

myFace

Changing Faces, Transforming Lives, and Ensuring No One with a Facial Difference Ever Feels Alone

By Katie Bazyluk

Every hour a child is born in the United States with a craniofacial condition, which begins a unique physical and emotional journey for both the child and their family. About 95% of these babies will undergo multiple surgeries and endure long-term medical care throughout their childhood and into their adult lives. Ad-

ditionally, the faces of another 100,000 individuals are altered through accident or disease each year. The goal of myFace, a non-profit organization based in New York City, is to be able to reach and support all of them.

For those who aren't familiar, a craniofacial difference is any anomaly affecting one's facial structure and skull. Facial

differences can affect more than one's physical appearance - they can impede the basic functions essential to survive, such as breathing, hearing and eating. Individuals with a facial difference - and their families - not only have to deal with the physical effects of their condition, but the challenging emotional impact as well, as they are often subjected to bullying and made to feel "less than" or "othered" by stares and rude remarks.

myFace, formerly the National Foundation for Facial Reconstruction (NFFR), was founded in 1951, under the leadership of pioneer Plastic Surgeon Dr. John M. Converse, to address the visible and invisible challenges of living with a facial difference. The organization's mission was to support state-of-the-art treatment for children, conduct innovative research, and provide medical training to inspire future generations of doctors. As the decades progressed, myFace recognized the importance of focusing holistically on the entire journey, encompassing both the physical and emotional, and everything in between. A cornerstone of myFace's work today is also to raise awareness about craniofacial conditions, and address the obstacles that people with facial differences overcome on a daily basis.

At the heart of myFace's approach are three pillars of support:

- **Grant Funding:** myFace provides grant funding to top-quality craniofacial centers across the country to ensure that patients are able to receive medical, dental/orthodontic care, and psychosocial care regardless of their ability to pay. This flagship work takes place at the myFace Center for Craniofacial Care at NYU Langone Health in New York City.

- **Direct Services:** myFace seeks to meet the day-to-day needs of individuals with craniofacial conditions through Support Groups that foster community and provide an environment where participants can feel safe, hopeful, and know they are not alone. Free and accessible accommodation and travel are delivered through a transportation grant



myFace Director of Family Programming, Dina Zuckerberg (second from left), pictured with several myFace Stars at the annual myFace Celebrates talent show in May 2022.

program and myFace Family Apartments, enabling patients to receive treatment in New York City. myFace also partners with Craniofacial Centers across the country to deliver free Newborn Craniofacial Care Kits that enable low-income families to adequately support their little one in their first months of life.

- Public Awareness and Education: myFace seeks to educate patients,



“Building understanding leads to empathy, and empathy changes society for the better.”

families, and healthcare providers across the country through the Transforming Lives Webinar Series; and raise public awareness through the Wonder Project school assemblies, and monthly myFace, myStory: Voices from the Craniofacial Community podcast, where individuals can share their stories, be seen, and be heard.

“A central part of our mission is to raise awareness of the craniofacial community to the general popula-

tion, and help them understand what individuals with facial differences and their families confront,” says Stephanie Paul, myFace Executive Director. “Building understanding leads to empathy, and empathy changes society for the better.”

myFace also hosts annual events where patients and families have the opportunity to meet one another and create an extensive community support system, such as myFace Celebrates, a special talent show that highlights the abilities of young people in the community, and Races for Faces, a 5k walk and carnival that brings together a diverse community to advocate for and celebrate those with facial differences.

myFace community member Alyse can attest to the real difference that myFace makes in the lives of individuals with facial differences. At the age of 2, Alyse was diagnosed with rhabdomyosarcoma, a form of soft tissue cancer. Though the chemother-

apy and radiation she underwent were successful in treating her cancer, the radiation affected the soft tissue and normal development of her facial bones, jaw and teeth – requiring close to a dozen surgeries over many years to reconstruct her face. As she grew up, Alyse and her family had little to no social support or resources - there was no “myFace” that she knew of to

provide the resources and necessary tools to support them through her journey. In May 2020, however, she came across a post in a Facebook group for those with facial differences, and was inspired to reach out to myFace.

Ever since, Alyse has been an active member of myFace’s Adult Support Group, and is grateful to finally be able to connect with others who “simply understand what it’s like,” and draw strength from shared experiences.

“Connecting and sharing experiences with others can bring a great amount of importance, meaning, and support into the lives of so many individuals and families. By being a part of the myFace community, I hope to make an impact and serve as an additional support for others living with a craniofacial difference,” she shares.

With a spectrum of programs, direct services, annual community events, and partnerships with craniofacial centers across the country, myFace is uniquely positioned to bridge the gap between the medical and emotional aspects of a craniofacial patient’s journey. myFace aims to ensure that children and adults with facial differences across the country - as well as their families - feel understood and appreciated in their uniqueness, and know that they are never alone.

To learn more about myFace, visit www.myFace.org.



myFace community member Alyse, an active participant in the adult support group.



A myFace family at the 10th Annual Races for Faces celebration held in New York City in September 2022.