

FACING THE FUTURE

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FFC's Virtual Young Adult Hangout. Come Join our Group!

Beginning in 2019, COVID-19 brought social lives to a halt for over two years. As the pandemic stretched on, FFC was stymied in meeting its major goal of connecting families and individuals in our community. A solution came when FFC invited Alexis Jones and Camryn Berry to lead the Virtual Young Adult Hangout (VYAH). The startup group first met in February 2022 and they continue to come together each second Wednesday of the month. Below are a few thoughts from Alexis and Camryn.



Hanging out virtually can lead to real meetups as on the day of the 2022 Paces-for-Faces Walk. Pictured here are Eddie Wang, J.R. Foley, Alexis Jones, and Lacey Clericuzio.

Fortunately, they can now help others with similar issues. Young adults with a craniofacial condition who are 18 years or older and looking to connect with same-aged peers are invited to hang out with the VYAH.

As members, Alexis and Camryn feel more empowered through their craniofacial differences and the community than ever before, connecting with peers who have experienced and understand shared struggles. The VYAH has traversed topics such as coping strategies, advocacy and even dating. Each member has something to contribute, whether it is advice, a confidence boost, or just a good laugh! Every meeting has a new topic. For the April 12th meeting, the group invited Dr. John Mulliken to speak about managing professional lives and healthcare needs as adults. Virtual meetings are on the second Wednesday of each month at 7 pm EST. If you are interested in joining, sign up on the website or go to the FFC social media page to sign up via the link. [📄](#)

Camryn Berry: Going through childhood with a craniofacial difference brings challenges which anyone reading this can likely imagine. What I hadn't anticipated as a kid was that adulthood brings an entirely different set of demands. Long gone are the days of playground bullying, but as it turns out, adulthood has its own amorphous tyrants: navigating health insurance, college, workplace accommodations and disability benefits are a few. Plus, managing friendships and relationships can be extra challenging for a young adult with a craniofacial difference. Foundation for Faces of Children offers a sense of community as we confront these challenges.

Alexis Jones: I always thought the problems I faced from my craniofacial difference as a child would just go away. That was not the case. As a young adult, I am still being asked awkward questions and judged within my career field. I am also frustrated by a lack of experience navigating insurance issues for surgeries or dental procedures.

Camryn and Alexis have learned that their experiences are not unique in the community.



Alexis Jones from Enterprise, Alabama, works as a Speech Language Pathologist Assistant (SLPA) at a private clinic and at schools in Greenville, SC. She connected with FFC through a research project that focused on social media as a platform for cyberbullying of individuals with craniofacial anomalies. Since, she has been actively involved in VYAH and mentoring other peers.



Camryn Berry from Livermore, Maine, is a PhD student at the University of New Hampshire. A former FFC scholarship recipient, she and her family have long been connected to FFC. Her parents also engage with the FFC parent support group.



HOW TO DONATE TO FFC:

Please make donations at facesofchildren.org/how-to-help or by check (payable to Foundation for Faces of Children) sent to:

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

In Your Own Words

One Family's Gratitude for FFC Support

by a parent in the Foundation for Faces of Children community

I am writing to let you know about my experience with the Vascular Anomalies Clinic of Boston Children's Hospital and most recently, my active participation in the Foundation for Faces of Children parent support group led by the beautiful and generous Monir Sakha and supported by Dr. John Mulliken and Dotty McDonald.

I am the parent of a 25-year-old son who was born with an arteriovenous malformation (AVM) on his nose, cheek and lip. While AVMs are most typically found in the brain and can be fatal if not treated promptly, my son's AVM is on his face. He has undergone over 20 invasive and risky procedures to control — not cure— his malformation and two extensive surgical procedures that were not without incident. He is scheduled for further treatment and surgery with clinicians in interventional radiology and plastic surgery at Boston Children's Hospital later this month.

After a misdiagnosis at birth and beyond, and many ineffective laser treatments, we interviewed endovascular surgeons, interventional radiologists and plastic surgeons at Beth Israel Medical Center in NYC, CHOP in Philadelphia and Boston Children's Hospital. Ultimately we chose to have him treated in NY as we live in NJ, but we maintained close communication with Dr. John Mulliken. He has been a resource, sounding board, wealth of clinical and practical knowledge, and friend. He recommend that our son have his blood drawn at the age of two to be analyzed by clinicians in Belgium who were looking for genetic mutations that might at some point respond to medical therapies in treating AVMs. He also became a consistent resource in discussing our son's treatment options, surgical interventions, and the emotional ups and downs we all experienced as we navigated a terrain that included fear, unpredictability and unknowns.

Much of what I learned about AVMs resulted from my own research and asking a lot of questions. In 2002, I began writing about my son's experience. I submitted articles to local, regional and national publications and medical advocacy newsletters including myFace, AboutFace, Children's Craniofacial Association, Let's Face It (US and UK,) ForwardFace, F.A.C.E.S. and FFC. I befriended the directors of these organizations and learned from their knowledge, understanding and expertise. I also wrote a short book for clinicians and parents of children with craniofacial anomalies called *Funny Face* and spoke on a NORD panel in Minneapolis about rare vascular anomalies. I have supported many parents of children with AVMs and advocated for our son in every possible way I've known how.

Since his childhood, high school and college experience, and through his current professional life and work on the West Coast, we are constantly seeking and considering the newest treatments for controlling his AVM.

Throughout the last 25 years, my husband and I have experienced a roller coaster of emotions in supporting our son. Nothing has paid off more in helping me to stay sane and anchored than my participation in the monthly Tuesday evening FFC online support group.

Talking candidly with other parents who have experienced what I have, regardless of our child's specific condition, has been without parallel. There is no one who can possibly understand what I feel and think, identify with the anguish I experience or know the pain of not having control over your child's experience than the moms and dads that commit to participating fully, listening without judgment, caring with genuine understanding and offering support from the heart.

On behalf of my husband, my son, and myself, I want to thank you for so freely offering this wonderful online service to me and the men and women who regularly (or intermittently) join the FFC group. I want to thank Monir Sakha for making time in her very full schedule to facilitate meaningful discussion amongst the members of our group. She is a guiding light, a patient listener, a humble moderator, and a selfless angel. I want to thank Dr. Mulliken and Dotty and the other health care professionals who throughout the years have offered their time and expertise to our group.

But mostly, I want to thank the women I've befriended in the past two years—the moms who wear my shoes and keep me grounded and understand like no one else can or ever will. And who, because I live in NJ, I'd never have met if it weren't for the opportunity to connect on your FFC Zoom account once a month for what's become an essential and therapeutic two hours of sharing. ■

“Our patients have been very grateful in receiving these gifts. A little goes a long way and most have used these gifts to meet basic needs, like transportation or gas.”



“The families have noted much thanks for this support and are very appreciative.”

“Thank you so much for your generosity!”

“We also had parents who bought the “CozeeCoo” garment which their child wore after surgery to protect the cleft lip and palate sites without being as restrictive as welcome sleeves or elbow restraints. The child and parents were both happy.”

The FFC Cares Grant After One Year

FFC Cares Grant has been going strong since it launched a year ago. The grant consists of donations that each New England Craniofacial Center may utilize to help their patients and families. It 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 to local hotel stay while receiving care, the FFC recognizes all of the lengths our families will go to receive care for their child. These costs add up, and we want to help. In addition to the testimonials above, the centers also sent the following comments:

- “Patients were very pleased to receive the funds. Patients often don’t have to pay for parking with medical providers in Rhode Island so don’t have cash with them. We were able to purchase \$2 parking vouchers with the cash to distribute to the patients attending the Cleft and Craniofacial outpatient visits.”
- “We do not have any easy options for food within walking distance. Families can have a tray brought to the room while bedside with their child, but if they want to leave the inpatient unit for food, options are limited and expensive. Many parents said how happy they were to get a hot cup of coffee or tea after a long night!”
- “We have patients that need frequent transportation back and forth for appointment to have adjustments for their nasoskeletal device or for cleft feeding support. Parents were thankful for the funds to pay for gas to enable them to keep the appointments.”

Upcoming Programs

Please visit facesofchildren.org regularly or follow us on social media (Instagram and Facebook) for updates!

Virtual Parents Support Group (via Zoom)	Tuesday, June 13 at 7pm EST	FFC will continue to host the virtual parent support groups the 2nd Tuesday of every month during 2023
Virtual Young Adult Hangout (via Zoom)	Wednesday, June 14 at 7pm EST	Join FFC for the VYAH the 2nd Wednesday of each month throughout the year.
Camp Reflections Sponsorship	August 13 - 19, 2023	Apply at Harbor Camps (see page four)
Sponsorship to Cher Retreat	June 22-25, 2023	FFC is sponsoring one family this year to attend the retreat
Virtual Scholarship Awards	June 15, 2023	We are excited to celebrate with and recognize the 2023 scholarship award recipients.
Paces For Faces 2023	September 24, 2023	Virtual or in-person at Lake Quannapowitt in Wakefield!



FFC Welcomes Ursula Costigan to the Board of Directors

FFC is happy to introduce our newest Board member! Ursula grew up in the mid-west, attending Miami University (OH) where she double majored in Political Science/International Studies. She moved to Boston after graduation where she met her husband, Casey. In 2005, she obtained her law degree from Suffolk University.

Ursula and her family have been strong supporters of the FFC since 2010 when they learned their daughter Norah — still in utero — would be born with a unilateral complete cleft lip and palate. FFC was a tremendous resource for information and connections as they navigated procedures for Norah. When Ursula was invited to help plan the Paces for Faces Walk in 2011, she was happy to become more involved and give back to the community. She continued to serve on the Walk Committee for several years before chairing it in 2013 and 2014, enjoying meeting many wonderful parents and families in the process. In fact, Ursula continued to participate in the Walk planning over the past seven years. But as her children have become more active in school, sports and music, she has had to step away from a more involved role with FFC.

Today, she is excited for the opportunity to re-engage as an FFC Board member and to help continue our mission of education and support for families.

Ursula, her husband Casey and their daughters Charlotte (14) and Norah (12) live in Amesbury with their much-loved labradoodle Ollie and 2 kittens, Ginny and Ron. The family enjoys watching and playing basketball, softball, family movie night and traveling. 🐾



Long part of the FFC community, the Costigan family includes Norah, Ursula, Charlotte and Casey.



FFC Sponsors Campers to Camp Reflections 2023!

Together with FFC founding member Priscilla Coffin, we will be sponsoring attendance at Camp Reflections summer camp once again this August. This week-long camp for children with facial differences and their siblings (ages 8-16) was founded to foster connection and friendship among children in our community. On a beautiful 116-acre lakefront property in New Hampshire, campers participate in fun daily activities including swimming, boating, sports, arts and crafts, music, drama, and a rock-climbing wall. Each night, the group gathers for an all-camp evening activity such as camp songs, s'mores, movie night, star gazing, and a talent show. A limited number of sponsorships are available for the camp from August 13 to August 19. If you would like to apply, please visit campreflections.org. On your camper's application, please mention that you heard of this camp from FFC. Applications are due by June 1, 2023. We hope to see you there! *Many thanks to Priscilla for her generous support of this initiative.* 🐾



FOUNDATION FOR Faces of Children

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info@facesofchildren.org
www.facesofchildren.org

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.

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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