

Changing Faces, Transforming Lives

CELEBRATING OUR DIFFERENCES AT ANY AGE

As told by *Luci Capo Rome*

Today, I enjoy being and looking different.

But that wasn't always the case.

I was born in 1951 with a congenital, severe and complete bilateral cleft lip and palate. I was missing my hard and soft palates, as well as bone that would have normally held my front teeth. My upper lip was totally open on both sides, and I had a distorted nose.

Not only did my cleft result in difficulty eating, drinking, speaking and breathing, my craniofacial difference brought shame, fear, anger, superstition and embarrassment to my family.

My mother was told that something was wrong with her to have had a baby that looked like I did. Not much was said back in the 1950's. There was no prenatal testing done back then and no special baby bottles with nipples to assist with my inability to suckle. A medicine dropper was used initially for my feeding. There was very little support and lack of education for parents and children at that time.

Over the course of my life, I've had dozens of surgeries (some successful, some not), speech therapy, and intensive orthodontic and prosthodontic care. Along my journey, I was also bullied, snubbed, and mocked by both children and adults.

I recognize that I am an intelligent, determined, and resourceful person. This, along with the support of friends and family over the years, are what got me



Age 17, following rhinoplasty surgery



Luci Capo Rome today

through some of the most difficult parts of my life when I felt most alone and vulnerable.

Today, I am a successful, retired advanced practice professional nurse whose passion is to improve the quality of life for mature adults with craniofacial differences - acknowledging them and their needs as they age. It's rewarding to let them know they are not alone and that their peers have formed a community where they will be welcomed and embraced.

I've made it my mission to be their advocate, and to reach out to them to welcome them into the community. No one, at any age, should feel isolated and alone. Older individuals, like myself, deserve to be heard and not hidden.

We should all enjoy being and looking different.

Thank you, myFace, for being an important resource for adults like myself, improving our lives and celebrating who we are!

myFace provides virtual support groups for Adults, Adolescents, Youth, and Parents and Prenatal Parents impacted by a facial difference. For more information, visit myFace.org/online-groups or contact Sandy Gilbert at Sandy@myFace.org.

SAVE THE DATE

myFace Celebrates...
A JOURNEY OF HOPE
PAST. PRESENT. FUTURE.

Wednesday, June 5, 2024

6:30-9:30pm

Guastavino's,
409 E 59th St, New York

Join us as we honor the legacy, embrace the present and unveil a vision for an ambitious future.

Cocktail Reception, Seated Dinner, Award Ceremony and Performances by our myFace Stars



FROM KANSAS CITY TO NEW YORK CITY: HOW ONE FAMILY FOUND “HOME” 1,200 MILES AWAY

In August 2023 the Metivier family traveled from Kansas City to New York City with their daughter, Jade, so that she could undergo surgery at New York-Presbyterian/Columbia University Medical Center. This was Jade’s 6th surgery. She was born with a cleft lip and palate, and when they adopted her from China at 2 years of age, she had not yet undergone any surgeries. At 12 years of age, Jade was also diagnosed with Midface Hypoplasia, and they were told she’d need a Le Fort III Distraction and Rhinoplasty to reposition her cheek bones, eye orbits and upper jaw.

When they first began to plan their trip out east, they were not aware that the **myFace Family Apartments** existed as a free resource to families coming to NYC for treatment. Thankfully, the team at NYP told them about myFace, and we gladly accommodated them for 26 days!



“We are grateful to have called the spacious and cozy apartment “home” for almost a month while Jade underwent surgery and follow-up medical appointments. We can’t thank myFace enough for taking the burden of housing off of our hands and allowing us to fully focus on Jade’s rehabilitation and recovery. We are proud to consider ourselves a part of the myFace family, and will never forget their support and kindness during this time.”
– Christi Metivier

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

ASK THE EXPERTS: Q & A

From left to right: Pradip R. Shetye, DDS, BDS, MDS; Travis L. Gibson, DMD, MSc; and Nicholas Zollo, who provided the young adult perspective



On October 24th, myFace presented a free educational webinar as part of our **Transforming Lives** series entitled: "Orthodontic Management of Cleft Lip/Palate." Below are some of the questions posed to our speakers during the webinar:

We live over an hour from our craniofacial center. How can we find a local orthodontist with experience treating cleft palate so that we don’t have to commute back and forth to the craniofacial center for all of our child’s orthodontic care?

Dr. Shetye: You might try asking your cleft team if they have a recommendation for an experienced orthodontist in your local area. If they don’t have a recommendation, you might try reaching out to another cleft team closer to you (if available) to see which orthodontist(s) they work with. Alternatively, you might be able to find a local orthodontist in private practice who has some experience managing patients with cleft palate.

What is the right age to do alveolar bone grafting? And what are the success rates that a patient might expect?

Dr. Gibson: Alveolar bone grafts might be performed on patients ranging from age 5 to age 10. In some instances, alveolar bone grafts are even performed on adults around the time of jaw surgery. The success rate is generally high – around 80% to 90%, with variation depending on the materials used, the orthodontic preparation, the individual situation, and other details that can be addressed in a conversation with your treating surgeon.

I like what you said about deciding not to undergo rhinoplasty to change your nose because it makes you unique. However, I have not yet reached that level of self-acceptance. What advice do you have for those of us who are still learning to embrace ourselves?

Nicholas Zollo: Ultimately, I think it comes down to your preferences and how you view yourself. I know in my heart that my nose looks fine and that it does what it needs to do. Don’t get a rhinoplasty because others think you should. Get it because YOU want to get it. Make it YOUR choice. Make this decision yours and yours alone.

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

PERSISTENCE PAVES THE PATH

CAMERON'S JOURNEY OF TRANSFORMATION

Cameron is a 15-year-old sophomore in high school. He's a conscientious student and a talented Lacrosse player. He has a beautiful smile which emanates from his core.

Today, he has a lot to be grateful for, and so does his family.

Cameron was born with Craniosynostosis, however, his condition wasn't properly diagnosed until he was 5 years old. His parents knew something wasn't right from the beginning - from the shape of his head to the headaches and stomachaches he suffered from as early as two years of age. Their pediatrician insisted this would pass, and that he would "grow" into his head.

Everything changed when Cameron fell while playing outside and suffered a concussion. His parents took him to the ER where they received his Craniosynostosis diagnosis.

"It means so much to our family to still be a part of myFace to this day." - Tara, Cameron's mother

Unfortunately, their journey was met with frustration and disappointment. The two surgeons they visited in Ohio at two different centers told his mom, Tara, that at 5 Cameron was too old to have surgery.



Cameron before



Cameron with Dr. Staffenberg

Unsatisfied with that response, Tara started researching other centers and found Dr. David Staffenberg at the myFace Center for Craniofacial Care at NYU Langone Health. She sent him photos and CT scans, and within one hour he replied, and an appointment was on the books.

The Pendleton family left Ohio for NYC where Cameron underwent Cranial Vault Remodeling for Sagittal Craniosynostosis under Dr. Staffenberg's care.

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EXPRESS YOURSELF

MYFACE DEBUTS DRAMA THERAPY GROUP FOR YOUTH

myFace recently debuted a new **Drama Therapy Group** for Youth with Facial Differences (ages 10-14). The group provides an inclusive and welcoming space for youth to meet and engage in role-playing, games, improvisation, storytelling and creative expression. These activities help participants to build confidence and self-awareness. Because it encourages teamwork and social interaction, the group also helps participants to connect with one another and build their communication skills. By tapping into the imaginative and playful aspects of drama, the group supports participant's emotional well-being and overall development.

The group is led by Patricia Contreras, who has a Master's Degree in Drama Therapy from New York University. Patricia has a facial difference herself, as she was born with a Port Wine Stain Birthmark.



"I've come a long way in accepting my birthmark. When I was younger, I wanted to have it removed. I'm glad I didn't though, because I've come to accept it and love it now. My hope is that participants in the Drama Therapy Group will come away with a sense of belonging, and a better understanding of their own unique strengths. I'd also like for them to celebrate their differences, as this can lead to self-acceptance and resilience."

- Patricia Contreras

The myFace **Drama Therapy Group** for Youth meets on Zoom the first Saturday of each month from 12:00pm-1:00pm ET/9:00am-10:00am PT. There is no cost to participate. For further information, or to join this group, please contact Dina Zuckerberg at Dina@myFace.org.

MYFACE'S ANNUAL HOLIDAY PARTY

WHERE KIDS GET TO CELEBRATE BEING THEMSELVES

Every year, myFace hosts an annual holiday party for children and their families - to provide a safe and festive place to celebrate the holidays - but more importantly, a place where each and every member of the craniofacial community can celebrate being themselves.

On Friday, December 15, 2023, 231 people gathered together at the Church of the Holy Apostles in NYC, including a special guest elf, and of course, Santa Claus! Partygoers enjoyed face painting and arts and crafts, a meal catered by Michael Muoio of Villa Rustica Pizzeria and Trattoria, and gifts for each child to take home. This year, piano prodigy and myFace Celebrates Star, Logan Riman, entertained us with festive holiday songs.

A shout-out goes to the many donors and volunteers who helped make this holiday party a success including those who hosted toy drives to support this event: (1) NYU College of Dentistry's Oral and Maxillofacial Surgery Society; (2) Marymount Psychology Club; (3) Dina Zuckerberg; and (4) fellow nonprofit UNITY SME. Kudos to the dedicated volunteers from the NYU College of Dentistry, Unity SME, and S&P Global for bringing joy to all at the event. We couldn't have done it without you!

We are still feeling warm and fuzzy two months later, and will continue to reflect on the generosity of our community until we gather together again next year.



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Shortly after they returned home from their visit, Cameron woke up one morning and inquisitively asked his mom, "Where did my boo boo headache go? They went bye bye?"

It was at that moment Tara knew they made the right decision - something she, Cameron and their family would never forget for the rest of their lives.

Tara knows that Dr. Staffenberg changed the trajectory of her son's life when the other surgeons were quick to say it was too late.

And though Cameron was very young when all this took place, he and Dr. Staffenberg have a very special bond to this day.

Dr. Staffenberg was more than just a surgeon to them. He was their lifeline. And still is.



BE A MYFACE AMBASSADOR AND MAKE A DIFFERENCE

From birthdays to marathons to your own unique ideas, you can spread awareness for myFace while fundraising for a special occasion.

- 1) Choose Your Event
- 2) Create Your Page
- 3) Spread The Word

It's that easy! And we've got all the resources you need.



TAKE ACTION

- View our *Transforming Lives Webinar* series.
- Visit our *myFace, myStory Podcast Library*.
- Mark your calendar: **June 5, 2024** for *myFace Celebrates...*
- Join our mailing list to stay informed with monthly programming updates.



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.

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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.