

FACING THE FUTURE

2010 FFC Scholarships

Each year the Foundation for Faces of Children awards scholarships to young adults born with a facial difference who are pursuing post-high school education. This year we will be naming one of our scholarships in honor of our past president and board member Jane McDaid, who passed away in 2009.

High school students and graduates living in Connecticut, Maine, Massachusetts, New Hampshire, Rhode Island or Vermont are eligible to apply for the \$1,000 scholarships. The application deadline is May 1, 2010.

Please go to our website www.facesofchildren.org for scholarship applications and instructions. Click on **For Patients and Families** at the top of the page and then scholarship information. Or call Mary Lania, scholarship committee chair, evenings or weekends at 781-255-8931.

www.facesofchildren.org

Scholarship applications are due May 1.

A Dental Home for Children with Facial Differences



Dental department coordinator Leah Ledgewood with (left to right) Drs. Stephen Shusterman, Daniel Kennedy, and Richard Bruun

Dental care is an important part of the team approach to the treatment of children with cleft lip and palate, and other craniofacial differences. Combining dental treatment with surgical care is key to achieving the best aesthetic and functional results. At Children's Hospital Boston, pediatric dentists and orthodontists work with an oral surgeon and prosthodontist to provide personal, comprehensive dental care. This care is carefully timed to coincide with medical and surgical procedures.

"Children with facial differences have a dental home they can always come here, at least for advice if not for treatment, from birth until maturity," says Stephen Shusterman, DMD, Dentist-in-Chief Emeritus at Children's Hospital.

The craniofacial team at Children's Hospital Boston provides an example of the value of involvement of the dentists and orthodontists in team care. Many cleft lip and palate and craniofacial patients come to Children's for dental care, ranging from annual checkups to braces to tooth replacement. Others, especially those who live far away, see a local dentist or orthodontist with guidance from Children's experienced dental team.

"Active treatment that involves a cleft-related malocclusion [undesirable positioning of the teeth] needs, at the least, to be coordinated by a cleft team," says Richard Bruun, DDS, a pediatric dentist and orthodontist at Children's. "It requires specific expertise, acquired through training and experience, that many pediatric dentists and orthodontists may not have. The more complex a patient's case is, the more benefit there is in coming here."

Cleft lip/palate and craniofacial team doctors meet regularly to discuss the best treatment for each individual patient. These multidisciplinary conferences include plastic surgeons, oral and maxillofacial surgeons,

continued on page 2

Insurance Bill Update

Patients, parents, and medical experts spoke ardently about the need for cleft lip and palate insurance coverage at a public hearing at the Massachusetts State House on December 16, 2009. Their testimony was in support of House Bill 932, which requires health insurance to cover all medically necessary treatment related to cleft lip and palate, including dental care. (California passed similar legislation advocating on behalf of children affected by cleft lip/palate in October 2009.)

"To cover our kids, the cost for each member insured or premium per year will be only 24 cents," says Adrienne Musto, a parent lobbyist for the bill.

The hearing brought the real-life stories of children and their families into the policy debate. It allowed patients and parents to talk about their treatment and the considerable expense it poses. Speaking at the hearing were: Matthew Rushford (age 8), Thomas Chappuis (age 14), and Nicole Lania (age 16) along with Kate Rushford, Tom Chappuis, Mary Lania, Eric Loeffler, and Adrienne Musto. Drs. Stephen



Courtesy of WBZ-TV Boston

Thomas Chappuis speaking out at the State House hearing.

Shusterman and Richard Bruun of the Department of Dentistry at Children's Hospital Boston testified about the medical necessity of dental and orthodontic care. They pointed out that patients were spending

significant amounts of money for what was considered dental treatment and, therefore, not covered by medical insurance.

WBZ-TV aired coverage of the testimony during their "Health Watch" segment with Dr. Mallika Marshall. Video of the WBZ report may be viewed at www.bit.ly/HouseBill932.

"Presently Bill 932 is awaiting a joint financial committee vote, which we expect to be yea," says Adrienne. "Then it's on to a gathering of the executive committee where a recommendation will be made for the next steps."

Watch the FFC website for further details. 

A Dental Home *continued from page 1*

pediatric dentists, orthodontists, prosthodontists, speech pathologists, and audiologists. At times, specialists in genetics and neurology may also join the team discussions.

Timely Care

Children with cleft lip and palate often have misshapen, misaligned or missing teeth, making good dental care essential. In some children, especially those with repaired complete cleft lip and palate, the upper jaw may not grow forward as much as usual, affecting the bite—the way the teeth fit together—resulting in an underbite.

Children with complete cleft lip and palate may first see a dental specialist within days of birth (long before they have teeth) to assess the need for an oral device to reposition the segments of the palate before surgical lip repair. At Children's Hospital Boston, doctors often recommend a Latham device—an appliance that is fixed to the upper jaw—to narrow the gap in the lip and gum and facilitate the surgical repair. The use of this device, which is inserted when the child is 5 or 6 weeks old and adjusted over a period of several months, results in less scarring after cleft lip repair.

After infancy, until school age, the dental team sees children in the cleft lip and palate clinic once a year, unless a child has a specific problem with tooth eruption or decay. During this time, the focus is on protecting the teeth from cavities with regular cleaning of the teeth (brushing and flossing), good nutrition, and fluoride applications. Dentists generally recommend sealants to prevent cavities on the first permanent molars between the ages of 7 and 9, and on the second permanent molars between the ages of 12 and 14.

Orthodontic care to straighten the teeth and improve the bite starts during the early school years. At approximately age 8, depending on the development of their teeth, children begin what is known as Phase I of orthodontic treatment. The first step is to acquire diagnostic records—a series of digital X-rays (which expose the patient to less radiation than traditional X-rays), photos, and dental impressions for a model of the child's mouth—which help the dental team, sometimes in collaboration with the oral and plastic surgeons, plan the best treatment possible.

"Based on the records, the doctors in the cleft lip and palate and craniofacial team put together a unique treatment plan for each patient," says Leah Ledgewood, the coordinator for the Cleft Lip/Palate and Craniofacial Program, who joined the Department of Dentistry in August. "Then the parents, along with their child, come in to discuss the treatment plan as well as insurance and scheduling logistics. Timing of the treatment depends on medical

necessity but usually begins one to three months after the diagnostic records are taken."

Phase I treatment generally involves a maxillary expansion appliance, which changes the shape of the roof of the mouth; braces to align the teeth; and sometimes, additional appliances to help the development of the upper jaw. After expansion and preliminary alignment is complete, children are ready for a bone graft. During this operating room procedure, oral and maxillofacial surgeon Bonnie Padwa, MD, DMD, takes a small amount of bone, usually from the hip, and places it in the cleft area in the jaw. At the same time, any openings from the nose to the mouth (fistulas) are closed. The bone graft is timed to allow permanent teeth to grow through the newly placed bone.

At age 12 or 13, Phase II treatment occurs, if necessary. This treatment focuses on specific dental issues, such as assisting the eruption of the canine tooth after bone grafting, relief of crowding, further alignment of the teeth with braces, and use of reverse headgear to lessen a developing underbite (when feasible).

Phase III takes place as a child's growth is completing. "Not everybody, but some of the patients, depending on how they grow and their malocclusion, need Phase III treatment, which involves braces often combined with surgery to align their jaws," says Daniel Kennedy, BDS, DCLinDent, an orthodontist from New Zealand, who is a craniofacial orthodontics fellow in the Department of Dentistry. "Phase III usually starts around age 15 in girls and age 18 in boys."

After this Phase III treatment, patients may still have aesthetic and functional issues, such as missing or malformed teeth that require the services of Lawrence Phan, DMD, the prosthodontist at Children's Hospital. This treatment may include single or multiple tooth implants, crowns, or bridges.

"Dr. Phan has specialized knowledge in prosthetic dentistry for kids with cleft lip and palate," says Dr. Bruun. "He knows they'll have different quality and quantity of bone where teeth are missing and that building a bridge across those areas is like building a bridge across a river with unstable abutments. His level of knowledge, expertise, interest, and time committed to treating cleft lip and palate patients make him an extremely important part of the team."

An Ongoing Relationship

Members of the dental team see children and parents frequently over the years and establish ongoing relationships. "We get invested in our patients," says Dr. Bruun. "Parents and their children have a close relationship with us. I know that personally because when I had my injury [an infection that led to amputation of his hand], many of my

continued on back page

TEEN CORNER

If you missed "The Teen and Young Adult Forum on Cleft Lip and Palate" last fall, you can now watch the presentations online. To view the videos, go to www.facesofchildren.org, click on "FFC Community," then select "Teens and Young Adults" from the menu. The featured speakers include: psychiatrist Myron Belfer, MD; plastic surgeon John Mulliken, MD; oral surgeon Bonnie Padwa, DMD, MD; and dentist/orthodontist Siva Vasudavan, MDSc, MPH. As an added bonus, former patient Rob Southern shares his views on treatment for cleft lip and palate.

This spring, join us for some social events like going to the movies and bowling. Become a fan of FFC on Facebook (go to www.facebook.com and enter Foundation for Faces of Children in the search box) or e-mail karajackman@yahoo.com to learn more about these upcoming events. ■

Saturday, April 17, 9 am – 1 pm

Overcoming Insurance Obstacles

Byers Room A & B, Children's Hospital Boston

FFC invites parents of children with cleft lip/palate and other craniofacial differences to join in a discussion of health insurance matters. Learn how to successfully deal with insurance issues related to your child's medical and dental care. Hear an update on the Massachusetts House Bill 932, dealing with cleft lip/palate health care coverage. Guest speakers for the event will include Beth Dworetzky, Massachusetts Family-to-Family Health Information Center; Adrienne Musto, parent advocate; Leah Ledgewood, coordinator, Department of Dentistry; and Nancy Velasquez, billing coordinator, Department of Dentistry. Lunch will be provided following the presentations. When you sign up, please let Mairi know what your primary concerns or obstacles are, or have been, with insurance, so that the speakers can address them.

Mark Your Calendars!

Here are some upcoming FFC events

Contact Mairi Bleakie at mbleakie@facesofchildren.org or 781-545-5086 for more information or to sign up for any of these events.

Thursday, June 24, Noon – 1 pm

FFC Luncheon and Presentation at the 20th Annual Cher's Family Retreat Hyatt Regency, Cambridge, Mass.

If you plan to attend the Children's Craniofacial Association (CCA) 20th Annual Cher's Family Retreat from June 24 to 27 at the Hyatt Regency in Cambridge, you are invited to join your FFC friends at a free lunch on Thursday June 24. Please RSVP to Mairi (lunch is for retreat registrants only). At the retreat's educational symposium on Thursday, FFC board member Kara Jackman will speak and present the videos from our fall Cleft Lip/Palate Teen Forum. Other activities planned during the retreat include an ice cream social, an outing to the New England Aquarium, and a pool party. Retreat registration fee is \$60 per family and includes the cost of most meals. The hotel is offering a discounted room rate of \$150 a night. For more details and to sign up for the retreat, go to www.CCAkids.org.

Sunday, September 26, Noon

14th Annual "Paces for Faces" Walk and Family Picnic

Lake Quannapowitt, Wakefield, Mass.

The date is set for the next FFC Walk and Family Picnic. Please help us make the event a success by joining our organizing committee. Volunteer opportunities include: team recruitment, sponsorship, media/public relations, activities planning, and logistics. You can register for the event online and create a personal fundraising page at www.firstgiving.com/16357. Registration is free (ignore the "Price" box), but participants are encouraged to raise funds for FFC.

Friday, July 23, 10 am – 1 pm

Developing Effective Coping Skills for Children with Facial Differences

Byers Room A & B, Children's Hospital Boston

Learn ways to help your child cope with with medical procedures and social-emotional challenges. Drs. Elisa Bronfman and Lauren Mednick, psychologists at Children's Hospital Boston, will offer their clinical expertise on: preparing for medical procedures, dealing with questions or teasing from classmates, and developing coping strategies for life. FFC will provide lunch.

Introducing...

For **Emily Ridgway, MD**, this year's craniofacial fellow at Children's Hospital, returning to Boston was a homecoming of sorts. She was born at Brigham and Women's in Boston and lived in Wayland, Massachusetts, while her parents were residents-in-training at the Massachusetts General Hospital. During her teen years, her family moved to Colorado.



After receiving her bachelor's degree magna cum laude from the University of Virginia in Charlottesville, she received her medical degree from the Columbia College of Physicians and Surgeons in New York City. She then went on to train in neurosurgery at New York University Medical Center. Before beginning her fellowship, she was a resident in the Harvard Plastic Surgery Training Program.

In 2008, she was awarded the Regan Fellowship from Operation Smile and participated in an international medical mission in Urumqi, China. She was later awarded the American-Israeli Plastic Surgery Fellowship and the ASMS Fellowship and was able to travel to Israel with the Beth Israel Deaconess Plastic Surgery Chief, Dr. Sumner Slavin.

As the craniofacial fellow at Children's, Dr. Ridgway is conducting numerous research projects in addition to clinical work. One project involves studying the use of endoscopic surgery for craniosynostosis, and cleft lip and palate. During this minimally invasive procedure, surgeons insert an endoscope—a lighted, flexible tube—through small incisions and operate with miniature surgical tools. Dr. Ridgway has already published a dozen journal articles as well as several book chapters.

"I am very grateful for the amazing mentorship I receive from the esteemed John Mulliken and Gary Rogers," says Dr. Ridgway. "Both are terrific mentors and surgeon-scientists."

In her spare time, she enjoys oil painting, western horseback riding, running, tennis, and travel. 🏡

A Dental Home *continued from page 2*

patients, even teenage boys, and their parents wrote me heartfelt letters, which meant a great deal to me.”

Dr. Bruun continues to take an active role in the cleft lip/palate and craniofacial program. He helps plan orthodontic treatments, supervise the craniofacial orthodontic fellow, and advise parents.

In addition, Andrew Sonis, DMD, a pediatric dentist and orthodontist with specialty training in oral medicine, is increasingly involved in cleft lip/palate and craniofacial patient care. He also works with the craniofacial orthodontic fellow in planning and treatment.

“The team approach greatly benefits the long-term management of cleft lip and palate and other craniofacial differences,” says Dr. Shusterman. “That’s why we try to integrate dental care as closely as we can with surgical procedures. With everyone communicating and working together, the final result is always better. Children will always have a ‘dental home’ here.”

Visit www.facesofchildren.org/timeline to learn about timely dental and surgical care for a child with cleft lip and palate. 

 **Go Green!** Help save the environment and reduce our printing and mailing costs by reading your newsletter online. If you sign up for our e-mail list, you will receive an alert when the newsletter is posted on our website along with monthly news updates. Please visit www.facesofchildren.org and click on “Join our e-mail list.” **Thanks!** 



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*
John M. Condon
Kara Jackman
Mary Lania, RN
Dorothy M. MacDonald, RN, BSN
John B. Mulliken, MD
James O'Sullivan

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*



This issue of *Facing the Future* was made possible by proceeds from the 2009 **PACES FOR FACES** Walk and Family Picnic.