

# FACING THE FUTURE

## Call for Volunteers!

Want to help out with next year's Face-to-Face Walk and Family Picnic? This is our major fundraising event, and we need volunteers for jobs ranging from planning to set up and clean up.

Our current need is for a new coordinator. After a number of years of heading the FFC Walk, Paula Woodman is stepping down. Paula did an outstanding job soliciting donations from individuals and companies, many who return year after year to give us their support. She also handled arrangements with the town and the church, where the post-walk picnic is held. Thanks to her organizational skills, her successor's job should be much easier.

If you are interested in volunteering as the coordinator for the fall 2008 event, please contact [info@facesofchildren.org](mailto:info@facesofchildren.org).

## An Inside View

Advanced imaging technology is giving physicians and parents a high-definition view of babies before birth. Three-dimensional (3-D) ultrasound and magnetic resonance imaging (MRI) produce detailed pictures that enable physicians to visualize the growing fetus and diagnose facial conditions, such as cleft lip and palate.

"Cleft lip, with or without cleft palate, is the most common facial malformation," says Judy Estroff, MD, co-director of fetal imaging at Children's Hospital Boston and associate professor of radiology at Harvard Medical School. "Although ultrasound is routinely used to evaluate fetal structure at 18 to 20 weeks of pregnancy, cleft lip and palate often go undetected."

To enhance detection, radiologists in the Advanced Fetal Care Center (AFCC) at Children's Hospital Boston now examine the fetal face with both 3-D ultrasound and MRI. AFCC is among just a handful of hospitals nationwide to offer comprehensive services ranging from prenatal diagnosis to care for the baby after birth.

The detection of fetal anomalies often better prepares parents for the birth of their child. But because early diagnosis of an abnormality also sparks questions, worries, and fears, counseling of the prospective parents is an essential part of care.

### Imaging in All Dimensions

Ultrasound imaging, also called sonography, is a safe, painless diagnostic test that uses sound waves that penetrate deep within tissue and are reflected back to form an image. A routine part of prenatal care, ultrasound can show the presence of twins or other multiples and detect many fetal abnormalities.

More recently, researchers have developed 3-D and 4-D (full-motion 3-D) ultrasound using powerful computer-based image processing methods. Interestingly, much of the current volume-rendering technology employed in medical imaging originated from computer scientists at Pixar Animation



Dr. Judy Estroff reviews fetal images.

Studios, famous for 3-D computer-animated movies.

Unlike standard ultrasound, which displays flat, thin sections of the body, 3-D ultrasound produces images with greater detail. "Conventional ultrasound," says Estroff, "is like a flashlight beam cutting through the body. It can show only one thin slice at a time. In contrast, 3-D ultrasound acquires a thicker slice and shows a volume of tissue, which can be viewed in any plane. This 3-D technology allows us to render a realistic image of the soft tissues of the face and see the fetus yawn, smile, or grimace."

"It was amazing," says Kira Adams of Peabody, who had one of the first 3-D sonograms at Children's in 2005. "I could see a lot more than in a regular ultrasound, including features like the nose."

While commercial enterprises like "Womb with a View" take keepsake 3-D ultrasound images and videos for baby scrapbooks, Estroff urges pregnant women not to substitute these for a comprehensive fetal sonogram performed by a trained medical specialist.

High quality 3-D ultrasound often improves detection of cleft lip by scanning the surface of the face. However, it cannot easily penetrate bony structures, so determining whether a fetus has a cleft of the soft palate is difficult.

"To detect cleft secondary or soft palate on ultrasound,

*continued on page 2*

## Family Fun and Fundraising

FFC families and supporters joined together for the **Face-to-Face Walk and Family Picnic** on Sunday, September 16. Bright sunshine and cool fall air made for perfect walking weather. Participants, including some large extended families, embarked on the three-mile loop around Lake Quannapowitt in Wakefield, Mass., to raise funds for FFC's educational services.

The event also gave families a chance to meet. Some were veteran walkers of five or more years, while others were newcomers.

Loyal supporters once again contributed to the FFC cause. Erik Lania of Watermark Donuts, a Dunkin' Donuts franchise, provided donuts, coffee, muffins, and bagels to get the walkers off to a good start. Afterwards, participants enjoyed pit-smoked barbecue from Blue Ribbon Barbecue of Arlington, Mass., which was donated by the Synthes Corporation (a surgical implant manufacturer). Joe Carroll of our Advisory Board supplied beverages and the First Parish Church of Wakefield kindly provided tables, chairs, and their church hall for the feast. For the fourth year, Wal-Mart gave generous financial support. FFC also received discount rates from Sean Kane Party Tent Rentals and Handy House of Foxborough. Thanks to all our walkers, volunteers, sponsors, and the town of Wakefield.



Inside:  
Walkathon  
Photos!

Amy Foley  
and her  
daughter  
Grace.



## An Inside View *continued from page 1*

we must use indirect signs, such as the tip of the nose is pointed away from the cleft, the tongue is in an unusually high position, and the eyes are more widely separated than usual,” says Estroff. She notes that gaps in the horseshoe-shaped tooth-bearing alveolar ridge are another indication that the cleft involves more than the lip.

### A More Definitive Answer

To diagnose fetal cleft lip and palate more precisely, Estroff and other specialized pediatric radiologists, began using a combination of fetal ultrasound and MRI in 2002.

Ellen Caille, who was 7 ½ months pregnant at the time, volunteered for the MRI study after a cleft lip was seen on a routine ultrasound. MRI revealed a high probability of cleft palate as well, and indeed, her daughter, Catherine Souza, was born with both.

A noninvasive test, MRI combines the forces of a powerful magnetic field, radio waves, and computers to create detailed images of internal body structures, including deep, soft tissues of the mouth. MRI offers a view of the entire fetus and can also focus on tiny structures like a 2-millimeter gap in the tooth-bearing alveolus. At Children’s Hospital Boston, fetal MRI is performed anytime after 16 weeks of gestation.

“With fetal MRI, bony structures are no obstacle,” says Estroff. “MRI is a great way to look at the soft palate, which is located deep in the head and is surrounded by bone.”

Improved visualization of bone and soft-tissue facial structures by the combination of ultrasound and MRI has led to more accurate detection of anomalies. AFCC now detects nearly all cases (about 97%) of fetal cleft palate associated with cleft lip.

### Being Prepared

When a craniofacial anomaly is suspected, a pregnant woman, her obstetric caregivers, or her previous ultrasonologist can seek a second opinion from AFCC. In a one-day appointment, the mother can have fetal ultrasound and MRI, and see specialist doctors, nurses, and other health care professionals, such as genetic counselors, as needed.

After imaging, radiologists often explain what was seen to the mother and her family. The craniofacial specialist also reviews the images, discusses the diagnosis, and explains the surgical implications to the family. “The strength of our program is the team of specialists who work together to care for as well as counsel the mother-to-be, discussing the range of outcomes for the baby and for the family,” says Estroff.

Radiologists in AFCC, working with Dr. John Mulliken, chief of the Craniofacial Centre at Children’s Hospital Boston, also act as a resource for people outside of the Boston area, who may send fetal sonograms for an interpretation free of charge.

“If the parents know what to expect, and how expertly Dr. Mulliken and other craniofacial surgeons repair clefts, they feel more confident,” says Estroff. “The parents are better prepared for their child’s birth and later corrective operations.” ■

## A Rough Start, A Great Finish

Julie Powers had a “high risk” pregnancy, so her obstetrician (OB) recommended ultrasound imaging before every prenatal visit. She viewed these screenings as great opportunities to see her baby develop. But at her five-month appointment, the usually cheerful and bubbly technologist became strangely silent as she drew the ultrasound probe across Julie’s belly. “Is something wrong?” Julie asked.

“Yes, I think there’s a problem with your child,” she replied as she abruptly walked out of the room, leaving Julie and her husband panic stricken. When she returned with the radiologist, they spoke together in hushed tones, ignoring Julie. Finally, the doctor announced that her baby had a cleft lip and told her to go to her regularly scheduled OB appointment. In the OB’s exam room, Julie began to cry hysterically. Her only knowledge of a cleft lip was from the film “Red Dragon,” in which a serial killer was supposedly driven by social rejection resulting from cleft lip and palate.

A nurse reassured Julie that this was a repairable condition and recommended contacting Children’s Hospital Boston. Follow-up ultrasound imaging at Children’s was inconclusive, because the fetus’s position prevented a clear view. But a subsequent MRI procedure found a unilateral cleft lip and palate. Afterwards, she met with Dr. John Mulliken and craniofacial nurse Dotty MacDonald and was comforted to know that she was in such capable hands.

Her son Tyler was born on March 6, 2007 and is a happy, healthy child. He has already had two successful surgical procedures for his cleft lip and palate and is scheduled for a third in November.

Despite her initial disturbing experience, Julie strongly recommends fetal imaging. “By knowing ahead of time, we were better able to prepare,” she says. “We bought a Haberman feeder [a bottle specially designed for babies with cleft or craniofacial conditions], practiced using it, and trained many of my relatives.”

When her eight nieces and nephews ask why Tyler looks the way he does, Julie simply says, “God made him that way so he can smile bigger.” ■

Julie Powers with her son Tyler.



From Children’s Hospital: Drs. Stephen Sullivan, craniofacial/pediatric plastic surgery fellow; Michelle Bigorre, visiting physician from France; and John Mulliken, chief of the Craniofacial Centre.

FFC co-presidents Johanna Smith (left) and Jane McDaid with the Bouncing Tiger.





## A Winning Style



Twenty-one-year-old Mike Kozlowski is a student at the highly competitive Massachusetts Institute of Technology (MIT). While majoring in mechanical engineering, he has managed to maintain a perfect cumulative grade point average. In addition to his studies, the Melrose,

Mass., native is captain of the school's varsity hockey team and active in the Sigma Nu fraternity. He belongs to four academic honor societies and takes part in community service.

And, oh yes, he was born with a bilateral cleft lip and palate. "A facial deformity, or any deformity, does not prevent success," says Mike. "The challenges associated with being different cultivate many positive characteristics, including endurance, courage, and leadership."

Mike, who has had 14 corrective procedures at Children's Hospital Boston, believes the challenges associated with having

cleft lip and palate have helped him develop valuable skills that have benefited him at MIT and throughout his life. Besides physical endurance, he stresses the importance of mental fortitude—the ability to be patient and know that you can withstand challenges. Although he admits to being nervous before procedures, he says he's had so many that he knows what to expect and he's trained himself to get through them.

### Building Confidence

While growing up, Mike encountered "the normal troubles" associated with being different, but by and large, people respected and liked him. Friends and family always supported him. And he met his current girlfriend during high school.

"There were a few incidences where I got into disagreements with other kids and their comeback had to do with how I looked," says Mike. "They were trying to be tough guys and used that to put me down. But I always stood up for myself and took the high road."

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## Face-to-Face<sup>SM</sup> Walk

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Diba Jalalzadeh and her mom Monir Sakha are greeted by a big orange friend.



Catherine Souza takes a ride on the slide after the walk.

Danny's Team: nine-month old Danny, big sister Grace, and parents Michelle and Mike McHugh (center) with grandparents, aunts, uncles, and cousins.



Joey and Kira Adams enjoy the sunny day.



Children's Hospital nurse Dotty MacDonald, RN, with Michelle Kapala.

## A Winning Style *continued from page 3*

In school, Mike studied hard and participated in soccer, baseball, hockey, and football. These sports helped him develop good friendships and mentors as well as keep physically fit. And he points out, “As part of a team, you work hard for a goal, and when you succeed, it builds confidence and self-respect.”

### A New Face

Mike believes that appearance may attract people initially, but after that, it’s all about character. People like him, he says, for who he is, not how he looks.

Last summer, though, he underwent plastic surgery at Brigham and Women’s Hospital in Boston to put some final touches on his face. After establishing an identity for 20 years, altering his appearance was hard for him. But he now loves the new way he looks.

“I was apprehensive, but after I was comfortable with how I looked and being around my family, I started seeing my girlfriend again,” says Mike. “And when I was comfortable with her, I started seeing my closer friends. After that, I was able to approach all others at school. I got a few confused looks, but I was strong enough to think, ‘They’ll get used to it. Just give them time.’”

As Mike reaches the end of his cleft lip and palate surgical journey, he encourages others with any kind of disability not to be held back by feelings of inferiority and to pursue their dreams. ■



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.

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. If you would like to participate in or sponsor a fundraising event, please contact us at **Foundation for Faces of Children, 258 Harvard Street, #367, Brookline, MA 02446** or **617-355-8299**. You may also send e-mail to us at [info@facesofchildren.org](mailto:info@facesofchildren.org).

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617-355-8299 | [www.facesofchildren.org](http://www.facesofchildren.org)  
E-mail: [info@facesofchildren.org](mailto:info@facesofchildren.org)