Newsletter of the Foundation for Faces of Children Fall 2021 Vol. 32, No. 3

FFC 2022 Scholarship Program

Starting January 2022, FFC will be accepting applications for our 2022 Scholarship Awards. Visit our website for details. Since its inception in 1999, the FFC scholarship awards program has distributed 81 scholarships totaling \$219,000. The program awards post-secondary 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, 2022.

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



Paces //

The 25th Anniversary Paces for Faces Walk proved to be a huge success despite being the second year we were unable to

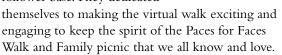
gather together in Wakefield. Although not an easy decision, FFC held its second Virtual Walk Along on the weekend of September 18–19. It was full of community engagement, fun, and family — with participants from coast to coast!

Leading up to the walk, FFC's Paces for Faces was featured on WCVB's *5 for Good* segment with Erika Tarantal. Erika also recorded a special kick-off message which was shared through the FFC's social media outlets over the walk weekend. FFC is grateful for this very special PSA and support from our local network.

This year's virtual walk was among the FFC's most successful fundraising events, which speaks to the commitment and dedication of our community. A total of 33 teams totaling 139 participants registered and brought in 587 individual donations. Team Sonny's Smile led the top of the leaderboard with over \$12K in donations! Fundraising efforts raised over \$50K, and donations continue to be accepted until October 31st.

This is the 10th year that FFC has recognized those individuals who have raised \$750. We had a record number this year! 20 teams earned Smile Strider status and our deep gratitude goes to each of this year's Smile Striders (featured on page three). An extra special shout out to the 2021 Walk Committee: Olivia Oppel, Meera Oliva, Clarissa Kwan, Monica Trivedi, Monir Sakha, Kara Jackman, Tara Greiner, Liz O'Keefe, Ann Marie Rogers and

Ursula Costigan. This team was responsible for the behindthe-scenes planning, managing the OneCause Platform, tracking registration, soliciting corporate sponsorships, creating social media content and increasing our follower base. They dedicated



We also want to thank our platinum-level corporate sponsor, Roche Brothers. We greatly appreciate their continued support.





If you are interested in serving on next year's walk committee or volunteering to help the day of the walk, let us know. You can email us at walk@facesofchildren.org or call us at 617-355-8299.

We look forward to seeing everyone in person next year for our 26th annual Paces for Faces Walk and Family Picnic!

FFC wishes everyone a safe and healthy end to 2021, and a hopeful and bright 2022!



Dear Friends and Supporters,

As the Foundation for Faces of Children approaches the end of 2021, we continue to navigate an everchanging environment. In a world that is not always gathering in person, we have been monitoring elements of our programming and delivering on our mission.

We learned last year that holding our annual Paces for Faces Walk as a virtual event was very effective. So we decided to utilize our social media platforms once again to host this year's 25th anniversary walk.

We also concluded that several of our programs could be well delivered through online video meetings. Our next Virtual Parent Support program will be held on November 11, 2021. Please remain connected with the FFC through our website, Facebook, Instagram and other social media sources so you don't miss any of the upcoming programs.

As always, we are relentlessly focused on our mission to provide patients and families with the most accurate, up-to-date, and accessible information about facial differences and to advocate for the best care possible. However, that mission is made possible only through the generous contributions from our friends and families and so more than ever we appreciate each of you who participated in our virtual walk or contributed to our fundraising efforts during this year.

We wish you each a wonderful holiday season and here's to turning the calendar to 2022!

Kind regards,

Mapal C. Ssim Michael Greiner, FFC President



In Your Own Words

An Update: Fall — a Season of Transition

by Teagan Dymek (2021 Dorothy MacDonald Scholarship Recipient)

As fall approaches, the colors of leaves change and summer visitors leave Cape Cod, my home. I too am entering a season of transitions. I've left behind family, friends and Cape Cod Youth Rowing for Sacred Heart University (SHU) where I've joined the Division 1 rowing team

with new coaches and teammates. Moving into this new phase of my life, as exciting as it is, has also been a bit stressful. I'm being pushed out of my comfort zone as I work to become more responsible for things such as laundry, and management of time and money.

Tropical Storm Henri postponed SHU move-in day so we had very little time to set up my dorm room. But once finished and following tearful good-byes to my family and boyfriend, other students began stopping by and I was able to begin to make new friends.

I have changed my major to Neuroscience which involved making appointments and interacting with professors on my own without any help from my parents. The staff at the Office of Accessibility have been helpful in setting me up with their scribe service. They have also helped me contact my professors to see that my accommodations for my hearing loss and auditory processing disorder are in place. I have had to change my class schedule several times to accommodate rowing practices, weight-lifting sessions and required study halls.

After more than a year of both fully-remote and hybrid classes, I welcomed the transition to full time in-class courses but it has been quite

a change to be sitting in the same room with my professors after hiding behind a computer for so long. The face-to-face interactions which can sometimes make me uncomfortable are becoming easier, plus we are all still wearing masks. Thankfully, the professors wear clear masks for me, so I can read their lips.

A very sad transition is that of not having the support of my grandmother, who passed away very suddenly on August 25. She, her mother and her grandmother were women ahead of their time. My mother and her siblings joke that "Nanna could have beaten every Jeopardy champion!" She instilled in all of her children and grandchildren her love of the sciences, music, art and travel. The matriarch of our family, we referred to her as "our Queen." One of my aunts said, "she was our Sun, our North Star, and her children and grandchildren were her satellites held tightly in her orbit by her incredible spirit and energy." I miss being able to FaceTime almost daily to tell her all about school and rowing. I know she would have been so excited to learn that the study abroad program at SHU goes to County Kerry, Ireland, where her family was from.

The wonderful FFC scholarship I received is certainly being put to good use. I have already used it to purchase books for several classes. I am hoping to step out of my comfort zone to study in Ireland next fall and the scholarship I received will help with some of those expenses. I will be forever grateful to my FCC and Boston Children's Hospital family for all they have done for me.

At times, I have often lacked confidence and self-esteem, in part, due to having to wear hearing aids. Looking back, I am happy that I applied for the scholarship not simply because of the money it provided me for school, but also because of the feeling of pride I experienced upon learning that I had been awarded the Dorothy MacDonald Scholarship. I have proven wrong those who believed my auditory processing disorder would hinder my ability to excel in academics. But more importantly, I have proven to myself that I am capable of being successful. My season of transitions continues to evolve. I feel that despite the stress I sometimes feel, I am able to confidently accept and face new challenges. I am not sure I am totally ready for "adulting," but I am inching forward with this new phase in my life. I *have* mastered laundry ... perhaps cooking will be next!

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Foundation for Faces of Children 2022 Scholarship Awards



Jane C. McDaid Memorial Scholarship



Barbara Seltzer Memorial Scholarship



Dorothy MacDonald Scholarship



Dr. John B. Mulliken Scholarship

These awards recognize promising students born with a facial difference and residing in New England. Award recipients are selected based on academic performance, extracurricular activities and community service.

These scholarships are named to honor extraordinary people who have made their mark not only within FFC, but throughout the craniofacial community.

Application deadline: March 1, 2022



Teagan's dad comforts her following her cleft repair surgery.

2012 London Olympics at the Aquatic Venue.



UPDATE: FFC Continues to supports the MacLaine Appliance



Last Fall, we ran an article on Dr. MacLaine's efforts to develop a new Pre-surgical Orthopedic device for cleft infants. These appliances reduce the tension on the lip, which improves the initial lip repair by the Plastic Surgeon. Both the Latham Appliance and the NAM technique — the two current

most-used methods — have limitations. His goal was to create a device which would not 'collapse' the cleft gum segments but would position them according to a more ideal anatomy. The first concept came to him in 2014 during his Fellowship in Craniofacial Orthodontics, and in subsequent years, Dr. MacLaine made efforts to realize these concepts into real-life products.

In 2017, the FFC gave Dr. MacLaine a grant to further develop the device. By then, he had self-taught 3D design software, and, thanks to the ever-decreasing cost of technology, Dr. MacLaine was able to experiment with various desktop manufacturing techniques, primarily 3D printing, injection molding, CNC milling, and Arc welding. After many design evolutions, in late 2020, a device emerged with the right combination of function, size and robustness.

Since then, Dr. MacLaine has used the new device on several infants, all of whom have had excellent results. It works

by first advancing the smaller of the two jaw segments, then rotating the segments towards each other. These photos show the progress in a typical case:



Dr. MacLaine has many ideas for further innovations. He next plans to develop a new retention system for the device. Currently, the device is held onto the gums by the traditional Latham pins which are very tricky to fit, owing to their design. For this reason, a general anesthetic is required for its insertion. Dr. MacLaine plans a simple pop-in-pop-out pin system, which, he hopes, will enable the device to be inserted without the need for a general anesthetic. He also has a new device for Bilateral infants in the works, along with a one-screw version of the Unilateral device. Dr. MacLaine says, "This progress has only been possible thanks to the financial support given by the FFC. Current and future generations of cleft children will hopefully benefit from the advances we are making."



Mark Your Calendars! Virtual Parent Support Meeting Thursday, November 11, 2021 | 7 – 8:30pm

FFC's monthly Virtual Parent Support Group will be held on November 11th, from 7 to 8:30 pm. Parents will lead the group, hear from each other, share their experiences, bring their questions to other parents and professionals. The group will include parents of children of all ages with craniofacial and Cleft Lip/Palate conditions from newborn to adulthood. There will be age-based subgroups for more in-depth discussions. Please see our website at facesofchildren.org and follow us on Facebook and Instagram for additional information. Register by November 9th.

Hope to see you soon! **NOTE:** Zoom sessions and discussions are confidential and won't be shared with any organization or third party.



FOUNDATION FOR Faces of Children

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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.

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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