

AboutFace

LEADING THE WAY FOR PEOPLE WITH FACIAL DIFFERENCES

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## Raising Twins with a Facial Difference

By Todd M. Kubon, BA, MAMS and Anna Pileggi

Todd Kubon is an Anaplastologist at the Craniofacial Prosthetic Unit, Toronto Sunnybrook Regional Cancer Centre and The Hospital for Sick Children, Toronto, Ontario.

*Bob and Diane Moore are the parents of four girls. The youngest two, Brittany and Kayla, were born with hemifacial microsomia (stunted growth to one half of the face) and microtia (small ear) of varying degrees, affecting the opposite sides of their face. Brittany and Kayla both choose to have implant retained prosthetic ears made to replace their missing ears at the age of eleven. Now, at the age of thirteen, Brittany is looking into treatment options for having corrective surgery for her jaw. The following is an interview with Bob Moore about raising Brittany and Kayla from a father's perspective.*

*Todd: How do you encourage individuality between twins without stigmatizing their difference or overlooking their individual strengths?*

Bob: Basically you do this by treating them as individuals from an early age. We try to support and encourage them to develop all of their abilities. Over time, you will find that one child may be better in academics or sports, or even have stronger social skills than the other. We make an effort not to compare them to each other and to allow them to develop apart from one another as well as together. When they were little, we would dress them the same, but they begin to show their own individual strong points and weak points and we support them in that. If there is one thing that their mother and I tend to do that is not good, is to refer to them as "the Twins", where it would be better to refer to them separately as Kayla and Brittany.



*Kayla, Bob and Brittany*

One issue that can be challenging at their age is socialization because children tend to show their values by how many friends they have. If they are going to have two different groups of friends, which is what being an individual is all about, then sometimes it can be an issue. For the most part though they do have many of the same friends because they are the same age, living together in the same area, but they also do have a few friends that are different.

*Todd: What do you do to encourage your individual connection with each child?*

Bob: I make an effort to spend time with each of them separately, which gets easier as they get older. When they were small, it was easier to take care of them together. As they get older, there are more opportunities to spend time with them individually because one child might be off with

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# News from Edward Street

by Anna Pileggi, Executive Director

School's out and for many it's a time of rest and relaxation. Except for parents, we never get a break! That is why we have dedicated this newsletter on parenting issues facing parents of children with facial differences. Like all parents, we worry about the future and welfare of our children. However, for parents of children with facial differences, there is often a period of heightened stress and anxiety as they prepare to take on the challenge of raising a healthy, well-adjusted and confident child regardless of their difference and society's stigmas. The parent child relationship is the single most important factor that will contribute to the psychological foundation of the child. A parent's attitude toward their child has a significant influence on how the child perceives him/herself. This ultimately helps form the child's sense of self. It will impact their body image, self-esteem, confidence and future relationships. Therefore, it is critical that parents receive early on emotional support and information to help ground them so that they can in turn create and nurture a healthier environment for their child. Moreover, it is critical to remember that a child with a difference is a child first and requires the same stimulation, affection, discipline and structure as any child does.

Our feature article is about parenting twin girls born with a facial difference, from a dad's perspective. We hope that you will enjoy their story.

On another note, I am delighted to announce that we have finished production on our new school program, **Facing Differences**. This independent program has been developed specifically for teachers and schools. AboutFace has already begun sending copies to elementary schools across Canada.

We are looking to you as parents and community representatives to help us reach out to your local elementary schools to raise awareness of **Facing Differences**. This fall, we will be publishing a special "back to school" edition of the newsletter for you to take to your child's school. In addition, we are working with teacher organizations to help promote the program directly to educators. You can find out more about **Facing Differences** on our web site at [www.aboutfaceinternational.org](http://www.aboutfaceinternational.org)

Finally, I am saddened to report the loss of a great woman and advocate for facial differences. Ms. Frances Cook Macgregor, died late last year in her retirement home in California, at age 95 of congestive heart failure. Ms. Macgregor forged an eclectic career that included professional photography, sociology, anthropology and pioneering work with the psychological issues caused by facial deformities following WWII. She wrote three books on the psychological and sociological impact of facial difference and plastic surgery, which fueled the development of many self-help and support groups for individuals and their families. Ms. Macgregor was a long time supporter and advocate of AboutFace and will be missed.

*A lifetime of little kindnesses  
may well outweigh one of  
great achievement.*

## NEWSLETTER

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### AboutFace International

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

### Charitable Registration

#12676 1410 RR0001

Executive Director  
Anna Pileggi

### AboutFace U.S.A.

P.O. Box 969  
Batavia, IL 60510-0969  
tel. 1-888-486-1209  
fax 630-761-8719  
aboutface2000@aol.com  
www.aboutfaceusa.org

### Charitable Organization

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U.S.A. Director  
Rickie Anderson

# Weaning from Bottle to Cup Prior to Palate Surgery

by Lori Burton BA, BHScOT

Occupational Therapist, Cleft Lip and Palate Program  
The Hospital for Sick Children, Toronto

Most children have their cleft palate repaired between 12 and 18 months of age. It is recommended that your child be completely weaned from bottle drinking and effectively drinking from a cup, prior to palate surgery. The reason for this is that after surgery the bottle nipple can rub against the stitches, leading to a breakdown of the repair. In addition, after your child's palate is repaired, he/she is now able to create suction inside his/her mouth. This can also interfere with the repair.

For many parents the idea of having to wean their child off the bottle prior to palate surgery presents a huge challenge. The following are some suggestions for helping you to get started in the weaning process and to address some of the questions you might have. Remember also that these are just suggestions and may need to be modified to best suit the needs of your child.

## *When should I start to wean my child?*

Weaning from bottle to cup is something that is meant to take place over a period of time. You can begin by offering the baby liquids from a cup at approximately 6 months of age to allow your child to become familiar with this new skill and experience. Choose a particular meal or snack (outside of their bottle-feeding schedule) when you will consistently give a liquid from a cup and continue with this chosen time. Begin with a liquid that your child likes and is familiar with.

Once your child is comfortable using a cup, you can begin replacing a bottle feeding with drinking milk from a cup. It is up to you to decide which bottle feeding is best to replace first. However, it is recommended that you replace a mid-morning or mid-afternoon bottle feeding with cup drinking because it is the easiest to maintain. For most children, early morning or bedtime bottle feedings are their favourite feeding times and are typically the most difficult to wean off of. Leave these times until last to replace with the cup.

Gradually, replace each bottle-feeding with cup drinking. In

the beginning stages, when your child is not taking large volumes of liquid by cup you may wish to offer the bottle a short time after the cup experience. In this way, you can encourage your child to get the most nutrition from solid foods and the cup. Eventually, your child will get enough liquid from cup drinking that interest in the bottle will decrease and weaning will be completed.

You may find that your child seeks or needs additional sources of comfort during this weaning process. Try to find other ways to comfort your child, such as providing a special comfort toy or blanket, and lots of affection.

## *What type of cup should I buy?*

There is no specific training cup for a child with a cleft palate. There are several types of training cups available with lids, spouts, and handles in the market. Although the final decision is up to you and your child, there are some limitations you should keep in mind. Here are some helpful tips that may assist you in your selection:

- Avoid giving your child a “non-spill” cup as these cups have a one-way valve system that requires the child to suck the liquid from the cup. This can be very difficult for your child to do prior to surgery. The creation of suction in the mouth may also interfere with the palate repair after surgery.
- Avoid cups with long spouts as these may rub against the cleft palate repair.
- Many parents have found that cups with a short, soft spout are gentler on teething gums and work well for their children.

## *Other Helpful Tips:*

It is common for all children to experience some dribbling or coughing when cup drinking is first introduced. This situation should improve on its own with practice and time.

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# House Rules - How to lay down the law

By Catherine Rondina

*This article was reprinted with permission from CITY Parent Magazine, April 2002.*

“How come she gets to stay on the computer longer than me: why does he get to stay up later than me? Whose turn is it to take the garbage out?”

Recognize these phrases? If you're from a typical family household in Canada, you've probably heard them all. So how do you keep the peace around your home, while still trying to maintain a sense of responsibility and fairness? Establishing house rules may be your best plan of action. Here's how to go about planning your strategies.

- **All come to order** – The best way to ensure that house rules are followed is to negotiate them together. Sit the whole family down for a meeting to discuss the rules of the house. Establish what needs to be done, who is responsible for it, and how it will be carried out. Having the kids be apart of this process lets them see the democratic way of doing things.
- **Post the rules** – Once you've hashed out the bare bones of the rules write them for everyone to see. Place them in a prominent place where the whole family can refer to them when necessary. If a problem erupts anyone can go to the “rules board” and confirm the dictum.
- **Draw the line, clearly** – Be sure the perception of fairness is clearly defined. If one child is going to be allowed to stay out later because she is the elder child, make sure the distinction is clear and why it's being made, to everyone involved.
- **Spell it out** – Be sure if you are asking children to carry out a task that they understand the directions. Be specific in your request. If you want them to empty out their gym bags after school, be precise. “Please put your dirty gym cloths in the laundry hamper after school.”
- **Avoid the pitfalls** – Don't set yourself up for a fall. Avoid any rules that can't be enforced. Don't threaten a punishment that you know you won't or can't carry through. “If you can't learn to share your toys with your brother, then you can't go the soccer banquet this weekend.”

- **Crisis, what crisis?** – Don't try to come up with a new rule during a crisis. Settle the crisis as best you can and wait for everyone to gather before you try to draw up new rules as a result of the dispute.
- **Reward the positive behaviour** – When a child has abetted by the rules for a period of time, have a reward system in place. Let him choose a favourite meal or TV program for the family to enjoy, and praise his good behaviour.
- **Go with the flow** – If changes need to be made, make them. Just like in life, rules are made to be changed. As your child matures and your expectations of them change, so also must the rules of the household.
- **Hold your ground** – Be consistent. It may be difficult, but try to stick to the rules, even if it's only on a part time basis. It can make a difference in your child's understanding of following rules both within a family and in the outside world.

## Special Things

By Kyle Mckenzie

I know that I'm special and I'm glad of it too,  
Look at all the great things I get to do.

I made a video with Paul Stanley from the rock band KISS,  
Now that's an event you wouldn't want to miss.

I met Antonio Davis of the Toronto Raptors too,  
Boy o' Boy, does that man wear a big shoe!

I wrote a story for the AboutFace newsletter,  
And I hope after reading it, children will feel better.

I participate in improv classes through a program called  
Making Faces, Michael Williams-Stark really put us  
through the paces!

I'd like to thank AboutFace for all they have done.  
I've really had a lot of fun!

# Focus on an Interest and Make it a Strength

*Rebecca Goga lives in Southern Ontario and travels across North America providing wire art training and courses to others.*



**M**y name is Rebecca. I was born with a facial difference and other disabilities involving Chromosomes 6 and 7. The result was that some pieces of the chromosomes had switched around and caused me many surgeries including ones on the face, T-tube ear surgeries and life-threatening surgeries on my neck. I also had to

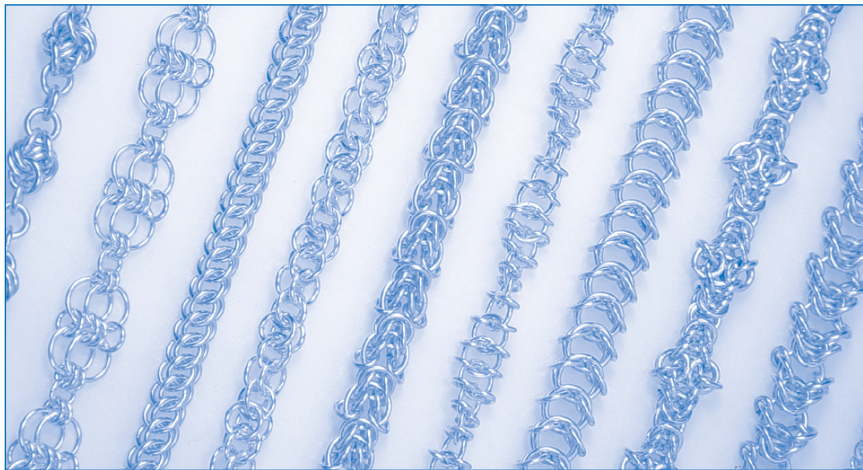
overcome a late-diagnosed hearing disability. I feel that these problems have made me a stronger person.

When I was a kid in school, I wanted (or tried) to be just like everybody else, just a normal kid. People stared at me since I looked noticeably different and it made me uncomfortable. Some people thought I was mentally disabled. One day, when my mom was driving me to high school, I felt miserable about my different looks. So mom explained that the kid who had a spike hairdo or the girl who dyed her hair purple, they dared to be different. But then she pointed out that these kids had a choice but I didn't. She then had me think about those times when looking different had worked for me.

I collect gemstones and unusual rocks and when Mom used to take me to rock-and-gem shows, I met different people and negotiated with the dealers for stones. I always get a good deal for a gemstone! But it didn't start that way. The first time I walked into a show and talked to a dealer he looked uncomfortable. But after a while, when they realized that I had a good

knowledge of gemstones and rocks, they became very friendly and supportive. Now when I meet the same dealers at different shows, they always have a smile and a hug for me. That was when I realized that I could have an interesting life even though I looked different.

Years went by, and Mom asked me to help her with the magazine, *The Wire Artist Jeweller*. Each month, Mom, Pop and two other partners pool their time and efforts to think of new ideas and new projects. One day, I saw Pop making a beautiful bracelet out of gold wire. So, I asked Mom to teach me how to make it. She showed me, and it was hard doing the pattern at first, but I did get the hang of it. While I was making this Byzantine-link chain, another idea popped into my head. I thought about it, pursuing the idea, and it worked into a link-chain pattern. Six months later, Mom bought a book on chain making and I came across many new ideas from the book and sharing ideas from other wire artists. Now I create my own ideas for chains, and I was featured in the June issue of *The Wire Artist Jeweller* because I am now a recognized chain designer.



My dream is to be become a gemologist (a person who studies the nature, chemistry and myths of gems), having collected gemstones from around the world since I was a little girl. From time to time I go on the internet to look up where the country is located, what the people do for a living, etc. It taught me to understand

the world around me. From a little girl born with deformities, I was able to focus on an interest and make it a strength.

So, by focusing on my strengths and not paying as much attention to my appearance, I have become more settled and productive. And I have a lot of friends to show for this attitude!

# Squabbling Siblings

*This article was reprinted from Kids' Health, published by The Hospital for Sick Children, 2002.*

A typical day in a typical family may include some conflict and friction among children. Disputes, petty arguments, fighting over the use of toys, and a dozen other scenarios can produce tears and a variety of emotions for kids, such as jealousy, anger and frustration.

A certain amount of this kind of behaviour is a perfectly normal family process. Family living is a kind of laboratory where kids can grow and experiment. Children learn to become advocates for their own needs and assert themselves, as well as express themselves as individuals. They also learn how to balance relationships and share parents with their siblings.

Sometimes, fighting among siblings can become overwhelming and have a negative impact on family life. Sibling rivalry can occur at any age in childhood, although after the age of 12 years children's concerns may reveal themselves in other issues. Parents should use their judgment to gauge if there is a serious problem and if arguing between siblings becomes too intense.

There are a number of reasons why siblings may begin to clash on a regular basis.

- If a child perceives that his parents are spending more time with his sibling, and that he isn't receiving as much love and attention as the other child, then that can create difficulties.
- The quality of a marital relationship may also affect sibling interaction. If parents are experiencing difficulty and conflicts in their relationship, less warmth and caring is often displayed between siblings.
- Parents experiencing a lot of stress in their daily lives and who are pulled in a lot of directions may find their children to be more likely to fight with each other.

Evidence suggests that brothers in a family may experience more rivalry than the combinations of sisters together, or a brother and sister together. This may in part be due to our socialization of boys and girls. Even in today's society, subconscious messages from parents may convey to girls that it is good to be caring to others, more so than this message is sent to boys.

Parents who are able to engage with their children in a warm and loving manner provide an indispensable benefit. Children have a need to feel connected with their parents and to know that their needs are understood. Parents who can spend time with their children, either as a couple or individually, will also help alleviate problems. Families can benefit from spending time together or pairing up to spend individual time with each sibling. Creating structure and routines in family life can also play a positive role in kids' lives.

Having at least one adult involved and concerned about a child's daily experiences can help that child develop in a healthy way. Even older siblings can be a great resource to younger children in the family. It is often when children feel they aren't getting enough positive experiences with key adults in their life that they begin to compete with siblings.

When sibling squabbling has reached its peak in intensity, parents shouldn't feel that they are alone in the trenches. Help is available through schools, your family physician, place of worship, community agencies, and parenting courses. Sometimes, simply opening up to a good friend can help you feel less stressed and more focused on positive solutions.



# General Parenting Resources

Here is a list of books and websites for parents on parenting issues, self-esteem and other child development and rearing topics. Most of these publications are available in the AboutFace resource center and are available to members on loan. Please call AboutFace at 800-665-3223 or email us at [info@aboutfaceinternational.org](mailto:info@aboutfaceinternational.org)

## Books:

- **Full Esteem Ahead: 100 Ways to Teach Values & Build Self-esteem for All Ages**  
By Diane Loomans with Julia Loomans  
Published by HJ Kramer Inc., CA, 1994      ISBN -0-915811-57X
- **Self-Esteem: A Family Affair**  
By Jean Illsley Clarke  
Published by Winston Press, MN, 1978      ISBN-0-86683-615-2
- **Becoming the Parent You Want to Be**  
By Laura Davis & Janis Keyser  
Published by Broadway Books, NY, 1997      ISBN-0-553-06750-8
- **Yes You Can! A Guide for Parents of Children With Disabilities**  
By Mark Nagler, PhD with Adam Nagler  
Published by Stoddart Publishing, Toronto, ON, 1997  
ISBN-07737-5866-6
- **Kids Are Worth It! Giving Your Child the Gift of Inner Discipline**  
By Barbara Coloroso  
Published by Somerville House Publishing, Toronto, ON 1995  
ISBN-1-895897-57-2

## Web Sites:

Canadian Parents Online:	<a href="http://www.canadianparents.com">www.canadianparents.com</a>
Disney Family Fun:	<a href="http://www.family.go.com">www.family.go.com</a>
Family Education Network:	<a href="http://www.familyeducation.com">www.familyeducation.com</a>
Education Planet:	<a href="http://www.parents-planet.com">www.parents-planet.com</a>
Parent Soup:	<a href="http://www.parentsoup.com">www.parentsoup.com</a>
Parent's Tool Box:	<a href="http://www.ctw.org/parents">www.ctw.org/parents</a>
Parent Bookstore:	<a href="http://www.parentbookstore.com">www.parentbookstore.com</a>
City Parent:	<a href="http://www.cityparent.com">www.cityparent.com</a>
Today's Parent:	<a href="http://www.todaysparent.com">www.todaysparent.com</a>

## Sharing Strategies!

Through our experiences, we have developed our own set of strategies for coping or talking about differences. If you would like to share your ideas with others, send them to AboutFace. We welcome your personal stories, helpful resources, and personal tips on living with a facial difference.

**1-800-665-FACE**

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

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However, if this persists, you may want to try thickening the liquid slightly so that it flows more slowly. You can do this by mixing strained fruits or vegetables with water or milk.

Children who learn to fall asleep with the bottle often find it more difficult to give it up. If you take the bottle away before your child falls asleep, he/she will learn to fall asleep by him/herself. This will make the transition from bottle to cup easier for everyone.

Weaning from the bottle to the cup can be very challenging for your child and you. This is meant to be a time of gradual change and increasing skill on your child's part. Try to remember to be patient, stick to your routine, and keep trying.

# Advice for Parents: Helping Children to Tell Peers About Their Difference

By Alice Pope, Ph.D.

1. **Help your child to decide on a simple, straightforward, unapologetic explanation of what her difference is, and how it came to be.** Often, simply stating, “I was born this way,” is enough of an explanation. Children may want to add that it was nobody’s fault, and that they have special doctors to help them.
2. **Prepare your child to answer questions from others.** Other children often have concerns: Does it hurt? Can I catch it? Did you fall? Will it go away? Again, simple answers allaying these worries are in order.
3. **Help your child to understand that he can choose how much to tell, depending on how he feels.** Although it’s helpful to address the issue of the difference, especially with children your child will see often, your child should feel no obligation to go into the entire song and dance every time somebody at the playground expresses curiosity. Simply saying, “I was born with this. It’s no big deal,” and going about his business is enough.
4. **Talk with your child about how it makes her feel to talk to others about her difference, and discuss ways she can keep her cool when she does this.** If your child feels anxious or angry at these times, help her to adjust her thinking about others’ attitudes. Most children are curious but uncritical. They just want to understand, and then they are happy to resume playing. It is really important for your child’s social development to adopt an attitude that most children are kind and friendly most of the time. If she can keep the assumption that most children have no intent to be hurtful, then she can avoid feeling upset when she gives her explanation.
5. **If your child is teased, respond with constructive problem-solving, but keep your upset feelings to yourself.** Remember that all children are teased at one time or another, and that teasing is not devastating if a child keeps a reasonable perspective. Help your child to think of positive ways to respond the next time. The best responses are calm but firm, such as, “I don’t like that, and I want you to stop. I’m going to play soccer with the others now.” The crucial pieces are to make a clear, unemotional statement that teasing is not acceptable, and then to confidently leave to be in the company of more accepting children. Alternatively, some children find a way to use humor to defuse the situation, so that everyone ends up laughing it off – and the teaser learns that he doesn’t get anywhere. It is important for parents to model a matter-of-fact response and to explain that teasing happens to everyone; the more upset you are, the more upset your child will be.
6. **If your child is chronically taunted by one or more other children, step in.** Most everyday teasing resolves itself, especially if your child can handle it well. But if your child is being bullied or humiliated week in and week out, you need to take action. If this is occurring at school, you need to inform the principal and the classroom teacher. Solutions to bullying problems need to be classroom-wide, and possibly school-wide, as all children – victims, bullies, and bystanders alike – are negatively affected by bullying. Important steps to take involve creating an environment where it is clear to everyone at school that intimidation and hurtful behavior are not tolerated, and that children who are victimized must be encouraged to speak out so the bully can be stopped by adults. If the bullying is being done outside of school, try to resolve the situation through calm discussion with the other child’s parents. As a last resort, help your child to avoid the bully, and remind her that no one is deserving of such treatment.
7. **Role-play with your child.** Children naturally find play-acting appealing, and it is an easy and concrete way for them to learn new things. Even adolescents can benefit from trying out new skills in this way. Take turns; sometimes you could be your child, other times you could be a peer. Practice until your child feels ready to go solo. If you see your child using strategies for discussing her difference that you think are counterproductive, stop and help her think through what might result – and then

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# Fatherhood

Dads of today are much more involved in their child's life and daily care than ever before. More and more men are taking an active role in child rearing because women insist that they do, and other than breastfeeding, there isn't a single parenting job that a man cannot do, once they learn how. As well, many men want to a part of their children's lives. One of the most important things to remember is "quantity" of time is perhaps more important than "quality" of time. This is no different for dads of children with facial differences. You cannot be an effective dad if you are not around. As a new dad, you need to get involved early, here's how:

- **Get to know your baby** – right from the start, get involved in holding, bathing, changing, and soothing your new baby. Babies need to be held and touched often. If you feel awkward holding the baby in the beginning, then let the baby lie on you while you cuddle her. Don't be afraid to try different positions to comfort your baby.
- **Play with your baby** – the best toy you can give the new baby is you. Walk, dance, talk, tickle, and sing with your baby. This will be enough entertainment for a few months.
- **Take an active role in your child's medical needs** – for a child with special needs, there maybe many medical appointments and treatments. Be a part of that process right from the start so that you and your partner can be clear on expectations, make informed decisions, and provide a strong support for each other.
- **Take care of your partner** – for new moms this time is also overwhelming. A new mom not only needs to deal with the needs of her new baby, but the changes in her body and in her life. Be supportive and patient.
- **Keep a healthy balance** – it is important to remember that being a good father also means being an active father. Try to keep a good balance between work and family time.
- **Talk with other dads** – it is helpful to find a supportive peer group that understands and can help you find ways to cope and affirm your feelings of fatherhood, particularly if your child has a difference. It will help you to talk with other dads who understand.
- **Work as a team** – for new parents, talking to each other openly and honestly will go along way to working as an effective team. You will understand each other's needs better, and will love each other more for it.
- **Take time out** – all parents need time out. Go out as a couple for dinner or a movie away from the baby once and a while. Or find activities that you can do together, like walking in the park or a music festival.

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think again about ways of talking that would be more likely to lead to the desired outcome. Remind her that the goal should be for both herself and the other child to feel more comfortable about the difference after talking.

8. **Try to resist overprotective impulses.** It is natural to want to protect your child from distressing situations, particularly when your child has had to deal with many stressors already in his life. While it is appropriate to make good judgments about which social situations your child is

exposed to, at the same time it is important to let him take some risks. Only by trying new things can your child gain the confidence to develop the independence he needs. Helping your child to find comfortable ways of handling discussions about his difference is a positive step that lets him know you have faith in his ability to handle himself with peers. Remember, sometimes your most important work is behind the scenes, providing your child with the necessary skills to go out and be successful on his own.

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a separate group of friends, or watching a favourite TV show that the other child doesn't want to watch, so you get to spend time with them separately. It's a good idea to start spending time with each one separately at an earlier age though to encourage their individuality.

*Todd: What do you and Diane do to ensure a connection and a strong relationship with each other?*

Bob: We spend time apart... (Bob laughs - he's just kidding). I know that for parents who are faced with the challenge of raising children with medical problems it can be very strenuous and difficult on their marriage. Generally, we have just always kept things open from day one. We have always talked openly about everything, and knowing that there was a difficult road ahead of us we agreed to always look to the future. We would always try to find time for ourselves, like anniversaries, and going out for dinner, or sneaking away to Dairy Queen without the kids knowing about it. You've got to or else you're not going to make it.



*Todd: When disciplining your children do you have standard expectations, rules, or are there loopholes because they have a facial difference?*

Bob: I have always disciplined all my girls the same way. We look at the end goal: what do we ultimately expect from our children when they are adults. If you let them grow up without any rules or regulations, you will end up with some pretty irresponsible adults. I don't believe that's the way to raise kids. However, like all parents, we probably let them get away with stuff, but I try not to let it get out of hand. After all, they are kids (teenagers now), and they can see through you and they might try to play on your weak spot if they find it.

The twins have never been allowed to use their difference as a crutch. I have never really given them that opportunity. It has always been: this is the way you are to grow-up, and this is what is expected of you. I may ease-up on the disciplinary action, or avoid saying something to the twins in the way that I might have said to my older daughters because of their differences, especially when they were younger. In general though, I have four children and if I treat the twins too differently, then the other two will notice and might feel that I am treating them unequally.

*Todd: Between you and Diane, who takes the lead role in overseeing treatment?*

Bob: This role is definitely shared between us. However, I did take more of a lead role in a time where there were a lot of treatments for the twins, because I had sustained an injury and I was not allowed to work for 16 months. Obviously, it was easier for me to take the lead, only because I had the time, where as Diane had to be at work. But generally, we tend to share this responsibility.

Also, we found out early on when the twins were first born that we would come back from a medical appointment having forgotten to ask something. So we will always go home and write down the questions that we would like to address at the next appointment. The only difference now is that with all of our experience we don't need to have a cheat sheet anymore.

*Todd: How did you prepare the twins for the numerous amounts of appointments that they have had with various doctors, and clinics?*

Bob: As far as preparing them to talk to any of the healthcare professionals involved in their treatment, it's been a natural, gradual process. Everybody has always treated them well, so the twins are very comfortable with the medical team. As far as preparing them for surgery or what's ahead, they know that Diane and I have always been open and honest with them, and that there is nothing that we are going to hide from them. The decision for elective treatment has always been theirs, with us helping them out in terms of assessing the pros and cons. Basically, we take the time to discuss things with them after their appointments until they have a full understanding of the options, the risks and their expectations. And this is not a simple and quick process. We take all the time they need to feel completely confident and comfortable.

*Todd: What did you do prepare the girls for school?*

Bob: From an early age, we knew that these girls had to be mature individuals, and needed to be treated that way. We knew that they would have challenges to face, in the schoolyard, in the classroom, and in other social situations. I am sure if you asked the girls, from as early as they can remember, we would sit around the supper table and talk about daily issues. We would talk about scenarios that they might find themselves in and we would always try to build up their self-confidence and self-esteem to handle those situations. For example, we talked about if they would rather be stared at or would they

*Continue over*

rather someone ask what happened. As we worked it out, they would rather have someone come up and ask them because then the staring would stop. So in this way they develop a good understanding of what they expect from other people and how to handle it. Then, as situations would arise at school, they would come home and feel comfortable talking to us about it, and together, we would come up with solutions. In that way nothing was embarrassing to them. I remember that people would think that they were Siamese twins and that they were born together joined at their ears. It's funny, but one thing that we have learned over time is that they would get less of a reaction from other kids than from the adults.

*Todd: When the twins started school did you go in to talk to the teacher and principal about their conditions?*

Bob: Yes, actually just to make sure that they would pay attention to whether or not they were able to hear O.K. and if not then to seat them in the front of the class. The teachers would have access to their medical forms and the girls have had good teachers along the way. Then they would know about it before parent teacher conferences and if they had any concerns at that time we would talk about it then. We would make sure that their teachers were aware and informed of the time frame involved with any of the medical procedures that the girls were going to have.

*Todd: When did the twins notice that they were different or come out and ask you about their difference?*

Bob: Diane and I were so conscious about talking to them about their difference from an early age, that I don't think we ever had a "discovery" moment. From the time that they could understand us, we started talking to them about it. One day, when their Mom was giving them a bath, Kayla started pointing and laughing at Brittany's ear, but they were both too young to really realize why it was different. But other than that, it's never really been an issue.

*Todd: Did you take baby pictures of the twins and share them with the girls growing up?*

Bob: Ya! We have shoeboxes full of pictures and always have had pictures hanging up in the house. Actually, the last couple of weeks Brittany has had a project to do at school about herself. So she knew that we have family pictures all over the house from all ages of her life so she has been breaking into those boxes to put together her project.

*Todd: What are some of the current issues for Brittany and Kayla right now?*

The main issue right now for Brittany and Kayla is that ever

since they have had their prosthetic ears made they definitely do not want anyone to know that they had a problem with that side of their ear. Which at first took me back a little bit. I thought they would want to be more outgoing and show their new ear off, but actually they didn't want anybody to look at it or know about it. One of them said to me that we had this done so that nobody would know that it was there, which made sense to me. They have both recently transferred to a new school and they don't want their new friends to know or the other kids at school, to the point where they rather their teachers not know, they don't want their soccer coaches to know, or anybody else.

They would rather that people just assume that their ears were normal rather than make an issue out of something that may never become an issue. That was their whole reason for going through the prosthetic treatment. And, it's not that they have lost any self-esteem, but rather that they have become so confident in their treatment. It has given them a lot more self-esteem and confidence. We have always tried to build their self-esteem, but since they have had that done they are so confident in themselves in any type of situation. In fact, in the next couple of weeks Brittany will begin the first part of her reconstructive treatment for her jaw, and is being fitted with braces for her teeth.

*Todd: What advice would you give to new parents who might be facing some of the same situations that you have faced?*

Bob: I think what has helped Diane and myself is that we had a good grasp on what to expect from the very beginning. It's easy to fall into a "why me" type of attitude but we never did. For us, it was always about what could we do for these girls when they get older to make them good adults, and that's all you can do. Be open with your children from an early age. Ideally, it would be nice if your kids could grow up in a world where nothing is going to happen to them, but that's not realistic. There is always going to be issues, and you know what the issues are because they are the same ones we faced growing up. There were always kids around who were different, and not just physically. You know the things that are said and done, whether it's staring or talking or saying mean and nasty things, they are going to happen to your kids too, regardless if they have a visible difference. It's important to talk to your children and be open with them and treat them like adults in that way. It's hard for a kid to be teased and understand that they are not the one who's wrong. They just feel hurt. As they get older they will see that it's the other people who really look stupid, not them. Help them to understand at an early age that it's not their fault and it's O.K. to be different.

# Dates to Remember

## Symposium & Workshop, Chennai, India

*October 25-27, 2002*

Speech Disorder in Individuals with Cleft Lip and Palate-Assessment, Therapy and Surgical Management

For more information visit:

[www.cleftspeech2002.ontheweb.com](http://www.cleftspeech2002.ontheweb.com)

Contact: Prof. Roopa Nagarajan,  
[cleftspeech2002@rediffmail.com](mailto:cleftspeech2002@rediffmail.com)

## Family Education Day, Toronto, Ontario

*October 26, 2002*

Family Strength: A Patchwork of Our Experiences

For more information visit:

[www.aboutfaceinternational.org/programs/familyday](http://www.aboutfaceinternational.org/programs/familyday)

Contact: AboutFace at 800-665-3223  
or [info@aboutfaceinternational.org](mailto:info@aboutfaceinternational.org)

## Access to Success, Toronto, Ontario

*December 10, 2002*

An educational forum featuring international speakers for corporate management leaders.

For more information visit:

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

Contact: Lorine at 905-713-3222 or  
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