

FACING THE FUTURE

Walking for the Children

A sea of blue t-shirts (some purple too!) to support FFC circled Lake Quannapowit under what turned out to be beautiful sunny skies. This year, nearly 600 family members, friends, and staff from Boston Children's Hospital enjoyed the 17th annual FFC Walk and Family Picnic on September 22, 2013. "Our hope was to build on the success of last year's record-breaking attendance and fundraising" says walk co-chair Jennie Keniston. "We succeeded in attracting new families and friends, as well as many who have joined the Walk for years, even with a soggy start to the day!" Supporters raised more than \$55,000, which will further FFC's educational outreach through free publications,

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2013 Walk
Photos!

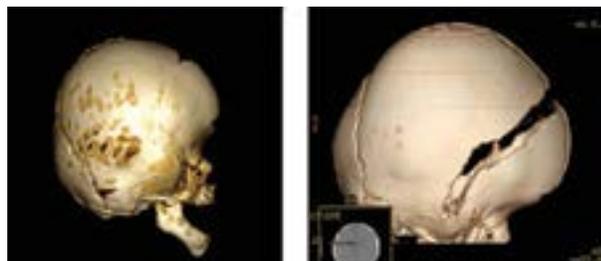
Early endoscopic release of craniosynostosis

By Mark Proctor, MD

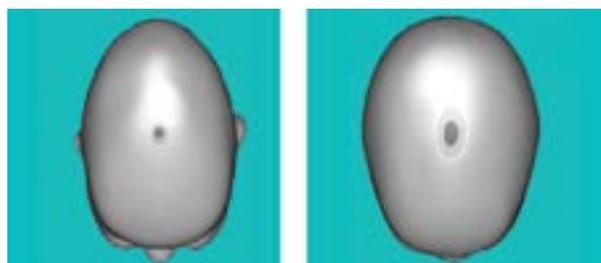
The only technique available in the early days of surgical correction of craniosynostosis was the simple release of the fused suture via a large scalp incision. While effective in some children, this method had a high failure rate because the cranial bones would fuse back together before the brain was able to re-create the normal shape of the skull. Because of the failure of these release procedures, larger operations were adopted. The open-approach requires a large scalp incision; the bones are released physically, placed into a more normal position, and fixed (usually with resorbable plates). The success rates are high with this traditional open-method.

Over the past two decades, advances in the field have incorporated some of the old techniques with some modern technologies. Drs. Jimenez and Barone developed a procedure whereby small incisions were used and an endoscope was inserted beneath the scalp to remove the fused suture. To avoid the early problem of bony re-fusion, this husband-wife team employed an orthotic molding helmet to reshape the head, thereby avoiding the failures seen in the early era of suture release.

There are now almost 100 articles in the literature supporting the safety, and short- and long-term efficacy of this endoscopic technique. It can be used for all forms of single suture synostosis, as well as for bilateral coronal synostosis. The operation needs to be performed early, generally between 2 to 3 months of age, which differs from the larger open operations that are optimally performed closer to 8 to 12 months of age. Endoscopic release also requires the use of the helmet



CT scans showing the bone removal accomplished via two small incisions and an endoscope in an infant with bilateral coronal synostosis.



Changes to the skull shape over 6 months in an infant who underwent endoscopic release of sagittal synostosis followed by helmet therapy.

to reshape the skull, very similar to the helmets being used frequently for the correction of sleep-related cranial deformities in babies. The benefits of this technique include small incisions, minimal blood loss, and a much shorter hospital stay. The downsides include the need for the helmet, and more frequent follow-up in the 6 to 9 months following the operation for helmet adjustments and visits with the surgeon. In summary, the endoscopic approach to correction of craniosynostosis is an effective alternative to the open operations for families that wish to pursue it. ■





All Walk photos courtesy of Sarah Santos Photography (facebook.com/SarahSantosPhotography)

Walking for the Children *continued from page one*

videos, and informational programs, as well as the Foundation’s website. The money will also be used to fund student scholarship awards. “This event has grown enormously over the past 3 years thanks to the wonderful energy and enthusiasm of our amazing Walk committee!” says John Condon, FFC president. “We are so grateful to all the families who participated.” “It’s fantastic to see our special community come together for this family friendly event that provides an opportunity to connect and share experiences,” adds Ann-Marie Rogers, Executive Vice President. “I applaud the efforts of all the walkers and their supporters.”

To accommodate the growing size of the crowd, the family picnic portion of the day was again held outside under a tent, with a delicious and nutritious lunch donated and served by Whole Foods Market. “We are so appreciative of the time and commitment that Whole Foods put into planning such a wonderful picnic lunch for our walkers” says Monir Sakha, Food Chair for the Walk, “and the walk participants definitely enjoyed it!” Following lunch, children’s activities included face painting, coloring, a scavenger hunt and a judo demonstration all while enjoying festive music provided by Event Pro DJs, DJ Thrilla.

For a second year, **Smile Striders**, individuals who raised over \$750 online by September 14, were recognized for their extraordinary commitment to fundraising (pictured above in purple Smile Strider t-shirts alongside Dr. Mulliken). Although not formally recognized, committee and board members also joined their ranks. Our deep gratitude goes to all of the

following: Hailee Bergeron, Katey Brown, Gina Brown, Kerri Chatten, Karen Foley, Melina Fortin, Leah Hatch, Elise Joyce, Brenda Lee, Amanda MacKinnon, Casey McMahon, Liz O’Keefe, Meera Oliva, Tyler Powers, Michelle Riley, Daniel Rogers, Monir Sakha, and Brenda Yorba.

“Overall it was a wonderful event and day,” says Ursula Costigan, co-chair. “Our goal is to create a positive experience for all of the families and friends that join so people make this an annual tradition and come back next year.”

Congratulations and thank you to the Walk Committee for their tireless work on registration, food, raffle prizes, children’s activities, and more: Jennie Keniston, Ursula Costigan, Colleen Loughlin, Liz and Logan O’Keefe, Meera Oliva, Monir Sakha, and Jennifer Dodwell. Thank you also to the members of the FFC board of directors who worked alongside committee members on the day of the event to ensure it was a success.

Planning Committee Members

Co-chairs: Ursula Costigan & Jennie Keniston

Registration and Fundraising: Meera Oliva

Raffle: Colleen Loughlin

Food: Monir Sakha

Merchandise: Liz and Logan O’Keefe



Co-chairs Jennie Keniston (L) and Ursula Costigan were presented with fresh flower bouquets by the committee.

Parent Support Drop-In Sessions

Both Prescription Parents and Foundation for Faces of Children have found parent support meetings to be very helpful over the years. Prescription Parents began support meetings back in 1973 while FFC hosted monthly “AboutFace Teas” in the early 2000s. In 2010, Prescription Parents merged with FFC in order to cast a wider net for parent support. Last year, four drop-ins took place on Saturday mornings at Boston Children’s Hospital and were very well received by those who attended them.

In October, FFC in cooperation with Prescription Parents held its first of several planned Parent Support Drop-In sessions in Newton. The drop-ins provide the opportunity for parents to meet other parents and talk about issues related to raising a child with a craniofacial difference. Past participants offered that they found the sessions to be both invaluable and tremendously supportive. The hope is to develop a sense of community where parents of older children may be able to offer support and insight to parents of younger children and newborns. For families who have a child affected by a craniofacial difference it can be a long journey filled with surprises, stresses, ups and downs, and uncertainties. These relaxed, low-key drop-ins offer a way for parents to come together in a non-clinical setting to meet one another and to provide both support and encouragement to each other through each milestone.

During these drop-ins, parents are able to explore available resources and share personal stories, needs and concerns. Common themes for discussion include caring and feeding issues of younger children; preparing for surgeries; dealing with insurance issues; and coping with teasing. Our hope is that by participating in these drop-ins, parents will feel better supported through the difficulties and uncertainties of raising a child with a craniofacial difference.

“The purpose of the Drop-in Program is to have open conversations and not lectures.”

– Dotty MacDonald, RN

Future drop-ins are scheduled for January 15 and April 16, 2014 from 7:00 to 9:30 pm at the Newton Senior Center, 345 Walnut Street, Newton, Mass. While registration is not required, it is certainly helpful for planning. Please send an email to parentsupport@facesofchildren.org and provide your name(s) and your child’s information

(name, age and craniofacial condition). You will then be added to our Parent Support e-list and provided with up-to-date information on future drop-ins, as well as other parent support programs and opportunities. ■



In Your Own Words

My name is Emily. My older brother was born with a cleft lip and palate. If you asked me if that makes him different than any other teenage boy, I’d tell you no. The little scar under his nose is the only sign someone can see of his cleft. His birth defect hasn’t really kept him from doing anything he likes to do. Like every other teenager, he likes spending time with friends, listening to music, and playing video games. He’s really smart and is an amazing musician who can play many instruments. He is also an awesome artist — he draws things and makes them look so realistic. I don’t ever see him being treated differently because of his condition.

The worst thing about having a brother with a cleft is getting dragged along to his appointments at Children’s. There are so many steps to prepare him for braces. He even had a surgery called a bone graft. Afterwards, most kids get to eat stuff like pasta or ice cream, but since Daniel has so many food allergies, he would only eat mashed potatoes. My parents mashed 10 lbs. of potatoes every day for like 8 weeks. That was crazy. So even though my family worries a lot when surgery time comes around, it’s not long before Daniel is back to being an annoying older brother. Hmmm ... maybe I could ask Dr. Mulliken to sew his mouth shut. I don’t know why I never thought of that before! ■

Your Donation Dollars at Work



FFC's new feeding video *Cleft Lip and Palate (CLP): Helping the Newborn Thrive – A Guide for Clinicians and Parents* has been very well received since its debut in April 2013. To date, over 300 copies of the DVD have been distributed to over 30 countries worldwide. Most recently, FFC created its own YouTube channel to better facilitate distribution of the DVD and to reach a much broader audience via the internet. In addition to the new feeding video, FFC's original video, *Understanding Cleft Lip and Palate: A Guide for Parents* in both English and Spanish is posted at www.youtube.com/facesofchildren.

The videos are also available for live stream viewing at www.facesofchildren.org on the Library and Resources page. The Spanish translation of the new feeding video is under way with the hope that it will be posted on both our website and YouTube channel by year's end. If you wish to support FFC's ongoing video projects, donations can be made at www.facesofchildren.org using the new drop-down menu on the Make a Donation page, or you can send your check to:

Foundation for Faces of Children, Video Distribution,
258 Harvard Street, #367, Brookline, MA 02446. ☒



Please join FFC in wishing its Operations Manager, Mairi Fuller, a fond farewell

Mairi, who worked part-time for the Foundation for Faces of Children since 2007, leaves behind her friends to take her talents to a full-time position as the Philanthropy Manager at Linden Ponds in Hingham. Although Mairi has been, and will continue to be, greatly missed with her day-to-day presence, her support and participation in the Foundation goes on in many ways. Special recognition and thanks were shown to Mairi at the recent Paces for Faces Walk and Family Picnic on Sunday, September 22. Mairi had played an instrumental role in the Walk's success over the years and the committee will miss her involvement. Join us in saying "Thank You" to Mairi for her dedication and support of the Foundation over the years. We wish her well in her new position! ☒



FOUNDATION FOR Faces of Children

258 Harvard Street, #367
Brookline, MA 02446

617-355-8299

info@facesofchildren.org

www.facesofchildren.org

Connect Online

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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