Newsletter of the Foundation for Faces of Children

> Fall 2020 Vol. 31, No. 3

FFC 2021 Scholarship Program

ATTENTION College Students and High School Seniors: Starting January 2021, FFC will be accepting applications for our 2021 Scholarship Awards. Visit our website for details. Since its inception in 1999. the FFC scholarship awards program has distributed 75 scholarships totaling \$189,000. 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, 2021.

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

FACING THE TUTURE



The Paces for Faces Walk-Along was a huge success! We were unable to gather on the green in Wakefield this

year, but the weekend was still full of community engagement, fun, and family. Participants across the nation – from New Hampshire, to Florida, to California – completed the walk during the weekend of September 26–27.

This year's virtual walk was one of FFC's most successful fundraising events which speaks to the commitment and dedication of our community. In all, 32 teams consisting of 174 registered participants brought in 474 individual donations totaling \$43,122. Plus, additional donations are being accepted until October 31.

This is the ninth year that FFC has recognized **Smile Striders**, those individuals who raised \$750 or more. This year, a record number earned this elite status! Our deep gratitude goes to our 17 Smile Striders:

Owen Gingrow Meera Oliva Tara Greiner Ellen Caille Paul Silverman Connor Silverman Lucille Ward Julia McGillivray Dhruy Trivedi Cameron Bergeron Kathy Gambino Eric Zhang Ursula H Costigan Deb Breen Kara Gray Monica Trivedi PK Nelson

Olivia Oppel, Walk Chair, was interviewed about FFC's virtual walk by Jordan Rich from WBZ-AM 1030 radio and the piece was aired on WBZ New

England Weekend program! The FFC is grateful for this special PSA and support from our local network.

Fifteen year old Eric Zhang, gifted pianist and member of the Walk's Team Zhang Gang, performed three pieces to fundraise for FFC. He wanted to use his talent to support FFC and bring joy to our community. Eric's videos are on our YouTube channel.

An extra special shout out to the 2020 Walk Committee who were responsible for the behind the scenes planning! From managing the OneCause Platform and tracking registration, soliciting corporate sponsorships, creating social media content and increasing our follower base, this team was dedicated to making the virtual walk exciting and engaging, in keeping with the spirit of the Paces for Faces Walk and Family picnic we all know and love. The committee included Olivia Oppel (Walk Chair), Meera Oliva, Clarissa Kwan, Monica Trivedi, Monir Sakha, Kara Jackman, Tara Greiner, Liz O'Keefe, Ann Marie Rogers, Helen Ng and Ursula Costigan.

We are especially grateful to our corporate sponsors:

Platinum Sponsor





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 617-355-8299.

(continued on page 3)



Dear Friends and Supporters,

By any assessment, 2020 has been one for the record books! As the end of the year approaches, FFC is working to ensure that we fulfill our mission during a time of uncertainty, less face to face interaction and heightened stress.

First, we determined that a virtual "Paces for Faces" annual walk could be very effective by utilizing social media to expand our reach. We also concluded that several of our programs could be delivered through

chat and video so we will be launching our first virtual program on November 9 (see page four). Please remain connected with the FFC through our website and social media.

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 only made possible through the generous contributions from our friends and families. We recognize that 2020 has been a difficult year for many and so more than ever appreciate each of you who participated in our virtual walk or contributed to our fundraising efforts.

We wish our entire FFC family a wonderful holiday season and the joy of turning the calendar to 2021!! Kind regards,

Michael Greiner, FFC President

In Your Own Words



What a Foundation for Faces of Children Scholarship Means to Me

by Bridget Burke (2013 Jane C. McDaid Scholarship Recipient)

In such an unprecedented year, it's a relief that fall continues to be fall. Even this year, in the midst of a global pandemic, kids log onto their first day of (Zoom) school, families pick apples with masks on, and Starbucks rolls out their pumpkin cold brew coffee. It's the most reliable season — and reliably, every fall, I reflect on the role the Foundation for Faces of Children has played in the woman I am today.

This fall, I'm turning 25 years old and wrapping up my first year as a pediatric registered nurse. I'm celebrating a birthday, but also celebrating my 25th anniversary of showing up to this world with cleft lip and palate. People spend their whole lives trying to find their "purpose," the thing they're most passionate about, the driving force that motivates them every day. I'm lucky — I was born with mine on my face. Growing up with a "birth defect" allowed me to recognize, accept and embrace what makes me different; in turn, this has enabled me to live everyday with compassion and fairness.

Of course, I didn't have this wisdom my whole life. As a kid, when peers would ask about my lip, my responses were simple and matter of fact: "I was born like this!" Their reactions, as innocent as they were, stung: "Oh, that's weird." I became acutely aware of how others viewed me, and I internalized it — before I could even articulate what was happening. As I gained confidence getting older, insecurity lingered in the back of my mind.

During my senior year of high school, I applied for a Foundation for Faces of Children scholarship. In my essay, I wrote about my cleft lip and palate, and how ironic it is that the "incompleteness" of my physical face actually completed my purpose. To be honest, I'm not sure if I believed what I was writing at the time. Something compelled me to write it, and for the first time, I had the opportunity to own my "defect" for what it was — an asset. That spring of 2013, I was awarded a scholarship. I was proud of myself for owning the narrative around my craniofacial difference, and thankful for the opportunity to do so.



Bridget, 25 years ago.



Bridget with her proud parents.

What I didn't know then was how pivotal earning this scholarship would be. I've come to realize that this distinction meant more than financial assistance. Receiving a scholarship from the Foundation for Faces of Children was a whole community looking me in the eye and telling me that it's worth investing in my confidence and self-esteem, supporting my commitment to furthering my education, and enabling me to develop into a compassionate registered nurse.

After 25 years, with a handful of surgeries, support from FFC, strength from two incredible parents and six very brilliant younger siblings, a couple of college degrees and a job as a pediatric registered nurse — I'm able to give the most valuable gift of making kids like me feel empowered and confident in themselves. Since receiving a scholarship, I graduated from UMass Amherst and completed my second bachelor's degree at MGH Institute of Health Professions less than two years later. After I passed my registered nurse exam, I began my career in pediatric nursing at Franciscan Children's Hospital — right down the street from where my journey all began 25 years ago.

This fall is special, to say the least. As I take off my mask after a long day of caring for a special pediatric population, and look into the mirror, I certainly don't see a "birth defect." I see the story of a young woman who consistently takes people for more than their "face value," someone who rolls with the twists and turns and someone who could not be happier to share the vulnerable moments that contributed to where she is now.

Foundation for Faces of Children 2021 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.

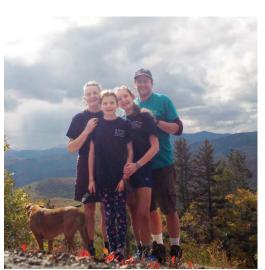
Application deadline: March 1, 2021

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We look forward to seeing everyone in person next year for our 25th annual Paces for Faces Walk and Family Picnic. Wishing everyone a safe and healthy end to 2020, and a hopeful and bright 2021.

The following Walk teams posted amazing team photos and tagged @ foundationforfacesofchildren which were re-posted by FFC: Team Dhruv, Team Kara, Team Emma, Miss Springfield Illinois, Team Zhang Gang, Team Owen, Team Zoe, Team Cat, Team Ganske, Team Smiles for Maya, Team Wyatt, Team Breen, Team Elan, Team Matthew, Team Amy, Team Oppel Family, Team Diba, Team Captain Connors Silver Squad, Team Daniel and team Huettig Hikers!





















FFC supports the MacLaine Appliance



During his Fellowship in Craniofacial Orthodontics in 2014, Dr. James MacLaine had the idea for a new device to improve on existing appliances for pre-surgical orthopedics. The purpose of this appliance is to reposition the gum segments of cleft infants. These appliances reduce the tension on the lip, which improves the initial lip

repair by the Plastic Surgeon. Each of the two most frequently used methods, the Latham Appliance and the NAM technique, have inherent limitations. His goal was to create a device which would not 'collapse' the cleft gum segments but would position them according to more ideal anatomy. Dr. Shusterman, then still working, was very encouraging and supportive of the concept.

At that stage, Dr. MacLaine had some basic design skills but not enough to develop a prototype himself. With funds from a Boston Children's Hospital grant, he engaged an outside company to develop a prototype. Unfortunately, they used most of the money but delivered a non-functioning prototype. Lesson Learned!

In 2017, the FFC gave Dr. MacLaine an additional grant to

further develop the device. The most important thing about this grant was that the money could be used to buy equipment which he could then use himself to make prototypes.

By now he had mastered 3D CAD 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 (~30) design evolutions, he has apparently found the right combination of function, size and robustness.

In the future, this appliance will hopefully be available to our families, after clinical trials to measure its performance. Dr. MacLaine reflects, "None of this progress would have been



possible without the grant money from the FFC and I am very grateful for their assistance. It is my hope that future generations of cleft children – either directly or indirectly – will benefit from this investment. Hopefully very soon!"

Prototype MacLaine Appliance

NEW Virtual Parent Support Meeting

Monday, November 9, 2020 | 7 - 8:30pm

Foundation for Faces of Children has been thinking of families during this long COVID-19 pandemic. We are excited to have our first "Virtual Parent to Parent Support Group" on November 9th from 7-8:30 pm. Parents who have children with a craniofacial difference will share their insights and experiences which will be followed by sub-group breakouts that will include Boston Children's hospital

professionals, Dr. Ingrid Ganske, Nurse Olivia Oppel, and retired nurse Dorothy

MacDonald to answer medical and care questions. The group will include parents of all ages of children with craniofacial and Cleft Lip/Palate conditions from newborn to 18 years old. There will be age-based subgroups for more in-depth discussions. Please RSVP by October 30th at https://forms.gle/wRPFLYUzMc7urXM29. **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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www.facesofchildren.org

Connect with FFC Onlin









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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