



AboutFace

LEADING THE WAY FOR PEOPLE WITH FACIAL DIFFERENCES

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Walk a day in my shoes

Written by Anthony Laflamme-Lemieux and his classmates of École Sainte-Marguerite-Bourgeois, Unionville, Ontario.

Walk a day in my shoes
And you will see
What it feels like
To be me

I'll walk a day in your shoes
Then I'll know too
What it feels in your shoes
To be you

Different sizes, different faces
Big, small, scars and traces
Different brands, different
spaces
Nike, Reebok, Velcro, laces

Walk a day in my shoes
And you will see that I'm differ-
ent in my shoes
Inside of me

Walk a day in my shoes
And look deep inside
There you will see
I have a lot to hide

Inside these shoes
Deep secrets lie
Behind this smile
I often cry

Please look a little deeper
And maybe you will see
The lonely sad boy
That lives inside of me

Walk a day in my shoes
And maybe you will feel
The feelings I have
in my heart that are real

Walk a day in my shoes
You may be discouraged
Cause it's hard to be different
To fear rejection, to lack
courage

Please don't judge me by my
face
My impulsive or my hyper pace
Please don't laugh when I read
or when I stare
What matters most is how I care

Please don't laugh at what I do
I don't laugh at you
Please don't think that I forget
The things you say that make
me fret

Walk a day in my shoes
And maybe you will see
That you can't be fooled
By what you see

Don't be fooled by these shoes,
I swear
Don't be fooled by this face I
wear,

The face, the legs, the feet, the
hair
Are but a part of me...beware!

Walk a day in my shoes
And you will see
Behind my face, inside my soul
What makes me, ME!

For all of me is what I dream
I dream of peace, of love and
friendship
Of melted anger and lighter
hardships

For all of me is what I think
I think of talents, of courage
and grace

Of differences in one same place
Each time you're kind and gentle
Each time you try to understand
My shoes have wings
To fly and reach your hand

Each time you see my courage
Each time you show you care
My pace becomes a little lighter
To walk more freely, like on air

News from Edward Street

by Anna Pileggi, Executive Director

AboutFace was delighted once again to present the Annual AboutFace Volunteer Service Awards at our annual fundraising gala, Voices of Children. It is an honour to recognize individuals who have dedicated themselves to supporting and enhancing our mission. AboutFace is about people who care, share and give. Thank you to all the volunteers who are a part of our family!

The Betty Bednar Community Service Award



This award is presented to an individual who has dedicated him/herself to supporting and serving the AboutFace mission through his/her work in the community. This year's recipient is Mr. Peter Wheatley.

Peter Wheatley joined AboutFace as a father of an affected child searching for an outlet to help his daughter. In the process, he realized that he had much to offer others and reached out to help AboutFace in so many wonderful ways. Over the last eight years, he has been a support volunteer willing to talk to other dads about their feelings; he has supported Colleen in working with AboutFace, driving her to interviews at 5 a.m. just so she could be on CBC on our behalf. He has been an active volunteer in all our special events freely sharing his time and expertise. He took the initiative to set up an AboutFace basketball team to actively demonstrate what the organization was about. He coached our women's team and has played on our men's team for the last three years. As a Board Member, he has shared his gift of time and provided support and guidance as a way to influence growth and change. Today, he continues to be an active volunteer and advocate on our behalf and for that we are very grateful.

The Dr. Richard Ten Cate Professional-Community Service Award

This award is presented to a health care professional from any discipline who dedicates him/herself to supporting the work of AboutFace and encouraging community involvement and outreach. This year's recipient is Dr. Arlette Lefebvre.



Over the history of our organization, Dr. Arlette Lefebvre has been involved in various levels of our growth and development. She was one of the founding visionaries of AboutFace and helped to write and prepare booklets, pamphlets and other family-friendly resources. She introduced AboutFace to local medical teams and helped us by advocating on our behalf. She has been one of our strongest allies, spreading the word about the need and benefit for peer-to-peer networking. Even today, Arlette continues to be a dependable resource, a friend, a donor, a mentor. Her work has been a strong force in our growth, and we thank her.

NEWSLETTER

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AboutFace U.S.A. Director
Rickie Anderson

Management of the nose in cleft lip and palate (Rhinoplasty)

by David M. Fisher MD FRCSC
Cleft Lip and Palate Program
Hospital For Sick Children Toronto

Much can be done at the time of the initial lip repair to improve the appearance of the nose. However, with the exception of very minor clefts, the nose will not be completely corrected at the first operation. If your cleft lip repair is nicely balanced and the lip scar is mature, chances are the most noticeable feature is the nose. In unilateral (one-sided) clefts the nose is characteristically asymmetric. The nose might appear vertically longer on the side of the cleft. The nostrils may be asymmetric. The tip of the nose may not project as far forward on the cleft side. The columella, the part of the nose between the nostrils connecting the lip to the tip of the nose, may be slanted off the midline. This is largely due to the fact that the underlying bony skeleton of the face is asymmetric and this is something that is not corrected at the time of the initial lip repair. Why not? Well, we feel that too much surgery, particularly skeletal surgery, at an early age may predispose to facial growth disturbance. In bilateral (both sided) clefts the skeletal deficiency affects both sides so there is less tendency for the nose to be asymmetric. Instead, the nose in bilateral clefts tends to be broad and flat with a shortened columella.

The bony asymmetry of the underlying skeleton can be improved at the time of alveolar bone grafting. We recently discussed this in a previous newsletter. However, we don't have to wait until alveolar bone grafting is complete to work on the nose. If the asymmetry is significant, we can improve the appearance of the lobule (the flexible part of the nose) by working to improve the asymmetry of the cartilages of the nasal tip [figures 1 and 2]. Later, in the teen years, more work can be done to the cartilaginous septum (the division between the right and left nasal airways), which is often deviated, from the midline, the nasal bones, and again the tip of the nose [figures 3 and 4].

Most of these surgeries are done through a single skin incision across the columella in combination with a series of intranasal incisions. The skin scar generally heals very nicely and is very difficult to see unless you are looking for it.

The nose is probably the most difficult challenge for the cleft surgeon. So try to be realistic. Expect to be in hospital overnight and out of school for a week. Expect improvement but not perfection.





Voices of Children 2002

Special thanks to all who participated in Voices of Children 2002, our Annual Gala celebration. Held at the Royal York on Saturday, February 16, 2002, the event was attended by over 250 guests and raised over \$70,000. We couldn't have done it without the generosity of our sponsors, our volunteers, and all of our guests. It was a truly unforgettable evening. Thank you!

A special thanks to three AboutFace Ambassadors, Anthony Laflamme-Lemieux, Kariym Joachim, and Kyle McKenzie, who presented poems they had written for the occasion. As well, we would like to thank Novelette Munroe for allowing us to use her poem as our event opening.

All guests received logo lapel pins identifying them as ambassadors of AboutFace. Diana Abbott and John Bradley were presented with gold pins in recognition of their outstanding service to our organization.

Volunteers

Mary DaSilva
Robin Finklestein
Ron Finklestein
Natalia Kuhn
Dawn Mulder
Nancy Newman
Lisa Pasquin
Annleigh Wallace
Colleen Wheatley
Patricia Bain
Lindsay Turner



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The Preservation Fine Art
Gallery
The Raptors Foundation
The Wine Establishment
Toronto Blue Jays Baseball Club
Toronto International Film Festival
Toronto Maple Leaf Hockey Club
Vincor International
Woodbine Entertainment Group



Hoops

AboutFace would like to extend a heartfelt THANK YOU to all the individuals associated with this phenomenal event! Thank you to the organizing committee members, sponsors, participating teams, and volunteers who helped to make this event the best ever! This year, Bay Street Hoops raised \$130,000 in support of AboutFace and Big Brothers/Big Sisters of Toronto.

BAY STREET HOOPS: A Perspective

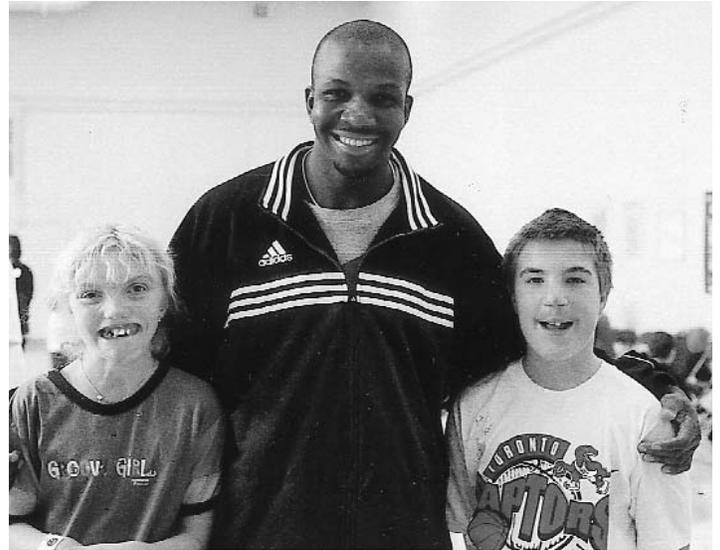
*This piece was written by Lisa Pasquin,
a Humber College PR Intern working with AboutFace.*

Walking into the gym for the first time, the noise washed over me immediately: the enthusiasm and spirit of the teams at play, the jeers and cheers from the sidelines, the heated discussions between coaches and referees. The noise was the first indication that I had arrived at an extraordinary event, but it certainly wasn't the last.

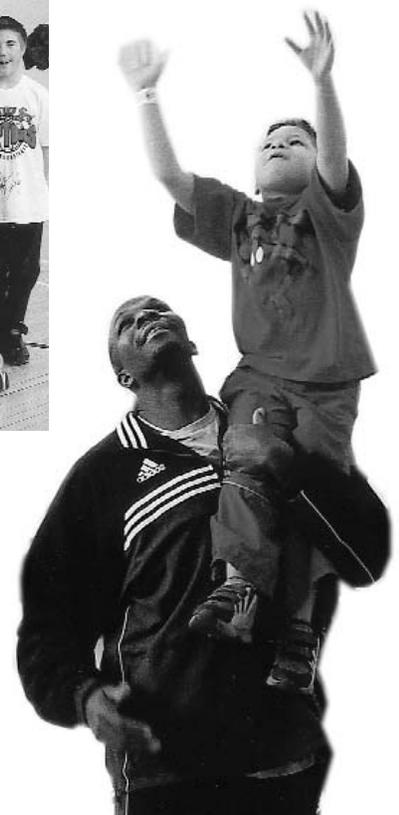
Indeed, the rest of the weekend confirmed that Bay Street Hoops was unlike any event I had ever attended. Over 550 players, 48 teams, 14 referees and more than 100 volunteers coming together to raise money for two extraordinary causes: Big Brothers & Big Sisters of Toronto and AboutFace.

I arrived at the University of Toronto Athletic Centre on Friday evening with my roommate in tow, prepared to volunteer but unsure what we had signed ourselves up for. Over the next two days, in between mixing Gatorade and running scores and even playing a little basketball, I began to get a sense of what Bay Street Hoops was really about. It was more than winning or losing or free hats or cool prizes. It was more than basketball. The Bay Street Hoops that I saw was about community: a community of people who have accomplished so much success, helping others to make their dreams come true; a community of people to whom much has been given, brought together by a desire to give something back.

I have been interning with AboutFace for almost eight weeks. In that time, I have learned about the impact that the money raised by Bay Street Hoops will have for this organization and the people it supports. But more importantly, I have learned that people drive this organization: families, children, staff, volunteers, donors and sponsors. The people who made Bay Street Hoops happen – players, coaches, organizers, sponsors, and volunteers – are also an important part of our community, and we are so grateful.



Thank you





Men's Team

Andre Hylton
 Daniel Da Silva
 Darwin Downner
 Denis Gardin
 Edd Gardin
 Maurice Nix
 Parry Tsaroui
 Peter Wheatley
 Shannon Kay
 Tommy Young
 Wade Williams



Women's Team

Annleigh Wallace
 Ashley Sage
 Claire Wheatley
 Colleen Wheatley
 Klalinkha Wallace
 Labretta Quick
 Lindsay Bernemann
 Lisa Pasquin
 Shara Dubeau
 Sue Snell
 Suzanne Poirier

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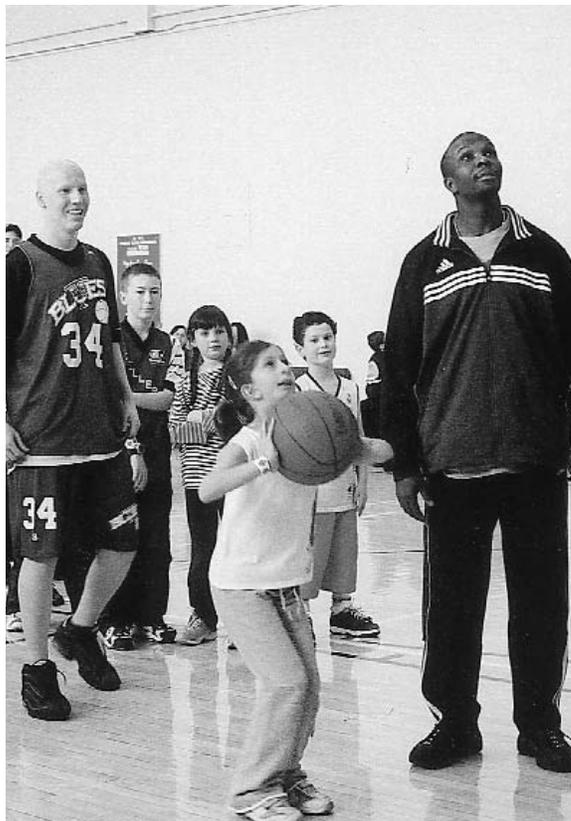
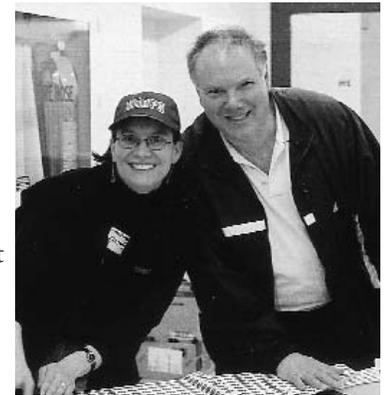
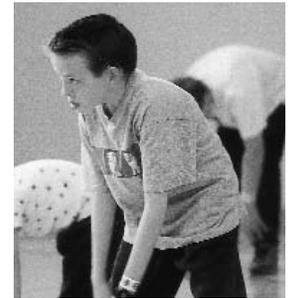
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Please Don't Stare at Me

By Deborah Breslow with narration by Kenny Breslow

Deborah Breslow is a freelance writer and mother of three boys. Kenny was born with an arteriovenous malformation (AVM) of the nose, cheek and lip. Much of this story is adapted from Ms. Breslow's recently published book FUNNY FACE.

You can write to her at funnyfacestory@aol.com.

Kenny's mom and dad were happy to have another baby boy. When a nurse in the hospital whispered, "Too bad about the bruise on his nose," they told her they loved him just the way he was.

When I grow up, I'm going to be a fireman. I'll slide down the pole and ride in the fire truck and wear my fireman's hat. I'll save people's lives. Then they won't stare and make fun of me.

Kenny, now five, is a great kid. But some people can't see past his nose which is big and red. At first, doctors said it was a birthmark – a port wine stain that laser therapy could fix.

But after a treatment, I looked like someone burned my face with a cigarette. People stared at me and at my mom as though she did it! Then they whispered mean things.

Mom says to ignore what people say if it isn't nice.

She says I can answer questions saying: "It's a birthmark. Some people have birthmarks on their backs or their arms. I have a birthmark on my nose."

Many people judge a person's "insides" based on their "outsides." They don't take time to know a person.

Kids are different in a lot of ways. No two ever look exactly the same.

What's the big deal? I didn't ask for a big, red nose! I don't not like kids who wear glasses because they need help to

see. In the hospital, some kids don't have any hair! I would never walk away so I wouldn't have to look them in the eye.

Kenny's nose is red because of all the blood that flows to it. Every few months, doctors operate to slow the blood flow.

I try real hard not to let people bug me. My big brother almost yelled at someone making fun of my nose.

At a birthday party, one girl covered her eyes. "I can't look at that boy. His nose is so ugly!"

Kenny has his own responses. Once he told kids the red berries he ate from a tree made his nose red. He said the black scab from an operation was "a bee sting on my birthmark." This helps him cope.

Kids stare when they see my nose for the first time. Their impression of my nose is their impression of me. What's so bad about looking different?

"Being different makes each of us special in our own way," Kenny's mom says.

"You mean it's okay to look different?" I thought it wasn't.

When I grow up, I still want to be a fireman and help people. Not so they won't stare or make fun of the way I look. Just because that's what I really want to do.

There's more to me than just my nose.



Laughter as Therapy

By Iren Tajbakhsh

This article was reprinted with permission from the Women's Counselling and Referral Education Centre, Toronto.

Therapy can be defined as “an activity or treatment intended to alleviate an undesirable condition.” With that in mind, let's explore the therapeutic benefit of laughter for the body, mind and spirit.

Throughout history, we have discussed the importance of attending to the body, mind and spirit. Humor is one of the pleasures of life. To dispense laughter will directly enhance the quality of life and perhaps the will to live – this may be the most important result of all. The will to live is a force which is difficult to define but can be a powerful influence in the recovery process. Humor and laughter can create an environment where hope can flourish because it provides a sense of joy, helps us connect with family and friends, and inspires an appreciation and gratitude for life.

Physiological Response

Humor is a perpetual process while laughter is a behavioral response. This behavior creates predictable physiological changes within the body. With vigorous sustained laughter, the heart rate is stimulated, sometimes reaching rates of above 120 bpm; the normal respiratory pattern becomes chaotic; respiratory rate and depth are increased while residual volume is decreased. A variety of muscle groups become active during laughter.

Laughter and Well-Being

How is laughter therapeutic to the body? Laughter is a pleasurable experience; it momentarily banishes feelings of anger and fear. It gives us a feeling of power and control; we feel care-free, lighthearted, and hopeful during the moments of laughter. These feelings may have therapeutic benefits by reversing the immunosuppressive effects of the emotions of anger, fear, or loneliness, which often accompany illness or other stressful events. These emotions are known to produce physiological changes that are harmful to the body; changes which the use of humor and laughter can ease.

Psychological Impact of Laughter

Humor and laughter affect how we perceive and respond to change. Herbert Lefcourt has explored the possibility that a sense of humor and its use can change our emotional response to stress. Humor can also influence the mind by enhancing the ability to learn because it can capture the attention of the learner, enhance retention of the material, or help to release the tension that blocks learning.

Spiritual Effects of Humor

Spirit can be defined as the vital essence or animating force of a living organism, often considered divine in origin. Spirit can also be regarded as vivacity or energy. The word humor itself is a word of many meanings. The root of the word is “umor” meaning liquid, fluid. One dictionary defines humor as “the quality of being laughable or comical” or “a state of mind, mood, spirit”. Humor is something that flows, involving basic characteristics of the individual, which express themselves in the body, in moods and emotional reactions, and in qualities of feeling, of mind and of spirit. The qualities of humor and spirit are similar and, I believe, interdependent.

Therapists facilitate the healing processes within the body and mind. To be most effective, we must direct our efforts to the body, mind and spirit. The root of the word “heal” is “haelen”, meaning to make whole. I have attempted to provide information and inspiration for the possibility that laughter and humor can be a source of therapy.

My intent was to answer the questions: “Why are humor and laughter important? What happens to the body, mind and spirit when we laugh?” You are now probably wondering: “How can I get myself and others to laugh more? When is humor appropriate to use? Who is most likely to laugh?”

Begin to explore your own style and appreciation of humor. Find what works for you. Remember that the shortest distance between two people is a shared laugh.

Stress

by Barry Strader

Stress - the underarm dampening, jaw clenching, finger tapping entity that ties nerves into knots and drives emotions to distraction. It is as much a part of our everyday lives as bills and cell phones.

All agree that stress is big - it is the live, floating mine in the choppy sea of daily existence. Yet there seems to be a subtle difference in dealing with it depending on your particular gender. Males tend to handle it with an almost reactionary comeuppance and indignant denial. Females appear more meticulous and reasoned in their approach.

In typical male *modus operandi* manner, I would keep it far too long, leave it completely unattended and advise my partner that it was her problem and she should have dealt with it

before it created this crisis for me! Being a facially-challenged male, stress was as prominent as a third eye. I had more insecurities and anxieties than Laura Secord has chocolates.

For both those “normal” of face and those of us facially unique, stress is present. My maleness faces stress on more levels than a computer game. Its roots anchor in every aspect of my life - social, personal, workplace and emotional. It has more branches than a chartered bank. I cannot remove it, only attempt to control it. It is like a journey. In mapping out the situation, I discharge my self-determination and hope my will to succeed overcomes my self-worth’s fear of failure. When I do that stress is diminished...

Of course, if I were a woman, I could do it in half the time – still stopping to ask for directions.

Resources-What’s New?

STOP SINGING PEOPLE MIGHT HEAR YOU

Maria Burtlehaus is 34 years old and was born with a cleft lip and palate. Her book, *Stop Singing People Might Hear You, My Cleft Book* is an honest account of one woman's struggle to better herself through the trials and tribulations of being born with a facial difference. Maria teaches us that a person can use a congenital anomaly as a way to strengthen one's character. *My Cleft Book* is intended to inspire people who seek to enhance their lives by using their gifts as an opportunity to overcome adversity.

Visit Maria's website at www.mycleftbook.com

FUNNY FACE

FUNNY FACE, penned by Deborah Breslow, is an unusual story about her son, Kenny, who was born with an arteriovenous malformation on his nose, cheek and lip, resulting in his living with a big, red nose.

The book is written in two voices. The mother explains the more technical side of various treatments her son has undergone. Four-year-old Kenny talks about his love of fire

engines, of enduring scores of trips to the hospital, and his feelings about being teased and stared at.

The article is a quick look into this book. For more information contact Ms. Breslow at funnyfacestory@aol.com

THE HURTING ANGELS

Delores Lekowski is a burn survivor and author of *The Hurting Angels*, a book with a special message for children who have suffered burns, illness, or other traumas that may hurt their self-esteem. She published this book with the complete support of the National Association of State Fire Marshals in July 2000. For a free copy of the book, visit their website at www.thehurtingangels.com

For more information contact: deloreslekowski@hotmail.com

How to Manage Stress Better

Regular life stress is all around. You cannot protect yourself from stress. However, there are strategies to help you cope with normal life stressors. By developing strategies to manage stress, you will be in a better position to notice stress in yourself and in your child.

1. Notice your stress

Don't ignore it. Become aware of it and determine the emotional and physical reactions you have. List how stress affects you.

2. Identify what stressors you can control

Can you change or eliminate the stressor? What can you do to reduce it? Can you remove yourself or shorten the exposure (take a walk)?

3. Reduce the intensity of your reaction

Are you viewing your stressor in exaggerated terms? Are you overreacting? Put the situation into perspective. Are you expecting to please everyone or prevail in every situation? Try to temper your excess emotions.

4. Learn to moderate your physical reactions to stress

Slow down, take a deep breath, relax. Relaxation techniques can help you bring your heart rate and breathing back to a normal level.

5. Build your physical reserves

Exercise regularly (three to four times a week). Get enough sleep. Maintain a healthy weight through balanced nutritious meals. Be consistent with your sleeping schedule and take a break when you can.

6. Maintain your emotional reserves

Develop a supportive circle of friends. Set realistic and meaningful goals for yourself. Expect some frustrations and failures. Be a friend to yourself!

Noticing Stress in Children

Children often do not exhibit stress the same way as adults. The younger the child, the less likely they are to be able to communicate their troubles. Therefore, children are more likely to exhibit their stress in their actions/behaviours.

Things to Watch out for

As parents we know our children well enough to know when things are not right. One of the first things to consider when you notice changes in your child's behaviour, is what behaviour is "normal" for your child and his/her age group. For example is he becoming forgetful in simple daily tasks, or is she overeating, or challenging authority; and how do these characteristics relate to adolescents? Try to understand what behaviours are typical for your child's age group and how they fit within that context. You can talk to a teacher, your family doctor, or social worker to help you understand what "normal" behaviours are. However, sudden or drastic changes such as the following are signals of stress:

Irritability and anxiety; Increase or decrease in appetite; Increase or decrease in sleep; Engaging in dangerous behaviours; Lack of motivation; Trouble falling asleep or excessive sleeping.

To help your child cope with normal life stressors, teach them simple strategies that they can apply to daily challenges. In time, they will learn to adapt and apply these to more serious situations.

1. Teach your child simple breathing and relaxation techniques (i.e. stretches).
2. Teach your child ways to protect their health, proper eating, hygiene, and exercise.
3. Talk with your child – every day ask your child about school and friends.
4. Watch your child interacting with other children – see the dynamics among the group.
5. Always provide adequate supervision for your child with respected adults so that the stress of protection is removed from your child.

Dates to Remember

Ottawa Family Day

Saturday, June 1, 2002

*Sponsored by: Meeting Planners
International, Ottawa Chapter*

For more information call

AboutFace: 800-665-3223

Or go online to:

www.aboutfaceinternational.org

Moebius Syndrome Conference

Friday, July 19- 21, 2002

*Pheasant Run Conference Centre,
St. Charles, Chicago, IL*

For more information call:

540-752-7834

Or email: sbdeveney@hotmail.com

Family Day 2002 – Sharing Strengths: A Patchwork of our Experiences

Saturday, October 26th, 2002

Holiday Inn on King,

370 King Street West, Toronto, ON

For more information call

AboutFace – 800-665-3223

Or go online to:

www.aboutfaceinternational.org/specialevents

Access to Success 2002

Tuesday, December 10th, 2002

*Sheraton Centre Hotel Toronto,
100 Queen Street West, Toronto, ON*

For more information call

The Brickenden Speakers Bureau:

905-713-3222

Or go online to:

www.brickenden.com

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