

FACING THE FUTURE

FFC Scholarships

Apply now for the 2007 Foundation for Faces of Children (FFC) scholarship program. If you're a high school senior or graduate living in New England, you may be eligible to win a \$1,000 scholarship to a college or vocational/technical school.

Begun in 1999, the scholarship program benefits young adults with cleft lip/palate and craniofacial conditions. Each spring, FFC awards two or three scholarships to deserving students from New England (Connecticut, Maine, Massachusetts, New Hampshire, Rhode Island, and Vermont).

Applications are due April 1. 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.

You may also call Mary Lania, Scholarship Committee Chair, at 781-255-8931 (evenings or weekends).

Scholarship applications are due April 1.

Preparing for the Hospital

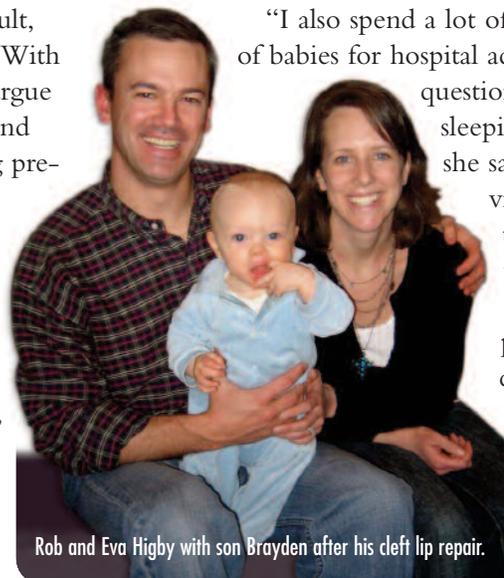
Two weeks before the birth of Rob and Eva Higby's son Brayden, a prenatal ultrasound scan revealed that he had a bilateral cleft lip. The first-time parents began searching for a surgical specialist, and with the help of Eva's brother and sister-in-law, whose child also had a cleft lip, found Dr. Mulliken and his team at Children's Hospital Boston. In November, when he was four and a half months old, Brayden had his lip repaired and nose reshaped.

Today eight-month-old Brayden eats and sleeps well and already knows how to shake his head to signal "no." The Higbys say he has "turned a corner," not only in terms of his cleft but also in his overall development.

Rob Southern, 24, estimates he's had between 12 and 15 operations to correct his bilateral, complete cleft lip and cleft palate, but he's lost exact count. "I've always been used to it," he says, noting that volume two of his medical record is two inches thick. A native of Concord, Mass., and a graduate of Emory University in Atlanta, Rob had his first procedure at Children's at three months of age and hopes that his latest one will be his last.

Facing hospitalization is difficult, especially if it's for the first time. With very young children, one could argue that the parents feel more stress and anxiety than the child. But being prepared and knowing what to expect helps to relieve worries for both patients and parents.

"Many times we meet with prospective parents for prenatal consultations while the fetus is in utero," says Dotty MacDonald, RN, clinical coordinator of the Cleft Lip/Palate and Craniofacial Program at Children's Hospital Boston. "The birthing process is much easier when the parents are well informed and comfortable with their health care team.



Rob and Eva Higby with son Brayden after his cleft lip repair.

"I also spend a lot of time preparing parents of babies for hospital admissions and answering questions about feeding, sleeping, and procedure issues," she says. In addition, she provides detailed explanations to young children and their parents, and refers them to the hospital's pre-operative (pre-op) child life specialist.

Hayley Bray, the child life specialist, is available to meet with parents and patients during their pre-op visit. She talks to children about their feelings and what to expect during their hospital stay. She assesses

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RESOURCES

- **Foundation for Faces of Children**
www.facesofchildren.org The FFC website contains information about dozens of craniofacial conditions and links to other resources.
- **Cleft Palate Foundation**
www.cleftline.org This site offers fact sheets and brochures as well as listings of cleft palate/craniofacial teams nationwide.
- **Children's Hospital Boston**
www.childrenshospital.org The "Preparing Your Child" pages (under "For Patients & Families")

offer information on how to talk to children in an age-appropriate way about going to the hospital and provide a list of books for you to read with your child.

- **Arthur's Guide to Children's Hospital**
www.childrenshospital.org/arthur
On the Children's Hospital website, this guide uses familiar PBS characters to discuss pre-op visits and hospital stays.
- **Pre-op Child Life Specialist**
617-355-2164 The child life specialist at Children's can help prepare your child for the hospital.

- **Medical Coping Clinic**
617-355-6688 A counselor can talk about your child's worries or fears about the hospital.
- **Children's Hospital of Philadelphia**
www.chop.edu The animated "Kids Health Galaxy" (accessible through the hospital's home page) features information for children ages 6 to 12 about hospital stays.

Hitting the Ice for FFC



Madison Parks at a Syracuse Crunch game.

A charity hockey game raised \$1,000 for Foundation for Faces of Children (FFC) on March 10, 2007. Sponsored by the Syracuse Crunch Hockey Club, an American Hockey League farm team for the Columbus Blue Jackets, the game was played by team alumni, coaches, and top ticket sellers. This is the second time the club has held a benefit for FFC.

The Syracuse Crunch donated the money to honor Madison Parks, daughter of Teri and John Parks.

Her father played center in the charity game. Madison, who lives with her family in Clay, New York, was born on Christmas Eve 2003 with unilateral craniosynostosis, a condition in which a bony suture closes prematurely, affecting one side of the head. A patient of Drs. Proctor and Rogers, she comes to Boston regularly for doctor visits and has already undergone two eye operations.

On New Year's Eve, the Parks celebrated the birth of son, Gavin. He no doubt will soon be on skates like sister Madison, who began skating at age 1. Our thanks to the Parks family and the Syracuse Crunch for their continued support. 

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their needs based on age and whether they are new to the hospital or have had past hospital experiences.

"A picture book and medical play are used to help prepare children for the hospital," Hayley says. "If age appropriate, children can also take a unit tour. One way we help children to cope during their hospital stay is to encourage them to make an "All About Me" poster or create their own picture book of their hospital experience."

Information Please

Learning more about your child's cleft or facial difference can help you feel more knowledgeable and comfortable. Reading basic information on the condition and corrective procedures is one way to start. Then you might want to make a list of specific questions to ask members of your child's treatment team.

Rob S. turned to the Internet to do online research before his recent operations. "I try to really understand what's going to happen," he says. "I read online illustrated textbooks and medical forums."

Eva and Rob H. also found information on the Internet through the FFC website, which includes links to medical

Dr. Mulliken Honored with Endowed Chair

Named in honor of the renowned surgeon, the John B. Mulliken Chair at Children's Hospital Boston was established in 2006 to support a young plastic surgeon or researcher in the fields of cleft lip/palate, craniofacial and vascular anomalies.

Dr. Mulliken is a dedicated physician-scientist, well known for major contributions he has made to pediatric plastic surgery. He is also a founder and member of the board of directors of Foundation for Faces of Children.

The endowment will ensure the continuation of his work by funding young clinician-researchers in the Department of Plastic Surgery, enabling Harvard Medical School to advance its research and knowledge in these disciplines.

Other White Coat Notes

John Meara, MD, DMD, MBA, became the new chief of Plastic Surgery at Children's Hospital in August 2006. Formerly surgeon-in-chief at Royal Children's Hospital in Melbourne, Australia, he completed his residency in otolaryngology at the Massachusetts Eye and Ear Infirmary, his plastic surgery residency at Children's and Brigham and Women's Hospital, and a fellowship in cleft/craniofacial surgery at Royal Children's.

Gerald B. Healy, MD, otolaryngologist-in-chief at Children's Hospital, was recently named president-elect of the American College of Surgeons (ACS), the largest scientific and educational association of surgeons in the world. Founded in 1913, ACS is dedicated to improving the care of surgical patients by setting high standards for surgical education and practice.

journal articles. In addition, they read *Your Cleft-Affected Child*, a book written by the mother of a child with a cleft palate, which discusses both emotional and medical issues.

Rallying Support

Contacting other parents who have had similar experiences is another way to gather information. "A lot of people have been through this, but you don't hear about it too much, unless you have a connection to it," says Rob H. "We made a decision early on to not be private about this, so we could have access to those resources."

One out of every 600 newborns is affected by cleft lip and/or cleft palate, making it the most common birth defect in the U.S. If the condition is known before birth, Dotty MacDonald encourages parents to speak to delivery room staff about their child. "Knowing that the hospital staff are aware of the diagnosis makes a huge difference," she says.

Parents and older patients can gain emotional support by talking to friends, relatives, or co-workers. "When Brayden was born," says Eva, "we sent out pictures and joyfully

The Royal Treatment

Eight-year-old Emma Harwood-Schofield of Warton, England (just outside Lytham St. Anne's in Lancashire), recently received a very special award. Emma, the youngest of four children, has Crouzon syndrome, a form of craniosynostosis. Her mother, who describes Emma as "the apple of our eyes," wrote FFC the following letter:

Here in the UK, we have a magazine called *Woman's Own*, and every year they ask for people to nominate a child who has shown courage and overcome prejudice. They then select children to honour at a service at Westminster Abbey in London.

Emma was chosen for having to endure stares and mimicry because of the way she looks and for [bravely undergoing multiple] hospital operations.

On the 13th of December 2006, Emma went with her daddy, her brother, and me to London, where we had two lovely (very busy) days. First, Emma went to 10 Downing Street with nine other

"Children of Courage" to meet Tony and Cherie Blair. Then she went on to Westminster Abbey, where she was presented her Child of Courage medal by Her Royal Highness Camilla, the Duchess of Cornwall. Emma then met stars of television and had lunch with them at the House of Lords. We sat at the table with Giles from "Buffy the Vampire Slayer." Emma enjoyed all the attention. On the 14th, Emma was on GMTV, a morning programme here in the UK.

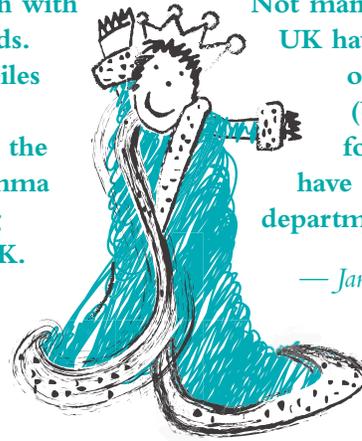
[To fulfill her] special wish, *Woman's Own* gave Emma a two-day trip to Euro Disney in Paris.

Emma loves all the Disney characters—she enjoyed having breakfast with Mickey Mouse; Goofy was her favourite.

Emma accepted this award to promote awareness for children with a craniofacial syndrome.

Not many people in the UK have seen or heard of Crouzon's. (We only have four hospitals that have a craniofacial department.)

—Janet Harwood-Schofield



announced here is our son. We reached out to people, and in turn, we got a lot of support."

Rob S. is fortunate to have caring friends as well. One friend also has a repaired cleft lip, so he, perhaps best of all, can understand what Rob's going through.

Friends, family, and neighbors can provide invaluable encouragement and assistance after leaving the hospital. Rob S. relies heavily on help from his parents while in the hospital, and when he returns home (and feels better), he invites friends to visit.

For the Higbys, having Eva's parents fly from North Carolina to Boston for the operation and then help them take care of Brayden for the next two weeks made a tremendous difference. "We could not have done it without my parents," Eva says. "They were willing to wake up in the middle of the night with Brayden and keep a close eye on him during the day."



Rob Southern uses the Internet for medical research.

Easing Anxiety

Experts at Children's Hospital advise telling young children about going to the hospital a day or two ahead of time and giving simple explanations of what will happen. Older children can be given more advance notice and could be involved in the preparations.

Recognizing potential fears, such as being left alone, spending the night in a strange bed, or having painful procedures, can help parents decide how best to talk to their child. Be careful to use neutral words, such as the doctor is going to fix your lip, and let your child know that you or another family member will sleep at the hospital, too.

Reading an age-appropriate book is another good way to prepare your child for the hospital. A variety of books are available that will help familiarize your child with hospital personnel and procedures.

When packing your bags, be sure to bring comfort items, such as a pillow or blanket. Young children may want a favorite stuffed animal, doll, or other toy. Older children or young adults may want an iPod to play music or watch

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videos, a hand-held game, or laptop computer.

The Craniofacial Centre team encourages babies, children, and adolescents to use relaxation techniques to help them cope. Before going to the hospital, have your child practice doing deep breathing, either through the nose or the mouth (as Darth Vader in *Star Wars* does). You could also ask them to imagine a calm or happy place, such as being at the beach on a sunny day, having fun at an amusement park, or just being at home in a favorite room. A 2004 study published in the journal *Pain* found that children who used such guided-imagery had less anxiety prior to, and on the day of, the operation. Other studies have discovered that imagery can ease pain and speed recovery after the procedure.

If your child seems especially worried or frightened about going to the hospital, you may want to visit a counselor at Children's Medical Coping Clinic. The counselors work with parents and children to prepare for upcoming procedures, offering evaluations, treatment, and support. (Note: This is not covered by all insurance plans.)

Rob S., who knows the hospital routine all too well, says he combats nervousness by putting his faith in Dr. Mulliken and the rest of the team at Children's. "I know he'll do a good job," he says. "When I'm worried, I remind myself that he's done a lot of these before, and I've always been happy with my results in the past. I trust him; he hasn't failed me yet." 



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. 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 write to **Foundation for Faces of Children, 258 Harvard Street, #367, Brookline, MA 02446** or call us at **617-355-8299**.

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