

FACING THE FUTURE

Foundation for Faces of Children Scholarship Program

You may become a winner! Each spring we award two or three scholarships to students with facial differences from New England who are pursuing post-secondary education. The application deadline is **April 1, 2005**.



For more information and an application, visit our website at www.facesofchildren.org and go to "About Us."

A Walk in the Park Raises Funds

The rains from Hurricane Ivan let up just in time for the Eighth Annual "Miles for Smiles" Walkathon on September 19. About 75 friends of the FCC participated in the hour-long walk around Lake Quannapowitt in Wakefield, Massachusetts.

"Everybody had fun," says Paula Woodman, coordinator of the walkathon. "People were laughing and happy, and they enjoyed the barbecue. It's fun for families to see each other."

Supporting the Cause

The day began with coffee and donuts donated by Starbucks and Krispy Kreme. While adults chatted, kids colored with crayons on paper-covered tables. Once assembled, the walkers, some pushing strollers and wearing FCC shirts, set off around the lake. After the walk, they returned to a tasty barbecue prepared by



Lacey Clericuzio brought her favorite doll to the Walk and met Leona from the television show *Between the Lions* (see inside for details).

Blue Ribbon Barbecue of Arlington, Massachusetts, and underwritten by Synthes, Inc., an international manufacturer of prosthetics and surgical implants.

In addition to Synthes, event sponsors included Wal-Mart and, for the second year, Edy's Ice Cream. Both provided generous financial support. Other event contributors included Festive Occasions of Woburn, Massachusetts, which supplied tables and chairs free of charge; Handy House, which provided discounted portable toilets; and Brigham's Ice Cream, which gave certificates for free ice cream to all the walkers.

The First Parish Church of Wakefield, notes Woodman, was very accommodating, allowing tables and chairs to be stored there overnight.

continued on page 2

Gene Linked to Cleft Lip and Palate

AN INTERNATIONAL TEAM OF RESEARCHERS has discovered that a variation in a gene increases the risk of developing cleft lip, cleft palate, or a combination of the two. Their findings were reported in the August 19, 2004 issue of *The New England Journal of Medicine*. Mutations in this gene, known as Interferon Regulatory Factor 6 (IRF6), are involved in about 12 percent of all patients with non-syndromic (sporadic) cleft lip and palate.

Researchers examined DNA samples from more than 8,000 people in nearly 2,000 families, most with a history of clefting. They found that the presence of the genetic variant of IRF6 tripled the chance of recurrence — from 3 percent to 9 percent — in families who already had one affected child.

"This new finding is a major step in understanding why cleft lip and palate occurs in some families," says FCC medical advisor John B. Mulliken, MD, Director of the Craniofacial Centre at Children's Hospital, Boston. "Someday, based on

genetic understanding, physicians may be able to prevent this common facial anomaly."

In a perspective accompanying the article, Dr. Mulliken says that a cleft results from a complex interplay between genetic and environmental factors and that there are a number of recently discovered mutations in specific genes that may cause cleft lip and/or cleft palate. Native Americans and Asians, he notes, are most likely to develop cleft lip and palate, while people of African ancestry are least likely.

His commentary, "The Changing Faces of Children with Cleft Lip and Palate," describes the great strides in surgical repair in the last 25 years. The zigzag scar on the lip left by earlier surgical methods has been eliminated, and the nose can now be aligned at the same time that the lip is closed. Today the repair of bilateral cleft lip is as successful as that of unilateral cleft lip.

continued on page 4



A Walk in the Park

continued from page 1

I N G R A T I T U D E

Walking in "Miles for Smiles" on behalf of his granddaughter and other children with craniofacial conditions, N. David Bisson of Dayton, Ohio, received pledges in excess of \$500. He wrote the following poem to thank his supporters:

How Do I Say Thank You

If I could I'd pluck the brightest star
Out of the clearest
Most star-studded magnificent night
Put it in a basket
Lined with the richest silk
And leave it on your doorstep
With a card that read
This is for you from my heart.

Or

If I could I'd take all of your problems
Put them in a burlap sac
Tied tight so none could escape.
I'd carry them on my back far away

On a path no matter how perilous
And dump them in a hole so deep
None could ever climb out.

I want you to know
I will wipe these tears
You've put in my eyes
Dry them like roses
Hang them high
In my mind's trophy room
To always remind me

Of your generosity.

N. David Bisson



Leona and Arthur with Dr. John Mulliken and his dog Girlie, as well as FFC Co-Presidents Joey Smith and Jane McDaid (seated).

Team Lacey

Thanks to WGBH, the kids had a chance to meet some of their favorite PBS characters — "Leona the Lion" from the show *Between the Lions* and "Arthur" from the Marc Brown series. The costumed characters gave out hugs and stickers and posed for photos. They were especially a big hit with four-year-old Lacey Clericuzio. Lacey, who has median cleft face and is hearing impaired, enjoyed signing with Leona and Arthur and making her baby doll, also along for the walk, sign with them, too.



Cameron and John Russo meet Arthur.



Raymond Gagnon and grandson Colin support the Walk.

"Team Lacey" has participated in four walks since Lacey's birth. This year the team included her parents, 3-year-old brother, grandparents, aunt, and her cousin and her boyfriend. Their combined efforts raised over \$825.

"We want to do anything we can to support Dr. Mulliken," says Melissa Clericuzio, Lacey's mother. She also notes the helpful information provided by the FFC through its video, publications, and Website.

Success!

The "Miles for Smiles" walkathon raised more than \$6,500 for the Foundation's programs and services. Special thanks to all the walkers, sponsors, and the six students from the

Belmont High School community service program who volunteered at the event. "I hope even more families will join us next year," says Woodman. ■



From left to right, Charles Gagnon, Jerome Murphy, Ben Lania and Mark Lania enjoy the barbecue.

Cautions about Cleft and Craniofacial “Virtual” Communities

By Kara Jackman, MA



Due to constantly improving technology, it is easier than ever before to “reach out and touch someone,” via the Internet, phone, or fax.

Rapidly improving technology has led to an increase in the availability of information

and in places for people to come together to discuss topics of mutual interest. These are “virtual” communities in most cases, but communities no less, filled with people building relationships and trading information and experiences. Such communities include newsgroups, chat rooms, and bulletin boards, where messages can be posted. Another community forum is a listserv in which members post suggestions or ask questions via e-mail messages broadcast to everyone in the group.

Finding a good listserv can be difficult. Some people may want information, while others may be looking for support, kindness, and friendship. If you are searching for information and advice, here are a few things to keep in mind:

- **Not all information found on listservs is accurate.** This is the most important thing to remember about the Internet, but especially about listservs. Even if the group is part of a reputable association or hospital, information being traded within the listserv may still be unreliable. Think of it as a conversation; not all conversations are helpful or convey accurate information. If you are seeking a definitive answer to a question, listservs are not the place to find it. Doctors and nurses are a better source for that type of information. But if you would like suggestions and advice as to how to approach a problem, a listserv may be a good place for you to find it.
- **Choose a listserv that is moderated or monitored.** To increase the likelihood of good information, choose a listserv that is moderated or monitored. When listserv groups are moderated, responses are reviewed before

being posted or sent out to members. This does not mean that all the information will be right all of the time, but it does increase the probability of higher quality.

- **“Lurk” for a while before you post.** “Lurking” involves reading the listserv responses without contributing to the discussion. From this monitoring period, you will be able to see whether the listserv is a good fit for your needs.
- **Listservs may stray from the topic.** Listservs tend to very easily wander off topic. As in any conversation, the topic can change quickly, and before you know it, numerous responses may have little to do with the purpose, in this case, craniofacial issues.

A good example of a listserv about craniofacial issues is “Cleft Talk” at www.Widesmiles.org. This is a great resource for parents, physicians, and nurses who would like more information on cleft lip and palate issues, including hearing, feeding, and developmental growth. Monitored by nurses and doctors, this listserv gives members the opportunity to exchange knowledge based on personal experiences. Submitted queries commonly receive 10 or 12 responses in a day.

Another active and informative listserv is “Cleft Club,” which is a mix of parents and cleft affected teens and adults. To sign up, go to “mailing lists/forums” on Cleft Club’s website at www.cleftclub.com. Additional listserv groups can be found through search engine websites, such as www.msn.com or www.yahoo.com.

Kara Jackman has undergone treatment for bilateral cleft lip and palate at Children’s Hospital Boston. A graduate of the College of the Holy Cross, she recently received a master’s degree in archival studies from the University of Pittsburgh. ■

Introducing...

Ananth S. Murthy, MD, has been appointed a fellow in craniofacial surgery at Children's Hospital Boston for 2004-2005. An Ohio native, Dr. Murthy graduated from Northeastern Ohio College of Medicine and completed his residency in plastic surgery at Summa Health System in Akron. He aspires to become a first-class pediatric plastic surgeon.

Some of his clinical research focuses on speech patterns in patients with repaired cleft palate. In one study, he is assessing speech improvement after a surgical procedure called a pharyngeal flap in patients with Robin sequence, velocardiofacial syndrome, and non-syndromic cleft lip and palate.

Dr. Murthy is also conducting research on craniofacial asymmetry. Using an array of digital cameras, he is able to capture three-dimensional images. These digital images can be used to perform indirect surface measurements and to evaluate facial growth in children with cleft lip and palate or coronal synostosis.

Outside the hospital, Dr. Murthy enjoys golf and biking. ■

Gene Linked continued from page 1



Dr. Mulliken emphasizes that every newborn with a cleft lip with or without cleft palate should be cared for in a regional cleft lip/palate center. Qualified surgeons at these centers, he says, perform a high volume of procedures, leading to better results and fewer revisions. He also cautions parents to select a surgeon

who is active in an established regional team, rather than one who operates on clefts, primarily and periodically, in other countries.

In addition, Dr. Mulliken recommends that humanitarian organizations that send surgeons abroad to repair clefts redirect their energies toward educating local cleft-care teams. "Surgical safaris," he says, "only perpetuate the lack of continuing care in the developing country. Fortunately, at least two U.S.-based nonprofit organizations, Interplast and especially The Smile Train, are working to establish such centers overseas." ■

MEDICAL TALK: The medical world has a language of its own. To better understand your child's (or your) condition and to become a better patient advocate, you may want to learn more "medicalese." Here are two useful medical dictionaries to choose from:

Dorland's Illustrated Medical Dictionary, 30th edition. Philadelphia, Pa: WB Saunders; 2003.

Stedman's Medical Dictionary, 27th edition. Baltimore, Md: Williams and Wilkins; 2000.

To save money, you may want to purchase a used book or a slightly older edition. (On-line booksellers often offer used books as well as new books.) Look under "**LIBRARY**" on our website for other helpful books, videos, and on-line resources.



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**.

Board of Directors

Jane C. McDaid,
Co-President
Johanna (Joey) Smith, Esq.,
Co-President
William L. Pratt, CPA,
Treasurer
Alfred C. Frawley, Esq.,
Clerk
Anne-Marie Gagnon, MSW
Mary Lania, RN
John B. Mulliken, MD

Advisory Board

Joe Carroll
Patricia Connery
Kristin DeKuijper, Esq.
Ellen Kelly
Dorothy M. MacDonald,
RN, BSN
Sheryl Rosner, Esq.
Beth Tomasello, Esq.
Paula Woodman

(617) 355-8299 | www.facesofchildren.org