Newsletter of the Foundation for Faces of Children

> Fall 2018 Vol. 29, No. 3

Apply for a 2019 FFC Scholarship!

Since its inception in 1999, the FFC scholarship awards program has distributed 66 scholarships totaling \$144,000. The program awards post-secondary education scholarships of \$5,000 each (for college or vocational/technical school) to promising students born with a facial difference. High school graduates or students currently attending college who are residents of New England (Connecticut, Maine, Massachusetts, New Hampshire, Rhode Island, and Vermont) are eligible to apply. The Foundation selects award recipients based on their academic performance, extracurricular activities, and community service.

All are welcome to attend our Annual Scholarship Awards presentation in June when we celebrate the accomplishments of the recipients. FFC is honored and proud to be able to play a small role in helping their dreams to come true as they move through their college experiences. Many of our scholarship recipients return to FFC as volunteers — helping at events, offering support to younger generations and establishing themselves as mentors and role models.

Deadline for applications is March 1, 2019. For information or to download an application, visit www.facesofchildren.org and select "Scholarship Information" under the "For

Or email
Mary Lania,
Scholarship
Committee Chair at
programs@facesofchildren.org

Patients and Families" tab.

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It was a beautiful fall day for the 22nd annual Paces for Faces Walk and Family Picnic! More than 400 participants attended, most completing the 3.5 mile walk around Lake Quannapowitt in Wakefield.

More Walk

Photos!

Over \$63,000 was raised by the event, primarily by the walkers who performed the hard work of soliciting donations. The balance came from those who participated in the raffle and purchased FFC merchandise on the day of the walk. These funds will be used to further FFC's educational outreach through free publications, videos, informational programs, the Foundation's website and the annual student scholarship awards.

At check-in, FFC families greeted friends from past years, mingled and enjoyed coffee, cocoa

At check-in, FFC families greeted friends from past years, mingled and enjoyed coffee, cocoa and donuts provided by Erik Lania and Dunkin Donuts.

Children were entertained with face painting, temporary tattoos, and balloon creations. Our red-carpet "photo booth" for team photos was a hit again this year.

As walkers finished the route, they were greeted at the tent by some lively strolling entertainment including juggling, hula hooping, stilt-walking and more balloon creations. A delicious lunch was provided in part by Roche Bros, and a beautiful cake by D'Amici's Bakery.

For the seventh year, FFC recognized "Smile Striders," those individuals who raised \$750 online by September 14. They were set apart in bright yellow t-shirts to feature their successful fund-raising work. Our deep gratitude goes to each

of this year's Smile Striders: Peter Barden, Bridget Burke, Lacey Clericuzio, Norah Costigan, Jackie Dolan, Eliana Dormitzer, Maya Gray, Kate Greiner, Niko Joakim, Nicole Kowalsick, Emma Malayandy, Abby McGillivray, Corinne Miller, Milton Rogers, Dr. Stephen Shusterman, Gabriel Therrien, Dhruv Trivedi, Paul Ward and Michael Yorba.

To our dedicated walk committee, and to those of you who worked on tent set up, registration, food, raffle, merchandise, and children's activities, we extend our deepest thanks! This year's hard-working walk committee was lead by chairperson Olivia Oppel, and included

FFC Vice-President Ann-Marie Rogers, Monir Sakha, Liz O'Keefe, Jennifer Dodwell, Kara Jackman, Claire Barden, Ursula Costigan, Tara Greiner and Helen Ng – with generous support from many others! Thank you to the FFC Board of Directors and the 27 additional volunteers who donated their time to ensure the walk's success. Many thanks to the individuals, families and businesses who donated prizes for this year's raffle, which raised over \$1,600. And finally, a special thank you to Roche Brothers, Dunkin' Donuts and D'Amici's Bakery for their donations again this year.

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're looking forward to seeing you all next year!





Our thanks to Paces for Faces Walk & Family Picnic chairperson, Olivia Oppel, pictured here with husband Ryan and daughter, Avery.

2018 Smile Striders



We are deeply grateful to the 2018 Smile Striders, some of whom are shown above: Peter Barden, Bridget Burke, Lacey Clericuzio, Norah Costigan, Jackie Dolan, Eliana Dormitzer, Maya Gray, Kate Greiner, Niko Joakim, Nicole Kowalsick, Emma Malayandy, Abby McGillivray, Corinne

Miller, Milton Rogers, Dr. Stephen Shusterman, Gabriel Therrien, Dhruv Trivedi, Paul Ward and Michael Yorba.









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Empowerment Programs with Danielle Craig



Danielle Craig has taught six Women's Studies courses over the last six years as an Adjunct Professor at Ramapo College, William Peterson University and Fairleigh Dickinson University. Her work seeks social justice, equality, and empowerment for all groups of people who have been considered inferior socially, psychologically, physically or spiritually. Championing

social causes and having a childhood dream of teaching came full circle when she became an adjunct professor of Women's Studies.

She was inspired to build children's and teens empowerment programs from her college courses. Body image, for example, was something she struggled with as a high-schooler and she did not have an outlet where she could discuss how she felt. She points out that body image, which is strongly connected to self-identity at that age, was unfortunately built on idealized, photo-shopped images of women in magazines, billboards, and movies. Today kids have the added bombardment of social media where girls compete with selfies to meet unrealistic goals in the mass media. These visuals are very powerful and suggestive to growing girls (and boys) ultimately forming some negative self-beliefs about their body.

She thought it would be timely to reach children with positive

messages while they are still developing. And so, *Girl Empowered Body Image*, her first empowerment class was born. Followed shortly thereafter with, *Girl Power: Compassionate Leadership for Girls* to teach girls that they can be leaders and they should lift one another up instead of competing against one another. She also wanted to address gender stereotypes that boys deal with because they are given significantly less attention which she feels is an injustice. Boys need to know that they can and should have positive male role models in their lives that are strong, and sensitive, and empathetic too. To serve boys in the community, she developed *Be Your Own Superhero: A Boys' Empowerment Program*.

All programs integrate guided discussion where they can process their experiences and thoughts with peers, and activities like art projects or acting skits. Her programs serve elementary school students beginning with 2nd graders, middle school, high school, and college students. She is constantly evolving her programs to mirror contemporary issues and trends that arise for youth, and thinking of new ideas that will interest kids and inspire them to learn important life lessons.

We are excited that Danielle will be offering Empowerment sessions to the FFC community in February of 2019. Check the listing by visiting facesofchildren.org and selecting "News + Events" to register your children!

2018 Children's Craniofacial Association Retreat in Salt Lake City

For the second year, FFC was pleased to have sponsored two individuals at the CCA Retreat. The weekend Retreat provides individuals affected by a facial difference with an opportunity to interact with others who have endured similar experiences — to share ideas, problems and solutions and form life-long friendships. We asked Nate and Joyelle to write about their experiences:

NATE: I attended my first CCA Retreat last June. Some participants were newcomers like me and others were long-time attendees. Even a few cast members from the movie Wonder were there! It was like a big, extended family — there were definitely more hugs than handshakes.

Unlike the outside world, there was no gawking or mean comments. At other conferences, I can skip wearing a name tag after the first day because I look different that everyone remembers my name. Not at this retreat! Whether it was their first or tenth time, everyone felt included and welcomed. For example, on the first morning, one of the organizers I had not previously met, recognized me from a photo and introduced herself.

All types of craniofacial differences were represented at the CCA Retreat, including Apert Syndrome, Pfeiffer Syndrome, Crouzon Syndrome and Treacher Collins. Although most participants were young children and their families, a good portion of adults with craniofacial differences also attended. There was far less explaining to do about my differences because people could authentically say they knew what I was experiencing. Genuine smiles, love and compassion prevailed.

Even though there seemed to be a lot of unstructured time in the schedule, I did not feel like I was bored. During the downtime, I found myself engaged in conversations with peers, sharing my experience with younger families, and getting outside of the hotel to explore Salt Lake City. The four days of the retreat seemed to go by in a flash, and I am definitely looking forward to attending the 2019 retreat in Scottsdale, Arizona.

JOYELLE: At the Retreat in Salt Lake City, I learned two important things:

1) Never judge a person by their facial appearance; and 2) Even if someone looks different, they might astound you with their amazing talents.

The Retreat's atmosphere was wondrous. There were activities all day. People enjoyed talking with each other and I shared stories about space camp and my work at Midcoast Humane. At the talent show, I was deeply struck by a performer: Kate, who is hearing impaired, signed to the song "This Is Me" from the Greatest Showman. Her passion, heart and soul were so emotionally powerful that the entire room gave her a standing ovation.

I made many friends, splashed with the girls in the pool, and had my first dance with a boy at the celebratory gala. I also hung out with wrestler champ Ben Kjar, who cheered me on during my last surgery. During the educational symposium, he spoke about being a victor, not a victim. I love telling my friends at home about meeting a special sassy girl; Elle McKinnon who played Charlotte in the movie Wonder!

The Retreat allowed me to meet some very special individuals and to reflect on my own life. When you see someone who has a difference, you might think, "I can't talk to her." But maybe that person has something to say that you've been trying to figure out. Maybe that person has the knowledge you are looking for. You might realize, "Oh, this person has so much to say!"

The Retreat broadened my perspective of what impacts I can make in the world. Be kind. Open the door. Write a thank you. Ask how you can help. Sometimes being different is cool. Being kind over being right and being you is what matters most in the world. I am thankful to the Foundation for sending me to this Retreat!

The Foundation will begin accepting applications in February for the 2019 Retreat in Scottsdale, Arizona.

FFC is grateful to all those who helped make our 22nd Annual Paces for Faces Walk & Family Picnic a tremendous success!



FAMILY PICNIC PROVIDED IN LARGE PART BY



SHEET CAKE PROVIDED BY



Reading, Massachusetts

DONUTS, MUFFINS, COFFEE, AND COCOA PROVIDED BY



Watermark Donut Co. (Erik Lania), South Boston, Mass.



LOGISTICS SUPPORT

Apex Tent Rental, Newton, NH – tent, tables, and chairs

The Throne Depot – portable toilets

Joanne & Jethro Mills Professional Karaoke & Disc Jockey Services (W. Newton) – music and emcee

Stoneham Sports Center -

walk, volunteer, and Smile Strider t-shirts

Diana O'Keefe, Threads & Ink, Braintree – sweatshirts and winter hats

Helen Ng, Bailey Hull -

photography

First Congregational Church of Wakefield

Town of Wakefield Wegmans, Burlington

RAFFLE PRIZES

American Hockey League

Bailey & Sage

Bertucci's Corporation

Boston Celtics

Boston Red Sox

Boston Super Soccer Stars (Charlestown)

Canobie Lake Park

Colley Hill Candles

Darci Dormitzer, K&E Burpies

(Chelmsford)

Discovery Museum

Dunkin Donuts (Braintree)

King's Cares (King's Bowling)

Legal Seafood

Mass Audubon

New England Patriots

Old Town Trolley Tours

Scholastic

Showcase Multiplex

SkyZone

Wilson Farm

XtremeCraze (N. Andover, Woburn, Westborough)

CHILDREN'S ACTIVITIES

Balloons and Strolling Entertainment:
Circus Dynamics (N. Providence, RI)
FFC Red Carpet Photo Booth Photos:
Bailey Hull

VOLUNTEERS

Claire Barden Luke Loeffler
Kristen Beaudouin Emily Macfarlane

Usha Beijnen Anna Mak

Sydney Cerveny Dr. John B. Mulliken

Ursula Costigan Helen Ng Kit Cunningham Jenna O'Brien Tara Greiner Liz O'Keefe Michael Greiner Logan Okeefe Samantha Hall Olivia Oppel Olivia Hull Ryan Oppel Bailey Hull Ray Oppel Matt Hull Debbie Oppel Kara Jackman Alex Oppel Suzanne Kinahan Cory Resnick Clarissa Kwan Ann-Marie Rogers Megan Kwan Robin Ronca

Hubert Kwan Dr. Stephen Shusterman

Monir Sakha

Mary Lania Patrick Sviokla Mark Lania Dave Turecek

Betsy Loeffler Chris Loeffler

Emma Kwan

PLANNING COMMITTEE MEMBERS

Committee Chairperson: Olivia Oppel

Registration and Communications: Claire Barden

Raffle Solicitations: Tara Greiner and

Ursula Costigan

Food/Beverage Coordinator: Monir Sahka

Merchandise: Liz and Logan O'Keefe

Children's Activities: Jennifer Dodwell

and Kara Jackman

Logistics: Ann-Marie Rogers

BCH Welcomes Christopher Hughes, MD, MPH, to the Team!



Dr. Hughes with wife Amy and their daughters.

Christopher Hughes MD, MPH, is this year's incoming Pediatric Craniofacial Fellow at BCH. Born in New Jersey, he attended grammar school and high school at The John Cooper School in The Woodlands, Texas following his family's move to Houston. He graduated magna cum laude from Boston College with a degree in English Literature before becoming interested in population-based and global healthcare delivery and earning Masters of

Public Health from Yale University. Chris went to medical school at Loyola University Chicago, graduating cum laude with Alpha Omega Alpha and Alpha Sigma Nu honors. He completed a general surgery residency at the University of Connecticut.

During his training, Chris spent two years doing global surgical research in Haiti, Rwanda, Liberia, and Ecuador with Dr. John Meara from Boston Children's Hospital and the Program in Global Surgery and Social Change at Harvard Medical School. He completed training in the Harvard Plastic Surgery Program. His clinical interests are focused on pediatric plastic surgery, specifically cleft care and craniosynostosis. He is currently working on research projects evaluating speech outcomes after palatoplasty, defining and categorizing the dynamic facial movements after cleft lip repair, describing the outcomes of patients with a special type of cleft lip, and evaluating outcomes after cranial remodeling in patients with craniosynostosis. Chris is also working on the development of a self-contained, mobile operating unit designed for resourcelimited areas. He lives in Boston with his wife, Amy, a pediatric otolaryngologist at Boston Children's Hospital, and their two daughters, Isla (three years) and Elowen (18 months).

JOIN US FOR THESE FREE PROGRAMS!

Saturday, 9:30am November 17, 2018 to 12pm

2pm to

Saturday, December 8, 2018

2pm to 4pm

Saturday, February 9, 2019 Parent Forum – A parent support meeting for adults only. Embassy Suites in Waltham, Mass.

Paint Party! The Paint Bar in Newton, Massachusetts. The whole family is welcome. Minimum enrollment of 15 participants is needed by November 10.

Empowerment Sessions with Danielle Craig – Programs being offered:

- Empowered Body Image
- Be Your Own Superhero: Boys' Empowerment Program
- · Sheroes Throughout History: Role Models of Female Empowerment.

Different sessions being offered for different age groups. Minimum enrollment of 5 needed by Jan. 15 for each session. Please visit our website to see which session fits your child.

For full details of each event, visit our website and select "News + Events." We hope to see you at one or more of these events!







FOUNDATION FOR Faces of Children

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www.facesofchildren.org

Connect with FFC Online





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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.

Board of Directors

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Joseph (Joe) Carroll, Treasurer
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