

FACING THE FUTURE

10TH YEAR ANNIVERSARY OF FFC Scholarships

Attention students:
Applications are now being
accepted for the 2009
Foundation for Faces
of Children (FFC)
scholarship
program. This is
the 10th year
that FFC has
offered college
or vocational/technical school
scholarships to promising
students born with a facial
difference.

High school students or
graduates living in New
England (Connecticut, Maine,
Massachusetts, New Hampshire,
Rhode Island, and Vermont)
are eligible to apply for the
\$1,000 scholarships.

Applications are due
May 1, 2009. For links to
scholarship applications and
instructions, visit our website
www.facesofchildren.org
and click on "For Patients
and Families" at the top of
the page. Or, call Mary Lania,
Scholarship Committee Chair,
at 781-255-8931 (evenings
or weekends).

www.facesofchildren.org

Now in 3-D...

Advanced 3-D imaging technology is now being used at the Craniofacial Centre at Children's Hospital Boston to examine facial features of patients. Simultaneously photographing a child's face from a variety of angles and then combining those digital images on a computer gives a highly accurate three-dimensional image. Unlike 3-D movies, these sophisticated, mathematically derived images do not require special glasses for viewing.

External 3-D imaging, technically called "active stereo photogrammetry," allows for repeated examination of a patient to document growth-related changes and for surgical treatment planning. Currently, surgeons and orthodontists use this technique to study facial soft tissue anatomy of their patients.

This year's craniofacial fellow, Dr. Stephan Tan, is working with Dr. John Mulliken and other investigators on several research projects using 3-D imaging technology at Children's Hospital. Dr. Tan came to Children's from Amsterdam, The Netherlands, as a Fulbright scholar to study facial asymmetry in children with repaired cleft lip (and palate)



using a 3-D imaging system. After completing his yearlong fellowship in September, Dr. Tan will return to the University of Amsterdam and hopes to write a PhD dissertation on surgical and orthodontic management of cleft lip and palate.

A Brief Bio of Dr. Tan

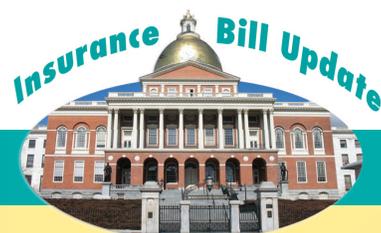
HOMETOWN: Amsterdam, The Netherlands

UNIVERSITY AFFILIATION: Visiting Fellow, Harvard University

EDUCATION AND TRAINING: Earned a doctorate in dental surgery and completed his residency at the Academic Centre for Dentistry Amsterdam (ACTA), The Netherlands

HOBBIES: Running (he ran the New York City Marathon soon after arriving in the U.S.), tennis, and skiing. He also enjoys traveling and has visited more than 30 countries on four continents.

LANGUAGES: In addition to his native Dutch, he speaks English, German, and Indonesian. 🗣️



Reducing the Financial Burden

In Massachusetts, a bill that would require insurance coverage for all medically necessary treatments related to cleft lip and palate, including dental care, is making headway through the legislative process. First introduced by Representative Louis Kafka in May 2007, the bill (now known as H. 932) was refiled in January 2009 with 15 representatives as sponsors.

"We are close to making this a reality," says Adrienne Musto, self-appointed parent lobbyist for the bill. "Sometime in the next three to nine months, depending on the docket, a public hearing will take place. We now need anyone passionate about this cause to put pen to paper and write a letter to his or her state representative."

Adrienne has become an activist because of her own family's frustrations dealing with insurance issues, even in the early stages of repair of her four-year-old son Tony's unilateral complete cleft lip. She has high hopes for the bill, which provides coverage for any procedure or treatment a doctor determines is medically necessary. This would include, but not be limited to: special feeding bottles, extractions of teeth, rhinoplasty, and speech therapy.

All letters submitted will be read and entered as evidence in support of the bill at the hearing. Adrienne suggests that letters include: the child's (or your) diagnosis, age, stage of repair, and insurance

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In Support of FFC

Evening Benefits FFC

More than 150 family members, friends, and caregivers dined and danced at a February 7 FFC fundraiser organized by Amy Foley. Amy's daughter Grace, 4, was born with a unilateral cleft lip and palate.

At the event, held at the Malden Irish-American Club, guests enjoyed a dinner buffet, followed by dancing to popular music and oldies. The evening also featured raffle drawings for fabulous prizes, including Bruins tickets, Boston Symphony Orchestra tickets, and a \$350 American Girl dollhouse. Brian Abbott, winner of a 50/50 drawing, generously donated his purse to FFC, and Richard Olsen bigheartedly offered to match it.

The event raised more than \$6,000 for FFC. "I wanted to show my appreciation and to support this organization for Grace and all the other brave, strong children, who have undergone numerous surgeries, and their families," says Amy.

Many thanks to Amy and all who made the evening a success.

Putting on a Show for FFC

Mark your calendars for Saturday, June 6, at 7 p.m. That's when "The Friends of Broadway" will perform a musical revue to underwrite the cost of FFC's Teen Symposium (see next page). This lively song-and-dance show will be held at the Curtis Middle School, 22 Pratts Mill Road, in Sudbury, Mass. The young and old alike will be entertained by this talented group of more than 20 girls, who travel the country performing Broadway hits, pop tunes, and old-time favorites.

Now in their 10th season, The Friends of Broadway was founded by Samantha Hammel to share her love of music and help worthy nonprofit organizations raise money. Each year Samantha, who was born with cleft lip and palate, choreographs and directs a new show, and auditions a new cast of girls from second grade through college.

For tickets and more information, contact The Friends of Broadway at fobma@aol.com or 978-443-2400.



Lively dancing at the fundraiser



Jimmy and Amy Foley (left) with John Mulliken, MD, and Dotty MacDonald, RN holding a photo of Amy with her sisters Leah and Michelle and Amy's children Grace and Lauren

WANTED: STUDY PARTICIPANTS

Volunteers are needed for two studies related to cleft lip and palate now underway at Children's Hospital Boston. This research may increase knowledge about this common but not well-understood condition and help improve the quality of care.

One is a survey of mothers and fathers, conducted by John Mulliken, MD, to determine what factors, in addition to genetics, might be involved in the development of cleft lip and palate.

The other deals with perceptions of facial appearances of individuals with unilateral cleft lip and palate. Led by Richard Bruun, DDS, this study asks participants, who include patients, parents, schoolteachers, and health care providers, to view and judge profile photographs of patients.

The studies can be sent to you online or through the mail. To volunteer or for more information, contact Nina Anderson at Nina_Anderson@hsdm.harvard.edu or call 617-432-3856.



Adrienne Musto with her four-year-old son Tony.

Reducing the Financial Burden

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company information. Also, detail insurance struggles, coverage denials, and how this has affected your family. Adrienne has drafted a sample letter, soon to be available on the FFC website, that you can customize and send to your representative.

“The volume of letters received will give this bill more momentum and priority in this legislative session,” says Adrienne. “If everyone gets involved, we can make a difference for our children.”

In addition, Adrienne is looking for five to seven parents or patients willing to present oral testimonies — personal narratives of their experiences — at the State House on hearing day. To volunteer, obtain electronic letter copies, or ask any questions, call Adrienne at 508-339-1623, or email her at ahogland@msn.com.

Meanwhile, the Division of Health Care Finance and Policy, a state agency that reviews all bills that propose new mandated benefits, is currently considering how this legislation will affect the cost of health insurance and the use of medical services. As part of the evaluation, the agency is assessing out-of-pocket costs for patients with help from the Cleft Lip/Cleft Palate Team at Children’s Hospital Boston, which has supplied information to the analysts. A final report will be completed for review by the legislature in April 2009.

Stay tuned for future progress reports. 📺

“If everyone gets involved, we can make a difference for our children.”



Stirring Up Charitable Spirit

Last summer, seven-year-old Claire Meyer of Bloomington, Illinois, “won” a free lemonade stand from Sunkist’s “Take a Stand” program, which helps young entrepreneurs support their favorite charity. Then one hot July morning, Claire, along with her brothers Parker, 5, and Blake, 2, sold lemonade in their front yard. They donated the resulting profits of \$12.20 to FFC.

“The children were so excited that they even knocked on neighbors’ doors to let them know about our lemonade stand and paid for a glass of lemonade for themselves with their own money,” says their mother, Laura.

The family made the donation in appreciation of the support FFC gave them when Blake was born in September 2005 with a cleft lip and palate. Blake currently receives care from the Carle Clinic Cleft Lip and Palate Team in Urbana, Illinois.

Thanks to the Meyer family for their efforts! Visit www.sunkist.com/takeastand for more information on the Sunkist program. 📺

Teen Topics To Be Discussed

This fall, FFC will host its first ever “Teen Symposium” for teens with cleft lip and palate at Children’s Hospital Boston. The event will feature presentations by medical and psychological specialists on later stages of treatment and social and emotional implications of being a teen with cleft lip and palate.

Following the presentations, the specialists and patients who have completed their treatment will lead an interactive discussion of medical and social issues, such as bullying, dating, and how to plan and time further procedures.

“The hope is that we all can learn from each other,” says Kara Jackman, coordinator of the symposium, “and that the event will help teens better understand their treatment choices.”

The event will conclude with a reception where refreshments will be served. Please let us know if you are interested in attending the Teen Symposium by sending an email to karajackman@yahoo.com.

Look on the FFC website (www.facesofchildren.org) for more details next month. 📺



Web Corner

We would appreciate your feedback on the FFC website. Your suggestions will help us further develop the website to better meet your needs. Please let us know the following:

1. What is your overall impression of the website?
2. Are you able to easily find what you are searching for?
3. Do you think the website provides enough information? If not, what else should be included?

Please e-mail your comments to info@facesofchildren.org or call FFC director Mairi Bleakie at **781-545-5086**. Thanks for your input.



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. Please contact us if you would like to participate in or sponsor a fundraising event:

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

Telephone: **617-355-8299**

E-mail: info@facesofchildren.org

October 4, '09
Save
the **Date**
Walkathon Family Picnic

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