

Changing Faces, Transforming Lives.

MEET JACOB

A FIVE-YEAR-OLD WITH THE COURAGE OF A SUPERHERO!

Jacob may only be 5 years old, but he already knows he wants to be a doctor, rockstar, astronaut, ballerina, and superhero when he grows up. His mom, Tara, says that even at 5, he has the personality and wisdom of an old man. Jacob is friendly, yet fearless and adventurous - and "couldn't care less about what anyone thinks of him."

"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!



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!

Sharing messages of *hope, resilience and community* through musical performances and storytelling to benefit the craniofacial community

myFace Celebrates...

Starring

GRACE, 15 SAMIR, 12 ANA, 15 KAYLEE, 15

MONDAY MAY 2 2022 Guastavino's
409 East 59th Street
New York, NY 10022

*A livestream broadcast starting at 7:30pm ET will be available for those who cannot attend the in-person benefit.

Get your tickets today at myFaceCelebrates.org | #myFaceCelebrates

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.



Anibel and her mother, Lenica

"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

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ASK THE EXPERTS

Pictured from left to right: Lauren Beckett, MS, CCC-SLP, Meg Lico, MS, CCC-SLP and Meg Edwards



On January 25th, myFace presented a free educational webinar as part of our **Transforming Lives** series that explored how a cleft palate can affect early speech and language development, and provided strategies parents can use at home to help their child progress. Below are some of the questions posed to our speakers during the live Q&A.

How can I find a speech therapist near me with lots of cleft palate experience?

L. Beckett: Reach out to the speech therapist on your craniofacial team. They are considered a cleft expert, and they will work with your treating speech therapist to ensure your child is working on the best goals. If you aren't established with a team, you can find a nearby team to contact on the ACPA website at bit.ly/ACPAapproved.

How often should my child attend speech therapy?

L. Beckett: This depends on (1) what your child's speech concerns are and (2) access to therapy. In many settings, children with cleft palate are seen once a week for speech therapy.

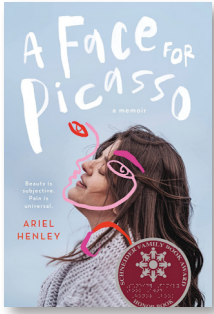
M. Edwards: Our son received speech therapy as often as 3 times per week. 2 sessions per week were provided through Early Intervention (EI) in New York City (although this varies from state to state). We also arranged for an additional private session each week because we thought it was so important for his development.

How long will my child need to undergo speech therapy, and at what age should we start?

M. Lico: Recent research indicates that approximately 50% to 70% of children with a cleft palate will need some speech therapy until age 5. It is child-dependent in terms of when to start and for how long it may be needed. Your craniofacial team can give you the best advice that is tailored for your child's needs.

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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.

"Part 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.

The myFace
wonder
Project



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.

"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



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.

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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.



ASK THE EXPERTS

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English is not our family's primary language. Is it OK to raise a child with a cleft palate to be bilingual? Should we look for a speech therapist who can work with us in our native language?

M. Lico: Yes! We want to encourage any language development that will enable the child to communicate within their family and community. You should apply the same rules regarding babbling development prior to cleft palate repair to whichever language you plan to teach your child. It is also best (if possible) to find a speech therapist who can work with you and your child in your primary language, or a bilingual speech therapist if you plan on teaching your child two languages. If the speech therapist does not have prior experience with cleft palate, they can simply reach out to your craniofacial team for assistance with any cleft-specific concerns.

All **Transforming Lives** webinars are archived and available to view on myFace.org/transforminglives.



Transforming Lives Webinar

April 26th, 7pm ET

**The Adventure of Moving On:
Transition of Care for Individuals with
Cleft and Other Craniofacial Differences**



Brenda Louw
DPhil, SLP



Linda D. Vallino
PhD, MS, CCC-SLP/A

Register today at myface.org/TransitionOfCare

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.



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.