

FACING THE FUTURE

Evaluation Begins with Baby Talk



While on a mission to Ecuador, Katie Engstler poses with a young cleft patient.

"I'm looking for clouds coming from your nose," speech-language pathologist Katie Engstler, MA, CCC-SLP, tells a child as she holds a small mirror under his nostrils while he speaks. Fogging of the mirror indicates that air is escaping through the nose, which can result in a nasal-sounding voice or noises like snorts.

Children with cleft lip and palate and other craniofacial conditions generally have normal language development — learning of words and sentence structure — but may have problems producing the different sounds necessary for speech. Speech-language pathologists, who have completed a two-year master's degree program as well as a fellowship, are important members of the craniofacial team at Children's Hospital Boston. Both Katie and her colleague Asako Wehner, PhD, CCC-SLP, evaluate the speech and language of children in the Cleft and Craniofacial Clinic, usually starting at the age of 12 to 18 months. After children turn 3, the focus is on speech production skills alone.

If problems are detected, the speech-language pathologists recommend services for the child. Often services are provided within the community through early intervention or school programs.

Speech problems generally fall into two categories: articulation and resonance. "Articulation or speech production difficulties are often related to structural differences in the mouth due to craniofacial anomalies or to bad habits formed before the palate is repaired," says Katie. "They may also be developmental in nature. These difficulties can take the form of sound substitutions, omissions or distortions.

"Articulation problems require speech therapy to teach the child correct placement and marking of consonants. This therapy should be fun and motivating for the child, involving lots of play, games, and multi-sensory cues."

Excessive nasal resonance or hypernasality is a problem specific to children with cleft palate. To understand this, let's first look at what happens during normal speech: Air from the lungs and sound vibrations from the vocal cords travel up through the throat (pharynx) and then enter the mouth. The palate and the walls of the throat block the air and sound from going into the nose.

But if the palate and throat don't close effectively —

a condition known as velopharyngeal insufficiency or VPI — air goes up into the nose and makes the child sound hypernasal. This can occur, explains Katie, if the palate is too short or if the muscles aren't working correctly.

Diagnosing VPI

Using a mirror to look for "clouds" is one easy way to see if air is coming out of the nose. Another involves plugging and unplugging the nose while the child talks.

"We have them say different words and listen to the pressure behind their sounds," says Katie. "If the sounds are a lot stronger with their nose blocked, they might be losing some of the pressure out of their nose.

"You hear hypernasality with the sound of vowels," she adds. "So if the sound becomes clearer with the nose blocked, that indicates some hypernasality."

If VPI is suspected, the speech-language pathologists may refer the child for an x-ray study, known as speech videofluoroscopy. This involves taking a moving x-ray picture while the child is talking to determine why air is escaping.

Another diagnostic test that may be used is nasal endoscopy. In this procedure, an otolaryngologist or ears, nose, throat doctor inserts a slender telescope with a tiny camera attached inside the nose. This allows the doctor to see inside the nasal passages.

Treatment for VPI

Cleft repair generally resolves the issue of VPI, but sometimes the problem persists. "About 10 to 15 percent of kids have VPI after a cleft repair," says Katie. "Those children often require a secondary operation. Hypernasality and nasal air emission are structural issues that can't be corrected by speech therapy. That's when we look at how their palates are functioning to see if they would benefit from a surgical procedure to get better closure."

Postoperative speech therapy may be needed to help the child relearn how to produce sounds using the corrected structure. ■



Scholarship AWARDS

This year The Foundation for Faces of Children presented the 2011 **Jane McDaid Scholarship Awards** to four outstanding high school seniors. A reception was held recently in their honor at Children's Hospital Boston. Learn about our 2011 scholarship recipients on page 2.

Melina and her son Carter Fortin with Dr. John Mulliken at last year's FFC Walk and Family Picnic



September 25, 2011
Save the Date!
Walk Family Picnic
See page 3 for info!

FFC 2011 Scholarship Awards

The FFC **Jane McDaid Scholarship Award** recognizes students for their outstanding character, academic achievement, participation in extracurricular activities, and commitment to further education. The 2011 scholarship recipients are:



Kevin Hazel is from Chelmsford, Mass., and graduated from Chelmsford High School. He was involved in many extracurricular activities, including high school musicals, choir, mock trial, and the freshman mentor program. He was also a member of the varsity track and cross-country teams. He served on Student Council and, this past year, was president of his class. He was also a National Honor Society and Music Honor Society member. His community service included working with the Autism Speaks Foundation, volunteering at Lowell General, participating on the Chelmsford 24-hour Relay Team, and helping out with several Chelmsford-based activities for elementary children and senior citizens. He has a passion for playing the piano and singing, and more recently, learned

to play the guitar as well. Kevin will be attending UMass Amherst in the fall. He hopes to obtain a business degree, then go on to attain an MBA.




Julie O'Neil is from Methuen, Mass., and graduated from Methuen High School. She participated in her high school's theater productions, was an active member of the Key Club, and was a peer leader and algebra tutor. Her community service includes being a Relay for Life team member, volunteer at local elementary school, and Festival of Trees volunteer. She was a National Honor Society, Science Honor Society, and History Honor Society member. She has a passion for the theatre and is a baking enthusiast, too. Julie will be attending UMass Amherst in the fall, and her major is undecided at this time.



Ashley Robinson is from Chelmsford, Mass., and graduated from Nashoba Valley Technical High School in the dental assisting program. She has special interest in photography and writing and was a varsity member of her high school softball team. Her community service includes volunteering at the Tufts School of Dental Medicine as well as in local soup kitchens. She has a passion for antiquing and would like to own her own antique shop someday. Ashley has been accepted into the dental hygiene program at Middlesex Community College. She hopes to further her education and ultimately attend dental school.

Chelsea Williamson is from Franklin, Mass., and graduated from Franklin High School. She was involved in such extracurricular activities



as varsity lacrosse, the peer leadership program, and peer mediation. She was a National Honor Society member and received the Harvard Book Award and National Language Arts Award. Her community service includes volunteering at Caritas Hospital in Norwood for the past four years and volunteering in the Early Childhood Development Center, working with children with special needs. She has a special interest in science and hopes to work in the medical field in the future. Chelsea will be attending the University of Pennsylvania and majoring in bioengineering. Her future plans include graduate school. 



A HOT Rally Benefits FFC

The Hounds of Hades Motorcycle Club hosted a fundraiser for the FFC on Sunday, May 15, at the Abington VFW function hall in Abington, Mass. The event was inspired by four-year-old Shane, the son of "Lil-John" and Krystle McColgan, who was born with a unilateral complete cleft lip and palate.

Family, friends, and members of many different motorcycle clubs attended the fundraiser. The event featured a buffet lunch, music, a raffle, photography by German Rivera, face painting by Handi Mandi, and games for children, including musical chairs and hot potato. The "Hound" of the Hounds of Hades also made a special guest appearance.

Thanks in part to generous donations of goods from area businesses and participants, the event raised \$1,100 for the Foundation. The Hounds of Hades can't wait to hold this fundraiser again next year!

The McColgan family at the fundraising event – Lil-John holding Shane, and Krystle holding Peyton

Back on the Ice

Hockey players took to the ice for the 6th straight year in support of FFC on April 9th. The charity game, sponsored by the Syracuse Crunch Hockey Team, raised close to \$1,300 in honor of Madison Parks, the seven-year-old daughter of John and Teri Parks of Syracuse, N.Y. Madison was born with unilateral craniosynostosis, a condition where the bone sutures of the skull close prematurely.

“We are so pleased to once again help raise money for Foundation for Faces of Children through our Crunch Classic hockey game,” says Vance Lederman, Syracuse Crunch General Manager. “This is such a worthwhile cause, and we’re proud to say we’ve been able to raise over \$6,500 over the past six years. Many thanks to all the players who donate their time and money to the cause.”

Both Madison’s father and grandfather played in the game along with Crunch alumni and friends.



Madison Parks and her dad John on the ice



Join us for the 15th Annual FFC Walk and Picnic on Sunday, September 25, 2011. Set your own pace as you loop around Lake Quannapowitt in Wakefield, Mass., in support of a good cause. After the walk, enjoy food and fun with other families.

Registration starts at 11:30 am with coffee and donuts. The walk kicks off at noon, followed at 1 pm by lunch and special activities for the kids, downstairs in the church hall. The event will be held rain or shine.

“We’re hoping to get 300 people to attend this year,” says walk co-chair Melina Fortin, the mother of 20-month-old Carter, who was born with a bilateral cleft lip and palate as well as a heart defect. She and co-chair Jennie Keniston encourage participants to build teams. “The more people on a team, the more support,” says Melina.

The fundraising event makes possible FFC’s free publications, videos, and fact-filled website about facial differences. Donations also support informational meetings for individuals and families as well as annual student scholarships.



STEP BY STEP

STEP 1: FORM A TEAM. Invite family, friends, co-workers, and neighbors to share the fun and walk with you. If they aren’t able to, ask them to sponsor you. (All donations are tax deductible to the extent permitted by law.)

STEP 2: SIGN UP. Create a personal fundraising page online through First Giving at www.firstgiving.com/FFC. Or sign up by contacting Mairi Bleakie at 781-875-1914 or mbleakie@facesofchildren.org.

New this year: Register by August 1, and the name of your team will be printed on the back of the official walk T-shirt! You can use your child’s name or be creative. For example, past FFC team names have included Elan’s Team and HEARTSMILES.

STEP 3: COLLECT YOUR PLEDGES. Please bring your sponsor sheets, which are available through www.facesofchildren.org, and collected pledges to the walk. Make checks payable to Foundation for Faces of Children. Mail any remaining pledges by October 25, 2011 to FFC at: 258 Harvard St., #367, Brookline, MA 02446.

STEP 4: PICK UP YOUR T-SHIRT AND WALK! Meet on the common by the First Parish Congregational Church at 1 Church Street, Wakefield, Mass. Free on-street parking is available. After you check in at the registration table, you will receive your official walk T-shirt. Then enjoy your walk around the lake. The loop is about three miles long, but families are welcome to walk any portion of that distance.

Receive Rewards

We want to thank you for your efforts:

If you raise this amount...	You’ll receive this as a reward:
\$50	FFC bracelet
\$100	FFC baseball cap
\$250	FFC long-sleeve T-shirt
\$500	FFC fleece vest
\$1,000	FFC fleece blanket

FFC merchandise will also be on sale on the day of the walk (payable by cash or check).

Win Basket Raffle Prizes

Following the walk, you’ll also have an opportunity to participate in a raffle. Buy tickets for \$1 for a chance to win the basket of your choice.

Be an Angel Walker

If you can’t join us on the day of the walk, you can still collect donations and be eligible to receive thank-you gifts. Angel walkers can send donations to FFC at 258 Harvard Street, #367, Brookline, MA 02446.

For directions, sponsor sheets, and more information, visit our website at www.facesofchildren.org.



Recent appointees to the FFC Board of Directors (left to right) Ann-Marie Rogers, Meera Oliva, Adrienne Musto and Bari Popkin.

Parent Advocate and Board Member Adrienne Musto

This month we feature one of the Foundation's newest Board members.

After health insurers repeatedly denied claims for treatment of her son Tony, born with a severe complete unilateral cleft lip and cleft in his alveolar ridge, Adrienne Musto thrust herself into the role of legislative lobbyist. Since 2008, Adrienne has advocated legislation requiring health insurance coverage for all medically necessary treatment for children affected by cleft lip and palate or other craniofacial conditions.

Fortunately, Adrienne knows how to research and promote a cause: She graduated with a BS degree in marketing from Michigan State in 1997 and an MBA from Boston College in 2002. Her first job with the Appliance Division of General Electric brought her to Massachusetts after stints in Indiana and Kentucky. After earning her MBA in a part-time program, she worked in business development for Suffolk Construction and held marketing director roles at two other general contracting companies. She currently is taking a hiatus from full-time employment to be home with her children but occasionally teaches one of her favorite pastimes — gymnastics.

Adrienne, her husband Tom, and their three young boys (Thomas, 8; Tony, 6; and Owen, 4) live in Mansfield, Massachusetts. A self-described fitness fanatic, Adrienne enjoys being active and playing with her boys. In the winter, the family loves to ski, snowboard, and snowmobile near Saddleback Mountain in Rangeley, Maine; while in the warm weather, they spend time at a family cottage on the water in Wareham. 📷



Legislative Update

On June 28, a panel of parents and doctors testified at the State House in front of the Joint Finance Committee in favor of cleft and craniofacial bills H.2065 and H.321. “The hearing went extremely well,” says organizer Adrienne Musto. “The next step for both bills is a hearing with the Joint Healthcare Finance Committee, hopefully by the end of summer or early fall.” For more information, e-mail Adrienne at ahogland@msn.com.



The Foundation for Faces of Children is dedicated to improving the lives of children with craniofacial differences, including cleft lip, cleft palate, and other head and facial conditions.

Our mission is to:

- Provide patients and families with the most accurate, up-to-date, and accessible information about facial differences.
- Advocate for the best care possible for children with facial differences.

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:

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

Telephone: **617-355-8299**

E-mail: **info@facesofchildren.org**

Website: **www.facesofchildren.org**

Board of Directors

Johanna (Joey) Smith, Esq., *President*
 Alfred C. Frawley, Esq., *Clerk*
 Ron Parkinson, *Treasurer*
 Kara Jackman, *Secretary*
 John M. Condon
 Anne-Marie Gagnon, MSW
 Mary Lania, RN
 Dorothy M. MacDonald, RN, BSN
 John B. Mulliken, MD
 Katherine Murphy
 Adrienne Musto
 Meera Oliva
 Bari Popkin
 Ann-Marie Rogers

Staff

Mairi Bleakie, *Director*

Advisory Board

Joe Carroll
 Mary T. (Mate) Converse
 Kristin DeKuiper, Esq.
 Sheryl Rosner, Esq.
 Beth Tomasello, Esq.

Facing the Future Editorial Staff

Nancy Knoblock Hunton, *Writer and Editor*
 Cindy Shields, *Designer*