

FACING THE FUTURE

2013 Paces for Faces Walk Family Picnic

Join us for the 17th annual FFC Walk and Family Picnic around Lake Quannapowitt in Wakefield, Mass., on September 22, 2013.

The event is a great opportunity to enjoy a fun-filled afternoon of kid-friendly activities and to connect with friends – old and new!

“Last year was record-breaking both in turnout and fundraising! We are hoping to build on that momentum for our biggest year yet,” said Jennie Keniston, walk co-chair. “We hope to top 700 in attendance and over \$70,000 in funds raised.”

Registration begins at 10:30 am and the Walk kicks off at noon, followed by lunch and activities. This year’s event will take place outside on the Wakefield Commons, rain or shine.

The fundraising event supports the Foundation for Faces of Children’s ongoing efforts to provide information and programming for children and families affected by craniofacial differences. This includes funding the annual scholarship program, parent support, distribution of the new feeding video, educational seminars, and other opportunities to enable FFC to fulfill its mission.

The Walk continues to be an opportunity for families to meet new members and old friends. “I remember coming to the walk when my daughter was just three months old. We met other families and learned what to expect with upcoming surgeries,” says co-chair Ursula Costigan.

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Feeding Video Debuts to Enthusiastic Response

The Foundation for Faces of Children (FFC) proudly presented its new video, “Cleft Lip and Palate (CLP): Helping the Newborn Thrive — A Guide for Clinicians and Parents” on Sunday, April 21, 2013. Newly-appointed FFC President John (Jack) Condon delivered opening comments and a brief history of the Foundation to an auditorium filled with doctors, nurses, families, FFC board members, and friends. Dr. John Mulliken then reflected on his professional relationship with Dotty MacDonald, BSN, RN, project manager of the video, with whom he has worked side-by-side for many years.

Dotty shared the fact that when she started her career, there was little or no information about feeding infants with cleft lip and palate. Nurses generally counseled “do your best and just syringe feed.” But Dotty made it her mission to understand the suck, swallow and breathe sequence for feeding. She attributes her commitment to Dr. Anthony Bashir, a Speech Therapist who was very generous with his mentorship on how to feed infants. “It is an ongoing educational task working with both parents and staff,” said Dotty whose hope is that this teaching video will help others in the field.

Following a resounding round of applause as the video ended, Jack Condon presented Dotty with a bouquet of flowers on behalf of the Foundation and thanked her for her hard work and dedication in seeing this project to its completion. Dotty recognized those featured in the video, including Sharon Collier, MED, RD, LDN, Clinical Nutrition

Director; Olivia Beaudouin, BSN, RN, Department of Plastic & Oral Surgery; Kara R. Larson, MS, CCC-SLP, Speech Language Pathologist; and Cathy Noonan, MSN, CNP.

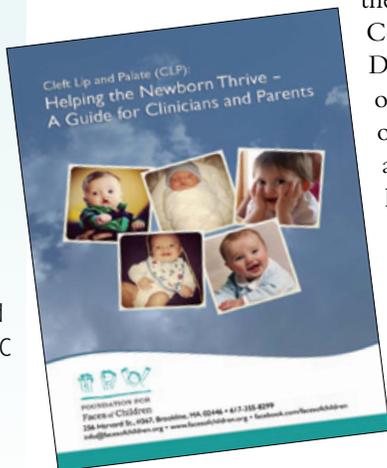
A few weeks later, FFC Executive Vice-President Ann-Marie Rogers joined Dotty to travel to Lake Buena Vista, Florida to attend the 12th International Congress on Cleft Lip/Palate and Related Craniofacial Anomalies. The 2013 Congress attracted more than 1,200 professionals and professionals-in-training from every corner of the globe with the hope of advancing the care of affected individuals worldwide. Attendee response to the FFC feeding video was overwhelming, with requests to ship more than 250 copies to over 30 countries worldwide.

FFC Board members remain enthusiastic about continuing the Foundation’s mission of improving the lives of children with craniofacial conditions, including cleft lip, cleft palate, and other skull and facial differences. The new video supports that goal by providing clinicians, patients and families with a tool for the most accurate and up-to-date techniques for feeding to ensure that CLP newborns thrive.

If you are interested in supporting video distribution, please visit www.facesofchildren.org and click on “Make A Donation Today.” Choose “Video Distribution” from the dropdown menu to make a donation through PayPal. If you would like a copy of the DVD mailed to you, please contact us at programs@facesofchildren.org.



Jack Condon extends well-deserved honors to Dotty MacDonald at the premiere screening of the FFC feeding video.



FFC’s feeding video is being distributed worldwide.

Congratulations to each of our 2013 graduates. See page two to read about this year’s Jane C. McDaid Scholarship Award recipients!



2013 Jane C. McDaid Scholarship Awards

The Foundation for Faces of Children hosted a reception Thursday, June 13 for the presentation of the 2013 Jane C. McDaid Scholarship Awards to five recent high school graduates. The award recognizes students for their outstanding character, academic achievement, participation in extracurricular activities and commitment to further their education. Meet our 2013 award recipients:



Thomas Chappuis of Sharon, Mass., recently graduated from Sharon High School where he was active in all of his school's drama productions — often

in leading roles. Self-taught in guitar, piano, harmonica, drums and ukulele, he loves entertaining in any capacity. He is also committed to academics and was awarded the Johnson & Wales Academic Achievement Scholarship. Volunteer efforts included mentoring troubled kids at the Cottage School and working with Veterans at Brockton VA. Tom conveyed his sensitivity and maturity about his experiences growing up with a craniofacial difference when he testified three times before the Massachusetts legislature in support of the Cleft Lip Palate Bill H2065 — now a state law requiring health insurers to cover all cleft palate care.

Tom will attend Johnson & Wales University this fall, majoring in hospitality services. Unsure of his career choice at this time, he hopes to find something that makes him happy, not necessarily rich. He also hopes he will be playing an instrument, making others laugh, or helping someone.



Joseph Levasseur is a 2013 Lowell Catholic High School graduate from Tewksbury, Mass., where he was a member of the school's football and basketball teams as

well as their 2013 Eastern Massachusetts Division 4 State champion baseball team. He was a mentor for the Little League Challenger division for disabled children who would otherwise be unable to play the game due to mental or physical challenges. Other volunteer efforts included visiting with senior adults, delivering food

to low-income households and assisting in fundraising events for the Multiple Sclerosis Society. Joseph was awarded the Ryken Scholarship from Lowell Catholic for four years. He was inducted into the National Honor Society and also selected three times for the Scholar Athlete Award (student athlete with highest GPA).

This fall Joseph will begin his studies in civil engineering at the University of Massachusetts Lowell.



Kristina Ladd of Ayer, Mass., is a recent graduate of Francis W. Parker Charter Essential School where she was an active member of her school's Model United

Nations team, winning two accolades for excellence in oral presentation. Kristina volunteered as a peer tutor while keeping up a work schedule of 10-20 hours a week at a local store. In the summer of 2012, Kristina studied college-level Spanish in Costa Rica, as well as completing two other exploratory academic summer programs; one at UCONN and the other at Dartmouth College. For her year-long senior project, she researched the psychological resilience of adolescents and, in doing so, recognized her own resiliency.

In the fall, Kristina will be attending Rowan University, majoring in chemical engineering. She hopes to attain her Master's degree in chemical engineering and looks forward to working for an international company where she can bring a global perspective.



Madeline Andrews of Wells, Maine, graduated from Wells High School in June. She was a member of the varsity lacrosse, soccer and indoor track teams, and was named

lacrosse team captain her junior year. Madeline has also qualified for the state indoor track meet and received academic athletic awards in both track and soccer. A member of National Honor Society, she received numerous Book and Principal's awards for academic achievement. Madeline performed volunteer work at elementary and middle schools; a camp for underprivileged children; and at her church. She plays trumpet in a directed-study band and was a columnist for her school newspaper.

This fall, Madeline will follow a pre-med focus at Colby College and hopes to be a physician some day so that she might help others in the same ways her doctors have helped her.



Bridget Burke of Westwood, Mass., is a recent Westwood High school graduate. Her passion is swimming; she was captain and most valuable player for her high

school varsity team and competed on the Shamrock Swim Club and Adirondack Aquatic Club. Bridget also participated in track, Westwood Ambassadors, Spanish Club, Key Club, an afterschool program for middle school students, and the Walk for Hunger. She is the recipient of the Boston Globe Scholastic Art and Writing Award. Along with all of these accomplishments, she works as a lifeguard, babysitter and scorekeeper.

Bridget will attend University of Massachusetts Amherst, majoring in Nutrition and participating on the university's Division 1 Swim and Dive team. She hopes to secure a career in nutrition helping others to feel good about themselves and would also like to travel extensively in Europe. ■

Born with Hemifacial Microsomia with Microtia, Lauren Dausch from Sharon, Mass., was a 2012 recipient of FFC's Jane C. McDaid Scholarship Award. This summer she will be working at Camp Starfish in New Hampshire, a sleep-away camp in for kids with emotional, behavioral, and developmental issues and disorders. Her dream career is to counsel children and teens as a social worker.

In Your Own Words

By Lauren Dausch

This is for self-love. This is for acceptance. This is for the hope to change people's minds about differences.

This is me.

For years I covered up my face, hiding in shame from the "ugliness" I thought I possessed. But I post this picture today to send a message: that even if you don't meet society's standards of attractiveness, that doesn't mean you're not beautiful, as I once thought. Differences ARE beautiful. Differences make change happen. If I hadn't been born this way, or felt these feelings of inadequacy and shame, I would not have dedicated my life to helping others. I want everyone to know that I am now not ashamed of myself. Just because my face isn't perfectly symmetrical, and just because I don't have two real ears,

or two perfect eyes, doesn't mean that I am not beautiful. Beauty comes from the goodness within and what you do with what you have. I suffered in silence for 16 years, then spent another 4 hiding behind a curtain of hair, until I realized that I could not live like that any longer. So I pulled my hair back and began the healing process. I want to be an example to those who suffered as I did; I want to show people that looks don't matter. Be proud of yourself and work hard to help others be proud of them too.

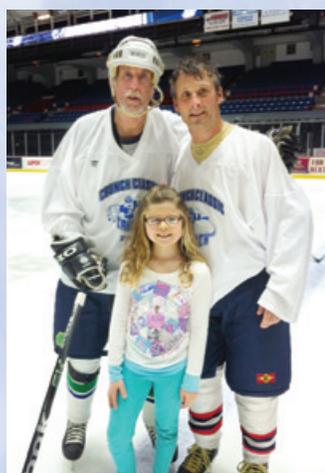
But you should also know that it's okay to stumble, it's okay to be ashamed sometimes. But you need to decide whether it's worth it to hide in anxiety and fear, or whether it's better to show the world that you can push through the difficult times and help others along the way. Because of

my surgeries and feelings around my face, I developed depression, anxiety, and other disorders; however I am not ashamed of this. I know mental illness is hard to talk about because of the pain and stigma around it, but it is very real and more common than you think. I am here to tell you that you can get through whatever struggles you are enduring—whether it be about your differences or maybe a horrible or traumatizing experience. You can heal and you can help others heal.

The world needs more love, and I wanted to share my story to help others, even if this only affects one person. Because every person matters. Everyone can make a difference. Open your heart up, accept people's differences, and spread love as much as you can. Thank you so much for reading this. 📌



Support from the Pros



Always at ease on the ice, Madison is pictured with two of her favorite players. Her grandfather David Parks (left) and dad John Parks skated in the Crunch Classic to support FFC.

In March, the Syracuse Crunch hockey team once again took to the ice for their annual "Crunch Classic" hockey game, raising \$1,800 for the Foundation for Faces of Children. The event is organized by John and Teri Parks along with their 9-year-old daughter Madison who was born with unilateral craniosynostosis. An avid Crunch fan, Madison also plays hockey herself. She started skating at the age of two.

The Syracuse Crunch hockey team is the American Hockey League affiliate of the Tampa Bay Lightning and the Crunch Classic remains a fixture on their annual schedule, drawing former players, friends and fans. Over the past 8 years, the event has collected more than \$8,000 in contributions to the Foundation.

FFC is deeply grateful to the Parks family and the Syracuse Crunch for dedicating their time and athletic skills to further our mission to educate families and medical professionals about craniofacial conditions. Their generous effort benefits families in need of information, support and networking opportunities.

This year the Crunch "made history in Syracuse," skating their way to the Calder Cup Finals (equivalent to the Stanley Cup in NHL). They succeeded in taking the Eastern Conference rounds. 📌



This August, a team of ten FFC runners will participate in the 41st New Balance Falmouth Road Race, raising funds to support the ongoing efforts of FFC, including our scholarship program, parent drop-in groups and distribution of our new feeding video. More than 11,000 runners will gather in Woods Hole for the event, including many who are running for a cause.

"When I had the idea to form a team last winter, it just seemed like such a great opportunity. Not only will the race help raise funds, but it will also get the FFC name out there as a resource for families who may benefit from its guidance and support," says Kate Clark, this year's Team Captain, and mother of a 4 ½-year-old son who is cleft-affected. Kate continued, "On the Cape, everyone has heard of the Falmouth Road Race. I've always wanted to run so I'm honored to do so this year while raising money for a cause so close to my heart."

A limited number of bibs are still available so please consider joining us in the running! To support the FFC team, visit www.facesofchildren.org. Click on "Make A Donation Today" and choose "Falmouth Road Race" from the dropdown menu to make a donation through PayPal. 📌

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“We have returned each year to meet new families in the same position we once were. The Walk provides an opportunity to offer these families the type of support we’ve been grateful to have. It gives you a sense of being part of a very rich and caring community,” explains Costigan.



Get Involved

STEP 1: Form a team. Invite family, friends and co-workers to do the walk with you. The more, the merrier! Individual walkers are welcome, too!

STEP 2: Sign up. To register, go to www.crowdrise.com/PacesforFaces2013.

STEP 3: Fundraise. Create your own fundraising page through the Paces for Faces registration page on Crowdrise. Once you create your page, it’s easy to ask family and friends to support your efforts! You can email the link, share it on your Facebook page, or tweet it to all of your followers! Or if you prefer, download and print sponsor sheets by visiting www.pacesforfaces.com. Bring the completed sponsor sheets to the walk along with your collected pledges.

STEP 4: Check in and walk. Meet on the common by the First Parish Congregational Church at 1 Church St, Wakefield, Mass. Free parking is available on the street. The Walk kicks off at noon!

STEP 5: Join us for lunch and a chance to win prizes. After the Walk, refuel with a hearty picnic lunch; participate in kid-friendly activities; and take part in a gift basket raffle. FFC merchandise will also be available for sale.

For up-to-date information about the Walk, please visit www.pacesforfaces.com.

Welcome Back to Boston



Alexander Allori, M.D., M.P.H., is this year’s craniofacial fellow at Boston Children’s Hospital. He was in fact born in Boston, the eldest son of Italian immigrants. He studied biochemistry and economics at Rice University and subsequently attended the University of Texas School of Public Health, where he obtained a master’s degree in public health with a concentration in management and policy studies. His thesis explored the proper and necessary methods for assessing the safety and efficacy of new technologies in surgery. Dr. Allori earned a medical doctorate at the University of Texas Medical School at Houston, completed general surgery residency at Beth Israel Medical Center, New York, and completed plastic surgery residency at Duke University Hospital.

He has also been very active in research and has trained in the bioengineering and regenerative medicine laboratories at M.D. Anderson Cancer Center and New York University Medical Center. His present research interests include clinical outcomes and health-services research related to pediatric surgical conditions, including cleft lip and palate, craniosynostosis, and brachial plexopathy.

On a personal note, Dr. Allori is married to Elizabeth — herself a pediatric nurse practitioner with experience in care of children with facial differences — and has three young children: Lucas (4 years old), Isabella (3 years old), and Alessandra (3 months old). He tells us he is quite happy to be moving back to Massachusetts and is ecstatic at the prospect of beginning his pediatric plastic and craniofacial surgical training at Boston Children’s Hospital. The Foundation welcomes Dr. Allori!



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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.

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