Tara was unprepared to care for a newborn with feeding issues, so the special basket of supplies she received from the care team at the myFace Center for Craniofacial Care at NYU Langone Health was a real lifesaver. Furthermore, when it was time for Jacob’s surgeries, the family stayed in the myFace apartments - conveniently located near the hospital - allowing them to focus on getting Jacob the care he needed without worrying about the expense or stress of accommodations in NYC. Jacob knows he will need more surgeries as he gets older, but he channels his superhero powers to ease any fears he might have. We are proud of you, Jacob, for being so brave, courageous, and confident!

“Jacob’s physical difference does not define who he is, but it is part of who he is.”
Tara, Jacob’s mom

He knows he is special, but at such a young age he doesn’t fully understand why.

Jacob was born with a complete unilateral cleft lip and palate. He’s had two surgeries to repair his cleft and a third surgery for his ear tube placement. Tara said that his cleft was a complete surprise to her and her husband, Will, when Jacob was born. At first they felt lost and had no idea what to expect. However, myFace was there for them when they needed it most.

Here is Jacob pictured as a baby, after his first surgery, and today, in all of his superhero glory!

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WHY WE NEED ELSA AND WHY ELSA NEEDS YOU

As members of our community know too well, medical interventions can cause considerable financial - as well as emotional - stress. At myFace, we believe families should be able to focus on what’s most important: getting their loved ones the care they need. That’s why we’ve joined a coalition of over 50 leading organizations in the craniofacial community, including the American Cleft Palate-Craniofacial Association, the American Dental Association, and the American Society of Plastic Surgeons, to advocate for the passage of the Ensuring Lasting Smiles Act (ELSA).

ELSA is an important piece of legislation that would provide more extensive healthcare coverage for medical and dental expenses related to any congenital or craniofacial anomaly, from childhood to adulthood. This bill would make a huge difference to so many of the families we serve - like Lenica and her daughter, Anibel.

“…In one instance, I had to write letters and get doctors to write letters to my insurance company explaining the urgent need for surgery to help open up Anibel’s jaw... The coverage for the procedure was finally approved and Anibel’s headaches disappeared after the surgery. But, she endured unnecessary pain. It was stressful for everyone involved.”

Lenica

Anibel was born with Nager Syndrome, and has had 36 surgeries in her short 16 years, with more to come. Recently, Anibel had a jaw abscess which eroded a tooth, and needed to undergo dental surgery. Unfortunately, Lenica’s dental insurance wouldn’t cover...
CELEBRATING 10 YEARS OF WONDER
A DECADE OF IMPACT

R.J. Palacio’s beloved book WONDER turned 10 years old on February 14th, 2022, and myFace joined in the celebration! We recognized the power of Palacio’s story to change the way people think about differences, and launched the myFace Wonder Project in 2015, which has reached over 60,000 students to date!

We are grateful for our partnership with Random House Children’s Books for expanding the reach of this program for the 2021-2022 academic year, allowing us to connect with more students on the importance of celebrating uniqueness, being an upstander, and always choosing to be kind. Participating schools receive a virtual assembly led by Dina Zuckerberg, featuring a variety of resources and activities that encourage students to consider how individual decisions impact others, and how their choices help shape society. To bring the Wonder Project to your school, visit myface.org/Wonder.

Want more WONDER? Check out the new, beautiful color-illustrated WONDER: ILLUSTRATED EDITION featuring over 25 pieces of original art from Tad Carpenter, an essay from R.J. Palacio reflecting on ten years of WONDER, and an introduction by myFace’s own Dina Zuckerberg! You can also listen to the WONDER episode of myFace, myStory podcast at myFace.org/WonderAnniversary.

FACING THE TRUTH
THROUGH A FACE FOR PICASSO

Ariel Henley is the author of A Face for Picasso, a memoir about her journey with Crouzon Syndrome. By the time she had graduated high school, Ariel had already had over 60 surgeries, more than anyone should have to endure in multiple lifetimes. Writing this book was a way for her to work through the trauma of everything she had experienced. In sharing her personal story, she aims to normalize facial differences, challenge society’s definition of beauty, and educate people about the importance of facial equality.

“Apart of my journey to healing has involved coming to terms with the truth.”
Ariel

Dina Zuckerberg, myFace’s Director of Family Programs, had the honor of interviewing Ariel on her podcast series myFace, myStory: Voices from the Craniofacial Community. It was a deeply honest and poignant conversation. Here are some of the highlights:

On why Ariel wrote her memoir: "Living with Crouzon Syndrome and a face that was different was challenging in a lot of ways… There was this whole part of my identity and life experience that made me feel alone…I couldn’t go into a bookstore and find a book that I could relate to or watch a movie and see someone who looked like me… There was nowhere in the world that I could go to find people like me. That was a lot for me to come to terms with.”

On the definition of beauty: “There’s this belief that to have an asymmetrical face means you’re not beautiful, and that assumption is really hard…. I like the way I look. I don’t want to change myself. I don’t want to fit someone else’s definition of beauty. To me, I am beautiful. And so that is what I would like people to understand.”

On having a community like myFace: “I think having a community like this growing up would have made a difference. The awareness, the education, the resources and the support network would have made me feel less alone.”

Ariel’s book is a must read. Her words are honest; her message strong. A Face for Picasso has the power to make a difference in the craniofacial community and in this world. To learn more about Ariel’s journey, listen to the full interview with Dina at myface.org/afaceforpicasso.

"Through sharing my story of growing up with a facial difference and the inspirational stories of others, the myFace Wonder Project brings to life the book’s central themes of acceptance and inclusion in real, meaningful, and teachable ways to students across the country.”
Dina Zuckerberg

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the procedure - leaving Anibel in pain, and leaving her mom scrambling to figure out how to pay for it.

Lenica and Anibel have also experienced numerous delays in care because of denied coverage.

If the ELSA Act is passed by Congress, it would have a huge impact on Lenica and Anibel, and other families like them. They wouldn’t have to fight so hard for necessary medical care.

"If ELSA gets passed, I could rest assured knowing that Anibel’s dental and medical needs will continue to be taken care of as she enters adulthood... The issues related to her condition will continue throughout her life, so the coverage for these issues should continue as well.”

Lenica

Join myFace and take action! Visit acpa-cpf.org/advocacy to learn more and send a pre-written letter to Congress to help get this landmark bill passed.

For more information or to learn more about the ways you can support myFace, please visit 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.