

FACING THE FUTURE

MAY DAY DEADLINE FFC Scholarships

Applications are now being accepted for the 2008 Foundation for Faces of Children (FFC) scholarship program. High school students and graduates may apply for a \$1,000 scholarship to a college or vocational/technical school. Each spring, FFC awards scholarships to promising and inspiring students born with a facial difference who are pursuing post-secondary education. To be eligible, the candidate must live in New England (Connecticut, Maine, Massachusetts, New Hampshire, Rhode Island, or Vermont).

Applications, which are available online, are due May 1. (Note that the deadline has been extended from previous years.) For details, visit our website at www.facesofchildren.org and click on "About Us" at the top of the page to find links to the scholarship forms and instructions. Or, call Mary Lania, Scholarship Committee Chair, at 781-255-8931 (evenings or weekends).



Scholarship applications are due May 1.

FFC Welcomes a New Director

The Foundation for Faces of Children has appointed Mairi Bleakie as its first professional director. This is a milestone for the organization, which previously has relied solely on volunteers to advance its educational and advocacy goals.

Bleakie was chosen to lead FFC because of her educational, career, and personal background. "We are excited about the skills she brings to the job, which have been built on years of experience in the development field," says Johanna Smith, co-president of FFC. "Her energy, enthusiasm, and ideas have already revitalized our efforts."

A native of Canada, Bleakie earned a B.S. and master's degree in child clinical psychology from Acadia University in Wolfville, Nova Scotia. For about a decade, she worked with organizations that provided services for children from at-risk communities. Most recently, she was the major gifts officer for Plimoth Plantation, a living history museum in Plymouth, Massachusetts.


The mother of 16-month-old twins, Bleakie has a personal connection with FFC. Twenty weeks into her pregnancy, doctors diagnosed her son—but not her daughter—with cleft lip and palate. She was referred to the Craniofacial Centre at Children's Hospital Boston, where she met John Mulliken, MD, and Dotty MacDonald, R.N.

Today she is passionate about educational and outreach efforts. "We are grateful for the comfort

and hope that both Dr. Mulliken and Dotty gave us then, and still do," says Bleakie. "And FFC's video was so helpful to my husband and me. I feel honored to be able to give back to the organization that has given us so much."

As the FFC director, Bleakie will interact with patients and their families, volunteers, medical professionals, health communicators, and other nonprofit organizations. She will manage all of the FFC's educational projects, including its website, publications, and video productions. She will also plan and participate in fundraising events, apply for grants for the organization, coordinate volunteer efforts, and generally oversee administration of its programs.

"I want to see the organization become the premiere educational resource for patients with craniofacial conditions and their families," Bleakie says, "and not just at birth but throughout the child's life."

She is looking forward to working with the FFC board to plan improvements, including an upgrade and expansion of our website. Her future plans also include connecting with parents through weekly visits to the craniofacial clinic as a representative of FFC. 



Director Mairi Bleakie is eager to bring her skills to the organization.

Growing Up Together

All sibling relationships have their ups and downs and tend to be a blend of loyalty and rivalry. "Families in which a child has a craniofacial difference are more alike than different from other families," says Elisa Bronfinan, PhD, a staff psychologist in the Medical Coping Clinic at Children's Hospital Boston.

But positive and negative emotions may be more pronounced for siblings of children with craniofacial conditions. Along with feelings of love, support, and protectiveness, they may be jealous of attention that their brother or sister receives or embarrassed to be seen with them in public.

Different factors influence the impact a child's facial difference

has, including its severity, the number of procedures required to correct it, and the age at which those procedures occur. The sibling's age and developmental level also have an effect on the relationship.

"Any medical problem that requires parental time and attention affects everyone in the



Ben, 10, and his 15-year-old sister, Nikki, who was born with bilateral cleft lip and palate, enjoy vacationing every summer with their family at Goose Rocks Beach in Maine.

family,” says Bronfman. “For example, a sibling may have to stay with relatives when his brother or sister has a procedure, which can be stressful.”

Rewards and Difficulties

Most siblings have positive childhood experiences and tend to be strengthened by their relationship with a brother or sister born with a facial difference. They frequently grow to be more mature, compassionate, and empathetic than their peers.

“Often siblings of a child with any special need are more sensitive and sympathetic to

others,” says Bronfman. “They know the adversity that goes with surgery. After the ordeal, they may come out on the other side having a more thoughtful approach to life in general.”

On the downside, reactions of others to a facial difference, such as staring, pointing, or teasing can cause the sibling emotional distress. “Some children are embarrassed by their brother’s or sister’s craniofacial difference and want to distance themselves from it,” says Bronfman. “They see kids staring and want to avoid that.”

They may even want to hide their brother or sister from their friends and hesitate to invite other children home. They may also want to exclude him or her from play activities.

In a small community, where everyone knows everyone else, there is often less gawking and teasing, Bronfman points out. “In a larger town or city, every new person they encounter has to figure it out,” she says. “Kids talk and stare—not so much to be mean, but wondering, ‘What is that?’”

The amount of parental attention that the child with the craniofacial condition receives may also be a source of friction. Siblings, especially younger ones, may feel shortchanged when it comes to time spent with their parents. And they may be envious

of the cards and gifts that their brother or sister receives after surgical procedures.

Supporting Siblings

How well parents cope with the stress of a child who needs special care affects how well the siblings cope. Siblings do best when their parents talk openly and express their feelings.

“Difficulties are diminished if the parents are thoughtful and help both children to feel loved,” says Bronfman. Spending special time with siblings—going to the movies or playing a game or sport together—can help them feel they’re receiving attention, too.

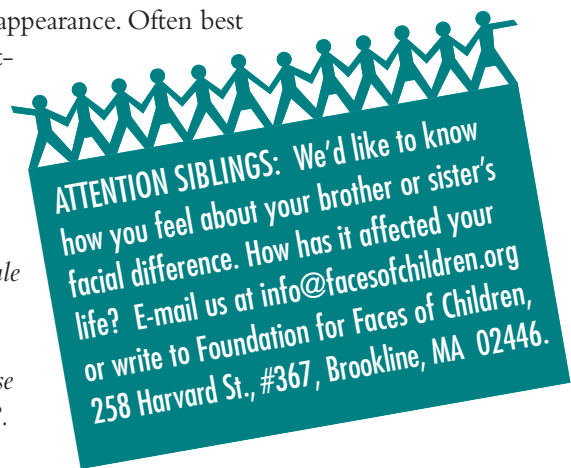
Sharing information with siblings and helping them to understand what’s going on can alleviate anxieties. As an old song by Mr. Rogers says, “I like to be told...It helps me get ready for all those things.” And by being “in the know,” siblings are able to explain their brother’s or sister’s craniofacial condition to their friends or classmates.

When a procedure is scheduled, Bronfman recommends the following to parents:

- Discuss with siblings what will happen after the procedure. Talk about adjusting to their brother or sister’s new appearance.
- Be thoughtful about when siblings can visit.
- Make sure visitors don’t pay attention only to the child who’s had the surgery. (As when a new baby is born, it’s nice to bring a present or card for the sibling, too.)

Role playing can also be helpful in teaching siblings how to deal with curious looks and inquiries from others. Parents can help children rehearse possible responses to questions about their brother or sister’s appearance. Often best are simple, straightforward answers such as, “He was born that way.”

For information about counseling services or to schedule an appointment at Children’s Medical Coping Clinic, please call 617-355-6688.



Introducing...

Stephen R. Sullivan, MD, is now the craniofacial/pediatric plastic surgery fellow at Children’s Hospital Boston. A native of Montana, Dr. Sullivan graduated from Carroll College in Helena, Montana, and went on to earn his medical degree from the University of Washington School of Medicine in Seattle. He continued his training in Seattle first as a research fellow, then as a general surgery resident, and finally as a plastic and reconstructive surgery resident. He came to Boston to begin his one-year fellowship in July. Dr. Sullivan enjoys a mix of clinical work and research. While he is experienced in all areas of pediatric plastic surgery, he has a special interest in craniofacial conditions and currently conducts research related to cleft lip and palate. He is the author of more than a dozen journal articles.

When he manages to find spare time, he enjoys hiking, skiing, and scuba diving.

She's an Inspiration

Mark Jackman wrote this tribute to his sister, Kara, in 2002 as a college admissions essay. Kara, a past FFC scholarship recipient, completed her B.A. and, in 2004, earned a master's degree in library and information science. She now works at the Boston University School of Theology Library as an archivist in charge of rare documents. She helps the Foundation in many ways, including taking minutes at monthly Board meetings.

She does not cry to get attention, complain when in pain, or show any signs of discomfort until it is unbearable. I have seen her remain calm in a situation where I would have been unsettled and tough it out when I would have fled. I am fortunate enough to live with the person who has inspired me the most and who has had the most influence on my life. This strong, yet shy and funny person is my 22-year-old sister, Kara.

Kara has been through several complex surgeries including the repairs of her cleft lip and palate, related ear and dental surgeries, and even braces, twice. The many years of doctors' visits were never viewed by the family as a hassle; they were just part of our lives. We all never thought them bothersome, just a way of finishing the work that God had left undone. And Kara, she never complained about the time or even the pain.

One example of her personality came when I was about the age of 12. My dad and I had traveled to Children's Hospital to visit my sister before surgery. As I entered the room of whiteness, deep in the hospital, I was aware of the very clean smell of the hospital and the lack of color. The only break in color was my sister, wearing a blue johnny, sitting up almost straight in her bed. She was calm and collected as a nurse repeatedly stuck an intravenous needle into her arm and continued to miss the vein. My sister did not flinch or cry, but let the nurse keep failing and did not say anything until she finally was able to complete the task. When she left, my sister responded by saying "rookie." She did not complain even though much blood was on her white sheets and the area on her arm that was probed was already turning black and blue.

I had to leave this room while she was being prepared for surgery. I sat in a large waiting area and watched one of two televisions. I was not really watching television, but staring at it to keep my mind off what could be happening to my sister. Soon lost in my thoughts of what it was like to be put to sleep, my parents entered and assured me that Kara would be fine. My stalwart sister was sleepy with anesthesia, at rest while a team of impressive surgeons finished God's work. She would awake, I knew, quietly and gently. We would know she was back when her blue eyes twinkled, and she offered a quip that would make us all laugh.

The surgery lasted more than four hours, and I was able to see my sister after the fifth hour. She was groggy, tired, and uncomfortable, but still not complaining. She showed strength even when in this, the worst of all states. Then those groggy blue eyes twinkled and she asked, "Hey, where have you all been?"

Growing up with Kara was tough, tougher than was necessary. It was not only the procedures; it was all that went along with having a cleft lip and palate. Children, and even some adults, would stop, stare, point, and say, "What's that?" The lip, the scar, the differences that made some people wonder. Was she made to feel different, left alone, and sometimes isolated? Oh yes. But when you look at her now, you would be amazed to see that even those painful experiences have shaped the reflective and deep person she has become. You would see that the experiences that made her so resolute have left her with a rich sense of humor and wit.



Kara is not one to tell how much pain, both physical and emotional, she has endured.

Kara makes the

impossible seem easy, and she never says a word about it, not for recognition or sympathy. There is no self-pity, despair, or resentment. There is just a young woman who sees and feels things in a way that no one else possibly could.

Today, my sister is in her last year at the College of the Holy Cross and is doing very well. She has a major in English and writes incredibly well. She brings to her writing a depth, a dimension of feelings and emotions that reflect who she has become as a result of facing extraordinary challenges. I know she will be successful in whatever she decides to do.

Not only my family and those who know Kara, but many others can gain something from my incredible sister. She has taught me not to worry about the small things, such as what to wear. She has also taught me to be strong and not give in to a problem but keep fighting and eventually conquer the fear or problem. For all that she has taught me, my sister is the most incredible person I know. I feel that I am a more complete and stronger person because of her. I have learned through her example that tolerance, patience, strength, humor, reflectiveness, and a sense of self are essential if one is to succeed and thrive. I hope to carry her ideals throughout my life.

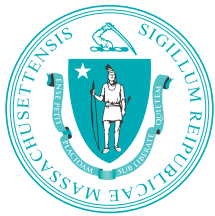
— Mark Jackman

Bill to Guarantee Insurance Coverage

Massachusetts lawmakers are considering a bill that would require health insurers to provide complete coverage for treatment of cleft lip and palate.

Representative Louis Kafka introduced a bill in May 2007 that says "...a health insurance policy that covers a child under the age of 18 must provide coverage for treatment of cleft lip and cleft palate for the child." Under this proposed law, coverage must include all medically necessary care related to the management of cleft lip and palate, such as dental care, oral and facial surgery, speech therapy, audiology, and nutrition services. This bill, now known as H. 4557 (formerly H. 4283), is currently before the Committee on Health Care Financing. (On February 27, it passed favorably—with some changes—out of the Joint Committee on Financial Services.) If approved by committee members, the bill will be released for a vote in the House of Representatives. The legislation must pass in both the House and Senate and be approved by the governor to become law.

Please urge your legislators to support this bill! You can find contact information for your representatives and senators on the legislature page on the Massachusetts state website:



For updates on this bill, go to www.Mass.Gov
Click on "Legislature" in the left column,
then type "4557" in the search box.



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. We concentrate our efforts on education, training, family support systems, and the dissemination of accurate and timely information. We also fund targeted research about the causes, treatments, and outcomes of these congenital conditions. The goals and strategies of the Foundation for Faces of Children are to...

- Provide leadership and advocacy through research and education.
- Distribute accurate and timely information as quickly and widely as possible to children, families, medical professionals, and the community at large.
- Endorse the team approach to treatment of craniofacial conditions; we believe that the best outcomes result from collaborative treatment by an experienced group of specialists.
- Partner with organizations that have similar goals and values.

We are a 501(c)3 not-for-profit organization supported entirely by private donations, grants, and fund-raising initiatives. We receive no government funding. If you are interested in having a board member speak to your group about our organization, or if you wish to participate in or sponsor a fundraising event, please call us at **617-355-8299** or write to:

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

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617-355-8299 | www.facesofchildren.org
E-mail: info@facesofchildren.org