much space between the teeth; a crossbite, where one or more upper teeth bite on the inside of the lower teeth; an open bite, where there is no overlap of the lower front teeth by the upper teeth; a deep bite, where there is too much overlap of the lower front teeth by the upper teeth; an increased overjet (commonly known as an "overbite"), where the upper front teeth project too far forward of the lower teeth, etc.

When a patient has a dental malocclusion, the problem only affects one or more teeth. In such cases the treatment most commonly consists of standard orthodontics (braces) to align the teeth and place them in the ideal position within the dental arch, as well as relative to the teeth of the opposite jaw. This may involve the removal (extraction) of teeth if the analysis that the orthodontist performs before the start of treatment shows that the esthetics of the face or the health of



Figure 1



Figure 2



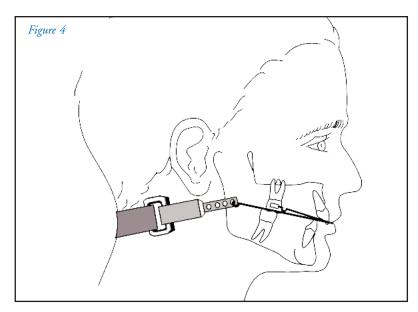
Figure 3

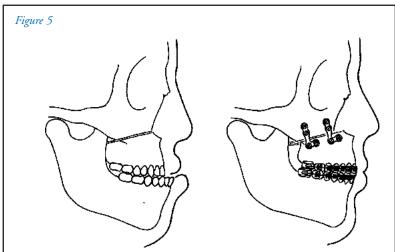
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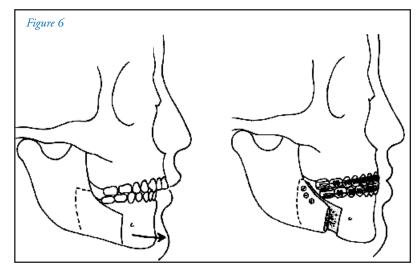
the teeth would be harmed if an attempt were made to fit all of the existing teeth within a small jaw.

When the origin of the malocclusion is skeletal, the type of problem and the age of the patient are very significant in the treatment plan decision. Some types of malocclusion can improve with the right therapy, provided that the patient is still actively growing (girls under the age of 11 or boys under the age of 13). For example, if a patient has a skeletal Class II malocclusion because of a lower jaw that is positioned too far back compared to the upper jaw, the appropriate therapy can use the patient's growth potential to make the lower teeth fit better with the upper. This type of therapy is called growth modification. A similar type of approach is the use of the "dreaded" headgear (fig. 4), an appliance that uses a heavy wire bow that attaches to braces on the upper back teeth, and a strap around the neck or head which delivers a posterior force to the upper jaw during the growth period, in order to correct a Class II malocclusion that is due to the upper jaw being too far forward compared to the lower.

However, if there is a moderate-to-severe skeletal problem, or when the patient is past their growth spurt, the treatment often is a combination of braces and jaw (orthognathic) surgery. In this way, a Class III malocclusion that is due to underdevelopment (hypoplasia) of the upper jaw (as is commonly the case in patients with a unilateral cleft of the lip and palate) can be corrected by moving the upper jaw forward surgically (fig. 5). Similarly, a Class II malocclusion due to a small lower jaw (as, for example, in patients with Pierre Robin sequence, or in some patients with an isolated cleft of the palate) can be corrected by an operation to bring the lower jaw forward (fig. 6). These operations are performed under general anesthesia, with incisions that are done inside the mouth to avoid any visible scars. The procedure takes a few hours and typically involves a hospital stay of two to four days. In the vast majority of situations the upper and lower teeth are no longer "wired shut", as was the case earlier on, and the patient can open and close their mouth from the first day after surgery.







* Figures 5 & 6 courtesy of Oral and Maxillofacial Surgery by Larry J. Peterson, ISBN 0-8151-6899-0, Mosby-Yearbook, 1998.

Live your life

By Michael Bungay Stanier. Michael is an AboutFace member. He has a cleft lip and palate, was a Rhodes Scholar at Oxford University, and is a life coach. He helps people get more of what they want into their lives.

Feeling stressed

There aren't many of us who don't feel stressed out some of the time. While some level of stress is actually not a bad thing – it can keep things exciting – too much just makes for a miserable life. Here are two ways to help manage your stress.

Sphere of control & sphere of influence.

In any situation, the stuff that's going on in your life can be divided into three basic categories.

- The stuff you can control what happens is up to you and what you do
- The stuff you can influence you have some ways of trying to get the outcome you want, but in the end it's not up to you
- The stuff beyond your control and beyond your influence this just happens, no matter what you do

Here's the secret. A lot of people try and control the stuff they can only really influence – and that's what causes the stress.

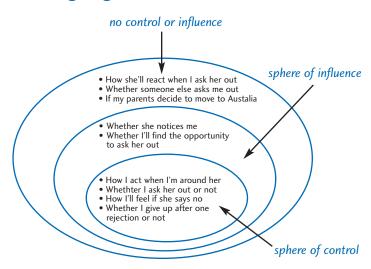
Step back and get perspective

To understand just what falls into what category, you have to step back from the situation and get a little perspective. Here's a tool that helps you do just that (and I'll work through an example, so you can see what I mean).

First, think of a challenge you have in your life that's causing you stress. Then, using the model below, fill out the spheres: what can you control, what can you influence, and what you can do nothing about?

I've given an example, using this challenge: "I'm too shy to ask out a person on a date." (I definitely had this the whole time I was a teenager).

Asking a girl out for a date



What do you do with this information?

Once you know what is what sphere, then it's clearer how to act about it

- In the Sphere of Control, you should be working hard to do what you want to do so you get what you want to get. Even if it's the tough thing to do (for instance, ask her out), you know that you alone are responsible for making it happen (so, no playing the victim role if you chose not to act)
- In the Sphere of Influence, you should be doing what you can to make things go the way you want, but you should also not worry about the outcome it will be what it will be. That's a tough thing to do, but if you can manage it, it's a great weight off your mind
- In the No Control, No Influence Sphere. The best thing to do here, whatever happens, is to throw up your arms in the air and say, "How fascinating!" There's nothing you can do about it, so you may as well laugh!

6

The other way of reducing stress

The second way of reducing stress is simple (which doesn't mean it's easy). One of the great causes of stress is having lots of things on the go and not yet finished –all the different projects mount up and start making us anxious.

Here's an exercise:

- First, write down all the various projects that you have going on in your life. The list should include:
 - projects at work or school (finish the team budget, write an essay for my English class)
 - projects at home (sort the basement out, tidy my bedroom)
 - on-going projects (get the bills paid by the 25th each month, walk the dog)
 - and the projects that exist as a sort of nagging reminder (try and get the family to eat healthier food; exercise more often).

- My guess is that once you've written them out, you'll be amazed at how much you have on your plate. So while you're here, acknowledge that you do a pretty fine job managing all of these things at once!
- Then, decide which ones you want to tidy-up and get off your list. You have two ways of doing this. Either tackle the project and complete it (actually sort the basement out). Or postpone/abandon it (the basement's not going to be sorted out until next year/ever, and I'm fine with that).

Reducing the number of unfinished projects in your life will reduce your stress.

I'm interested to know whether this has been useful. Email me at Michael@MaidaCC.com to let me know what you think.

NEW RELEASE!

AboutFace is pleased to announce the release of a new resource booklet

Acquiring a Facial Difference: Skin Cancer

This publication outlines the various characteristics of facial skin cancer and different treatment options when cancer affects your appearance, such as reconstruction or prosthesis. In addition, it outlines the psychological transition individuals go through from diagnosis to rehabilitation, as well as tell two personal stories of survivors.

To order a free copy of the booklet, please contact AboutFace at 1.800-665.FACE (3223) or go online to www.aboutface.ca A special thanks to The People Bridge Charitable Foundation for funding the production of this booklet.

CELEBRATE GOOD TIMES

HONOUR SOMEONE YOU LOVE WITH A GIFT TO ABOUTFACE

The season is upon us where many celebrations will take place to honour those we love... wedding, graduation, confirmation, bar/bat mitzvah, birthday, communion, etc.

You can honour your loved ones with a gift to AboutFace and we will send a card in your name to your guest of honour and list the occasion in our newsletter! Your gift will make a difference!

For more information or to order free gift cards, contact AboutFace at 1-800-665-3223 or e-mail us at info@aboutfaceinternational.org

A Man's Point of View

By Barry Strader

Recently, I was asked to write about deformity from a man's point of view. Well, it seems I'll be talking of something from which I believe both men and women with differences suffer from alike. For I think it isn't less painful for a man to be told he's ugly, than for a woman. Unfortunately in this world, in some people's mind, deformity means ugliness.

At the beginning of our life, we are not conscious of our image in a mirror. It takes some time before we get to understand we're actually seeing our reflection. I don't remember the first time I understood this, but also I don't remember feeling ugly either. I do however, recall as a child feeling somehow different and a little apart.

I spent my childhood in a village where almost everybody knew me and were nice to me. A cherished childhood with no dangerous world to face. Only a few times did I hear some kids tell me that I was ugly. Yet today, I hear it more and more, from adults and children alike. I will probably hear it until the end of my life. It's part of the game, it hurts.

It's possible to be proud of being different. For if difference didn't exist in this world, this world wouldn't exist. Not only because everyone of us is different in a special way, but also because there would be no reason to develop comprehension and tolerance, there would be no reason to love someone else.

But it doesn't seem possible to be proud of being ugly. I learned that AboutFace has a program to increase self-esteem among children with differences. I believe it may bring lots of good. I also believe that nurturing a feeling of pride wouldn't hurt.

We are part of this world and we have a role to play in it. Perhaps more important than we think. For fighting for defference is like fighting for conservation, for evolution, or for love.



BC Hike in support of AboutFace

Join Arleta Starzyk and friends on the 2nd annual morning up the Squamish Chief hiking trail. The hike began last year when a group of friends looking to raise money in support of Arleta while she was recovering from her mountain biking accident. This year, all donations from the hike will go to AboutFace. The hike is scheduled for mid October 2003.

About the hike:

There is something for everyone in Squamish, BC. It is approximately a 6.4 hike with 2000 feet elevation change. If it is a head throbbing, eye-bulging workout you desire, the Chief delivers. If it is a walk through a beautiful forest, past streams, with friendly conversations and incredible vistas, the Chief also delivers.

For more information, email Arleta at Arleta.Starzyk@creo.com.

Do You Love to Run?Then come RUN with US!

AboutFace is proud to be associated with the Scotiabank Toronto Waterfront Marathon on Sunday, September 28th, 2003

You can run the full marathon 42km or The half marathon 21 km Run or Join the family 5 km walk

If you love running or walking and would like to participate in this event, contact AboutFace 416-597-2229 x24 or for details on the marathon, go on line to

www.torontowaterfrontmarathon.org

We invite you to join the AboutFace Waterfront Marathon team!

BREAK OUT & have fun BC Family Retreat

Co-sponsored by: AboutFace International and BC Children's Hospital - Cleft Palate/Craniofacial Program

By Rene Tait

On the weekend of July 18 - 20, 2003, British Columbia had it's first annual gathering of families with Aperts syndrome. Aperts syndrome is rare with an occurrence rate of approximately one in every 160,000 - 200,000 live births. Children born with Aperts syndrome undergo numerous surgeries during their growing years. Often families who have children with Aperts syndrome never meet another family like them and this can lead to isolation for the family and for the child as they grow up.

The goals for this year's gathering were twofold:

- 1) For families, intimately involved with Aperts syndrome, to meet and gather for a non-threatening, relaxing, and fun time, and
- 2) To begin networking for the building of possible future friendships.

With the support of the event's two co-sponsors, these goals were amply met. Attending the event were seven individuals with Aperts; two adults and five children. At one time, the event had approximately 35 people gathered together.

We began the weekend with an evening 'Meet and Greet' where the goal was to settle in and get comfortable with each other. The children took to each other right away and entertained themselves very well. They even began to serve the adults some of the snacks while they sat and chatted.

On Saturday, the only planned event was a gathering at the local fire hall for a Barbeque. There were things to do for all ages and even the rain and a major fire call did not dampen the spirits of the attendees. In the evening, the families fed the 15 - 20 firefighters returning from the 3 - 4 hour fire call; it was greatly appreciated by the men who were very tired and hungry. On Sunday, the families all met for a Brunch that the host hotel puts on. The attendance was so large that the group had to be moved to a private location in the local lounge.

There the families ate, and made plans for the next gathering. Off times were spent swimming, taking the surrounding community, and meeting in small groups. Pictures and goodbyes were tearful and promises to meet again before next year were made. All in all, the event was a success and the consensus seems to have been that a good time was had by all.

A big thank you goes out to all the families who attended and to those who couldn't but will next year, and also to all the people who made the event a success.



A very special thanks to the Tait Family for having the vision to plan this event, and the spirit to make it come true!

Thank You Richard, Rene, Jennifer and Julia for all your hard work!

Co-sponsors:

AboutFace International B.C. Children's Hospital - Cleft Palate/Craniofacial Program

Community Partners:

Comox Kiwanis Club
Dr. Paul Helpard's staff
Coast Westerly Hotel & Jenn Tait
Quality Foods
Friends of Julia
Western Family Foods
Fish 'n' Stitches
Comox Fire Department & The Firefighter's Association

Smile at That Special Face!

Prepared by Lorine Scott RN BScN BCCH Cleft Palate/Craniofacial Program

Ever felt 'different'? Imagine that you joined a new club, and walked into the room for the first meeting only to find you don't know anyone; your friend is late; everyone is dressed in a special uniform and you are not. Would you feel conspicuous? Would you feel uncomfortable? Would you feel alone? A person smiles at you, a friendly face, you introduce yourself and the awkward situation is behind you.

All of us have probably experienced these feelings at one time or another.

Now imagine you have a facial difference. 'Standing out' in a crowd can be an every day occurrence. The question of 'will my child be accepted' is one of a parent's greatest fears. If their child is unable to develop skills to cope with social encounters, and continues to be faced with situations where they feel shy, awkward, conspicuous, and not included, social isolation, damaged self-esteem and very hurt feelings can often be the result.

Often, situations where we encounter people who may look different from us make us feel uncomfortable; we don't know how to act or what to say; we are very curious but don't want to ask questions. Most often we look away or move away to avoid contact; anything to avoid the awkwardness that we are feeling. Sometimes we stare. None of these behaviors are helpful and

they do nothing to ease the situation for anyone. They do cause hurt feelings and do contribute to society stigmas.

The great news is that each and every one of us has the power to change the situation. No matter how young or how old, we all possess the most amazing means. Our Smile! This simple 'at the ready' tool is easy to use and requires

no practice. It encourages, coaxes, reassures, and above all shows acceptance. Our smile makes the child feel welcome and is especially welcomed by par-

ents and family members as it indicates our wish to include them. Our smile sends an instant message that we are friendly and open to striking up conversation. When we smile at someone, we instantly get a smile back. Wow! Never underestimate the power of your smile. Get out there and smile! You may make someone's day very special, just a little bit easier and you may make a new friend.

The Cleft Palate/Craniofacial program at BC's Children's Hospital provides services for children with facial differences and their families on issues like teasing, peer relationships, school integration etc and in association with Aboutface (an international support group) works with local schools to incorporate the acceptance program 'Facing Differences' into the school curriculum.

Nutrition After Oral Surgery

fter any oral surgery, there are many important things to Aremember like oral hygiene and proper care of the surgical site. This is very important to prevent infection and encourage healing of the surgical site.

Another important element following oral surgery is nutrition. Often, people forget about nutrition because eating is difficult and food choices are limited. However, it is also a critical time for boosting the nutrient and calorie intake to help recovery.

Here is a list of some helpful hints during this difficult time.

- 1. Cut or grind food into small pieces and mix with cream sauces.
- 2. Make rich soups of creamed or blended meats and add a variety of vegetables, beans, lentils, soybeans, etc, to boost nutrient value.
- 3. Add eggs and cheese to increase protein.
- 4. Use milk instead of water for hot cereals.
- 5. Avoid carbonated drinks and sugary foods.
- 6. Refrain from using a straw as suction can cause other
- 7. Brush or rinse after every meal and at night before going to bed.
- 8. Use child size toothbrushes with soft bristles because they can get into tight spots for better cleaning.

Always talk to your oral surgeon, hygienist or nutritionist about what you could eat after surgery. Here are two excellent resources on this subject that provide a variety of tasty and well balanced meals for such times.

a. The Non-chew Cookbook, by Randy Wilson, ISBN 0-9616299-0-8

b. Drink to your health, by Denise Wolford, Dallas, Texas

High Protein Milk Shake

You can make a variety of high protein milkshakes in almost any flavour. Use this simple recipe and enjoy!

1/2 cup of your favourite fruit – strawberries, banana, orange juice, chocolate or butterscotch 1 scoop of vanilla ice cream

1/2 cup of milk

Put all ingredients in a blender and blend at low speed until smooth.

Mango Frappe

1 1/2 cups chopped mango or banana 1/2 cup milk

3 packets of Equal 1 tablespoons limejuice

1/2 teaspoon vanilla

6 ice cubes

Freeze chopped fruit for about 30 minutes. In a blender, combine the fruit, milk, Equal, limejuice and vanilla. Cover and blend until smooth. With blender running, add ice cubes through lid. Blend until thick and slushy. Pour into chilled glasses. Makes two servings.

11

Dates to Remember



Family Day 2003

Saturday, October 25th, 2003 Sheraton Centre Hotel Toronto Toronto, Ontario

TRANSFORMATIONS:

STRENGTHENING, ADVOCATING AND CELEBRATING OURSELVES

Join us for a fun filled day on October 25th, as we bring kids, professionals and parents together to learn, share and meet. Parents will enjoy the various panels and workshops, professional input, and networking with others. Kids will love the interactive programs, and teens can break free in an exclusive program for teens only. For more information, contact AboutFace at

www.aboutface.ca
email at info@aboutfaceinternatinal.org
call 1-800-665-3223 for a registration package

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

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