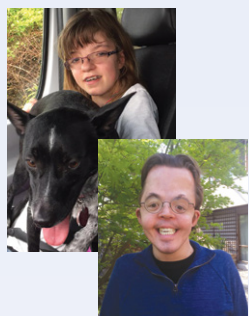


# FACING THE FUTURE

## Cher's Family Retreat and Educational Symposium



The Foundation for Faces of Children is sending Joyelle's family and Nate Finch to the 28th Annual Cher's Family Retreat and Educational Symposium in Salt Lake City, Utah. The annual weekend retreat is sponsored by the Children's Craniofacial Association. We are excited for them and look forward to sharing their experience with our FFC community. Watch for details on this retreat in our fall newsletter. CONGRATULATIONS!!



See Page 2

## Sunday, September 30, 2018

### 2018 Paces for Faces Walk Family Picnic

Please join us on Sunday, September 30, 2018 for the 22nd annual FFC Walk and Family Picnic around Lake Quannapowitt in Wakefield, Mass. The event will again take place outside on the Wakefield Commons in the big tent, rain or shine. We always have a great time.

Registration begins at 10:30 am, then the Walk kicks off at noon, followed by lunch. Fun kid-friendly activities will be available throughout the day. And there will be a large selection of raffle items available as well. The Walk is a short 3-mile stroll around a beautiful lake. And the family picnic is a great opportunity to meet new friends or reconnect with old ones while enjoying activities or over lunch.

**"Looking forward to  
seeing you all there!"**

— *Olivia Oppel,*  
2018 Walk Chair

Proceeds from this fundraising event support the Foundation for Faces of Children's ongoing efforts to provide information and programming for

children and families affected by craniofacial differences. Some of the programs include: the annual scholarship awards (totaling \$20,000), parent support, distribution of our videos, educational seminars, and other opportunities to enable FFC to fulfill its mission. Thanks to the support we received last year, we completed production of our third video which premiered on June 23.

The Walk continues to be an opportunity for families to meet new people and old friends. All are encouraged to register and bring their entire family for a day of fun and raising awareness. 🇺🇸

## Get Involved! Just follow these five steps to be part of FFC's 2018 Paces for Faces Walk:

- STEP 1: Form a team.** Invite family, friends and co-workers to walk with you. The more, the merrier! Individual walkers are welcome, too!
- STEP 2: Sign up.** To register, visit [www.pacesforfaces.com](http://www.pacesforfaces.com) where you'll find a link to set up a fundraising page.
- STEP 3: Fundraise.** Create a fundraising page, then ask family and friends to support your efforts! Email the link, share it on Facebook, or tweet it to all of your followers! Or, download and print sponsor sheets by visiting [www.pacesforfaces.com](http://www.pacesforfaces.com) (Bring completed sponsor sheets and collected pledges to the walk).
- STEP 4: Check in and walk.** Meet on the common by the First Parish Congregational Church at 1 Church St., Wakefield, Mass. We're not allowed to use the church parking lot, but free parking is available on the street.
- STEP 5: Join us for lunch and activities following the walk.** Refuel with a hearty picnic lunch; participate in kid-friendly activities; and take part in our raffle. FFC merchandise will be available for purchase.

For up-to-date information about the Walk, please visit [www.pacesforfaces.com](http://www.pacesforfaces.com).

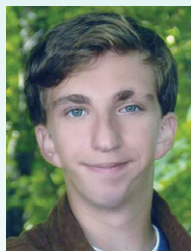


# 2018 FFC Scholarship Awards Program

The Foundation for Faces of Children hosted an event Saturday, June 23 at the Embassy Suites, Waltham, Massachusetts, to screen the new Latham video and award our 2018 scholarships to four deserving young adults. Meet this year's recipients:

## The Dr. John B. Mulliken Scholarship

*Awarded to an applicant who demonstrates excellence in academic scholarship and leadership. This scholarship honors Dr. Mulliken for his decades of expert care for our children.*



**SpiroAnthony Stathas** from Dracut, Massachusetts, graduated from Dracut High School. Active in sports, he participated in both varsity soccer and outdoor track. He holds a black-belt in karate. Spiro is a member of National Honor Society, the National Foreign Language Society and the National Business Honor Society. He has won awards twice from the National Academy of Future Physicians and Medical Scientists and served as delegate to the Congress of Future Medical Leaders. Leadership positions included president of the National Honor Society and president of his debate club. Spiro's community service ranged from volunteering at the VA hospital in Bedford, as the ESL interpreter for a Greek foreign exchange student, to search and rescue canine training with a local police service. Spiro completed an internship with the Alzheimer's Research service at the Bedford VA, contributing efforts towards a new spectrophotometry research funding grant. Spiro will be pursuing a pre-med track at the College of the Holy Cross in Worcester, Massachusetts. In ten years, he hopes to have completed his undergraduate work as well as medical school and begin training to be a neurosurgeon.

## The Dorothy MacDonald Scholarship

*Awarded to a young adult pursuing a career in a health profession. This scholarship honors our own Dotty MacDonald who spent the bulk of her nursing career assisting Dr Mulliken in the care of our kids at BCH's Cleft and Craniofacial Center.*



**Elizabeth Hodgkins** from Cumberland, Maine, graduated from Cheverus High School in Maine where she was active in the Key Club, French Club, Cheverus Pink Ribbon Club offering fundraising for breast cancer, and the Homefront Club supporting veterans. Active in sports, she participated in both Varsity field hockey and ice hockey as well as softball. To further her career exploration, Elizabeth participated in Maine Explorers based at Maine Medical Center as well as being selected for the Children's Hospital "SCOOP" Nursing intern position. Other community service included volunteering at Maine Medical Center, Turkey drive, Wreaths across America and Adaptive Skate programs in her community.

Elizabeth will be attending The Catholic University of America in Washington DC where she will major in nursing. She hopes to work in pediatrics as a subspecialty ultimately becoming a Pediatric Nurse Practitioner.

## The Jane C. McDaid Memorial Scholarship

*Awarded for strong community service, this scholarship honors the memory of the community-minded FFC president, Jane McDaid.*



**Julia Merrill** from Old Greenwich, Connecticut, graduated from Greenwich High School. She was active in sports as a varsity swimmer, serving as Captain her senior year and attaining impressive school records: All state in 50 Free, 100 Free, 200 Free relay & 400 Free relay as well as All American in 400 Free Relay. She was a Dartmouth Book Award winner.

Julia's community service includes traveling to Bogota, Columbia for a mission trip with Operation Smile and founding the Spreading Smiles Club to raise awareness and funding for children with facial anomalies along with promoting positive self-image. In addition, Julia provided peer mentoring at her high school and worked with the Junior League to promote positive self-image with middle school girls.

Julia will be attending Amherst College, majoring in political science/public policy. In ten years she hopes to be working for a governmental or national organization helping people. An additional interest for Julia, spurred by her trip to Bogota, is the field of global health. She hopes that whatever her position is in the future, it will have a wider impact on others.

## The Barbara Seltzer Memorial Scholarship

*Awarded to a young adult with cleft lip/palate who was active in the arts or who will be pursuing a career in the arts. This scholarship is named for Barbara Seltzer, a former president of Prescription Parents, who was very involved in the Cleft community.*



**Kristin Tagg** from Charlton, Massachusetts, graduated from Shepherd Hill Regional High School where she was active in Math Club and served as treasurer of the National Honor Society. She had numerous volunteer activities in her local community as well participating in a mission trip to an orphanage in Haiti. Kristin is a talented and competitive dancer. She has studied a variety of styles of dance as well as participated in musical theatre. For the last 4 years, Kristin served as an assistant teacher at the Cathy Taylor School of Dance.

Kristin will be attending Oklahoma City University where she will major in dance. In ten years, Kristin's dream is to work as a professional dancer or hold a marketing/business position related to dance.



Visit [Facesofchildren.org](http://Facesofchildren.org) and click on **EVENTS** to learn about FREE events & outings with other FFC families.



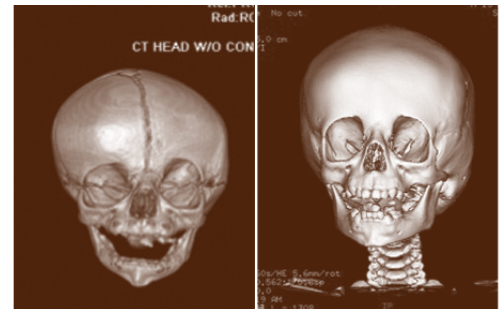


# Craniosynostosis, Explained

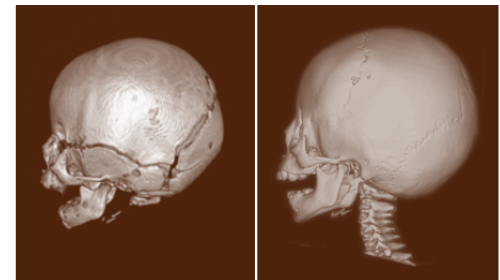
The human brain is one of the most complex things known to mankind, and it requires a complex structure to house and protect it. Because our brains are proportionally quite large, and because we walk on two legs and therefore have a narrower pelvic outlet than four legged animals, our brain must emerge at an earlier stage in development than any other mammal. In order for us to be able to ultimately gain the intelligence and skills we have as adults, the brain must grow a great deal after birth, especially in that first year of life before we learn to walk and talk. It is the complex skull that allows for this growth to occur.

The cranium is composed of five major bones separated by six major seams called sutures. The early closure of any of these sutures, which occurs in one out of approximately every 2,200 births, can lead to abnormal growth patterns of the head as the brain expands in ways it was not meant to. This condition, called craniosynostosis, can lead to an abnormal shape of the head, and in some children it can even affect normal brain development. For this reason, surgical repair of this condition is often recommended.

The methods for repairing craniosynostosis have come full circle over the years. The early operations involved a large incision, often extending from ear to ear, followed by release of the bones. However, this approach had a high failure rate, as many children fused the bones back together before the abnormal shape had



*CT images of a child before surgery and helmet therapy for left unilateral coronal craniosynostosis.*



*After surgery: formation of a new normal suture in the region that had been completely closed. Height of the eyes and asymmetry and tilt of the nose and jaw have corrected.*

## The 2018 Crunch Classic

**A big THANK YOU to the Parks family and the Syracuse Crunch Hockey Association for their continued support of FFC!**

**Organized by the Parks family, the Crunch Classic charity game has been held annually for 13 years in honor of Madison Parks, who was diagnosed with Unilateral Craniosynostosis as an infant. Now 14 years old, Madison enjoys participating in the event every year with her family and friends.**

**Vance Lederman, Syracuse Crunch General Manager summed up the team's commitment "We are happy to help support FFC each year with this fun event and enjoy working with the Parks family who are dedicated to this worthy cause."**

**The Foundation is grateful for the hard work and dedication of the Parks family and the Syracuse Crunch Hockey Association. This year's game, played on April 7 in Syracuse, New York, raised \$1,250! To date, the event has raised over \$17,000 so FFC can further its mission to help families with craniofacial differences.**

Pictured below is the Parks family, Teri, Madison, John and Gavin Parks.



**Madison, age three, at a Crunch game.**

corrected. This led to the development of large cranial vault reconstruction operations, where a team of plastic and neurological surgeons would remove and replace the cranial bones into a normal position. The advent of "minimally invasive techniques" using small incisions and endoscopes has brought the repair back to the early days of simply releasing the bones. Now the operations are highly successful because devices like helmets or internal springs direct growth in the proper orientation, and prevent the bones from fusing before things have corrected. This method takes advantage of the rapid brain growth that occurs very early in life. The optimal age for surgical intervention is before 3-4 months of age, as opposed to the larger operations which are frequently performed at 9-11 months.

Endoscopic surgery can be used for any type of fused suture. It is more successful in single suture synostosis than in the more complex forms, in which the children are quite prone to re-fuse the cranial bones. The operations are relatively quick, taking about 30-40 minutes and a total of two hours in the operating room. The recovery is rapid with just an overnight hospital stay. The risk of a blood transfusion is under 5%. The child is fit with a helmet within a week after surgery, and requires helmet therapy for several months, possibly until their first birthday. The correction requires patience, as it takes at least 3-6 months to occur, but gradually the head improves to a normal shape. The risk of needing an additional operation is as low as 1-2% for non-syndromic single suture synostosis.

In summary, there are two surgical options for correction of craniosynostosis when it is diagnosed early in life. The traditional cranial vault reconstruction remains a mainstay for older children. Endoscopic suture release and post-operative helmeting is an excellent alternative for children if undertaken in the first 3-4 months of life.

*Dr. Mark Proctor is BCH's Neurosurgeon-in-Chief; Director of Brain Injury Center, Professor at Harvard Medical School. He specializes in treatment of pediatric craniofacial abnormalities, spinal disorders, sports-related injuries and trauma to the brain and spine.*

## Meet FFC's Newest Board Member, Claire Barden!



FFC is pleased to announce its newest Board member, Claire Barden. Claire's second son, Peter, was born with a rare condition called bilateral macrostomia (Tessier Cleft No. 7) which meant that he had transverse lateral clefts on both sides of his mouth. His unique smile resulted in limited feeding abilities and oral function.

It confounded doctors and nurses and lactation consultants at the family's community hospital where no one could explain the anomaly to the new parents. On his first day of life, Claire began her own research into a world previously unknown to her and her husband Will — learning as much as she could about cleft and craniofacial anomalies. At two weeks old, Peter and his family met Dr. John Mulliken to begin their journey to restore function to what Claire describes as "Peter's extra special birth smile."

One of Claire's strengths is in making connections between people with like backgrounds or similar interests. She feels that

no family should walk this unfamiliar path alone, or without confidence in the quality of care they are receiving. As a Board Member, she hopes to further strengthen FFC's ability to connect parents, families, and children with craniofacial differences with each other. "Not all parents have the time, desire, ability, or resources to research and learn about the intricacies of their child's craniofacial condition in great depth. They may not be able to be effective advocates given the unknown territory. This is why I connect so strongly with FFC's mission to empower parents with accurate information so that their children can receive the best treatment available."

Before two little boys filled all the space in her heart and day, in her free time Claire enjoyed playing soccer, running, and even learning to play ice hockey. She still loves to be active and get outdoors, going for family walks, hikes, adventures, or trips to a beach or lake whenever possible.

A graduate of Northwestern University, Claire's professional background is in research and consulting, primarily in higher education. In 2017, Claire led a "virtual 5k" with participants around the U.S. that raised over \$7,500 for both the Foundation for Faces of Children and the Global Smile Foundation. 📷

## Mother's Day Brunch 2018



On May 5, FFC hosted "Lessons Learned: Mothers Perspective through the Craniofacial/Cleft Journey," at which Dr. Elisa Bronfman, Ph.D. spoke to a group of 40 mothers. Board members, and co-chairs Dotty MacDonald, RN, BSN,

and Mary Lania, RN, MSN, CCM, brainstormed ideas to host this brunch because of the success of the 2012 Mother's Day brunch.

Dr. Bronfman touched on psychological and social impact our children born with facial differences. Mothers of children ranging in age from birth to age 40, bonded as they shared advice and parenting experiences, following the co-chair's vision for a forum where mothers teach each other through their own experiences.

Women were seated at tables based on their child's age. In

attendance were Priscilla Coffin and Karen Foley, whose two sons are among the oldest age group.

The day began with a presentation from Dr. Bronfman (find slides in the resources section of the FFC website), followed by individual introductions and experiences of each guest. Each mom spoke of her child's journey, which in some cases brought the speaker and the audience to tears. Executive Vice President, Ann-Marie Rogers stated, "The support this forum offered was evident by the reactions of the moms. Had it lasted all day, it still may not have been enough time to answer all the questions the moms of younger children had for the more experienced ones." There is clearly a need for this type of support so the Foundation planning another similar event for the fall. 📷



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Faces of Children

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Connect with FFC Online



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.

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