Newsletter of the Foundation for Faces of Children

Fall 2022 Vol. 33, No. 2

# FFC 2023 Scholarship Program

Starting January 2023, FFC will be accepting applications for our 2023 Scholarship Awards. Visit our website for details. Since its inception in 1999, the FFC scholarship awards program has distributed 87 scholarships totaling \$249,000. The program awards postsecondary education scholarships to promising students born with a facial difference who are residents of New England (Connecticut, Maine, Massachusetts, New Hampshire, Rhode Island, and Vermont).



# The deadline for applications is March 1, 2023.

The Foundation selects award recipients based on their academic performance, extracurricular activities, and community service.

# FACING THE FUTURE



The Foundation for Faces of Children shared your wishes to return in person for this year's walk, and were thrilled

to offer the first ever Paces for Faces HYBRID Walk Along! We approached this year with excitement for families to walk in person around Lake Quannapowitt in Wakefield, and also virtually from home. One thing that we have learned from the COVID-19 pandemic is that virtual options allow us to share this special day with family and friends both near and far, so we expect a virtual option for this event will be here to stay!

Just under 140 people gathered in person on Sunday September 25th, with another 50 virtual walkers following along at home! Families enjoyed a beautiful fall day and caught up with each other in the sunshine. It was so fun to have our friends back from Circus Dynamics, who entertained us with stilt walking, ball juggling, hula hooping, balloon creations, and BUBBLES!

The Kona Ice Truck of Framingham/Natick, owned and run by Guy Tremblay, refreshed everyone with cups of shaved ice and a pour your own flavor station in fantastic color changing Paces for Faces souvenir cups! One walker called this a "brilliant idea!" and we hope to continue to surprise our walkers with fun treats like this again!

We continue to be impressed each year with the lengths our participants go to fundraise! Just under \$38,000 was raised and we had 14 total teams become Smile Striders. Seven reached Smile Strider status by

raising \$750; six were GOLD status Smile Striders bringing in over \$1,500; and one team achieved PLATINUM status by raising over \$3,000! All of your fundraising efforts help to support FFC programming such as family informational programs, sponsoring families to attend the CCA Kids Retreat and Camp Reflections, Paces for Faces Walk, Mother's Brunch Program, FFC Cares Grant, social events and gatherings for children and families, and our annual student scholarship awards.

Our social media presence was booming this year with pictures, videos and reels uploaded to our Instagram and Facebook stories throughout the walk and post updates for Smile Strider achievements and our "why I walk" series. Follow us online:



@foundationforfacesofchildren



@Foundation for Faces of Children - FFC



facesofchildren.org/pacesforfaces

This year's walk committee was led by walk chair Olivia Oppel, and included Vice-President Ann-Marie Rogers, Monir Sakha, Liz O'Keefe, Meera Oliva, Ursula Costigan, Tara Greiner and Emily Rogers with support from many others! Thank you to the members of the FFC Board of Directors and additional volunteers who also donated their time to ensure the walk's success.

A huge thank you to our wonderful community of family, friends and supporters! SEE you next year! ■

— Olivia Oppel, Paces for Faces Walk Chair

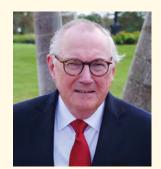


Michael Greiner, outgoing FFC president, with his wife Tara and their children, Kate and Matthew

# Many Thanks to Outgoing President Michael Greiner, and Welcome Back, Incoming Board President Jack Condon!

FFC would like to thank Michael Greiner for his service as board president. During his tenure, Michael's leadership provided the motivation and encouragement necessary to fulfill FFC's mission to our craniofacial community! We wish Michael well.

FFC would also like to welcome and thank John "Jack" Condon for stepping into the role of president. Jack has served on the board for many years, and previously held the president's seat from 2013 to 2017. We look forward to Jack's continued support, guidance, and collaboration as we return to our pre-pandemic programming and community outreach.



Incoming president, Jack Condon, has been involved with of the Foundation for decades.

Michael Greiner and his family continue to be involved with FFC. In fact, Tara Greiner, recently became a FFC Board member. While they reside in Milton, Georgia, Tara is thankful for the virtual environment which allows her to be an ongoing part of FFC, assisting with program planning and preparation.

# Respect & Love at the 2022 CCA Retreat

#### by J.R. Foley and Karen Foley

I do not think I have the words to say how awesome the retreat was. My heart was overflowing with joy and excitement finally meeting – IN PERSON – all the friends I have made over the past two years on Zoom. I am a very anxious person but this retreat was so calming for me. Whether it was participating in an educational class, sitting down to enjoy a nice meal, joining in an activity, or just plain hanging out — there was not one sad moment for me! Being with folks who have gone through so many surgeries, just like me, made me feel not so all alone. Not only was it fun, but it was also very moving for me. The retreat was a safe place. You realize that if a person has a disability or looks different, "WE" all have a gift to give to others: RESPECT & LOVE!!

It is hard to say what my favorite part of the retreat was but being in the talent show, with so many other talented folks, was high on my list. It's amazing to me how many people put their tireless work, devotion, and love to make this retreat a success. I am also amazed and so grateful to FFC for the sponsorship we received. Thank you, thank you! I'm already counting the days to the 2023 retreat; just hope it won't be as HOT as Dallas was (lol).

— J.R. Foley, Milton, Massachusetts



Most parents with a 32-year-old child are starting a new chapter in their lives by celebrating marriages and even grandchildren. And while you are extremely happy for those family members and friends who are on their new journeys, it sometimes can be hard because for me having a 32-year-old child with craniosynostosis, the same life continues: doctors' appointments, procedures, surgeries, and many different emotions. I tend to keep a lot of that stuff to myself but as a parent at the CCA retreat, you don't have to. You are with parents who get it, who have been there, and you truly feel safe. To be able to share stories and experiences with others who are just like you is invaluable. To be able to ask other parents for advice or opinions is priceless. The educational symposium part of the retreat is also greatly beneficial. In one of the sessions, I learned of a new hearing aid technology that I will now discuss with J.R.'s doctors.

I am so appreciative for the sponsorship that the Foundation For Faces of Children gave to us. We truly got so much out of the retreat. Thank you.

— Karen Foley, Quincy, Massachusetts



by Roselin Covas



Mila was born with a cleft lip and palate. Her early school years have been challenging as she's faced bullying for looking different and for wearing a hearing device. In June, she expressed frustration that no one looks like her, adding that she will never be pretty, and that with so many surgeries she will never have fun. I knew I had to move, AND FAST, My baby was spiraling into a dark place and I didn't know how to get her out. I touched base with her medical team at Shriners Boston. I was told that Camp Reflections would be a great opportunity. Mila had never been away from home, but I felt in my gut she needed this experience. I discussed it with her dad and submitted the application. The team was super responsive, cooperative, and put my doubts at ease. Before I knew it, she was off to camp.

The minute we arrived at Camp Reflections, Mila's eyes lit up. There were others like her and I could tell she felt at home. When we returned to pick her up, Mila talked our ears off the entire 2-hour ride home. She "loved the activities, trying new things, meeting new people, sharing stories, and even the chores." She said sometimes when her bunkmates would argue or "be mean," she would want to come home, but then they would talk it out or go off to an activity and she liked that. Mila is an only child so "problem solving," as she called it, is "not her thing." For us, the obvious exposure to new things and inclusivity that she got was what she needed. As mentioned before, her differences were used as punchlines when being bullied, and being at Camp Reflections was like being at a "homebase" with others who are familiar with her pain. It was amazing that she could experience child disagreements with RESPECT. She said she felt like a "normal kid and saw so many others she felt were stronger than her." Again, for us this was huge.

Mila went in for surgery #20 three days after returning from camp. Unfortunately, her medical expenses triumph over everything else. Had we not received the scholarship, Mila wold not have had the opportunity for such a wonderful, eye-opening and fulfilling experience. I was terrified to send her away but when I picked her up from camp, that "mom guilt" quickly turned into relief.



After suffering in a "dark place, Mila returned home from Camp Reflections as one happy camper.

### **MANY THANKS TO OUR 2022 SMILE STRIDERS!**

#### **PLATINUM**

#### raised over \$3,000

LATINUM GOL



Caitlin Hughes

#### **GOLD**

raised over \$1,500



Meera Oliva Ashleigh Dziedzic Brooklyn Hughes Ingrid Ganske Monica Trivedi Matthew Greiner

#### **SMILE STRIDERS**

raised over \$750



Kelsey Scott
PK Nelson
Emma Malayandy
Thomas Breen
Michal Yorba
Maya Gray
Ursula Costigan
Lacey Clericuzio





^ FFC Board members Ursula Costigan, Olivia Oppel, Ann-Marie Rogers, Dotty MacDonald, John B. Mulliken, Monir Sakha and Caitlin Hughes.

 Dotty with Lacey and Melissa Clericuziowith.

✓ Dr. Mulliken joins Team Dhruv for a group photo.



Circus Dynamics performers

were back to the delight of all!

# Welcome to Alistair Varidel, MBBS, BDS, new Cleft & Craniofacial Fellow at BCH



Dr. Alistair Varidel and wife Laura explore the nation's capital.

A 34-year-old Australian, Dr. Varidel moved to the United States in July for the Cleft & Craniofacial Fellowship at Boston Children's Hospital. As a youngster, Al's favorite pastime was woodworking and metalworking and he also developed a love of the sciences. He mowed lawns to earn money to buy anatomy and physiology books. He was naturally drawn to dentistry and medicine — a perfect combination of knowledge

and craftsmanship. After high school, he moved to Brisbane to complete the dentistry program at University of Queensland. While there, Dr. Varidel met his future wife, Laura, an Oral Health Therapist who heralds from a pineapple farm on Queensland's Sunshine Coast. She grew up down the road from Steve Irwin, who caught a "croc" on her farm!

In 2011, the couple moved to Sydney, where he earned his medical degree from the University of Sydney. An internship and general surgical residency at Westmead Hospital followed as he

concurrently completed a Masters of Surgery with a study using tranexamic acid to reduce blood loss in correction of craniosynostosis. During these two years, Laura spread her wings and moved to London to work and explore. She loves history and travel, and scoured the whole of Britain and the better part of Europe.

Dr. Varidel moved to Adelaide in South Australia for formal Oral & Maxillofacial Surgery training. Laura returned from England prior to the Covid-19 pandemic, and they build their first house together in Adelaide. Dr. Varidel sat for his written and oral boards before formally graduating as an Oral & Maxillofacial Surgeon in February of 2022.

After many delays due to training and Covid-19, the two were finally married in Queensland on April 2, 2022 before moving to Boston to commence his fellowship year at BCH. He considers the opportunity to learn first-hand from some of the world's most renowned cleft and craniofacial surgeons is an incredibly unique and humbling experience. Laura has taken the opportunity to explore the United States, in particular, learning about the history of New England and its role in America's independence.

Following Dr. Varidel's fellowship, they plan to return to Melbourne where he hopes to take up a position at the Royal Adelaide Hospital and Women's & Children's Hospital.



## FFC Welcomes Kerri Murray to the Board of Directors

A Rhode Island native, Kerri earned a BA in Biology from Providence College. She continued her education with a Masters in Public Health with a concentration in Epidemiology from Boston University School of Public Health. Kerri began working at Boston Children's Hospital as a Research Data Coordinator in 2011 and quickly became attracted to the clinical side of healthcare. She earned a MPAS at Massachusetts College of Pharmacy and Health Sciences – Worcester before returning to BCH as a PA in Orthopedic Surgery, specializing in upper extremity conditions. She admired the resilience and passion for achieving goals among her patients with limb differences and congenital anomalies.

Last October, she became the Cleft and Craniofacial PA in the Department of Plastic & Oral Surgery at BCH. Kerri feels fortunate to be working with patients ranging from newborns through young adults in the Cleft Lip and Palate

and Craniofacial clinics. She looks forward to teaming up with FFC to help patients and their families navigate their diagnoses and maximize their potential. In her free time, Kerri enjoys traveling, practicing yoga, and spending time with her husband Tim and sons, Owen and Liam.







FOUNDATION FOR Faces of Children

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Connect with FFC Online











The Foundation for Faces of Children (FFC) is dedicated to supporting the social, psychological/emotional, and educational needs of individuals, and their families, affected by craniofacial differences. We seek to improve the lives of children with craniofacial differences and inspire them to reach their full potential.

- 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

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 Caitlin Hughes, Treasurer Monir Sakha, Programs Co-ordinator

Joseph (Joe) Carroll Ursula Costigan Ingrid Ganske, MD Tara Greiner

Dorothy (Dotty) M. MacDonald, RN, BSN John B. Mulliken, MD, Co-Founder Kerri Murray, PA Olivia Oppel, RN Mary Lou Sauro, RN, BSN