

FACING THE FUTURE

SHARE YOUR STORY!

Do you have an interesting tale to tell related to your experience with a facial condition? What have you learned that might help other families? The Foundation for Faces of Children (FFC) is launching a new section on its website featuring family stories about their life experiences.

If you would like to share your story with FFC, send it in an e-mail to info@facesofchildren.org. Please keep your letter brief (300 words or less) and include your name, address, and phone number. If your story is chosen for publication, we will contact you. FFC reserves the right to edit or reject stories.

Changing Faces and Lives



As a medical social worker, **Cassandra L. Aspinall, MSW**, discusses face-altering procedures with children and their parents to make sure their expectations are realistic. "It's fine if someone thinks, 'I will be more positive about myself if my nose looks better,'" says Aspinall. "But there's nothing worse than a child thinking an operation is all that's needed to improve the chances of having a boyfriend or girlfriend or to be accepted by the popular kids for the first time."

Aspinall provides psychological and social support for families at the Children's Hospital and Regional Medical Center in Seattle, Washington. Working with the treatment team in the Craniofacial Center, she helps patients and their parents to better understand medical conditions and weigh the benefits and risks of treatment. Both she and her 14-year-old son were born with clefts, so she has first-hand experience in addition to her professional training.

Her role is to have in-depth conversations with patients and their families about their expectations, fears, and hopes for the future. "My responsibility is to introduce the idea of patient involvement," says Aspinall. "I ask children if what the doctor said made sense to them, if it was scary, if they have any questions. That allows them to understand that it's their body. Younger children, especially, don't want to be in charge and make all the decisions, but they do want the opportunity to participate along the way."

The Family

Acting as a translator of sorts, she makes sure the family understands their child's diagnosis and treatment options by encouraging questions, even those they may think

sound silly. And, in turn, she helps the craniofacial team understand the family's concerns and priorities. Each family, she says, has its own set of values that must be taken into account.

An advocate of family-centered care, she believes that parents have a right to protect their child and make decisions they believe are in the child's best interest. However, in some cases, children think that their appearance is fine, but their parents, doctors, and others imply that the way they look is a problem that has to be fixed. This can create a conflict that should be explored.

Some parents start the dialogue by dealing with their initial reactions to their child. "I encourage them to admit that when they first saw their child or learned of their child's diagnosis they were upset," Aspinall says. "Even for me, after having been born with a cleft lip and working with so many people with children with facial differences over the years, seeing my own child in delivery took

some adjustment. That doesn't mean I don't love him and accept him. It means I'm a human being."

The Community

As children head off to school, they have more social encounters and more chances to connect with others through sports, clubs, music, and social events.

"Identity development becomes more complex during this time, as children enter more formalized educational and recreational settings," says Aspinall. "All children, including children with facial conditions, must cope with how they are perceived."

Juggling treatments, seeking additional assessments, and evaluating elective procedures can further complicate the school year. Psychological rather than physical issues may drive changes to appearance, and both need to be considered in deciding the best course of action.

Parents may be nervous when sending their child to



A 16-year-old girl with cleft lip and palate decides to have another nose revision. Her main reason for undergoing the procedure? She has the romantic notion that it will improve her chances of being asked to the prom.

Save the Date!
September 16, 2007
See inside for Family Picnic & Walk info

The Foundation for Faces of Children is proud to present its 2007 scholarship to **Josh Bemis** of Plymouth, Mass. He will receive a \$1,000 award to help with his college expenses.

Josh recently received his high school diploma at the age of 16. He was home-schooled through an affiliation with the Lighthouse Christian Academy. A member of the National Association of High School Scholars, Josh was nominated for *Who's Who Among High School Students*.



Josh Bemis

Born with Saethre–Chotzen syndrome, a type of multiple–suture craniosynostosis, Josh has overcome many challenges to achieve success not only scholastically but in a wide variety of activities. He volunteers at a local hospital, serves as a member of the U.S. Civil Air Patrol, and is active in his church (the Helping Hands and nursing home ministries).

In addition, he has studied karate for 10 years and is preparing for his black belt.

Next fall, Josh will attend the University of Massachusetts at Lowell. He plans to study meteorology and hopes someday to work for the Weather Channel or the National Weather Service. *Congratulations to Josh on his outstanding accomplishments!* 🎉

Changing Faces and Lives, continued from page 1

school. “When your child is born with a medical condition you have over-activated radar—you’re on the alert for things that others don’t have to worry about, and you want to protect, protect, protect. But over time, backing off may allow your child that magical moment when he or she meets somebody who’s supportive and welcoming, and has such a great time.”

Society

In addition to the local community, society at large may influence a decision about whether or not to undergo a craniofacial procedure. (While some procedures like opening an airway are obviously not optional, others are.) Having cleft lip revision surgery, for example, may help the child and family feel more comfortable and accepted in society.

“Although parents love their children even before any operation,” says Aspinall, “they worry about issues of inclusion and acceptance. The decision to have surgery is bittersweet, because if the world were a perfect place, we would all tolerate each other regardless of how we look.”

Making modifications chiefly for the sake of appearance, particularly in children too young to give informed consent, is a matter of debate in medical circles. Many plastic surgeons argue that altering facial features is necessary to reduce possible stigma, while some medical ethicists counter that exposing a human to avoidable risk is unacceptable.

Aspinall encourages parents—and surgeons—not to automatically perform secondary revisions before a child enters kindergarten. The timing of such procedures and their impact on

the child needs to be discussed. In addition to providing a benefit, they can also pose risks, such as problems with anesthesia, infection, and unsatisfactory outcome. Other drawbacks to consider include missing school, extracurricular activities, and contact sports.

She reminds parents that improving their child’s appearance is not like other ways of improving a child’s life, such as going to soccer camp or signing up for French lessons. That is not to say that the physical risk isn’t worth taking, but considering this reality is important.

Ultimately, the risk belongs to the child, and, therefore, she believes children should be informed as much as possible and involved in decision-making in a developmentally appropriate way that also takes into consideration the values of the family. As patients change and develop, she urges them to examine the relationship between who they are and what they look like, and to carefully evaluate any alteration of their appearance.

Dealing with Feelings

How people look can strongly affect how they feel about themselves. Both boys and girls with facial differences may experience low self-esteem, anxiety, and depression but express it in different ways. Counseling may be needed to clarify the motivation for surgery and perceived benefit.

Aspinall fully endorses opting for reconstructive surgery if people believe it will help others to perceive them as they truly are. “I always tell insurance companies that the reality is that we’re not taking normal structures and making them more perfect,” she says. “We are taking abnormal structures and making them more normal.”

Her goal is not to dictate what other people should do but to discuss feelings and values. She constantly reminds children and their families to talk together about the bumps in the road. “They come up for everybody,” she says. “And the reality is your child will have a lot of strengths and a lot of interests. You’ll be proud of her and mad at her like any other child. The key is to remind ourselves that we can make it through life’s challenges, both planned and unplanned.” 🎉

Looking for reliable medical information online?
 MedlinePlus at www.medlineplus.gov can help you answer your health questions. Arguably the world’s best online medical library, MedlinePlus combines information from the National Library of Medicine, National Institutes of Health, and other health-related organizations. Here you’ll find the latest health news, an illustrated encyclopedia, a medical dictionary, and drug information. You can also read about clinical trials for new drugs and treatments and watch surgery videos.
 And don’t forget specific information on craniofacial conditions can be found at our website, www.facesofchildren.org.

FFC Family Picnic & Face-to-FaceSM Walk

- Preregister for the FFC Walk by e-mailing info@facesofchildren.org or by calling 617-355-8299. Give us your name, phone number, and the number of walkers in your group so we will know how many to expect.
- For directions or to download sponsor sheets for anyone wishing to participate, visit www.facesofchildren.org.
- Be sure to bring your sponsor sheet the day of the walk along with any pledges already collected. Mail remaining pledges no later than November 16, 2007 to:

Foundation for Faces of Children
258 Harvard Street, #367, Brookline, MA 02446

Questions? Call us at 617-355-8299 or visit our website, www.facesofchildren.org.

Registration and walk begin
at 12 noon. Picnic follows.

Hope to see you at
Lake Quannapowitt,
Wakefield, MA!



Foundation for Faces of Children

258 Harvard Street, #367
Brookline, MA 02446



The **Foundation for Faces of Children** is dedicated to improving the lives of children with craniofacial conditions, including cleft lip, cleft palate, and other head and facial differences.

Our mission is to:

- Provide patients and families with the most accurate, up-to-date, and accessible information about facial conditions.
- Advocate for the best care possible for children with facial conditions.

We achieve this by:

- Collaborating with leading specialists.
- Endorsing the team approach to care.
- Partnering with individuals and organizations with similar goals.

We are a not-for-profit organization entirely supported by private donations, grants, and fund-raising initiatives. If you would like to participate in or sponsor a fundraising event, please contact us at **Foundation for Faces of Children**, 258 Harvard Street, #367, Brookline, MA 02446 or 617-355-8299. You may also send e-mail to us at info@facesofchildren.org.

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