

AboutFace

LEADING THE WAY FOR PEOPLE WITH FACIAL DIFFERENCES

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Ellen – Giving Back

My name is Ellen Cappon. I was recently invited by AboutFace to discuss my career path and share some of the experiences and insights one 'faces' while living with a facial difference.

I was born into a large family and being the eldest of seven, I can't remember a time when I was not around children. For most of my childhood I lived in Pointe Claire, Quebec in a neighbourhood where everyone knew everyone. My family, friends and a few special teachers were the foundation of a vital and supportive network. I found the consistency of family, friendships, neighbourhood families and school to be a great asset when it came to growing up. For me, that consistency lent itself to easier acceptance from others. I have a large port wine birthmark, which covers a good portion of the right side of my face.

I can remember being asked about my birthmark by neighbourhood children and at times struggling to find ways to explain it because I was such an incredibly shy person. I can recall incidents where people who did not know me were particularly rude and mean. I felt very hurt, angry and embarrassed at these times and clearly needed to develop strategies to deal with people in these unpredictable situations.

Only through experience and maturity was



I able to discover my own comfort level and style of dealing with a facial difference. As a youngster, it is difficult to forecast your ability to feel empowered by this process.

One thing was for certain though, facial difference or not, I always wanted to work with children. It just seemed a natural thing for me to do!

I started out babysitting at an early age, moved on to volunteering, then worked at summer jobs as

a camp counselor. Following a family move to Oakville, Ontario I attended George Brown College in the Child and Youth Worker Program. This program trained students to work with emotionally disturbed children in a variety of settings.

I completed field placements in a maximum-security facility for young offenders as well as a group home for children who were permanent wards of the Children's Aid Society. In 1981, I joined the Halton District School Board and continue to enjoy my job as an itinerant Child and Youth Counselor working with elementary students who have a variety of social, emotional and behavioural needs.

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News from Edward Street

by Anna Pileggi, Executive Director

Happy New Year!

I hope this newsletter finds you well and full of aspirations for the coming year. At AboutFace we look forward to the year ahead, as it will mark some major milestones in our organization's history.

As we approach our 17th year in service, we are proud of our past and excited about the future! Over the past few years, AboutFace has established itself in the community through key programs.

- Connecting with parents early on through the newborn outreach program;
- Talking to kids in schools about differences with our school program;
- Sharing information and personal stories through our newsletter and publications;
- Working with individuals on skills in workshops and conferences;
- Building awareness about the cause and fostering acceptance in society.

These activities have become cornerstones for AboutFace, the foundation of which we were built on. As we move forward with the times, so do our programs and services. With the help of key individuals and sponsors we are reaching new heights!

- Our website is developing into a resource and information site with many personal stories, medical and support resources, and other articles of interest. In the coming year, we plan to make it more interactive.

- Our school program is almost ready to be released in its new format! Facing Differences is our new independent program that will provide educators with accessibility and flexibility to teach kids about facial differences and diversity issues in general. The program will be released in Spring 2002!
- Building Bridges, our adult skills program is in the final stages too! This summer, Building Bridges will release a tool kit for adults with facial differences and a resource for health care providers to give them practical strategies to work with individuals with facial and physical differences.
- To strengthen our relationships with Canadian Health Care Providers, AboutFace will be creating a database of professionals working in the craniofacial field. Our goal will be to bridge the gap between hospital and community for our shared clients by strengthening our relationship.

These initiatives are all in the works and we will keep you abreast of the developments as they emerge. Your continued support is very much appreciated and key to our success. Thank you to all our donors and sponsors for 2001! If you haven't given to AboutFace in the last year, I ask you now to please give so that we may continue to support the children, individuals and families who need us most.

NEWSLETTER

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AboutFace U.S.A. Director
Rickie Anderson

"What causes social anxiety and what can be done to cope with it?"

by Suneeta Monga, MD, FRCP(C), and Todd M. Kubon, BA, MAMS

Suneeta Monga is a child and adolescent psychiatrist in the Anxiety and Mood Disorders Clinic at the Hospital for Sick Children and the Centre for Addiction and Mental Health - Clarke Site. Todd Kubon is an Anaplastologist in the Craniofacial Prosthetic Unit at Toronto Sunnybrook Regional Cancer Centre.

Living Life with a Facial Difference

Whether you are born with or acquire a facial difference during your life, you will be faced with the challenge of adapting to a world that often places importance on appearance. Learning to live with a facial difference can be more difficult for some than for others. You may often worry if there is truly something wrong with you, or you may even feel guilty about desiring to look normal. The importance of looking normal can even become an obsession and the thought of going out in public with a facial difference can be terrifying. Undoubtedly, you will contemplate having a procedure to improve your facial appearance with the hope that some how it will make facing the world a little easier. Although facial reconstruction can improve your physical appearance and have an impact on your self-esteem, it is important to recognize that it may not solve all of your problems.

A person who is contemplating facial reconstruction should discuss their motivations for treatment and expectation of treatment with a multidisciplinary craniofacial team. Feelings of guilt, inadequacy, obsession, depression, or anxiety associated with a facial difference can be indicators of underlying emotional disorders and require attention beyond surgical or prosthetic treatment in order to achieve overall success. Since it is well understood that these feelings are often associated with a facial difference, psychiatrists and psychologists are often included on the treatment team. The scope of this article is intended to give the reader an overview of how to identify pathological anxiety in one's life and how to take steps towards coping. Whether or not you are contemplating surgical treatment, these emotional issues are serious health concerns and should be addressed.

Anxiety

Anxiety is an overwhelming emotion of apprehension and fear often marked by bodily distress such as nervousness, tension, and sweaty hands. We all feel anxious in different situations. Some individuals, however, feel anxious in all situations thus causing significant distress for them. For example, many individuals feel some anxiety when meeting new people or on the

first day of a new job, however, most individuals do not feel continuously anxious in such situations. When we feel so anxious, fearful and worried that it interferes in our day to day lives, we call the anxiety a disorder.

An Anxiety Disorder is a biological, biochemical disorder that develops in some individuals. Our understanding of the exact chemical cause is limited. Many researchers are studying this disorder of the brain and we know that the neurotransmitter serotonin is involved. Neurotransmitters help the brain process information correctly. People who experience an abnormal amount of anxiety are believed to have abnormalities in their serotonin system. Often, we see a clear history of anxiety disorders in families and there is evidence to suggest that anxiety disorders are genetically based. However, just because a parent has an anxiety disorder does not mean that their child will have an anxiety disorder. For someone who is genetically predisposed to developing an anxiety disorder, important events or circumstances in one's life can increase their risk for developing an anxiety disorder. Stressful and traumatic experiences, as well as continual exposure to negative environments, such as abuse or harassment, may exacerbate our anxiety levels. Sometimes individuals develop an anxiety-related syndrome known as Post-traumatic Stress Disorder (PTSD).

There are certain criteria that must be met to diagnose an Anxiety Disorder. Psychologists and medical doctors, usually psychiatrists, are the ones who will make the diagnosis.

Social Anxiety

Social Anxiety is one of several anxiety disorders that may occur. Social anxiety is a disorder in which an individual feels very anxious and uncomfortable in social situations or when meeting new people. In social situations, the socially anxious person may avoid speaking, eating or drinking in front of others. They may avoid social situations all together and stay at home wishing that they had enough courage to go out. Social anxiety is different from shyness. Shy people may feel a little awkward or uncomfortable when meeting new people, or going

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Through The Lens – AboutFace Family Day 2001

By Dawn Mulder

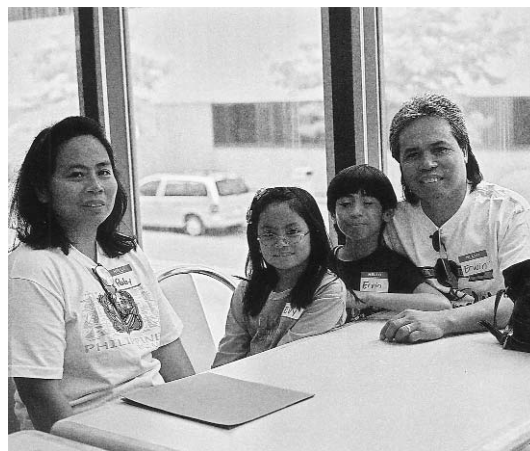
I was fortunate enough to experience the AboutFace family day from behind the camera. My main goal was to capture the day the way it happened, to create a memory, and tell the story. When I loaded the film and watched the day begin, I saw nervous little faces peaking from behind Mom's and Dad's skirts and pants. We all gathered in the auditorium to start and were greeted by the improv comedy of "The Parts". I saw those nervous looks turn into smiles and laughter and the uncertainty melt away.

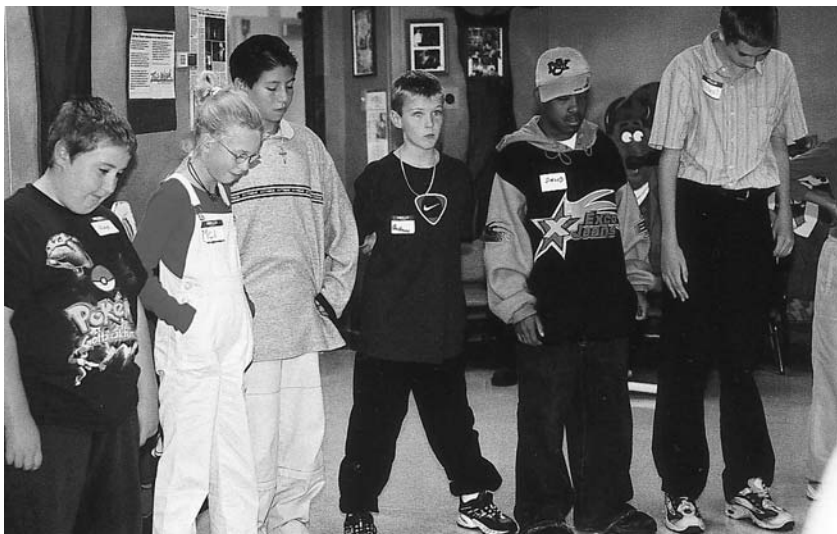
As the children started their activities for the day, the parents settled in for some discussion and sharing. The kids were grouped by age and introduced to one another through games that allowed them to meet others with facial differences, similar and different to their own. I watched the children slowly find comfort with each other. It is an extremely rare occurrence for these kids to be together in an environment fostering fun and enjoyment. The comfort level continued to increase as the children shared tickles, smiles and giggles. My lens allowed me to be invisible and let the happiness go on uninterrupted.

At the end of an eventful day, parents were greeted by their children who had made new friends, shared stories, and most importantly found a sense of belonging, if even for a day.

I am thankful for the opportunity to be part of such a wonderful day and to view it through the lens' eye.

THANK YOU!





*A very special thanks to
**The Hospital For Sick Children
Foundation**
for their financial support of Family
Education Day 2001.*

*In addition, we would like to thank
all the staff, volunteers and families
who helped make this day both fun
and educational.*

How dads relate to their child with a CFD

by Bruce A. Gallagher

The arrival of a newborn can be a time filled with both joy and sorrow. Such mixed emotions are experienced by both of the new parents. However, if the child is born with a craniofacial difference (CFD) or chronic illness, the shock and mixed emotion may turn into confusion and a desperate search for the possible answers to why this has happened.

There has been a considerable amount of research that has concentrated on how the parents react to the birth of a CFD or chronically ill child. I hope that by presenting a few of these reviews on fathers reactions to the birth of a child with CFD and chronically illness that, you may realize the feelings and thoughts that you might have are not unique to yourself.

What are the father's reactions to the child:

Cummings (1976) found that fathers of a chronically ill child were more negatively affected by their child's illness in such areas as, feelings of depression and more negative feelings with regards to fathering experiences than those fathers in a controlled group of healthy children. They had feelings of inferiority as fathers, and showed signs of a lack of relationship gratification with regards to the infant/child. These may affect the development of the bonding process between the father and infant as well as, the psychological well being of the father and infant relationship.

How do dads deal with their child's difference:

The fathers whom McKeever (1981) interviewed stated; that they had not received adequate support from the medical professionals after being informed of their child's illness. They felt that both they and their wives should receive professional assistance in order to deal with the unexpected crisis. However, the fathers stated that they were hesitant to join a support group as a means for dealing with their child's illness because, their child was not that ill.

McKeever's explanation for the father's unwillingness to participate in a support group was that the fathers were still in a state of denial. By attending a support group the father would be admitting that his child did indeed have a problem. This in turn may destroy a possible defense mechanism, which the father had developed to cope with the child's illness.

What is alarming, is that a study by Tavormina et.al. (1981) found that fathers of disabled children were less accepting of

their child. These findings would indicate that there is an extreme need to make every effort to reach out and encourage fathers who have children with anomalies, are disabled or chronically ill to seek out some kind of support. This may prove to be a difficult task as studies have found that fathers tend to have some problems when trying to express their emotions and their concerns about their child, McKeever (1981). That said, a father is quoted in a study by Eiserman (2001) in which, he expressed his feelings about his nine year old son who was born with a severe CFD and passed away. The father comments on how he wished that he could have removed the experience from his son's life. The father also expressed that, as a result of his son's birth it has influenced him and made him what he is today.

How are fathers' careers affected:

McKeever (1981) found that, fathers of chronically ill children who had conventional working hours were not able to have daily contact with the attending physician. Therefore, they relied on their wives to keep them informed.

However, fathers in a study by Knakl & Dixon (1984) wanted to have direct contact with the attending physician. These fathers planned their visiting hours to coincide with the physician's rounds. It was also found that a number of the fathers in the study changed their working schedule in order to provide care for other healthy siblings.

According to McKeever's (1981) study fathers felt that their careers had been directly affected by their child's illness or treatment. These fathers reported that they were not willing to leave their current employers or, even take a promotion which involved moving to another city, unless there was a medical center equivalent to the one their child was currently using.

In concluding, I hope that after reading this that fathers will come away knowing that some of the feelings that they might have are not theirs alone. The use of support groups such as AboutFace can introduce fathers who have had similar experiences. This in turn, may allow fathers to network and share strategies that they have used to cope. It is only through communicating that we all gain from the knowledge of others who have walked the path ahead.

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Access To Success 2001



AboutFace Ambassador Judy Maus

The 15th Annual Access To Success was held on December 11, 2001. This executive education forum featured 20 of North America's most esteemed speakers, consultants and musicians. The day was attended by over 400 people and raised in excess of \$50,000 for AboutFace. Special thanks goes out to Carol Brickenden and the staff of the Brickenden Speakers Bureau who generously donate their time and expertise to host Access. AboutFace would also like to acknowledge, Jackson-Triggs Vinters, KPMG, ROB TV, The Wine Establishment, Toronto Sheraton Centre, and TORYS for their support of Access.



Volunteers Emily Duron, Kathy Murphy, Kathy Cooper and Marta Ecsedi



Jeffrey Simpson kicks off Access To Success 2001



Charlene Guenette and Consuelo McQueen

Ask the Professional *continued from page 3 . . .*

to new places or being with a group of people, but they are able to do so. Shy people are able to 'warm-up' over the course of the event and feel more comfortable as they get to know people. The socially anxious person usually avoids such social situations all together, always afraid that the worst is going to happen. They often feel very anxious and panicky in social situations and may experience things such as increased heart rate, shortness of breath, and feeling nauseous. Some times, a social anxiety disorder can be so limiting that individuals can not work or interact with other people.

Controlling your anxiety

Reducing the amount of stress in your life can help to control your anxiety. Healthy lifestyle changes such as regular exercise, allowing yourself more time to accomplish a task, getting enough sleep, and limiting your use of alcohol, caffeine, nicotine and other drugs can contribute to lowering your stress levels. If you feel anxious, fearful and worried on a regular basis to the point where you feel your anxiety is interfering in your daily life, it may be helpful to see your family doctor. Your family doctor may be able to determine whether you have an anxiety disorder or s/he may refer you to a psychiatrist or psychologist.

If you have an anxiety disorder, there are many things you can do to help yourself. The first step is understanding the disorder and making a concerted effort to overcome your anxiety. Cognitive Behavioral Therapy (CBT) is a type of therapy that can help individuals to adjust to life with an anxiety disorder. CBT teaches behavioral strategies such as relaxation techniques. CBT also teaches cognitive strategies such as identifying our anxious thoughts and learning to reshape them so that they are more realistic and often more positive. As part of ther-

apy, a person with an anxiety disorder will learn that it is important not to avoid anxiety-provoking situations. Avoiding such situations only reinforces the fears that cause anxiety. As a result, our anxiety builds up, making future social encounters even more difficult. Armed with relaxation techniques and cognitive strategies, CBT encourages individuals to test out their ability to adjust to situations that cause anxiety. It is important to start with situations that only cause a little anxiety and work up to situations that cause a lot of anxiety. This is called building an Anxiety Hierarchy. For example, the socially anxious individual may start with the challenge of spending time with one new person before moving on to bigger social groups.

Sometimes, medications are necessary to decrease an individual's anxiety to a level so that therapy can help. The serotonin selective re-uptake inhibitors, are a type of medication that have been shown to be effective in decreasing anxiety. These medications work on the serotonin system in our brain. These medications are usually taken once a day and do not completely remove anxiety but help in decreasing excessive anxiety levels. It takes about two to three weeks before a noticeable change in one's anxiety level can be felt with the use of these medications.

Conclusion

Although Anxiety Disorders are lifelong disorders, they are treatable. It is important that individuals with an anxiety disorder learn effective coping strategies that will allow them to live a full, healthy life. Individuals with social anxiety can learn strategies that allow them to function in school, at work, and in social situations.

For Men *continued from page 6 . . .*

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Cover Story *continued from page 1 . . .*

When I go into a new work situation, as is often the case, I expect a reaction from children and adults alike. No matter what our age, it is a given that we have a natural tendency to want to look at something that appears different. I try to establish an immediate rapport by smiling and making direct eye contact with the students. I don't shy away from the issue and in fact, usually try to address it right away. I start by introducing myself and sharing information about my job in the school setting. I then go on to say, "there is another thing that I need to talk about and that is this large purple mark on my face. You are probably wondering what it is and I would like to tell you about it." I basically try to predict what they are already thinking.

When I do introduce the term 'birthmark', I ask them if they have any questions about it and we often go through another round of questions. They typically ask, "Why do you have it?.... How did you get it?.... Can someone else catch it?.... Does it grow bigger?.... Is it going to disappear?.... Does it hurt?"

The response is usually very accepting, as are children when they are treated with an open and honest approach. I am blessed with a keen sense of humour and have found it to be an invaluable tool in my day-to-day life, both personally and professionally. Sometimes, before explaining my birthmark, I go around the classroom and ask the students what they think it is. I get everything from "is it Kool-Aid, lipstick, a sunburn, cancer, flesh-eating disease, a rash, bruising" and on and on! I laugh out loud at some of their responses and when they see this I think they are much more at ease with continuing our talk. When I do introduce the term 'birthmark', I ask them if they have any questions about it and we often go through another round of questions. They typically ask, "Why do you have it?.... How did you get it?.... Can someone else catch it?.... Does it grow bigger?.... Is it going to disappear?.... Does it hurt?" I answer their questions honestly and simply. This also affords the children an opportunity to share things in their own lives that they may perceive as different.

Interacting with adults is often more difficult. When I am out in public, I can't always predict the kind of reaction I will receive. Sometimes people are very polite and simply ask about my birthmark, while others due to their own discomfort may turn away, stare or make insensitive comments. My confidence and therefore my responses vary from time to time. When I am faced with extreme rudeness and staring I tend to smile widely and stare right back. Usually this causes the person to experience the same level of discomfort. For me, this has proven to be effective.

Even though, 'putting yourself out there' is not always easy, I believe visibility and open interaction with people can increase others' understanding and tolerance of personal differences. I think that it also depends on what kind of support you have chosen to surround yourself with and your own willingness to accept that people will be curious. Early on, I made the decision not to cover my birthmark with make-up and simply be who I am. It is not always easy or pleasant to walk out into the world looking different, but my life experiences and the people that I have met along the way have taught me that my birthmark does not define me. By choosing a helping career, I have also learned that each one of us has personal challenges.

I have found it most important to develop my 'voice'. Words can be very powerful tools in defining how you want to be treated. Don't accept anything less than you deserve! You may wish to join a support group and learn from the experiences of others facing similar issues. My comfort level and self-confidence have grown over the years. I have realized that making mistakes, facing setbacks and allowing myself to feel the different range of emotions that go with having a facial difference are all part of my journey.

Discovering Your Career Path

- Find your voice and speak up.
- Prepare and practice techniques and answers to address others' questions.
- Accept yourself. Don't allow your difference to define you.
- Work on yourself. Develop your sense of self, humour and skill set.
- Get involved. Become a volunteer and join community-based organizations.
- Investigate different careers and talk to people in the field.

A Big Hero

Kariym Joachim was selected as a Mr. Big Hero on November 2, 2001 at the Toronto Raptors' opening home game for the season. The Big Hero Program is a partnership with Cadbury Trebor Allan,



Vince Carter's Embassy of Hope Foundation and The Raptors Foundation, which recognizes young heroes in the community. Kariym was chosen because of his work as an AboutFace Ambassador and his commitment to educating the public and medical community about living with a facial difference. Congratulations Kariym!

Facing Challenges

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

This edition we are featuring an exert from “Don’t Sweat The Small Stuff For Teens” by Richard Carlson, Ph.D.

Whether we like it or not, life is full of difficulties. It’s an evitable part of the package. The question becomes: Do our problems and difficulties ruin us or destroy our spirits? Or are they a source of growth, wisdom, perspective and patience? The answer is: It completely depends on how you look at them.

Don Juan once said, “The difference between an ordinary man and a warrior is that a warrior takes everything as a challenge, while an ordinary man takes everything as a blessing or a curse.” The good news is with a slight shift in attitude, you can become a “teenage warrior”, which will serve you now and for the rest of your life.

Think of all the people you respect the most – people you actually know, or heroes you have great respect for. How do they respond to the challenges and difficulties in their lives? Do they whine and complain – and feel like victims? Are they resentful? Do they feel sorry for themselves and tell themselves, “I’ll never get through this? Of course not.

Now think of all the people who complain about virtually everything.

Those who commiserate with others, whine, stomp their feet and fail to take responsibility for the quality of their own lives.

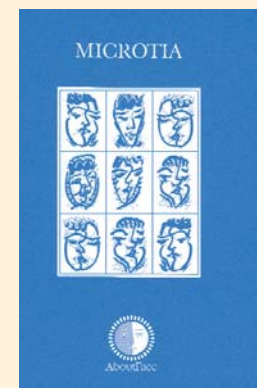
What’s the difference between these two types of people? Is it their circumstances or the severity of the difficulties they face? No way! In fact, if you look carefully, you’ll see that those people with the most courageous attitudes are the often the ones with the biggest problems and challenges. Circumstances don’t make a person – they reveal her or him!

The difference between an “ordinary” teen and a “teenage warrior” lies in the way they view problems, hassles, even legitimate hardships. An ordinary teen labels things as “good” or “bad” and feels troubled by his burdens. A teenage warrior, on the other hand, tries to find a hidden gift, however small, in each hurdle she faces.

When something goes wrong, rather than reacting as usual, feeling defeated, going crazy, or getting depressed, we can look at the situation differently. Is there something we can learn – patience, perspective, humility, generosity, perseverance, or something else? Is there some way this problem can make us better people? Do we absolutely, positively have to overreact? Or can we rise above it?

The simple act of being open to the possibility that your problems may be able to teach you something – that there just might be a hidden gift – is often enough to transform your problems into new opportunities. By keeping an open mind and looking at your problems in this way, you too can become a teenage warrior.

Resources-What’s New?



The Microtia Booklet is the newest addition to the AboutFace series of informational and resource publications.

For a complementary copy contact us at info@aboutfacetinternational.org

Dates to Remember

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 *special events section*.

Bay Street Hoops 2002

March 21, 22 and 23

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: info@aboutfaceinternational.org

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