Newsletter of the Foundation for Faces of Children

> Spring 2021 Vol. 32, No. 1



DONATION INSTRUCTIONS

Please make donations here or by check (payable to Foundation for Faces of Children) sent to:

Foundation for Faces of Children Annual Appeal 258 Harvard St, #367 Brookline, MA 02446



FACINGOFFUTURE

Camp Reflections Camp for Kids with Facial Differences. Think Summer 2021!



Camp Reflections is a week-long overnight camp in New Hampshire for kids ages 8 through 16 with facial differences (craniofacial differences, clefts, and others). Their siblings of that age range are welcome too. It is a typical overnight camp where kids play together, live in cabins and enjoy being around others who share similar experiences. We asked camper Carter to tell us a little about himself and his thoughts about Camp Reflections:

I'm in the 6th grade and I'm going to be 12 years old soon. I like to play video games and watch wrestling. I have a lot of WWE action figures. I like to play with my brother and sister. I also like building shelters in the woods and having camp-fires. One of my favorite things to do is play with my friends.

My absolute favorite thing at Camp Reflections is to use the swing. That's where you swing out over the water then let go and splash down!

I'm excited for everything I will get to do when I go back. I loved Camp Reflections the last time I went and was really sad to not go this year because of the pandemic. It is such a special place because I get to meet kids with facial differences like me and share my experiences with them.

The Foundation for Faces of Children, along with Ms. Priscilla Coffin, are supporting reservations for three campers this summer (August 15-21). See page four for information about applying.

Dear FFC Supporters and Friends...

In early 2020, I joined the Board of the Foundation for Faces of Children at the invitation of co-founder Dr. John Mulliken, my colleague, collaborator, and mentor. As a craniofacial plastic surgeon, caring for children with cleft lip/ palate as well as other congenital and traumatic facial differences is a great privilege and responsibility that extends beyond the hospital setting. Being a part of the FFC community has been a truly heartwarming experience and a wonderful opportunity to help in wholistically supporting children and their families.

This year we acknowledge great challenges but also celebrate great successes. The Covid-19 pandemic brought additional hurdles for families with children needing time-sensitive care and operations when hospitals were strained and capacity was limited.

Facing these challenges, FFC rose to the occasion, and we are happy to announce another successful event due to your continued support and participation in the *first* ever virtual version of our beloved annual Paces for Faces Walk. Although disappointed that we were unable to gather in person, we are thrilled that the Virtual Walk encouraged participation of families joining us from New Hampshire to Florida and even California!

Constraints from the pandemic did not prevent us from examining our mission and introducing programs to fulfill the organization's ongoing efforts to support children with facial differences. Here are two new initiatives we were proud to roll out:

Virtual Parent Support Groups: Being unable to gather in person, we organized our first-ever virtual parent support group. Overwhelming positive feedback has led us to regularly scheduled meetings and opening the events to participation by families farther afield. We look forward to building our on-line community even more in 2021.

FFC Cares Grant: Children with craniofacial anomalies often require many medical appointments and hospitalizations. FFC Cares is a pilot program to defray travel and associated expenses for families seeking care in any of the 11 American Cleft Palate-Craniofacial Association (ACPA) approved care centers in New England (see story on page 3).

I ask you to consider making a donation that will support the new and ongoing efforts of FFC. We remain committed to offering medically-accurate instructional videos and resources, educational programming and sessions on topics of social and emotional development, parent support, scholarship awards, and family gatherings to foster relationships within the FFC community. On the next page, you may read about some of these important initiatives.





You may donate securely at our website: facesofchildren.org/ how-to-help All contributions to the Foundation are tax-deductible.



ANNUAL APPEAL, continued

Each of these programs have a profound impact on the lives of children and their families:

Annual Scholarship Awards: Recognize exceptional young adults in New England who were born with facial differences, for their academic achievements and contributions to their communities. Each year the Foundation grants scholarships honoring four of our founders to assist the recipient students in attending their post-secondary institution of choice.

Retreat Sponsorship: FFC sponsors two New England families at the Children's Craniofacial Association (CCA) Annual Family Retreat and Educational Symposium. Held in a different city each year, the CCA "Cher Retreat" provides individuals affected by a facial difference, their siblings and their parents an opportunity to interact with others who have similar experiences. Families share ideas, problems, and solutions and make life-long friendships.

Camp Reflections Sponsorship: Located in New Hampshire, Camp Reflections is open to children with facial differences aged 8-16 and their siblings. FFC grants multiple scholarships annually to participants in this unique week-long summer camp (see story on page 1).

Social events: FFC provides a variety of opportunities for individuals with craniofacial conditions and their families to meet and connect with other families. These programs include sports events, art workshops, bowling, the Making Faces workshop, movie screenings and FFC's annual Paces for Faces walk. Our activities are virtual now, but once it is safe, we look forward to resuming in-person programming.

Educational seminars and workshops: FFC provides educational/informational seminars for families on different topics including speech and language, dental treatment/timing, insurance obstacles, and psychological support and coping skills for children with facial differences.

We need your support to touch even *more* lives in the coming year – your donation is important, no matter how small or large. Donations are tax-deductible, and the Foundation will send a gift acknowledgement.

On behalf of the Foundation and the children and families we serve, thank you for your generosity.

Warmest wishes for a healthy, happy 2021.

Ingrid Ganske, M.D. Board Member, Foundation for Faces of Children Craniofacial Plastic Surgeon, Boston Children's Hospital Assistant Professor, Harvard Medical School







Upcoming Programs

Please visit our webpage regularly or follow us on social media for updates!

Virtual Parents Support Group	April 8, 2021 at 7pm (Also, in June, August October & December)	FFC plans to host virtual parent support groups every other month in 2021. Please visit our <u>webpage</u> for updates.
Virtual Piano Tutoring	April to May	Our own Eric Zhang is offering free piano tutoring.
Virtual Scholarship Awards	June 2021	Celebrate with us as we recognize the 2021 FFC scholarship award recipients.
Camp Reflections Sponsorship	August 15 – 21	Apply at <u>Harbor Camps</u> (see page 4 for details).
Paces For Faces 2021	September 19, 2021	Save the date! Registration info will be coming in June.

Meet Mary Lou Sauro, RN, BSN, FFC's New Board Member!



Growing up with a passion for riding and working with horses, Mary Lou Sauro began her adult life as a veterinary technician at a small animal practice in her native Canada. But even as a vet tech, an experience from her childhood made her realize that pediatric nursing was her true calling. In 1993, despite still carrying the fearful memories of her experience as a young child admitted to an adult

hospital, she gained enough confidence to attend nursing school at Rivier College.

Mary Lou Sauro has been a pediatric nurse (certified in 2009) for her entire 25-year nursing career, working in various roles and institutions. As a new grad, she worked at Emerson Hospital in Concord, Mass. on the adult-pediatric medical surgical floor. During five of the seven years that she worked nights at Emerson, she *also* worked days as a certified school nurse at one of the largest middle schools in Newton, Mass. In 2003, a senior mentor pushed her to investigate opportunities at Boston Children's Hospital.

Mary Lou has worked at BCH for 18 years, spending eight years in the transplant unit and one and a half years on the plastic and urological surgical floor. There, she was first introduced to plastic and urological post-operative patients and learned to care for a wide range of cleft, craniofacial, and reconstructive plastic surgical patients. She discovered a love of working with this patient population and joined the team in the Department of Plastics and Oral Surgery in the spring of 2012. Since then, Mary Lou has been exposed to so much and has had the opportunity to care for so many children and their families.

She truly loves working with children, helping to alleviate their anxieties and fears before any procedure and teaching them how to care for themselves in the long-term. Her goal is, and always has been, to provide support and care to patients and their families to the best of her ability.

Outside of work, Mary Lou loves to be outdoors, including hiking, biking or running with her dog, Cash. Whenever there is snow on the ground, she can be found snowshoeing and watching Cash make snow angels!

Introducing Eric Zhang



Eric is 15 years old and is currently a sophomore at Bedford High School. He was born with a bilateral cleft lip and palate and has had seven surgeries performed on him from the young age of three months old until now.

Eric started playing the piano when he was five years old. He has accomplished much in the field of music, winning prizes in multiple local and international competitions. Last year, he advanced to the quarterfinal round of the Gina Bachauer International Junior and Young Artists piano competition. He is currently a finalist for NPR's "From the Top," as

well as being a recipient of both the Wanda Paik and Nancy Olivia awards from NEPTA. Eric has performed in the Weill Recital

Hall at Carnegie Hall, the DiMenna Center for Classical Music, the Kresge Auditorium at Interlochen, the Museo del Violino in Cremona, and Auer Hall at the Jacobs School of Music. Eric is thankful and feels very fortunate to have participated in masterclasses with various distinguished professional pianists.

Music is a big part of Eric's life. He says, "Whenever I play the piano, I feel nourished and refreshed. Interest in classical music is dwindling in the modern world, so I want to use my talent and passion to give everyone the opportunity to explore it. I want to use music to give back to the FFC community and our incredible medical team. Thanks to their efforts, I was able to grow up normally and pursue my dreams as a pianist."

Free Piano Tutoring with Eric Zhang



Weekly piano tutoring lessons will begin mid-April 2021 and run for four weeks. Scheduled directly with Eric. He has availability for two students ONLY, age 12 or older. Each private lesson will be 30 to 45 minutes long. Students

must have access to a piano or keyboard. Registration is first come first served.

»Please register here «

For more information, visit our website

Coming to a Craniofacial Center Near You: The FFC Cares Grant!

We are excited to announce that we have been working to expand our services to the craniofacial community through a new outreach program. Over the upcoming months, the FFC will be working with the 11 New England-based craniofacial centers to share details of the roll out of the **Foundation for Faces of Children Cares Grant.** Each craniofacial center can utilize grant funds to help their patients and their families. The FFC Cares Grant is intended to help offset a small amount of the cost burden for families who are receiving medical care. Whether it be assistance with gas for long distance travel, a meal voucher, parking assistance, or a contribution toward a local hotel stay while receiving care, FFC recognizes the lengths our families will go to receive care for their child. Costs add up, and we want to help. **Watch for details to come as the program rolls out**.

Meet FFC's New Part-Time Social Media Manager



Foundation for Faces of Children welcomes Mackenzie Gingrow as the new part-time social media manager. Mackenzie and her husband Larry are residents of Hingham, Mass. She is the mother to two-year-old twin sons Tommy and Teddy. Mackenzie's son Tommy was born with a cleft palate, which

Social Media Manager Mackenzie Gringrow with husband Larry and twin sons Tommy and Teddy.

was repaired by Dr. Mulliken and the team at Boston Children's Hospital when Tommy was nine months old.

Mackenzie earned her undergraduate degree at Denison University and has a Masters in Education from Boston University. Most recently, Mackenzie taught in Natick, Massachusetts; she is taking a hiatus from her career as a language arts teacher to raise her sons. Mackenzie is an accomplished cook, developing yogi, and avid reader.

The Gingrows have supported the Foundation for Faces of Children since their son was born, and this past year they participated in their first Paces of Faces Walk. They are particularly grateful for the support FFC provided while they learned to navigate the challenges of feeding an infant with a cleft palate. Mackenzie's goals for FFC include developing a vibrant social media presence that supports the mission of the foundation, to curate original content for FFC social media accounts, and to promote foundation programming.



FFC to Sponsor Camp Reflections Campers in 2021!



Together with Priscilla Coffin, a former long-time FFC Board member, we will be sponsoring attendance at Camp Reflections this August (see story on page one). A week-long camp for children with facial differences and their siblings (ages 8–16), Camp Reflections was founded to foster connections and friendship among children in our community. The camp takes place on a beautiful 116-acre lakefront property in New Hampshire. Each day, campers eat all their meals together and participate in fun activities (swimming, boating, sports, arts and crafts, music, drama, and a rock-climbing wall). Each night, the group comes together for an all-camp evening activity (camp songs, s'mores, movie night, star gazing, and a talent show). The 2021 camp will take place from Sunday, August 15 to Saturday, August 21.

A limited number of sponsorships are available so apply soon at <u>harborcamps.org/camp-reflections</u>. On your Camper's Application, be sure to mention that you heard of this camp from FFC. We hope to see you there! *Many thanks to Prilla for her generous support of this initiative*.



FOUNDATION FOR Faces of Children

258 Harvard Street, #367 Brookline, MA 02446 617-355-8299 info@facesofchildren.org

www.facesofchildren.org



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.
- We achieve this by:
- · Collaborating with leading specialists.
- Endorsing the team approach to care.
- Partnering with individuals and organizations with similar goals.
- Advocate for the best care possible for children with facial differences.
- 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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