

## Changing Faces, Transforming Lives

### A JOURNEY WITH CROUZON SYNDROME HOW ONE TEEN FUELS HER HAPPINESS

myFace has known the Diallo family for almost two decades - since their craniofacial journey began when their daughter, Didi, was born with a craniofacial condition called Crouzon Syndrome, where her facial bones and skull were prematurely fused. Didi is now 18 years old and has had more than 10 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 notes, "being born with a craniofacial condition is not only physically challenging, but mentally and emotionally challenging as well."

Didi attributes 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'm going through. I'm not really around many people with craniofacial conditions, so it's comforting to see that there are people like me who have had very similar experiences - ultimately making me feel less alone."*



Left: Didi, post-op, age 4 • Didi today: High school grad!

*"Find people who genuinely fuel your happiness."*

Having watched Didi blossom into a beautiful, talented, and accomplished young woman over these past 18 years is a privilege for us. Her differences never stopped her from pursuing her passion for dance; and she has impressed us all at her dance competitions in jazz, contemporary, lyrical, tap, and ballet. It's a "MAJOR" part of Didi's life, as she likes to emphasize, and an important creative outlet for her. 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. She is also looking forward to returning to **Races for Faces** in September!

The myFace team is so proud of the young woman Didi has become. We look forward to celebrating her successes and supporting her family along their journey for years to come.



RSVP & Register today at [RacesforFaces.org](https://RacesforFaces.org)!



**WHAT:** 5k walk, games, entertainment, & music for all!

**WHERE:** Pier 62 at Hudson River Park in NYC

**WHEN:** Sunday September 18th, 2022  
Registration @ 9am | Festivities @ 10am

## THE MYFACE FAMILY APARTMENTS

### A HOME AWAY FROM HOME FOR FAMILIES FROM NEAR AND FAR

Meet Julita and Marik Krakowska, who traveled 4,000 miles from Bydgoszcz, Poland, so that their sweet two year-old daughter Hanna, born with Pfeiffer Syndrome, could undergo Monobloc Advancement surgery at the **myFace Center for Craniofacial Care** at NYU Langone Health.

Despite all that she has to go through, Julita shares that "Hanna is a very cheerful girl. She's very smart and physically active. She loves people and especially animals - cats and pigs are her favorite!"

myFace has provided the Krakowskas with free accommodations in our Family Apartments, ensuring Julita and Marik can focus on what matters most: supporting Hanna during her extensive treatment and recovery period.



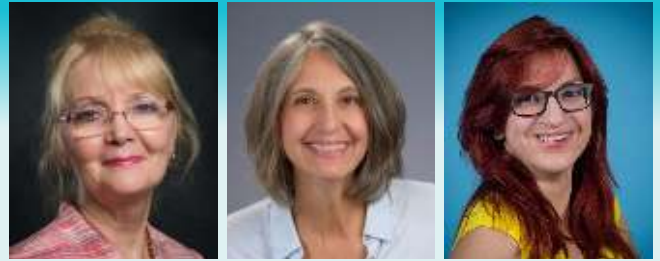
*"Thank you from the bottom of my heart for your help. The apartment is great. The doormen and neighbors are nice. It is a huge plus to be so close to the hospital so we can easily meet with the doctors. Everyone at myFace has been wonderful, and what you do for families like ours is amazing. Thank you so much!" - Julita, Hanna's mother*

We are so glad that myFace can be there for Julita, Marik, and Hanna during their journey, and that the **myFace Family Apartments** can be their home away from home while they navigate this difficult time. Generous donations from the myFace community allows for families like the Krakowskas to receive the care and support that they need and deserve. Thank you for all you make possible!

To learn more about the **myFace Family Apartments**, visit [myface.org/travel-housing](https://myface.org/travel-housing).

## ASK THE EXPERTS

From left to right: Brenda Louw, DPhil. SLP; Linda D. Vallino, PhD, MS, CCC-SLP/A, ASHA Fellow; and Yelena Jennings, who provided the young adult patient perspective.



In April, myFace presented a free webinar as part of our **Transforming Lives** series that explored the process of moving from pediatric-centered to adult-centered care, and provided strategies to help young adults navigate this transition. Below are some of the questions posed to our speakers:

### Was it challenging to transition from a pediatric team to adult services?

**Yelena Jennings:** Yes. My parents tried to foster my independence, encouraging me to make my own healthcare appointments, for example. But I avoided doing it and so they ended up having to continue to do this for me. Another concern is that when I turned 26, I was taken off of my parents' insurance. Also, there were some things I just wasn't concerned about when I was younger - like the fact that one of my nostrils is much smaller than the other. Even as a teenager, that was the last thing on my mind. But since it does impact my breathing, I want to get that fixed now. However, I'm concerned that this surgery might now be considered cosmetic, rather than medically necessary.

### My child is a young adult now, but I'm having trouble letting go of managing his healthcare needs. Do you have any suggestions that might help me let go of the desire to control this process - and trust him to take care of himself?

**Brenda Louw:** All parents struggle with this to some extent. However, it may be helpful to consult with the craniofacial team social worker and/or psychologist to discuss your changing role in supporting your child as they begin to manage their own healthcare needs.

**Linda Vallino:** I agree. You can also be open and honest with your child and say 'You know what - I'm scared, too. It's hard for me to let go.' It helps to acknowledge this, and to share your own concerns. But then you might add 'But don't be afraid - we'll get through it together' to reassure them that they still have your support and that everything will work out.

*Continued on the back page*

## THE HEALING POWER OF COMMUNITY

### WELCOMING DR. LEAH STOCK-LANDIS TO THE MYFACE FAMILY

We are thrilled to welcome Dr. Leah Stock-Landis to the myFace Family as the new Parent Support Group Facilitator. Dr. Stock-Landis has already been a huge asset since she began her role in June 2022, not only because she brings 27 years of expertise as a clinical psychologist and has a child who was born with a cleft lip and palate and other neurodevelopmental issues, but also because she has firsthand experience of having a craniofacial condition herself.



Dr. Stock-Landis was born with Goldenhar Syndrome and grew up dealing with the emotional, medical, and physical issues related to living with a facial difference, but it was never a focus of her clinical work - until now. She shares,

*“As I have become more engaged in the facial difference community, I have been inspired by activists and educators working to increase awareness and inclusivity... With soul searching, I realized that I had a voice - as well as important training and experiences - that might be of benefit to my community and the families who love and support them.”*

Dr. Stock-Landis has proven to be the perfect person to help myFace continue creating a safe and supportive environment where group members can benefit from the healing power of community and feel seen, heard, and understood.

In addition to the support group for parents of a child with a facial difference, myFace also offers support groups for adults and adolescents with facial differences, as well as a support group for Spanish speakers. **For more information on our support groups and to find the best fit for you, visit [myface.org/online-groups](https://myface.org/online-groups).**

## MAKING LIFE EASIER FOR PARENTS IN NEED

### NEWBORN CRANIOFACIAL CARE KIT PROGRAM HAS EXPANDED ACROSS THE COUNTRY

myFace launched a new program in February 2021 - in partnership with Welcome Baby - to provide **Newborn Craniofacial Care Kits** to parents of babies born with a craniofacial condition. Each kit contains essential items newborns will need in the first four weeks of life, including specially designed bottles and pacifiers donated by Dr. Brown's® Medical, a nursing pillow and baby wrap to help hold the baby upright after feeding, a swaddle to help keep the baby's hands away from their mouth after undergoing surgery, and Patricia Simon's classic book *Smile with Simon*. The kits also contain general newborn supplies such as diapers, baby wipes, a layette, creams, etc.

myFace provides these Kits to partnering hospitals free-of-charge, with the hospitals then dispersing them to families in need who are expecting - or have just given birth to - a baby with a craniofacial condition.

myFace Board Member Erin Ashayeri proposed we start this program after receiving a similar kit when her own son Greyson was born with a cleft palate, and understands firsthand what a difference it makes. myFace is currently partnering with 32 hospitals across 16 states to deliver the kits to families in need. We are so grateful to our partners and supporters for helping us make life easier for parents in the craniofacial community. **If you are interested in learning more or making a donation to support this program, please visit [myface.org/welcome-baby](https://myface.org/welcome-baby).**



These kits have been so helpful to families like Guadalupe's, whose son was born with a cleft lip and palate.

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### What can parents do to help with keeping track and organizing all of their child's care?

**Yelena Jennings:** My mother created a list of all 33 surgeries that I've had. It's very detailed, and includes names of the surgeons, dates of surgeries, and the reasons for the surgeries. She carried this with her at all times, along with a list of my medications..

### I'm an adult, but I never really learned to advocate for myself. What can I do to build these skills now so that I can get better care?

**Yelena Jennings:** Talking to a therapist can be a smart idea - they are there to help and guide you.

**Linda Vallino:** You might want to take advantage of support groups as well.



All *Transforming Lives* webinars are archived and available to view on [myFace.org/transforminglives](https://myface.org/transforminglives).

## INSPIRED BY THE WONDER PROJECT

### STUDENTS TAKE AN IMPORTANT LESSON TO HEART

The myFace  
**Wonder**  
Project



During the 2021-2022 school year, the **myFace Wonder Project** presented to 66 schools and reached over 17,000 students, led by myFace Director of Family Programs, Dina Zuckerberg. To date, the program has reached over 70,000 students of all ages nationwide, teaching them about the importance of empathy, inclusivity, and being an Upstander against bullying.

The fourth graders at the Convent of the Sacred Heart in New York City certainly took the important lessons imparted in *Wonder* by R.J. Palacio and the **myFace Wonder Project** to heart. After reading the book and participating in the virtual assembly where they learned more about craniofacial conditions and how they can respectfully approach someone with a difference, Sacred Heart students wanted to help!

Assisted by their teachers and families, the fourth graders pledged to take on a variety of chores at home to earn \$10 so that they could make a donation to myFace in support of those with facial differences - like Auggie, the protagonist of *Wonder*. **These kind-hearted and generous 10-year-olds ended up raising nearly \$600 for myFace.** A huge thank you to the students of the Convent of the Sacred Heart for choosing kindness!

To bring the **myFace Wonder Project** to your school, visit [myface.org/Wonder](https://myface.org/Wonder).

## THANK YOU!

A special shout-out to Coresight Research for being a **Leader Sponsor** and walking with us in our 10th Annual **Races for Faces**.



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Coresight provides research and advisory services to firms navigating the intersection of retail and tech.

For more information, or to learn more about the ways you can support myFace, please visit [myFace.org/waystogive](https://myface.org/waystogive). myFace is a recognized 501(c)(3) nonprofit organization. U.S. Registered Charity EIN #13-6013760. All donations are tax-deductible in accordance with IRS regulations.

**myFace**  
Changing Faces, Transforming Lives

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myFace is a non-profit organization dedicated to changing the faces - and transforming the lives - of children and adults with facial differences.