myFace | YOUR IMPACT
CRANIOFACIAL NEWSLETTER • WINTER 2020

Changing Faces, Transforming Lives

THANK YOU

FOR ALLOWING MYFACE TO BE NAOMI'S SECOND FAMILY

Twenty-one-year-old Naomi was born with Van Der Woude Syndrome, which resulted in her having a severe bilateral cleft lip and palate, as well as a lip pit in her lower lip. Because her cleft has affected how her ears sit, she is constantly getting new ear tubes.

Naomi is grateful that she has been a part of the myFace family throughout her journey, having undergone more than twenty surgeries to date with more to come once COVID conditions improve. From the nutrition/feeding therapy, social worker support, to the speech pathologists, visiting nurses and counseling all received through the myFace Newman Family Support Center, she has experienced it all.

> *"myFace has allowed me to connect with people who have gone through similar situations. Just being able to see people like me and talk about our unique struggles when it comes to having craniofacial conditions, has made all the difference in my life."*

Naomi's passion in life is to promote confidence and healthy self-esteem for others just like her. She knows how hard it feels to be treated differently, to be told she isn't good enough or to not have someone with shared experiences to look up to. Naomi never wants another child with a cleft or a craniofacial difference to feel that.

> *"When I think of myFace, the first words that come to mind are acceptance and community. No matter where you're from, who you are or what craniofacial condition you have, you have a place with myFace!"*
>
> *- Naomi*

Naomi is a fierce advocate for teaching children compassion and empathy. She recognizes that if more people tried to understand one another rather than make assumptions, the world would be a much better place.

> *"myFace is my community. Although we're all unique and have our distinct journeys, at myFace, people are able to come together over our shared experiences. It's like having a second family!"*

MYFACE ADULT SUPPORT GROUP TO LAUNCH A

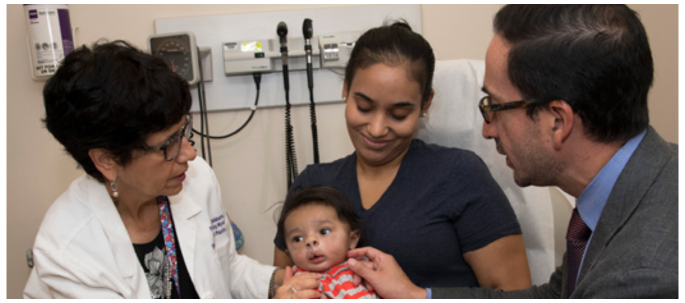
PODCAST SERIES

Dina Zuckerberg, myface Director of Family Programs, is working closely with members of the Adult Support Group to create and launch a unique ***Podcast Series*** in 2021. This series will inform and educate the general public about craniofacial differences and address the issues those with facial differences deal with as individuals and as a community. Sharing these stories through this podcast enables those within the craniofacial community to feel empowered by letting them know they are not alone and that someone understands. Stay tuned for our ***myFace Podcast Series*** launch!

myFace PODCAST

JOIN FAMILIES ACROSS THE NATION FOR THE TRANSFORMING LIVES WEBINAR SERIES

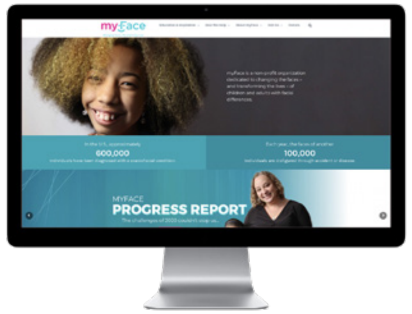
The myFace ***Transforming Lives Webinar Series*** kicked off its inaugural program on November 12th. The first topic presented was **The Difference a Craniofacial Care Team Can Make.** Experts, Dr. Joseph McCarthy and Patricia Chibbaro, RN, both from the myFace Center for Craniofacial Care at NYU Langone, shared critical information to help families understand how to navigate the selection of medical, surgical, and psychosocial specialists. The webinar centered around what constitutes a craniofacial care team, how to find the best team and important considerations as you make your choice. The webinar is available for viewing at **myFace.org/webinars**



Patricia Chibbaro, RN and Dr. Roberto Flores of the myFace Center

Throughout 2021, additional webinar programs will address prenatal counseling, navigating the insurance landscape, and the importance of psychosocial care. All webinars will be archived on myFace.org so families can access these important educational resources whenever they need. Follow us on social media and check **myFace.org/webinars** to stay informed.

MYFACE.ORG HAS A NEW LOOK!

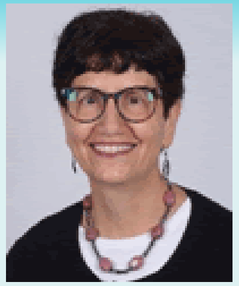


We've streamlined the navigation so you can find what you're looking for, and stay current on upcoming events, webinars and more! We've also added some new sections that provide critical information and resources to better support individuals and families in the craniofacial community. **Check out myFace.org and let us know what you think!**

ASK THE EXPERT

Patricia Chibbaro, RN, MS, CPNP, Pediatric Nurse Practitioner

myFace Center for Craniofacial Care at
NYU Langone Health, New York, NY



When should I start looking for the craniofacial team if I find out from the sonogram?

I recommend families contact a team right away. Many conditions cannot be seen on a prenatal sonogram, but for those that are, the family should get a referral to a comprehensive team immediately. In a prenatal consult they should expect to meet with the surgeon, learn how to prepare for the delivery, discuss feeding with a nutritionist, obtain resources and support from a social worker, and have an orthodontic team give an explanation about treatments that can be done even before the first surgery. These consults are invaluable for families because it gives them guidance, helps them prepare, and reassures them that there's a light at the end of the tunnel.

How important are the psychosocial aspects of the team – nutritionist, speech therapists, psychologist?

A child with any craniofacial anomaly should initially be seen by everyone on the team. Specialists will come in and out depending on where your child is with their treatment. It is important that a psychosocial team is always available pre-, during, and post-surgery as a resource. Some families need support more than others, and there should be no judgment about who needs help, and who doesn't. This is a journey, and that journey can go on for years.

Can you explain the role of a Pediatric Dentist?

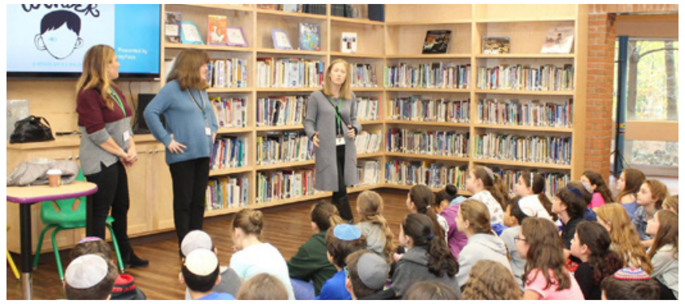
The Pediatric Dentist plays a critical role in team care because craniofacial dental issues are very different from those in adults. It truly requires a special personality to win the confidence of a young child. ALL children should start going to a dentist, not just kids with facial conditions, as soon as you see a couple of teeth. This will allow children to become desensitized to visiting a dentist, especially for children who we know have a higher chance of needing orthodontic treatment through their childhood and adolescence.

THE MYFACE WONDER PROJECT

HELPS STUDENTS TO CHOOSE KINDNESS AND PUT IT INTO ACTION

More than ever before, *choosing kindness* is critical to the wellbeing of our children and the health of our communities. As parents, caregivers, and educators, we have an obligation to promote empathy and kindness, and to teach acceptance for those with differences.

Over the past 5 years, schools across the country have been drawn to the myFace ***Wonder Project's*** pro-compassion English Language Arts Curriculum based on the best-selling book, *Wonder*, by R. J. Palacio. Through participation in this program, students learn how their own choices can help shape our society today, and they are encouraged to consider how individual decisions impact the course of their fellow students' lives.



Dina Zuckerberg, myFace Director of Family Programs, presenting *Wonder* to a class.

myFace is currently recruiting schools to join a pilot campaign where we are excited to launch a *new* philanthropy component – *A Week of Wonder*. **Students will have the opportunity to put *choosing kindness* into action while raising much needed funds to support our mission.** All program components can be conducted virtually or in-person and we will provide guidance on how to make the program work best for each school. **Bring the *Wonder Project* to your school! Reach out to info@myface.org for more details.**

OUR DONORS MAKE IT POSSIBLE

Working in collaboration with a fellow nonprofit, ***Welcome Baby***, myFace will launch in 2021 a new program to provide **Newborn Craniofacial/Cleft Kits** to mothers, containing the items they'll need for their child in the first four weeks of life. The kit will have items such as a **layette, baby carrier wrap, diapers, socks, creams, wipes, and Dr. Brown's bottles and pacifiers**, specially designed for cleft and craniofacial babies.

In addition to the normal stresses of a newborn, parents with a craniofacial baby have so much more to navigate, including breathing and feeding issues. We are excited to launch this program and take one worry off the minds of new parents with a child impacted by a craniofacial difference.

WHEN THOUGHTFUL KINDNESS MEETS OPPORTUNITY

As told by Erin, a grateful mom who's paying it forward

My son, Greyson, is a fun, silly, and happy little boy who today, at twenty months, is a smiling toddler who climbs on everything, loves trucks, playing soccer, and gives the best hugs.

But when Greyson was born, he tried to latch, but was having difficulty getting milk. The day after his birth, we were shocked to learn he had a cleft in his soft palate. All the emotions of excitement about the birth of our son soon turned to uncertainty and confusion. How were we going to be able to care for our baby when we knew nothing about cleft differences?

Fortunately, a member of the myFace Team was at our side within hours of the news. After a whirlwind of speaking with the cleft team at the myFace Center at NYU Langone Health, we were exhausted with digesting so much new information.

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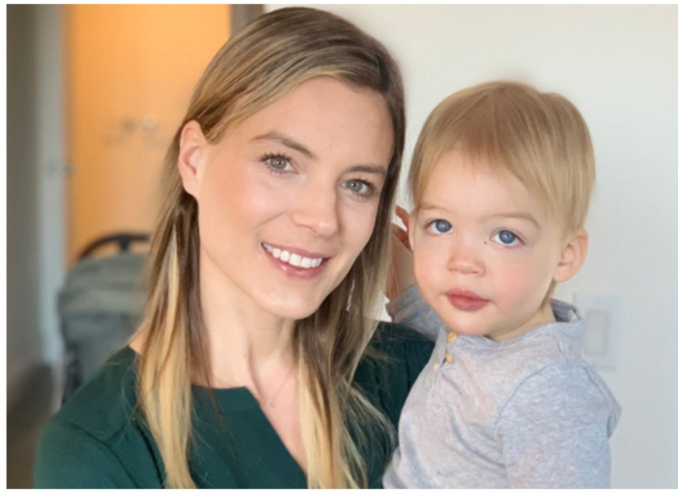

Erin and her son, Greyson

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That's when we were introduced to a young man who was born with a cleft lip and palate. As part of his bar mitzvah community service project, he was generously providing gift baskets to new parents filled with specialized products for cleft babies. It was only after we returned home with Greyson that we realized just how critical this basket was in the first weeks of our son's life.

> *"Knowing this wasn't a long-term program for this young man, we saw an opportunity to pay it forward and help provide vital products and resources to other new parents."*

I brought the idea to myFace. The stars were aligning because myFace was already brainstorming with ***Welcome Baby*** on how to expand the work they had launched years before. Could we all work together to expand ***Welcome Baby's*** mission to provide low-income mothers with one comprehensive kit that contains everything she and her newborn needs for the first four weeks of life? Yes we could, and from there the project took off! We are all very excited to launch this new program in 2021.

> *"Our hope in providing these kits to families with craniofacial and cleft babies is to simply make life easier."*

I want them to feel supported and to know they are not alone. Every mother deserves to feel confident that they can handle life with a baby who has a craniofacial difference. My husband and I are thrilled to have provided the seed funding to support the delivery of 130+ of these ***Newborn Craniofacial/Cleft Kits*** working in collaboration with myFace and ***Welcome Baby***. These essential products and resources for new parents will hopefully make the transition of bringing a baby home just a little easier.

A LASTING LEGACY

WITH MYFACE

By creating a planned gift with myFace, you can ensure that future generations of those with craniofacial differences have access to holistic comprehensive care, and are celebrated and treated with empathy, kindness, and support. Planned gifts are powerful ways to create a brighter tomorrow, often without paying anything today.

But nearly 70% of Americans don't have an updated estate plan, and many are unaware of the power that a gift in your plans can have. **If you'd like to create a lasting legacy with myFace, we have an easy way to get started.**

We've partnered with FreeWill to provide you with an online tool so you can easily write a will, protect the people you love, and create a legacy gift with myFace — at no personal cost. Over 170,000 Americans have used this tool because it is safe and secure. You can join them by visiting **myface.org/planned-giving**

MYFACE FAMILY HOLIDAY PARTY GOES VIRTUAL THIS YEAR

SAVE THE DATE: SUNDAY, DECEMBER 20, 2020

COVID-19 may have prevented us from hosting our in-person annual craniofacial family holiday party this year, but we won't let that stop us from celebrating with you! On **Sunday, December 20th at 4pm ET** we have a very special virtual event featuring the one-and-only Magic-Al! He will wow you all with his signature style of magic entertainment. The best part about this year's party is that you don't have to be in NYC to enjoy it.

If you are part of the craniofacial community and would like to receive an invite, please reach out directly to Dina Zuckerberg at Dina@myFace.org.

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.