



AboutFace

LEADING THE WAY FOR PEOPLE WITH FACIAL DIFFERENCES

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# Beauty comes from inside, not outside.

This was a letter sent to AboutFace from Vanisha Dayal.

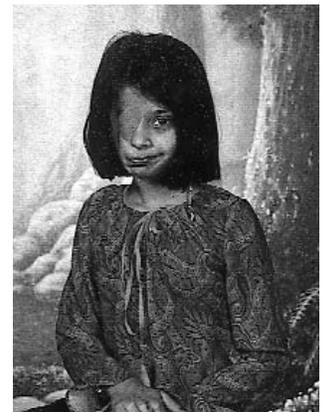
**M**y name is Vanisha and I am 12 years old. I live in Abbotsford, BC, Canada. I love my family and friends because they look into my heart, not at my facial deformity. I go to North Poplar Fine Arts School, and I love my school because everyone is very nice to me.

My first year at North Poplar School was a little hard on me because there were new kids and sometimes they called me “one eyed-person” or would stare at me and give me dirty looks. When that happens, it really hurls my feelings, and I wished that I looked normal like everyone else. This kind of teasing always happens, whenever there is a new kid in school.

I find it very hard and I get mad when adults stare too. I feel like hiding myself. This happens when we go shopping or go to a social event. I find it easier to answer kids because when they ask, I tell them the truth. I had cancer and because of the huge tumor, I had to remove my eye and a lot of tissue. If they ask what is cancer, I tell them it is a bad sickness that people can die and that I was fortunate to live. I tell them in a nice way, as I don't want to scare them. If it is a grown up, I say it as it is. But if it is a small child, I don't say too much.

Most of the time, kids are satisfied with my explanation and they go away. Some people treat me like they would treat everyone else. They do not pay attention to my deformity, and they see me as normal person. I feel happy when people like me for who I am and not feel sorry for me because of how I look.

My biggest fear now is that I will be going to high school next year. I will have to go through a lot of stares, questions, and maybe teasing. I find that as I get older, it is getting more difficult because I am aware of my looks. It is not easy living with a facial difference. It seems beauty is every thing these days. But I am not going to let this get to me. I believe that beauty comes from the inside not outside.



*Vanisha Dayal*

# News from Edward Street

by Anna Pileggi, Executive Director

As we head into the last quarter of 2002, we gear up for another season of fundraising and programs. Here is a quick glance of all the activities at AboutFace over the next few months.

**September:** our push will be back to school offering our new school program Facing Differences to all elementary school teachers. If your child is in grade 2-6, we encourage you to pull out the centerpiece of this newsletter and take it to their teacher. Parents are our greatest distribution channels. If you ask for this resource, chances are more likely that teachers will use it.

**October:** we will be hosting our annual family day in Toronto in collaboration with the Cleft Program at Bloorview MacMillan Children's Centre, and the Cleft and Craniofacial Programs at Sick Children's Hospital. If you have not received the mailing, but wish to attend, you can go on line to [www.aboutface.ca/programs](http://www.aboutface.ca/programs) and check out the itinerary for the day. Or, you can call us at 1-800-665-3223 for a copy of the brochure. For health care providers, if you would like free extra copies of the program to give out to your clients, please call or e-mail AboutFace. We are very excited about this year's program as we have expanded the day to include a track for Parents of Infants and a special track for Teens!

**November:** we will launch our adult resource called Building Bridges! This program has been in development for three years, with the financial support of the Ontario Trillium Foundation. Building Bridges is made of three key pieces: a guide for Health Care Providers outlining strategies to increase

and improve client relationships; tips for clients on working effectively with their health care provider; and a facilitators manual for professionals wanting to offer self help sessions for their clients in community integration and communication.

**December:** as always our year will go out with a bang! Access to Success will close our year again with a stellar line up of speakers. This year, Roberta Bondar, Rick Butts, Nick Bontis, Donald Cooper, and many more will join us. Space is limited so reserve your tickets now! For a complete list of speakers go online to [www.brickenden.com](http://www.brickenden.com) or call AboutFace for your copy of the invitation.

In addition to all this, AboutFace will forge ahead on its fundraising efforts. Unlike many charities, AboutFace is non-government funded and depends greatly on the generosity and support of its membership and sponsors. On page 7, you will read the many ways that you can financially support AboutFace. Your annual donation is very important to our continued success. If you have already given to AboutFace, we Thank You; if you haven't given, we hope you will.

Finally, after many years of service, a long time staff member of AboutFace has moved on to new and exciting things. Consuelo McQueen has decided to pursue other endeavors. We thank her for her many years of service and wish her much success.

## NEWSLETTER

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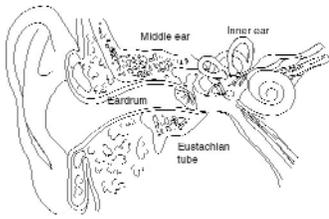
501(C)(3)  
U.S.A. Director  
Rickie Anderson

# Cleft Palate, the Middle Ear and Hearing Loss

by Jacob Friedberg MD FRCS (C)  
Otolaryngologist in Chief  
Department of Otolaryngology  
Hospital For Sick Children

**M**iddle ear fluid problems with or without ear infections are very common in all children and particularly common in young children with cleft palates.

The middle ear, the area behind the eardrum, is normally air containing. It gets its air from the Eustachian tube, a small passage connecting the middle with the back of the nose just above the level of the soft palate.



The muscles that normally open and close these tubes cross over in the soft palate connecting to and pulling against one another.

In the cleft palate child these muscles have little to pull against preventing air from entering the middle ear and it may take years for this function to return even after the most satisfactory palate repair.

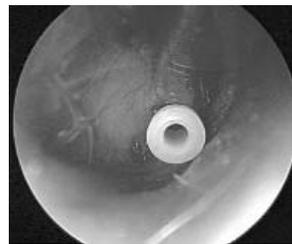
Whatever air may be present in the middle ear is absorbed causing a decrease in middle ear pressure and the formation of fluid in the middle ear. This fluid results in a mild to moderate hearing loss, usually 20 to 30 decibels which is about the same as sticking a finger in the ear canal. In most cases the inner ear (cochlea) and nerve of hearing are entirely normal.

The hearing loss may last for months or even years but will usually improve on its own by the time the child is four or five years of age. Nevertheless the child will have been deprived of a significant amount of hearing during those early years when language development is so important. Normal hearing during these years is critical for optimal language development.

The object of any treatment is to clear the middle ear of fluid, control infection and restore normal hearing. Antibiotics may be helpful in controlling ear infections but they have little effect on clearing middle ear fluid. Other medications such as antihistamines or decongestants have also been tried but they too have little effect. Making a small incision in the eardrum and draining the fluid out can instantly restore hearing; but, this will heal within days and fluid will promptly reform.

Middle ear ventilating tubes or pressure equalizing tubes have proven to be very effective in restoring hearing, limiting infection and preventing the formation of middle ear fluid. There are dozens of different tubes available but the most commonly used tubes measure 2 to 3 millimetres in diameter, are about the same length and have an opening of approximately 1 millimetre in diameter.

These tubes are inserted under general anaesthetic either at the time of palate surgery or as a separate procedure. It usually takes about ten minutes and causes little discomfort if at all. While in position the tubes will prevent the drum from healing, allow air into the middle ear and prevent the formation of fluid. They are automatically expelled by the ear, usually in



less than a year and in some children may have to be replaced until the Eustachian tube starts to function. The eardrum almost always heals once the tube finally comes out. There may be some residual scarring either from infection or from the tube but this is essentially cosmetic

and has no effect on hearing. In those rare cases where healing is not complete it is possible to repair the eardrum.

Occasionally the child may develop an ear infection with drainage of pus or mucous from the ear. The child is often not ill with this but there may be some local discomfort and the ear may certainly look messy. This drainage can be easily treated with an antibiotic eardrop. Antibiotics by mouth are rarely necessary.

Water will not go through the small opening in the tube unless it is forced through under pressure. Earplugs are not recommended for infants with middle ear ventilating tubes. Simple precautions to avoid getting soapy bath water into the ear are usually adequate. Earplugs may be considered if the child will be taking formal swim lessons but no earplug will be a guarantee against water when the child is diving or jumping into a lake or pool.

# The Victoria Cleft Lip/Palate Team

The Victoria Cleft Lip/Palate team is administered by the Vancouver Island Health Authority- Queen Alexandra Centre for Children's Health and has been operated in its present form since 1981. A brief historical review indicates that the original Clinic group was formed in 1964 by a group of professionals practicing in Victoria. Clinic services were governed by an independent society developed to give coordinated care to children on the Island with cleft lip and/or palate. In 1980, Dr. A. Baird, senior plastic surgeon and spokesperson for the board requested that the administration and management be transferred to the G.R. Pearkes Centre which became the Queen Alexandra Centre for Children's Health. The monthly clinics were later held at the Victoria General Hospital under QACCH direction/management for many years. In September 2000, the Clinic returned to the QACCH, when a newly renovated, child friendly, Clinic wing opened.

The Victoria Cleft Lip/Palate clinic team provides assessment, treatment, coordination of services, family education, and support for children born with cleft lip and/or palate on Vancouver Island and Island regional districts. Children with a submucous cleft of the palate or velopharyngeal insufficiency are also seen at this Clinic. Clinic services are available from birth to age 19. The team consists of the Pediatrician/Medical Coordinator, Otolaryngologist, Plastic Surgeons, Pediatric Dental Specialist, Speech-Language Pathologist, Clinic Coordinator, and Clinic Assistant. Regularly scheduled audiological services are available for all of the clients at the various audiology clinics operated by the Vancouver Island Health Authority. There is a universal newborn hearing screening program available in the Victoria area. If results from the initial otoacoustic emission screening test suggest further evaluation, a complete audiological evaluation (including BSER testing) is completed in the first 3 -6

months. In addition, services are available on an as needs basis from the orthodontist, medical genetics specialist, social worker, nutritionist, and others on referral. Clinic team members consult with specialists in the child's community in order to provide for continuity of care and appropriate treatment planning. Community team members are invited to the QAC Clinic conferences.

There are 25-30 referrals to the Clinic each year and an average number of 225 registered with the clinic who will be

seen for review and follow-up. The clinic team sees 6-7 children monthly. Families receive copies of Clinic documentation regarding their children. Referrals can be made by physicians, community health care professionals, and parents. Typically, an infant born with cleft lip and or palate is referred at birth. The Clinic Coordinator or Speech-Language Pathologist will contact the parents and arrange a meeting if the parents are interested. Information regarding Clinic services, feeding techniques, etc is

shared with the family and a Clinic visit with the full team is offered in the first 1-2 months. There is also a network of families who are readily available to support new parents. Newborns with cleft lip and/or palate are given priority for assessment visits at Clinic. If children present with velopharyngeal incompetence, assessment is available with nasendoscopic/videofluoroscopic procedures if surgery is being considered.

The Victoria Cleft Lip/Palate team is registered with the American Cleft Palate association (ACPA). Children with craniofacial conditions in addition to cleft palate may be referred to the Craniofacial Clinic in Vancouver but receive ongoing services in Victoria or in their own community.



*From left to right: Maureen O'Brien: Speech-Language Pathologist, Dr. Fraser Noel: ENT, Terina Preece: Clinic Assistant, Sherri McIntyre: Clinic Coordinator, Dr. David Naysmith: Plastic Surgeon, Dr. James Popkin: Pediatrician and Medical Coordinator, Dr. Jason Gray: Plastic Surgeon, Dr. Bob Ruzicka: Pediatric Dental Specialist.*

# Making the Transition to High School

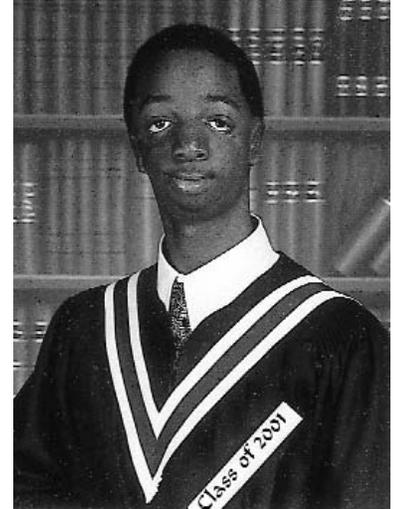
Kariym Joachim lives in Pickering, Ontario and is an active AboutFace member.

Last year as I was entering grade nine, I found myself apprehensive about starting high school. I was afraid that I would be stared at because of my facial difference and my Bone Anchored Hearing Aid. Just like everybody else, I had experienced teasing and staring in elementary school. This time, my parents and I decided to work with my new school before I started classes to make my entry more comfortable.

Early on in the school year, my teachers attended a meeting to discuss my needs as a hard of hearing student in the regular classroom. I decided to be proactive by telling them about Treacher Collins and providing strategies that I felt would make it easier for me to learn.

My learning strategies:

1. I try to choose a seat on the left side of a classroom so that my hearing aid is facing the teacher and my classmates. Then I will have better auditory and visual contact with them.
2. I ask the teachers to keep background noise to a minimum, as it is difficult to hear over it. It is harder to hear class discussions when it is noisy.
3. I find it helpful if the classroom door is closed because noise in the hallway is very distracting.
4. I ask teachers whenever possible not to talk while they are writing on the blackboard, as I cannot see their faces.
5. I find it helpful when teachers repeat or rephrase answers when they are being taken up or repeat comments during discussions.



It turned out to be very useful to meet my teachers as a group and start developing relationships and establishing open communication. I gained the support of my teachers, educational assistants and interpreters, which helped me cope and be successful. I learned that you have to actively participate in creating your own positive learning experience.

Looking back, it would be fair to say that I did well with all the support for my educational needs. However, because of the challenge of finding my way around a bigger school and meeting many new people, it took me a little longer to make the adjustment. At the time, I was also really worried about the social part of being in high school.

During the first few days, I nervously glanced around just waiting for those frequent little peeks and staring in the hallways. Despite my anticipation, I realized that I had very little to worry about. After taking a reality check, I actually found that people were generally accepting of me. I got the occasional stare early on, but it wasn't anything that I couldn't handle. High school students are older, a bit more mature, and busy dealing with their own lives and problems.

I realize that not everyone will have the same experience entering high school that I did. My advice is not to approach it as a challenge, but to look at it as an opportunity and find ways to actively make the outcome positive.

# When your Child Starts or Changes Schools

Many parents face the same questions and uncertainties when their child enters a new school or new peer group. While there is no single formula for successful integration, there are many wonderful transitions tips.

- When it comes to handling differences, always stress the fact that each face is unique... some just happen to be more distinctive than others. Yes, some faces stand out in a crowd and that makes people notice them more. But many “ordinary faces” would give anything for the opportunity to stand out in a crowd, too. How you handle that extra attention and what you make of it is entirely up to you. If you can’t fix it, feature it, and wear your face with pride!
- Preparing classes ahead of time, through the AboutFace school program, *FACING DIFFERENCES* for example, can help a lot by giving students a chance to learn about their thoughts and reactions to appearances. Little would be gained by having a lecture about your child’s medical condition before she/he meets the new classmates. Just focusing on the medical jargon and what’s “wrong” with your child’s face is not likely to accomplish much except scare the other kids off.
- DO share every bit of medical information you can get your hands on with teachers and principals! Let them know how much you appreciate their mentorship and faith in your child’s potential! Partnership in education and health care IS your goal. Think positively and expect

nothing but the best intentions from each and every one of the professionals dealing with your child. Treat people as trusted allies, and they will very often rise to the challenge.

- Set an example by modeling calm and matter-of-fact reactions to unexpected and sometimes rude comments or stares of strangers. If your child is about to meet many new peers and teachers, you may choose to gradually expose her/him to the reactions of a greater number of strangers, in excursions to shopping malls, camping trips, new hobbies, or extra curricular activities. Finding the right answer for the unexpected question or comment should be treated like a challenge to be met, not something to be feared or whispered about. Making friends out of curious strangers, and spreading enthusiasm for what you believe in... these things are acquired skills. The trick is to make them focus on what you excel at, rather than what you don’t.
- Never underestimate the power of self-confidence. If your child has done really well and has been accepted by his /her peers so far, chances are that’s what s/he expects will happen in years to come. There is a lot to be said for the magic of positive expectations. You may be old enough to remember sudden turns for the worse in your own life, but sharing these past disappointments or fears will not likely help your child tomorrow. Think positively and confidently, and that’s the way your child will perceive him or herself and react in the face of special stresses.

*“The cure for the human condition is the human connection.”*

Paul Stanley

This phrase sums up the power and possibility of peer-to-peer networking. One of our primary objectives is to connect people who share similar issues, concerns or conditions. If you would like to be connected with someone in your community or around the world, who you can talk with either on the phone, by email or regular mail, contact AboutFace.

*“Peer networking is the most powerful form of self help. Talking with someone who truly understands what you are going through is the most empowering experience anyone can have.”*

Adult with a facial difference.

**For more information on our peer networking program call AboutFace 1-800-665-3223 or [www.aboutface.ca](http://www.aboutface.ca)**

# Ways to give to AboutFace.... today and tomorrow

People have been donating to AboutFace in a variety of ways since 1985. As a result, they have been instrumental in:

- Establishing an international network of families and individuals with facial differences to let them know they are not alone;
- Creating a wealth of information resources on conditions, and syndromes and life issues to educate and support;
- Developing worldwide connections with hospitals, doctors, specialists, researchers, counsellors, educators, and ultimately communities;
- Helping to dispel myths about differences and educate kids in the school community and foster acceptance through understanding;
- Educating hundreds of thousands of people throughout the world on the issues of facial difference.

Those who donate annually have helped us to build and strengthen our foundation, as we do not receive government funding to realize our vision. As our dream unfolds, we want you to be aware that there are many ways to make a significant contribution to ensure that future generations will benefit from the support of those who care, understand and inspire others with differences to reach their fullest potential.

## Giving Today and Tomorrow

Giving to AboutFace can be done in many different ways whether you are thinking about giving today or tomorrow.

### Annual or Monthly Donations

You can donate on an annual basis by writing a cheque to AboutFace or by calling us directly and making a contribution on your credit card. For your

convenience, AboutFace has implemented a monthly giving program so you can make a regular monthly donation which would ensure that those we serve would be helped throughout the year. You can do this through your credit card or through direct deposit at your bank.

### United Way/Work Place Giving

Many individuals enjoy supporting their local United Way Campaign. Did you know that you can “designate” your contribution directly to AboutFace. You can support two causes at the same time with your local United Way or work place campaign, and AboutFace!

### Honouring, Remembering or Celebrating

You can use a special occasion to honour, remember or celebrate someone you love with a gift to AboutFace. AboutFace will issue a gift card to the Honouree or family on your behalf, and a tax receipt to you. You can get your children involved in giving early by helping them designate their holiday gifts.

### Giving through Insurance Policies

Sometimes, individuals cannot give regularly, but there is an option. You can designate your insurance policy to AboutFace, as the beneficiaries. The benefit to you is that you receive a charitable tax receipt for the annual premium every year and enjoy the tax credit now. You could also choose to continue to benefit by paying the premiums. In doing so each payment will also be considered a charitable donation for which you will receive a yearly tax receipt. For a few dollars a month you can ultimately leave a significant donation to people with facial differences.

### Securities, Stocks & Bonds

In this case any donation will be sold on

the donation day. You will receive a tax receipt for the value of the transaction on that day.

### Gifts-In-Kind

What about donating a Gift-In-Kind. This can include property items such as; artwork, shares, or real estate. This way your tax credit will be determined by an assessment called ‘fair market value’- which means the reasonable profit that you would have realized in the general market had you sold the property.

### Giving Tomorrow...Planned Giving

Giving tomorrow or Planned Giving is another generous way to donate.

Preparing a gift through your will is a way to make a significant gift now without paying until the future. Often when people are considering leaving a Planned gift, they frequently have questions like:

- What can I leave to AboutFace International in my will?
- Is leaving a Planned Gift expensive and complicated?
- Which option is best for my tax considerations?

Whether you have a will or are planning to make one, adding a donation to AboutFace International it can be done at no extra cost. It is as simple as including a clause in your will. Regardless, talk to your financial planner, chartered accountant, or lawyer to discuss which option best suits your financial needs.

You can help create a lasting opportunity for future generations of children and adults with facial differences and the society they live in.

If you have any further questions please feel free to contact us at

Phone: 416-597-2229

Email: [info@aboutfaceinternational.org](mailto:info@aboutfaceinternational.org)

# Family Day 2002

FAMILY STRENGTH: *A Patchwork of our Experiences*

Come one! Come All! To our 7th Annual Family Education Day  
Saturday, October 26th, 2002, at the Holiday Inn on King, Toronto

This one day conference is designed for kids, teens and parents touched by facial differences. We will provide an entertaining and educational experience like never before!

- For parents, we have medical panels and experts on child rearing issues;
- For teens, we have a careers panel and interactive workshops for self-discovery;
- For kids, we have active workshops to help them explore their hidden talents and abilities!

Need more information or want to register?

Contact AboutFace at 1-800-665-3223 or go online to [www.aboutface.ca/programs](http://www.aboutface.ca/programs).

Are you interested in family day, but are over 18? Give us a call!

AboutFace is recruiting young individuals who would like to volunteer with the day care center and kids program.  
For more information call Sharon at 1-800-665-3223 x23.

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