

# FACING THE FUTURE

## HELP US HELP YOU

This has been a productive year for FFC. We held our first Teen/Young Adult Forum, awarded scholarships to three deserving students, and provided accurate information to families through our video, website, and newsletter. With your help, we can continue our efforts to make a difference for children with craniofacial conditions and their families.

We hope you will support us in the coming year by making a tax-deductible donation to the Foundation's annual appeal.



Todd Kiley and his balloon-festooned son Brandon

## A Record-Setting Walk

A record number of participants turned out for the 13th annual "Paces for Faces" Walk and Family Picnic on October 4 at Lake Quannapowitt. More than 140 friends, relatives, and supporters rallied for the cause and helped us make this one of the most successful FFC Walks ever.

After registering, walkers received official T-shirts, thanks to Joe Carroll of the FFC Advisory Board; enjoyed breakfast foods provided by Erik Lania of Watermark Donuts (a Dunkin' Donuts franchise); and mingled under canopies supplied by Sean Kane Party Rentals. Then 12-year-old Jared Popkin climbed on a chair and, with a bullhorn, announced the start of the walk.

After a loop around the lake under sunny skies, participants ate a delicious Italian feast, catered by Bellino's Trattoria of Wakefield, who contributed one-third of the cost. The Synthes Corporation, a surgical implant manufacturer, underwrote the entire remainder of the cost of the meal.

In addition to the walk and lunch, this year's event featured a variety of new activities, including decorating paper pumpkins, applying temporary tattoos, and searching for treasure in foam peanut-filled inflatable pools. Many thanks to Jared and his mom, Bari Popkin, for organizing these fun activities!

"Mister Twister" (aka Bill Campbell) also gave the event a new twist by creating festive balloon hats and animals. And lunchtime visits by popular TV and book characters added to the excitement of the day. (Thanks to Eastern Coast Costume for supplying the costumes and donating the cost of a rental.)

FFC President Johanna (Joey) Smith recognized Elan's Team and Connor's Pacing Panthers for collecting the most contributions. These top two teams received special goody bags containing Highlights magazines, Webkinz stuffed animals, gift certificates for Kaplan Toys, and free coupons for Billy's Famous Roast Beef in Wakefield. We applaud and appreciate their efforts.

Many thanks to all our walkers, volunteers, sponsors, the First Parish Church of Wakefield, and the Town of Wakefield for helping to make this event a success.

For a link to our online photo album, please e-mail Mairi at [mbleakie@facesofchildren.org](mailto:mbleakie@facesofchildren.org).

## FIRST TEEN AND YOUNG ADULT FORUM

"I'm excited to finally be with my 'peeps,'" said Olivia Chartand of Ludlow, Massachusetts, at FFC's first Teen and Young Adult Forum, held at Children's Hospital Boston. Never before had she had the opportunity to meet others like her born with cleft lip and palate.

The September 12 event gave teens and young adults a chance to discuss physical, social, and emotional aspects of growing up with cleft lip and palate. They covered topics related to final operations like pain management, nutrition and weight loss, and regaining abilities, such as playing the clarinet and returning to sports.

They also talked about how a change in appearance can add to self-confidence but may not always be noticeable to others. Their conclusion about the best way to handle teasing was to ignore it. Overall, the group's opinion was that individuals born



Speakers and participants at FFC's Teen and Young Adult Forum on cleft lip and palate

with cleft lip and palate can be just as successful in life as anyone else.

The informative and inspiring forum, featuring presentations by medical experts as well as small group discussions, attracted more than two dozen teens and family members. Coordinated by FFC board member Kara Jackman and planned with the help of teen volunteers, the Teen and Young Adult Forum was dedicated in memory of former FFC co-president Jane McDaid (see box on page 3).

### Available Options

The forum began with a series of short talks by Children's Hospital medical staff, followed by questions and answers. First, dentist/orthodontist Siva Vasudavan, MDSc, MPH, described the range of treatment options, including braces, replacement of missing teeth with implants or bridges, and jaw surgery. Teens, he said, have the opportunity to be more involved in the decision-making process than children do.



## Successful Start to Fellowship in Craniofacial Orthodontics

Craniofacial Orthodontics Fellow Siva Vasudavan with (left to right) Drs. Richard Bruun and Stephen Shusterman

In the fall of 2007, the Department of Dentistry at Children's Hospital Boston launched a two-year fellowship program in Craniofacial Orthodontics. The program's goal is to provide advanced orthodontic training in craniofacial and cleft patient care in a hospital setting, using a comprehensive team approach.

"Very few orthodontists have experience with craniofacial conditions, so there is a high demand for this program," says Stephen

Shusterman, DMD, Dentist-in-Chief, Emeritus, who conceived of the fellowship program and is now its co-director.

The program consists of patient care, research, and instruction. "It is essential to share our knowledge with dedicated and motivated orthodontists who will go on to not only treat craniofacial and cleft patients but to contribute academically through research and publications," says Richard Bruun, DDS, co-director of the fellowship program.

The first Fellow to be appointed was Sivabalan Vasudavan, BDS, MSc, MPH, of Australia. "Siva has met and exceeded all of our hopes and expectations and helped define a program that now welcomes two new Fellows," says Dr. Shusterman.

The 2009 Fellows are Fioella Bellido,

BDS, of Peru and Daniel Kennedy, BDS, DCLinDent (orthodontics) of New Zealand. "Dr. Siva," as he's known, stayed on for several weeks to assist in the transition and will return to Children's every 6 to 12 months as an adjunct faculty member.

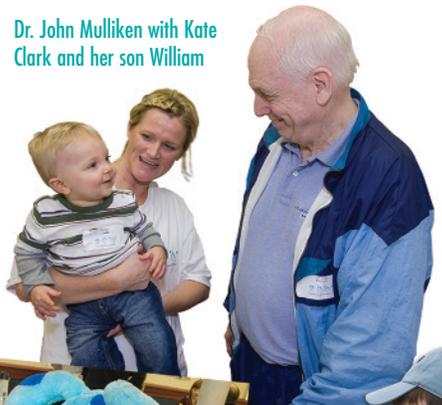
Inspired at age 16 by an article about Australian doctors treating children with cleft lip and palate in the Philippines, Dr. Siva pursued his career with single-minded determination — enrolling in dental school at the University of Western Australia in Perth and then a three-year orthodontics program at the University of Sydney. After earning a Master of Dental Science degree, he successfully passed a specialist examination from the Royal College of Surgeons of Edinburgh. In addition to the craniofacial orthodontics fellowship at

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## The 13th annual "Paces for Faces" Walk and Family Picnic — our biggest turnout ever!



Dr. John Mulliken with Kate Clark and her son William



◀ Connor's Pacing Panthers, a top fundraising team



▲ A winning team — Raul and Meera Oliva and baby Elan with FFC Director Mairi Bleakie

▼ Owen Kelley and his dad, Liam, with a blue friend



Jared Popkin announces the start of the walk.



◀ Tracey and Kenneth Kohlstrom with their children Owen and Olivia



◀ Volunteers from Cape Cod Regional Technical High School (from left) Lexa Inkley, Tyler Amato, Zach Riley, and Rebekah Wiegand with Rebekah's mom, Denise.



Small group discussions gave participants a chance to share experiences.

### Teen Forum, continued from page 1

“Decide what’s important to you,” he advised, “and find out what your options are. Consider time and costs when making your decision to go ahead with treatment.” He also said that delaying treatment until after college can be more inconvenient—requiring time off work—and may lead to problems with insurance coverage.

Next, plastic surgeon John Mulliken, MD, talked about typical “touch-ups” on the nose, lip, and palate. Among these optional treatments are: augmenting tissue beneath the lip scar, making the Cupid’s bow (the double curve in the upper lip) symmetrical, narrowing the width of the nose, straightening the septum, and surgically creating a pharyngeal flap, if necessary, to improve hypernasal speech. Functional procedures, such as septum correction for a breathing problem, are covered by insurance, he noted, while final aesthetic procedures sometimes are not covered.

In his presentation, psychiatrist Myron Belfer, MD, said teens and young adults should remember that personality is not dictated by outward appearance. He recalled how in his teens he was self-conscious about the size of his nose and early hair loss, but he compensated by running fast and joining the track and soccer teams. “The key to feeling good,” he said, “is knowing that you’ve accomplished something and that you’ve moved in a positive direction.”

In considering later treatment, he suggested focusing on facial corrections that will bring satisfaction rather than on perfection. He also said to be wary of blaming facial differences as the source of all problems.

Oral surgeon Bonnie Padwa, DMD, MD, covered procedures in her speciality including closure of oronasal fistula (abnormal opening between the nasal and oral cavities), jaw alignment, and tooth implants. She noted that treatment takes place after growth stops, which can be determined by X-rays of the hands and wrists, but is typically age 15 or 16 for girls and 17 or 18 for boys.

She explained that orthognathic or jaw surgery (also known as LeFort I) may be done with rigid fixation or, less commonly, distraction osteogenesis. The latter procedure involves wearing a halo device for three to five weeks while the upper jaw is slowly advanced forward. In a

dramatic series of before and after photos, Dr. Padwa showed how a canine tooth could be implanted in place of a missing incisor and how realigning the jaws can improve one’s profile.

### More to Come

Thanks to the organizing committee and, in particular, Forum Coordinator Kara Jackman for planning such a successful event. Appreciation also goes to the Friends of Broadway for supporting the forum through their ticket sales, Whole Foods for supplying both breakfast and lunch during the event, and Jaguar Press for donating printing of the forum flyers.

To reach a broader audience, FFC is in the process of producing a video based on information from the Teen and Young Adult Forum. (Thanks to the Southern family for sponsoring this.) Look for the video soon on our website!

Also, teen and young adult participants were enthusiastic about future forums and online discussions. Watch for these as well as a workshop for parents in early 2010 on insurance coverage of surgical and dental procedures. 

## IN HONOR OF JANE McDAID

On July 17, 2009, former FFC co-president Jane McDaid died of cancer at her home in Newton. Jane joined the board in 1998 and became co-president in January 2001. Ill health forced her to leave that position a year ago.



The recently held Teen and Young Adult Forum, which was long a dream of Jane’s, was dedicated to her memory. In addition, an FFC scholarship will be named in her honor.

“Jane did a great deal for the Foundation, leading us into the computer age by conceiving and implementing the website, and providing exemplary leadership,” says Johanna Smith, FFC president. “I know I personally strive to maintain the vision and high standards she had for us as an organization, and her impact will be lasting.”

Jane’s husband Jerry Murphy and daughter Margaret Murphy with FFC president Johanna Smith after the Teen and Young Adult Forum dedicated in Jane’s honor.



## Successful Start to Fellowship, continued from page 2

Children's Hospital, he also completed a master's degree in Public Health at Harvard School of Public Health.

Among the different research projects Dr. Siva worked on during his fellowship was a 3-D photogrammetry study with John Mulliken, MD, and Stephen Sullivan, MD, comparing nasal symmetry after repairs performed with a splint and without. Another cleft-related study, with Bonnie Padwa, MD, DMD, looked at changes in nose and lip tissue after patients have had the LeFort I or jaw procedure. And together with Dr. Shusterman, he is conducting a survey of North American practitioners who treat infants with cleft lip and palate to determine their preference for the Latham device, nasal alveolar molding (NAM) device, or no form of presurgical treatment.

Conducting such research "will improve care everywhere," says Dr. Shusterman. And he adds, "Fellows will not only benefit from seeing our patients but will spread our philosophy and techniques worldwide."

"When I return to Australia," says Dr. Siva, "the children I encounter will benefit from the wisdom and knowledge that Dr. Shusterman and Dr. Bruun provided me. And similarly when the next fellows return to Peru and New Zealand, respectively, they'll be able to share that knowledge as well." 



**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:

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