The myFace Support System: Along the Journey of Thousands of Children Like Didi Diallo and Samara Bacchus

By Andrea Newman, Senior Director of Development, myFace

myFace, the Informa Market's feature charity in 2022, has been changing faces and transforming lives since 1951. With a special focus on children and their families, myFace provides access to holistic comprehensive care, education, community support and public awareness that pave the way for better outcomes for those impacted by craniofacial conditions.



myFace has been there for the Diallo family for nearly two decades - since their craniofacial journey began. Didi Diallo was born with a craniofacial condition called Crouzon syndrome where her facial bones and skull were prematurely fused. Didi, now 18 years old, has had more than ten surgeries to address everything from the shape of her skull, to her vision, breathing and feeding issues. She and her family consider themselves so fortunate to have had access to the team at the myFace Center for Craniofacial Care at NYU Langone Health, where they received quality comprehensive medical and psychosocial care. As Didi noted, "Being born with a craniofacial condition is not only physically challenging, but mentally and emotionally challenging as well." Didi attributed her confidence and bravery to her friends, family and the myFace Community, all of whom have served as uplifting forces throughout her life, allowing her to "feel beautiful on the inside and out."

"At myFace, I have a whole support system who can understand what I am going through. I am not really around many people with craniofacial conditions, so it is comforting to see that there are people like me who have had very similar experiences – ultimately making me feel less alone."

Having watched Didi blossom into a beautiful, talented and accomplished young woman over these past 18 years is a privilege for us at myFace. As a recent high school graduate, Didi will be off to college at St. John's University in the fall where she plans to major in Marketing. The myFace team is so proud of the young woman Didi has become. We look forward to celebrating her successes and supporting her as her journey continues.



Didi was born with a craniofacial condition called Crouzon syndrome



Like Didi, Samara Bacchus and her family came to myFace when she was just a baby, traveling from their home in Trinidad-Tobago. Samara was the product of an uncomplicated pregnancy, but was born with a giant congenital melanocytic nevus, which covered the entire left cheek from the jawline to lower eyelashes, extending to the right side of her nose-cheek junction and over to the left side of forehead.

Through a charity grant from myFace, the Bacchus family was able to meet with the Pediatric Craniofacial Team at the myFace Craniofacial Care Center at NYU Langone Health, and a multi-staged plan was created by the surgeon, David Staffenberg, MD. The first stage would be the longest, requiring approximately two to three months for completion, and the family would be required to remain in New York City for the entire duration.

In May 2021, through the generosity of myFace, the family relocated to New York City, N.Y. staying in the myFace apartments near the hospital – enabling the family to focus on what was most important: getting care for their daughter without the worry or expense of staying in a hotel.

The first steps included surgery where tissue expanders were placed in the right forehead and left lower cheek. Tissue expanders are similar to flattened water balloons, placed underneath the skin. Over the course of the next couple of months, the water balloons are slowly filled with normal saline, stretching the healthy skin. This same technology has been previously used by Dr. Staffenberg to separate conjoined twins, joined together at the head.

In late August 2021, following weekly expansion of the tissue expanders, Samara was ready for the second stage of this surgery. The tissue expanders were removed, along with as much of the nevus as possible. The newly stretched healthy skin was shifted over to the portions where the nevus was removed. The family stayed for almost two weeks post-surgery to assure proper healing before returning home to their native country.

While a significant portion of the nevus was removed and the largest surgery completed,



Samara with tissue expanders that were placed underneath the skin to help stretch the healthy skin

Samara will require several smaller procedures to complete the excision over the coming months and years.

The completed surgery has made such a significant difference in the life of this family, and to four-year-old Samara, who has been so brave throughout this whole experience. We look forward to continuing to support the Bacchus family and caring for Samara throughout her journey.

myFace is committed to reaching across the country, and even the globe, to connect and serve as many people as possible who are impacted by facial differences.

Thanks to the generous support from Informa Markets and individuals in the medical aesthetic community, we can continue to reach so many – like the Bacchus and Diallo families. Please join our community in supporting these children and their families along their journeys. Your tax-deductible contribution to myFace directly supports services like providing complimentary accommodations to outof-town families seeking treatment, holistic comprehensive care, education, resources and so much more.

To learn more about myFace, please visit myFace.org or contact Andrea Newman at andrea@myface.org.

