

FACING THE FUTURE

Web Corner

Have questions about your children's teeth? Go to the FFC website and look under "News and Events" for a link to our new online brochure on dental care for children with cleft lip and palate. It features sections on caring for the teeth, infant presurgical treatments, orthodontics, and more. You'll also find a timeline that shows at what age your child should receive dental and surgical treatments.



Special thanks to dental experts Drs. **Richard Bruun** and **Stephen Shusterman** of Children's Hospital Boston for sharing their knowledge and for their ongoing support of this project. We're grateful as well for the assistance of Drs. **John Mulliken** and **Bonnie Padwa** of Children's Hospital Boston, **Barry Grayson** of New York University Medical Center, **Nicky Kilpatrick** of Royal Children's Hospital (Melbourne, Australia), and **Ronald Strauss** of the University of North Carolina at Chapel Hill.



Walk participants **Tracy and Ken Kohlstrom** with their children **Olivia and Owen**

Walking the Walk

More than 120 friends of FFC participated in the 12th annual "Paces for Faces" Walk and Family Picnic, making it the best turnout yet. Families from throughout Mass. as well as N.H., N.Y., and R.I. came together to help the cause and share their experiences with others. Held on October 5 at scenic Lake Quannapowitt in Wakefield, Mass., the fundraising walk benefited FFC's educational services.

Many supporters contributed to the success of the walk. Walkers gathered under a canopy tent provided at no cost by Atent for Rent in Dedham and were welcomed with free donuts, coffee, muffins, and bagels, supplied by Erik Lania of Watermark Donuts (a Dunkin' Donuts franchise). Handy House of Foxborough provided a portable toilet at a discount rate.

After registering, all walk participants received T-shirts, thanks to Joe Carroll of our Advisory Board. In addition,

the first 14 to sign up were given hats compliments of Upside Over.

After the walk, participants savored pit-smoked barbecue from Blue Ribbon Barbecue of Arlington, Mass., donated by the Synthes Corporation (a surgical implant manufacturer). Once again, the First Parish Church of Wakefield generously provided tables, chairs, and the church hall for the feast. While adults chatted, children drew with crayons donated by Itzaparty and were visited by a lovable tiger courtesy of Eastern Coast Costume in Waltham. As walkers left, they received ice cream bars from Edy's Ice Cream and FFC resource packets, which, as a bonus, included Blue Lizard face sunscreen.

New this year was a raffle with exciting prizes donated by Au Bon Pain, Boloco, Boston Duck Tours, Blue Man Group, Ganz Company, Gymboree, Harvard University Art Museums, Henry Bear's Park, Highlights Magazine for Kids, ICA, Life is Good, Magic Beans, Museum of Science, New England Aquarium, Picaboo, Puppet Showplace Theater, Starbucks, and Zoo New England. In addition, Ron Parkinson donated an Atari 2, and Portia Chiou donated a Rachel Ray cookbook. Congratulations to the winners!

Many thanks to all our walkers, volunteers, sponsors, and the town of Wakefield. For a link to our online photo album, please e-mail mbleakie@facesofchildren.org.

Getting by with a Little Help *Cleft Lip and Palate Support Group*

Would you like to find out more about cleft lip and palate-related issues like feeding and preparing for a hospitalization or share your experiences with other parents?

Prescription Parents, a Boston-based volunteer organization, offers a support group for parents of children with cleft lip and palate, which meets regularly in Newton, Mass. New members are welcome to join the free, informal discussions.

Prescription Parents, a member of the National Cleft Palate Association, is one of the longest running support groups in the country. Its name is based on the belief that parents should be "good medicine" for their children, meeting their needs and supporting them throughout life.

"It's so comforting to talk to someone who knows what you've gone through," says Laura Cohen, a 27-year member of the support group, whose daughter was born

with a unilateral complete cleft lip and palate. She says members of the group help each other deal with feelings of guilt or worry, repeated trips to the hospital, and

insurance coverage problems. Twice a year, the group holds social events, funded by an anonymous donor, to give children as well as their parents a chance to get together.

Prescription Parents promotes the team approach to medical care but does not endorse any particular hospital.

Professionals from Tufts Medical Center and Children's Hospital Boston serve on the organization's medical advisory board.

Support group meetings are generally held the second Tuesday of the month at 7:30 p.m. in Newton. To receive meeting notices or for further information, contact Laura Cohen at laucohen@aol.com.



IN GRATITUDE

Our heartfelt thanks to Jane McDaid, who recently resigned from her position as FFC co-president after leading the organization for seven years. A driving force in the Foundation, she led our effort to become a national center of information for families and medical professionals. She was instrumental in planning and implementing the FFC's website. We will miss her energy and devotion to the cause. *Thank you, Jane!*



Fun and Games Benefit FFC

Thanks to our supporters who are finding new and creative ways to raise funds for FFC! Here are just a few:

- **A DINNER DANCE.** And you're invited! Amy Foley is planning a dinner dance to benefit FFC at the Irish-American Club in Malden, Mass., from 7 to 12 p.m. on Saturday, February 7, 2009. (The Club has kindly agreed to donate its hall for the cause.) Adults and older children/teens are welcome to enjoy a dinner buffet, followed by dancing to a DJ, and raffle drawings. Tickets cost \$25 each and may be purchased in advance by contacting Amy at 781-321-1788 or FFC director Mairi Bleakie at 781-545-5086. A limited number of tickets will also be available at the door that evening.
- **A DINNER AND TRIVIA NIGHT.** Mary Montague and her husband, Bill Hurley, hosted a dinner and pay-to-play trivia contest at their home in Needham, Mass., this past spring. The lively event, attended by about 35 people, was inspired by Nicole Lania, who underwent a major craniofacial procedure in June. (Nicole's mother, Mary, a friend and co-worker of Mary Montague, has been active in FFC for the past 15 years.) Although contest entrance fees were to be split between FFC and the winning trivia team at evening's end, the winners generously donated their prize money to FFC as well.
- **AN INTERNET CAUSE.** Julie Powers is encouraging support of FFC through "Understanding Cleft Lip/Palate," a cause she created on [Facebook](#) (soon to appear on MySpace too). She found FFC through a built-in charity search engine, added a link to the Foundation's website, and posted her son's photo. Donations made through her cause page go directly to FFC. Visit Julie's page for her updates about insurance coverage legislation and fund-raising events. 

Scholarship Winners

Each year the Foundation for Faces of Children awards scholarships to deserving high school graduates to help further their education. We congratulate the following 2008 winners for their academic achievements, participation in extracurricular activities, and ability to overcome challenges:

Brian Pender is a graduate of Westwood High School, where he was a member of the National Honor Society and volunteered as a teen mentor. Born with Robin sequence (previously known as Pierre-Robin syndrome), Brian played both varsity hockey and baseball.

Brian is now attending Northeastern University and plans to study criminal justice. But his passion is music — both playing it and listening to it.

 **FUN FACT:** *Brian is a skilled lobsterman.*

Edward Strumm graduated from Boston College High School and worked part-time during high school. In his spare time, he volunteered with the homeless, tutored younger children, and played in the Boston

FFC President Johanna Smith (left) with Dotty MacDonald, RN, and Board Member Kara Jackman draw winners at the first-ever raffle.



Chief of the Craniofacial Centre John Mulliken, MD, with his wife Portia Chiou, MD



Katie Remley with her son Avery



City Hockey League. He also loves to draw and has won awards for his artwork.

Born with craniosynostosis, Edward currently attends Quincy Community College. He plans to pursue a management degree, enter the electrician trade, and someday own his own electrician business.

FUN FACT: Edward is an accomplished boxer.

Eric Riklin graduated from Newton North High School, where he was a member of the engineering team. He also played soccer in the Boston Area Youth Soccer league and volunteered as member of Young Adult Advisory Council, which assists youth with disabilities in the city of Boston. He was born with Crouzon syndrome, which results from a premature fusion of the skull bones.

Now a freshman at Rochester Institute of Technology, Eric plans to pursue his passion for engineering and robotics by studying biomedical engineering.

FUN FACT: Eric is an avid fencer.



Scholarship awardees (left to right) Eric Riklin, Brian Pender, and Edward Strumm pictured with Dr. John Mulliken, chief of the Craniofacial Centre.

Eleven-year-old Jared Popkin (below with his family) collected donations of \$1,314 from 25 friends and family members!



Brittany Cairns of Children's Hospital with Colleen Loughlin and baby Molly.

FFC Director Mairi Bleakie holds her two-year-old twins, Evelyn and Royce, as they admire the tiger.



Enthusiastic walkers display the official "Paces for Faces" T-shirts.



The Foley family starts the walk.

Left, Madison and Gavin Parks of Clay, N.Y.

Join Our Mailing List

Facing the Future is published three times a year (March, July, and November). If you are not currently on our mailing list and would like to be, please e-mail Mairi at mbleakie@facesofchildren.org or fill out the form below, and send it to:

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Brookline, MA 02446

NAME

ADDRESS

CITY/TOWN

STATE ZIP



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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