

FACING THE FUTURE

FFC Scholarship Award Program

April 1 Application Deadline

Established in 1999, the FFC Scholarship Award Program has distributed 49 scholarships in 17 years – totaling \$64,000. The Program recognizes promising students born with a facial difference by annually awarding post-secondary educational scholarships (college or vocational/technical school). High school graduates or college students who are residents of New England (Connecticut, Maine, Massachusetts, New Hampshire, Rhode Island, and Vermont) are eligible to apply. The Foundation selects award recipients based on their academic performance, extracurricular activities and community service. **April 1, 2015** is the deadline to apply for the FFC scholarships:

The Jane C. McDaid Memorial Scholarship will be awarded to the applicant with a history of substantial community service.

The Barbara Seltzer Memorial Scholarship will be awarded solely to an applicant with cleft lip/palate who will be pursuing a career in the arts.

The Dorothy MacDonald Scholarship will be awarded to an applicant seeking a career in the healthcare profession.

The Dr. John B. Mulliken Scholarship will be awarded to one who demonstrates excellence in academic scholarship and leadership.

Details about each scholarship as well as instructions on how to apply can be found at www.facesofchildren.org under the “For Patients and Families” tab. Or, call Mary Lania, Scholarship Committee Chair, evenings or weekends at 781-255-8931.

THE FOUNDATION FOR FACES OF CHILDREN: Where We Have Been, Where We Are Going

FFC has concluded another terrific year — one that might even be considered transformative. Some of the past year’s highlights include the Falmouth Road Race, 18th Annual Paces for Faces Walk and Family Picnic and our first “Facing the World” program promoting self-esteem. Throughout the year we communicated with families who are dealing with facial differences and hosted local events for fun and support. As we enter a new year and a new phase of impact, we are providing an update on our plan to grow the Foundation.

First, we want to thank all who have contributed over the years, either with their time or financially, to help us deliver on our mission. As a result of your efforts, the Foundation is on sound financial footing and will be establishing an endowment to fund additional scholarships and programming over the coming years. Additionally, we continue to seek enhanced methods to provide opportunities for learning and education within our established programs.

We are currently designing a follow-up to last fall’s well-attended self-esteem program, “Facing the World.” The new program will focus on the power of the mind (see related article on page 3). This year we also hope to branch out with additional age-specific programs to focus on the needs of those affected with a facial difference — from the newborn to the tween and teen to young adults.

We were encouraged by the success of the December 2013 event “Caring for the Newborn,” where we partnered with Boston Children’s Hospital to host more than 70 medical professionals at a regional seminar. We hope to work with BCH in the future to co-sponsor similar functions.

Since its April 2013 debut, 400 copies of our feeding video “Cleft Lip and Palate (CLP): Helping the Newborn Thrive – A Guide for Clinicians and Parents” have been distributed to over 30 countries worldwide. We are in the planning stages of our next video which will focus on the Latham device (see related article on page 2).

Finally, to expand outreach to craniofacial families in need, a new FFC brochure is being created. And as always, this year’s calendar will also include some FFC family-fun events.

Since its inception in the fall of 1986, the Foundation has supported thousands of craniofacial families in many ways. Thirty years later, we are proud of the many individuals who have grown up with the

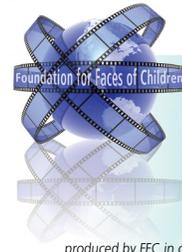


Foundation’s support and now live full and productive lives as young adults. In fact, many of them return to FFC to volunteer their time and services: assisting with our annual Paces for Faces Walk; hosting their own fundraising events; serving on the FFC Board of Directors; sharing their personal stories in our newsletters; or speaking to teens directly.

Given our past success, we are invigorated by our broadening presence within the craniofacial community. As we find ourselves at this important crossroad, FFC recognizes the need for careful financial planning while ensuring that our programs are far-reaching and provide the most accurate, up-to-date and accessible information about craniofacial differences. As we leverage our past successes to springboard the organization to a level of even greater impact, inclusive of psychosocial, financial and educational programming.

Please help us expand our communication efforts to reach all in need of support and education. We encourage you to sign up for one or more of our e-lists in order to receive information in a timely fashion. Visit www.facesofchildren.org and click on the “Sign Up for Email Updates” button on the homepage.

Again, we want to thank all of you who have contributed in the past and hope you will join us in making 2015 the catalyst for a bigger and better future. ■



Cleft Lip and Palate:
Helping the
Newborn Thrive
A GUIDE FOR CLINICIANS
AND PARENTS

produced by FFC in collaboration with Boston Children’s Hospital



DENTAL UPDATE:

Use of the Latham Appliance in Infants with Unilateral Complete Cleft Lip and Palate

by Elizabeth I. Ross, DDS

In the past six months, two important studies have been published from the Department of Dentistry at Boston Children's Hospital (BCH). These studies investigate the affects of using the Latham appliance in infants with unilateral complete cleft lip and palate.

The Latham appliance is a pre-surgical orthodontic device that is utilized to help decrease the width of the cleft prior to plastic surgical intervention. Typically the appliance is inserted within the first three months of life and is in place until the initial lip surgery. The appliance is custom made from an impression taken by your treating dentist. Both parents and the dentist will be involved in activating the appliance to facilitate closure of the cleft over a five-week interval.

The dental department at Boston Children's Hospital has been using the Latham device successfully for infants with cleft lip and palate since 1997. Dr. Stephen Shusterman pioneered this technique at Boston Children's after studying directly with Dr. Latham. Skeptics of the Latham appliance claim that it is a painful procedure for an infant to endure. The efficacy of correction with this device has also been questioned, as there are other appliances available which are less invasive. The two publications below refute the comments above and we are very proud that our recent orthodontic cleft and craniofacial fellows contributed to the literature.

Adele Bronkhorst was a recent graduate from the orthodontic cleft and craniofacial fellowship at BCH. She graduated in 2012 and currently works



Leo is one of our recent Latham graduates. Above, he is pictured prior to the Latham appliance insertion.



Five weeks later, Leo meets with his team at Boston Children's Hospital prior to removal of the device.

overseas in Dubai as an orthodontist with specialty training in cleft lip and palate. Bronkurst and her colleagues¹ in the dentistry department assessed the morbidity associated with application of the Latham appliance in infants. They studied 109 infants with unilateral and bilateral complete cleft lip and palates who underwent Latham appliance

insertion. Pain and discomfort were measured via vital signs and the standardized FLACC score (Face, Legs, Activity, Cry, Consolability). In this study patients were found to have a minimal change in FLACC scores initially post insertion, with return to normal scores by three hours. This data suggests that infants do not experience significant pain after Latham insertion and likely some of the alterations in FLACC scores can be attributed to irritability due to the size and location of the appliance.

Not to be outdone, Sath Allareddy, the orthodontic cleft and craniofacial fellow from 2013, who also holds an MBA, PhD and a Masters of Medical Science, recently published an article examining the post-operative effects of Latham appliance insertion. Allareddy and Boston Children's Dentists/Orthodontists² investigated 40 infants who had Latham application in the setting of a unilateral complete cleft lip and palate. Alareddy found that the application of the Latham device was associated with significant reduction in the width of the cleft and the outcomes were predictable without any major adverse events or complications.

These two articles clearly demonstrate the positive benefits associated with Latham application in the pre-surgical treatment for infants with unilateral and bilateral complete cleft lip and palates. We are fortunate at Boston Children's to be one of the leading centers that can offer this treatment to our patients affected by cleft lip and palate and we believe that it positively affects the outcome after plastic surgery. ■

¹Bronkhorst et al. Assessment of morbidity following insertion of fixed preoperative orthopedic appliance in infants with complete cleft lip and palate. *Oral Surg Oral Med Oral Pathol Oral Radiol.* 2015 Mar 119(3): 278-284. www.ncbi.nlm.nih.gov/pubmed/25592867

²Veerathapurush Allareddy et al. Operative and Immediate Postoperative Outcomes of Using a Latham-Type Dentomaxillary Appliance in Patients With Unilateral Complete Cleft Lip and Palate. *Cleft Palate Craniofac J.* 2014 Jul 24 [Epub]. www.ncbi.nlm.nih.gov/pubmed/25058119

The Power of Mind as a Tool for Coping

This past fall, the Foundation for Faces of Children took its first step toward the goal of providing our families with programs promoting positive self-esteem and strategies for coping with anxiety. The event, “Facing the World: Optimal Strategies for Children & Families with a Facial Difference,” launched our plan to offer better psychological support to our craniofacial families. One aspect of the program highlighted techniques for focusing on mindfulness to elicit a relaxation response and reduce feelings of anxiety and depression.

Laura Gray, PhD, and Eric Riklin, BA, discussed stress, the power of the mind and the relaxation response which can be used as a tool for coping. It was pointed out that physical and emotional self-care is important for staying balanced, feeling more calm and having increased control over one’s life. This balance ultimately leads to greater self-esteem and self-confidence.

If a person gets stuck in a pattern of negative reactions, the stress response can become chronic and lead to problems such as difficulty concentrating and impulsiveness or other physical and emotional symptoms. But if we are able to learn coping skills to change how we view stress, we can reduce that stress and the potential for anxiety or depression.

It has been proven scientifically that there is a strong mind-body connection. Persistent, toxic stress changes the chemistry of the brain and can cause an increase of blood pressure and blood sugar, digestive problems, memory and learning issues, as well as anxiety and depression. The good news is that the mind is flexible and we can change how we respond to the world and our



experiences. Relaxation as a coping strategy can diminish the stress experience by counteracting its negative effects. Positive, engaging activities elicit the relaxation response and combat stress and physical and emotional pain. The relaxation response can be triggered by using a number of meditative techniques such as diaphragmatic breathing, repetitive prayer, Qi Gong, Tai chi, yoga, progressive muscle relaxation, jogging or even knitting. There are also programs where one can learn how to elicit their own individual relaxation response.

The Benson-Henry Institute of Mind Body Medicine of Boston, Mass., offers training programs to deepen understanding of how stress influences health and illness. Students acquire skills in mind body practices to mitigate stress and build resiliency. FFC and the staff from the Benson-Henry Institute (www.bensonhenryinstitute.org) are working together to craft such a program to assist our craniofacial families in coping with anxieties that accompany

our children’s long craniofacial journey. The goal is to guide these families toward learning to reduce stress, build resiliency and enhance quality of life. We hope to schedule the initial Stress Reduction training program in late spring or early summer. Information about the program and how you can participate will be shared once the details are finalized. ■

Receive program and event notifications and registration information by visiting www.facesofchildren.org. Click the “Sign up for Email Updates” button, complete the form and select the “Programs” email list.

You may also email programs@facesofchildren.org with your name and contact information so that we can send registration information to you once it becomes available.

2015 PROGRAMS AND EVENTS



Pawtucket Red Sox (McCoy Stadium, Pawtucket, RI) Join us for the game against the Gwinnet Braves on Sunday, June 28 at 1:05 pm. It will mark our third year of attending a PawSox game!

Lowell Spinners (LeLacheur Park, Lowell, Mass.) What fun we had last year when FFC hosted a day at the ballpark with the Spinners! We are looking forward to doing it again July 26 at 3:05 pm against Auburn (NY) Doubledays (the single A short-season affiliate of Washington Nationals).



Falmouth Road Race (Falmouth, Mass.) August 16 will mark the third year that Team FFC runs the Falmouth Road Race. Our limited number of bibs come with a \$1k fundraising commitment to benefit FFC and will be assigned on a first-come, first-served basis. If you are interested in participating, please contact Team Captain, Kate Clark at roadrace@facesofchildren.org.

19th Annual Paces for Faces Walk and Family Picnic (Lake Quannapowitt, Wakefield, Mass) Join us for this year’s walk and picnic on Sunday, October 4. Please email walk@facesofchildren.org if you wish to lend a helping hand by serving on the walk committee or volunteering the day of the walk. Let us know how you would like to help and we will find a niche for you!



FFC Welcomes Craniofacial Surgical Fellow, Dr. Rottgers



Dr. Alex Rottgers enjoying family time with his wife Elizabeth and their son Henry.

The craniofacial surgical fellow at Boston Children's Hospital for 2014–2015 is Dr. Alex Rottgers. Alex attended Rice University in Houston, Texas, where he studied philosophy and biology, and stayed there to attend medical school at Baylor College of Medicine. While at Baylor, Alex recognized his love for caring for children and was exposed to the fields of plastic surgery and craniofacial surgery. After medical school, Alex completed training in plastic surgery at the University of Pittsburgh Medical Center. He took a year off during his residency to study the biology of cranial sutures (the structures affected in craniosynostosis). Alex will complete one year at Boston Children's Hospital as the cleft and craniofacial surgical fellow. He has a particular interest in maxillofacial disorders. His research topics include: how the nose grows after the repair of a bilateral cleft lip, cataloguing the types of clefts in patients with CHARGE syndrome, and measuring the outcome of minimally invasive sutural release on cranial growth in patients with bilateral coronal craniosynostosis.

Alex and his wife, Elizabeth, have a 2-year-old son, Henry. Elizabeth is taking a year off of her optometry practice while the family is in Boston. She and Henry are enjoying exploring the city and learning about New England. This summer the Rottgers family will move to St. Petersburg, Florida where Alex has accepted a faculty position with Johns Hopkins Department of Plastic and Reconstructive Surgery. He will be the first Johns Hopkins plastic surgeon to practice at All Children's Hospital, a new satellite of the Johns Hopkins health system. He is looking forward to a career taking care of patients with clefts, craniofacial differences, vascular anomalies and other pediatric patients in need of reconstructive surgery. 

Connect with FFC Online



FOUNDATION FOR Faces of Children

258 Harvard Street, #367
Brookline, MA 02446

617-355-8299

info@facesofchildren.org

www.facesofchildren.org

Support FFC

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

Board of Directors

John (Jack) Condon, *President*

Ann-Marie Rogers, *Exec. Vice-President*

Alfred (Fred) C. Frawley, III, *Clerk*

William (Bill) Pratt, *Treasurer*

Joseph (Joe) Carroll, *Assistant Treasurer*

Patricia (Tricia) Connery, *VP of Communications*

Mary Lania, RN, *VP of Programming*

John B. Mulliken, MD

Dorothy (Dotty) M. MacDonald, RN, BSN

Olivia Oppel, RN

Richard (Rick) Bellew

Ursula Costigan, Esq.

Michael Greiner

Elizabeth Ross, DDS

Monir Sakha