

myFace’s “Through My Lens” Photo Exhibition Puts Craniofacial Community in Focus

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myFace proudly hosted the *Through My Lens* photo gallery exhibit at the Positive Exposure Gallery in New York City. The event showcased powerful photography and deeply personal narratives from individuals and families affected by craniofacial differences. Photos were submitted by members of the craniofacial community from across the country, with 45 total participants contributing to the photo competition. The exhibit brought these voices together in one shared space, allowing participants to tell their stories through their own lenses.

Seventy community members, families, friends, and local partners filled the gallery throughout the afternoon. Many noted how meaningful it was to see such expressive and authentic work displayed so thoughtfully. We were honored to host our three competition winners—Johnathan Hornig (NY), Eilie Bell (NC), and Sophia Smilenov (TX).

The warmth, gratitude, and connection in the room made one thing clear: when stories and artistry are shared, belonging grows.

Johnathan reflected on what the day meant to him:

“What a celebration of life, love, healing, and community. I send an abundance of gratitude to the entire myFace organization for truly seeing, hearing, and honoring my story. Your award and recognition will last many lifetimes.”



myFace Through My Lens Winners: Sophia Smilenov, Johnathan Hornig, and Eilie Bell standing in front of honored entries.



myFace Community Members Anibel, Dina, Bridgett, Lily, Naomi, Ava, and Claudia at the exhibit.

The 2025 myFace Holiday Party Brought Together The Heart of Our Community.

An evening filled with joy, connection and celebration.



More than 300 guests, including myFace families, board members, community members, and clinicians from the myFace Center at NYU, joined us for this cherished annual tradition. Their experience was made possible by the dedication of more than 45 volunteers from NYU and Columbia Dental Schools, Bronx Science Key Club, and S&P Global.

For many families navigating financial, medical, and emotional stress, this celebration—and the donated gifts thoughtfully selected for every child—offered a moment of relief and a reminder that they are not alone.

As one parent shared:

“I was happy to see families from 10 years back and new ones, all connected under the kindness of myFace.”

Guests enjoyed a variety of interactive activities, including face painting, balloon art, arts and crafts, and cotton candy. Families also had the chance to take photos with Santa, and each child received a surprise gift generously contributed by community members and supporters.

The evening featured inspiring performances by myFace stars Logan Riman on piano accompanied by Hye Young Bang on violin, Sofia Gallegos on cello, and Kamea Pettway and her brother Samir, who sang beloved holiday songs.

The event was equally meaningful for our adult community members. Tom attended his first myFace event and was joyfully surprised to reunite with myFace Trustee and former classmate David Santiago. He shared how wonderful it felt to reconnect and to see so many in the community laughing, bonding, and truly enjoying themselves.

One mom shared:

“My son is already looking forward to the next event. I hope experiences like this will help him feel more confident, safe and understood.”

The 2025 myFace Family Holiday Party reminded us what makes this community so extraordinary.



A Partnership That Delivers More Than Logistics

We are grateful to recognize RDS as a valued corporate partner whose generosity supports myFace all year long. Through their FREE, year-round delivery service, RDS helps ensure our events and programs come together seamlessly, allowing our team to stay focused on the families and community we serve.

RDS has already supported two major myFace events—Races for Faces and our Family Holiday Party—playing a key role behind the scenes to make each one a success.

In November, Bill Villafranco and Karen Lazarus had the pleasure of meeting RDS Founder & CEO Larry Zogby at their LIC headquarters along with their team.

Their warmth, generosity, and genuine interest in our mission made it clear that this partnership is about more than logistics—it’s about community.

Thank you, RDS!



myFace Sets Sail with Second Annual Boat Cruise



On October 9, 2025, myFace hosted its Second Annual Boat Cruise on the Hudson River. With 77 attendees on board, guests enjoyed a delicious dinner, breathtaking views, and meaningful time together as the sun set over New York City.

The cruise featured beautiful sights, including a clear view of the Statue of Liberty, creating a warm and memorable atmosphere. Highlights of the evening included heartfelt remarks from Board President John Gordon, Executive Director Bill Villafranco, and a moving poem shared by Sarah Woodhouse.

One guest reflected:

“Sarah’s poem was truly moving, as was seeing the joy of all the young adults being together, connecting, and enjoying each other’s company.”

The night was a wonderful reminder of the strength and spirit of our community. We look forward to continuing this special tradition.

Ready to Experience the Magic of Camp?

Family Camp Weekends at Boggy Creek and Victory Junction, along with Craniofacial Camper Week at Boggy Creek, are *completely free* and give medically complex children and their families the chance to enjoy camp magic together. With fun-filled activities, quality time together, and a community that truly understands, families can focus on connection, laughter, and making memories.

Come experience the joy of camp—without limits!

**Camp Boggy Creek
Camper Week (Ages 5-17)
Eustis, FL
July 5-10, 2026**

Applications now available at boggycreek.org.

**Camp Boggy Creek
Family Weekend
Eustis, FL
September 18-20, 2026**

**Victory Junction
Family Weekend
Randelman, NC
October 16-18, 2026**

**The Painted Turtle
Family Weekend (Ages 4-17)
Lake Hughes, California
November 6-9, 2026**



NYU Story Hour: A Source of Comfort and Connection

On December 19, myFace hosted Story Hour at the myFace NYU Center for Craniofacial Care, offering families connection, comfort, and information during clinic visits. Program Assistant Naomi Levinshtein and Senior Program Officer Jackie Smith spent the day engaging children through play, answering questions, and sharing resources with parents and caregivers.

Families learned about myFace programs including support groups, the Family Apartment, and upcoming community events, and shared appreciation for the warm, informal setting. Story Hour continues to reflect the heart of myFace’s mission: meeting families where they are and building trust through consistent, compassionate connection.



Naomi and Jayden proudly showing off their coloring before his doctor’s visit.

In My Own Words: Maria-Elizabeth (Translated from Spanish)

Hi, I'm Maria-Elizabeth. I am 31 years old and originally from Cuenca, Ecuador. I was born with Treacher Collins syndrome. Growing up in Ecuador was complex.

I was deeply afraid of doctors' offices and surgeries because they were often painful experiences. Over time, this fear turned into trauma, and seeing any doctor filled me with terror. My family was very overprotective, and I grew up in a bubble. Because I couldn't hear well, I often felt isolated.

During my early school years, I was happy. I relied on my niece to help me hear, and we studied together. As I grew older, however, I experienced a lot of ridicule from my peers. I often found myself sitting alone and crying. In 2010, I came to the United States for the first time and lived for a year with my brother and his family in New Jersey. That time was very meaningful to me. Being with them showed me a different world, and I was truly happy. Eventually, I returned to Ecuador—a decision I still regret.

I continued my education in Ecuador and received my first bone-anchored hearing aids in 2015. I changed my university major several

times while trying to find what truly interested me and eventually graduated with a degree in Marketing Technology. Even then, I felt uncertain about my path. In 2021, I decided to move to New York City to begin something new.

“myFace became a refuge for me during a very difficult time in my life.”

I was close to giving up on myself and struggling to find purpose. Through this organization, I have been able to rebuild my confidence and self-esteem—work that I continue every day.

“The events I've attended have been meaningful experiences that helped me learn to accept myself and trust that there is a place where I belong.”

They made me feel liberated and saw me for who I am.

Today, life feels easier because I know I am not alone. I have people I can count on—people who accept me, respect me, and truly understand me.



This is me at 6 years old in Ecuador.



Here I am today at a myFace event in New York.

myFace Takes a Stand Against Bullying!

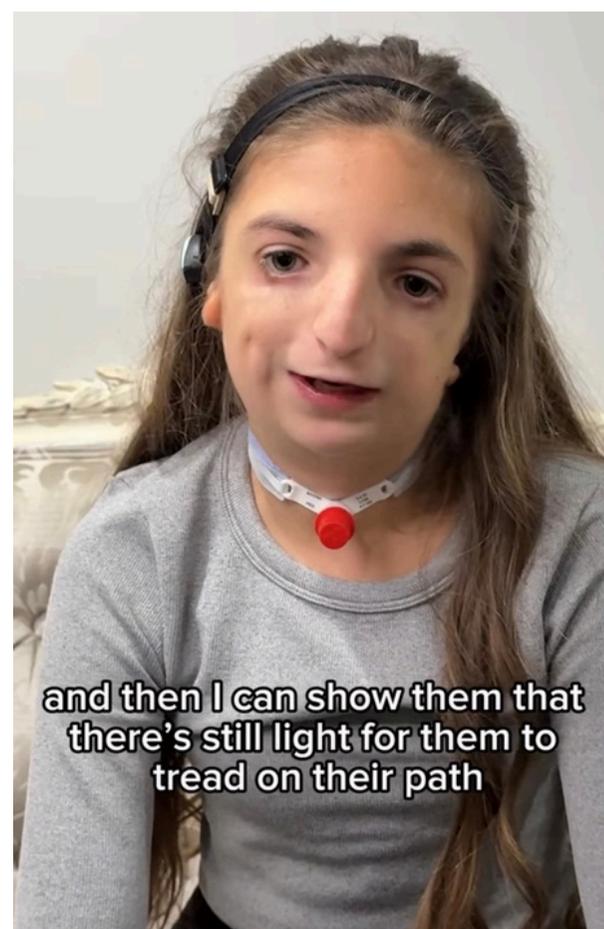
Every October, we recognize Bullying Prevention Month—a time to raise awareness about the challenges many in our community face. Studies show that approximately 50% of people with facial differences experience some degree of bullying.

To shine a light on this issue, myFace launched a social media campaign featuring the stories of four incredible members of our community: Andy, Cassidy (pictured on right), Bridgett, and Eric. They courageously shared experiences of being bullied, the people who stood up for them

and the moments when they became upstanders for others.

Each story highlighted honesty, resilience, and the strength that forms the foundation of the myFace community. We are deeply proud and grateful for their willingness to share.

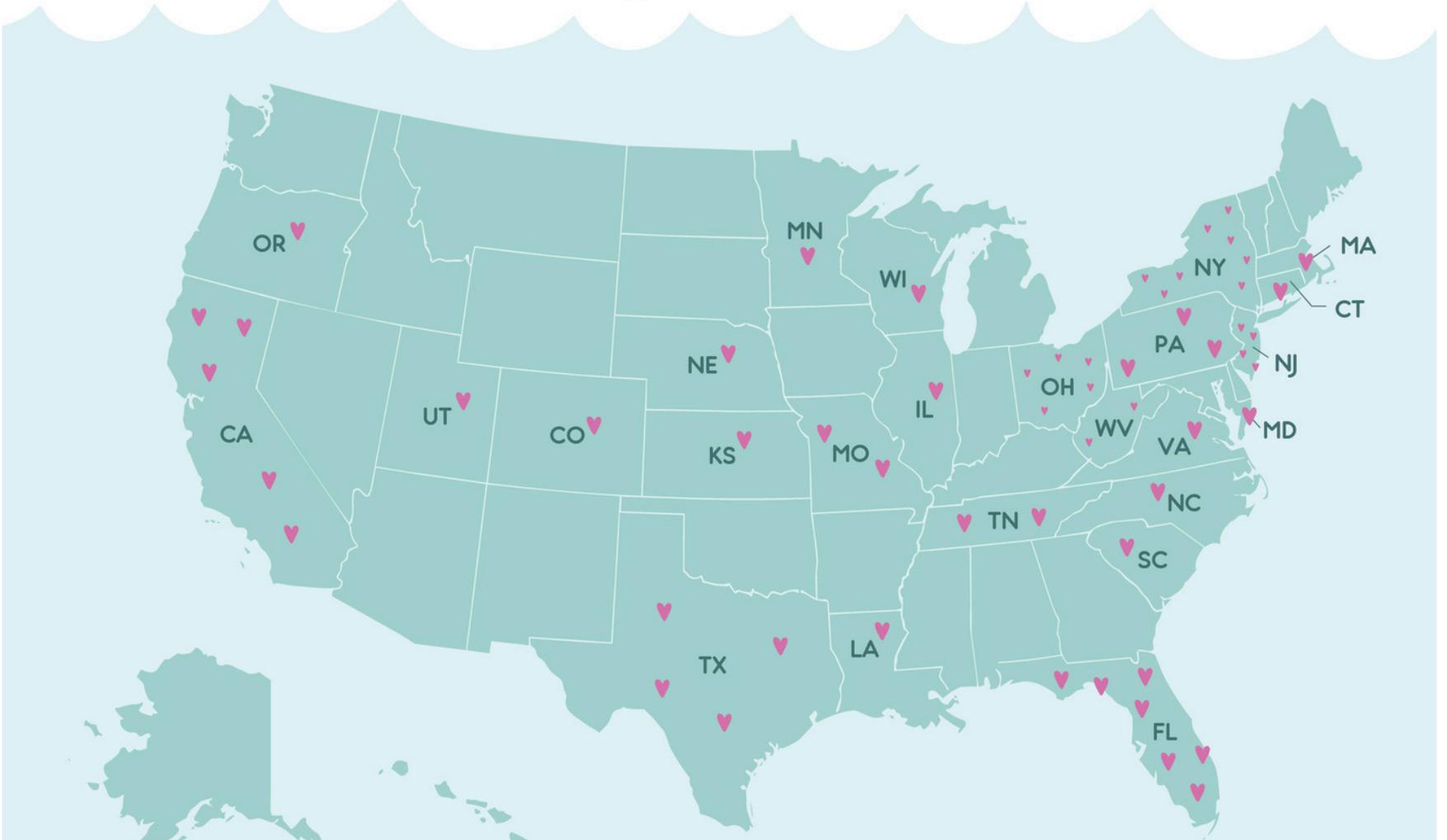
This campaign aligns closely with our school presentation series, **The myFace Wonder Project**. If you'd like to educate your community on facial differences, celebrating uniqueness, and emphasize the importance of choosing kindness, consider bringing **The Wonder Project** to your school.



and then I can show them that there's still light for them to tread on their path

59 HOSPITALS in 25 STATES.

tinyFaces 🧡



tinyFaces: Meeting Families at the Moment They Need Support Most

Through a growing network of hospital partners, tinyFaces reaches families across North America—meeting parents with connection, resources, and reassurance at the point of diagnosis and beyond.

Each tinyFaces backpack is shared with new parents during an often overwhelming moment. Inside are essential care items such as feeding supplies, burp cloths, bibs, and other newborn necessities—along with trusted educational materials and a handwritten note from another family who has been there. Together, these small but meaningful touches send a clear message: you are not alone.

The map featured here reflects the collective impact of tinyFaces and the many communities now connected through hospital partnerships. Thanks to our partners and supporters, tinyFaces continues to help families feel welcomed, informed, and supported from the very beginning.

Real Impact, Real Families.

Behind every tinyFaces kit is a family navigating an incredibly vulnerable moment.

When Elizabeth's family received their tinyFaces care kit during a visit with their daughter's plastic surgeon, the thoughtfully packed items—and a handwritten note from another parent—made a lasting impression.

“Our family felt very grateful for the tinyFaces care kit from myFace... From the burp cloth to the bib to the specialized bottle, we felt very seen and thought about. It was such a generous gift and made me feel not alone during a very scary time.”

—Elizabeth, St. Louis, MO

“Receiving the tinyFaces items made me feel seen and supported during a time when everything felt overwhelming.”

—Jonnie, mother of Leo, Las Vegas, NV (pictured below)



The Fireside CHAT AND LUNCH

In a world where appearances are often judged before voices are heard, the Fireside Chats provide something rare, an intimate space to hear unfiltered human stories of resilience, difference, and belonging. These gatherings bring together extraordinary individuals who have overcome trauma, visible differences, and adversity, not to be defined by them, but to show us the strength, courage, and wisdom that emerge from those journeys. The power of the Fireside Chats is simple yet profound, when voices like these are heard in person, they challenge stereotypes, open hearts, and spark change.



Bill Villafranco, Barbara Zuckerberg, Joe and Jessica DiMeo, Dr. Joseph G. McCarthy and John Gordon at myFace's Fireside Chat.

Amedy Dewey

An unforgettable afternoon of connection, truth and resilience.

At 18, Amedy survived a domestic-violence shooting—an incident, as she intentionally calls it—that claimed her mother's life and left her with an acquired facial difference and significant vision loss. Before this trauma, she described a joyful upbringing in rural Michigan filled with family adventures, competitive cheer, and soccer. Yet behind the scenes, abuse from her step-father was escalating.

During a family trip, a sudden act of violence left Amedy blinded and severely injured. Alone in freezing

conditions, she fought to survive until help arrived.

Her recovery—marked by surgeries, vision loss, PTSD, and night terrors—has been long and painful. But Amedy's story is one of rebuilding. With the support of therapy, her father, her grandmother, her best friend Becky, and her NextGen Face and myFace communities, she found strength and belonging.

Now studying psychology with hopes of becoming a trauma therapist, Amedy shared why language matters, choosing incident over accident: words, she said, should honor accountability and healing.

Her message was clear:

“He’s not going to win.”

Amedy's courage embodies the heart of myFace's mission — ensuring no one faces a facial difference alone.



Joe and Jessica DiMeo

Shared their extraordinary journey of survival, recovery, and love

In 2018, Joe was involved in a car accident that burned 80% of his body, leaving him in a coma for three months and forever changing his life. He reflected on returning home: “I felt like a four-year-old again. My mom had to cook, clean, change my bandages. Everything I'd known as independence was gone.”

Joe's determination carried him through a historic face and double hand transplant. He approached the process with courage and focus, celebrating each milestone as a step toward reclaiming autonomy and purpose.

A deeply moving part of the afternoon centered on Joe's relationship with Jessica. Their connection began over a shared love of dogs and admiration for resilience.

Jessica recalled seeing Joe's story and thinking, “He didn't care about his looks. He cared about getting back to work.” Their bond grew quickly, strengthened by humor, trust, and shared experiences, culminating in a small, intimate wedding in Hawaii.



Reflecting on their journey, Joe said:

“I don't want sympathy. I want people to get something from my story—motivation, a positive outlook, or even just a smile.” Jess added, “There is power in story. If our love story can give someone hope—especially someone with a facial difference wondering if they'll find love—then we want to share it.”

The afternoon concluded with profound reflections from the audience, including a mother whose daughter suffered a traumatic injury. She said Joe's honesty about losing friends and rebuilding life gave her daughter strength, and her other daughter added that watching Joe and Jess together made her feel hopeful for her sister's future.

Ali and Jim Stroker

A powerful conversation rooted in truth, courage, and choice.

myFace was honored to welcome back Tony Award-winning actress, singer, and disability advocate Ali Stroker, alongside her father, life coach and author Jim Stroker, for their second Fireside Chat with our community.

Ali shared her story of sustaining a spinal cord injury at age two, leaving her paralyzed from the chest down and a wheelchair user.

Growing up surrounded by messages about “getting better,” she eventually reached a life-changing realization that she was never broken and did not need fixing.

Instead, she is better because of her challenges, not in spite of them. Ali spoke powerfully about reframing trauma and choosing how to respond to adversity, an approach that helped

propel her to become the first wheelchair user to appear on Broadway and the first to win a Tony Award for her role in *Oklahoma!*.

Throughout the conversation, Ali reflected on moments when institutions were unprepared for her presence. From skepticism and access challenges during her time at NYU’s Tisch School of the Arts to inaccessible Broadway theaters, she encountered repeated barriers. Rather than accepting exclusion, Ali described how she chose to “host the party,” taking leadership in creating solutions and expanding what participation could look like.

Jim offered a parent’s perspective shaped by decades of coaching and leadership. He shared how Ali’s accident transformed his understanding of what it means to “coach,” introducing his guiding framework E + R = O (Event + Response = Outcome), which emphasizes the power of response over circumstance.

Ali also highlighted the import-

ance of a personal “home team,” a community of people who provide different forms of support.

The conversation was deeply moving, with messages of tenacity and authenticity that speak directly to the values at the heart of the myFace community. To top it off, Ali surprised attendees with a joyful a cappella performance of her favorite holiday songs, an uplifting close to a powerful afternoon.



UPCOMING SPEAKERS



Dr. Felicia Rosario, trauma survivor and advocate featured in Hulu’s *Stolen Youth*, will lead a myFace fireside chat on reclaiming identity and resilience, offering tools to navigate judgement and empower the facial difference community.



RSVP Here



Dr. Felicia Rosario
January 30th



Dr. Becky Clark is a trauma-informed leader, 3x Deaflympian, and global advocate whose lived experience with hearing loss, stigma, and identity fuels her work at the intersection of mental health, disability, sport, and inclusion.



RSVP Here



Dr. Becky Clark
March TBD

Event Details

Location: Harvard Club
35 West 44th Street, New York, NY 10036

Presented by myFace

Our Fireside Chats are COMPLIMENTARY with 50 tickets available. (First Come, First Served.)

Stories worth hearing!



Scan here to explore recordings from previous myFace Fireside Chats.



When Theater Sparks Dialogue

myFace Brings Craniofacial Awareness to Detroit

In December, the myFace team partnered with the Wayne State University Theatre Department during its production of *Violet*, a Tony-nominated Broadway musical based on the short story *The Ugliest Pilgrim*.

Set in the 1960's South, the show follows Violet, a young woman with a facial difference, as she journeys towards healing, self-acceptance, and belonging—themes that closely align with myFace's mission.

Wayne State's Department of Theatre and Dance pairs each production with a community organization connected to the show's core themes. Sophia Esch, Managing Director of the Professional Youth Theatre of Michigan and Michael J. Barnes, Chair of the Department of Theatre and Dance, invited myFace to participate.



myFace staff joins Violet cast post show talk back.

myFace provided a pre-show presentation to the audience with resources that grounded the story in real-world context, highlighting resources, services, programs, and advocacy efforts for individuals and families affected by facial differences.

Following a sold-out performance, myFace staff along with parent, Stephanie Mercier, joined the cast and director for a post-show talkback. The

conversation moved beyond the stage, addressing representation, lived experience, and the importance of visibility.

myFace helped bridge the artistic narrative with practical information, offering audiences insight into how support, connection, and community exist beyond the theater.

Ring in the New Year Together at Kohl's Children's Museum

This New Year's Eve, myFace Chicago rang in 2026 at the Kohl's Children's Museum, to create meaningful connections with children and their families. Four families joined the celebration—two new to myFace and two returning from our very first Chicago event. The afternoon was filled with joyful moments: children playing together freely, while parents relaxed and connected with ease.

“Walking into a new environment can feel intimidating, wondering how others might react. But being surrounded by people who truly understand makes all the difference. Marley had a blast playing with kids from the craniofacial community and beyond, while I felt grateful connecting with other parents and knowing our children were welcomed and included.”

– Sarah, Marley's Mom





When Connection Takes Root: Gathering at Didier Farms

Earlier this year, Lara Kraus reached out to myFace seeking a place where her family could connect with others who truly understand life with craniofacial differences. Her son, born with unilateral anophthalmia—where one eye is completely absent—had already connected with families through online groups, but Lara hoped for a more personal community experience.

This past October, myFace Chicago Senior Program Officer Rena Rosen had the pleasure of meeting Lara, Nathan, and their son at Didier Farms in Lincolnshire, IL. As they enjoyed the fall festivities, conversations flowed from childhood memories and carnival rides to experiences that resonate deeply within the craniofacial community. Lara shared how important it is for their son to grow up knowing others who look like him, while Nathan mentioned the inspiration they have found in learning about older individuals with similar conditions.

Lara expressed gratitude for being welcomed into the myFace family, looking forward to future activities. These intimate moments highlight the power of connection and belonging.

Ann & Robert H. Lurie Children’s Hospital Clinic Story Hour

Following the success of our Story Hour program in New York City, myFace is excited to share that Story Hour was brought to Chicago. Led by Senior Program Officer Rena Rosen, the program offered a calm, welcoming presence for families in the waiting rooms at Lurie Children’s Hospital, creating moments of connection through shared reading, conversation, and informal support while families waited for appointments.



Milkshakes, Crafts, and Holiday Cheer at JoJo’s Shake Bar

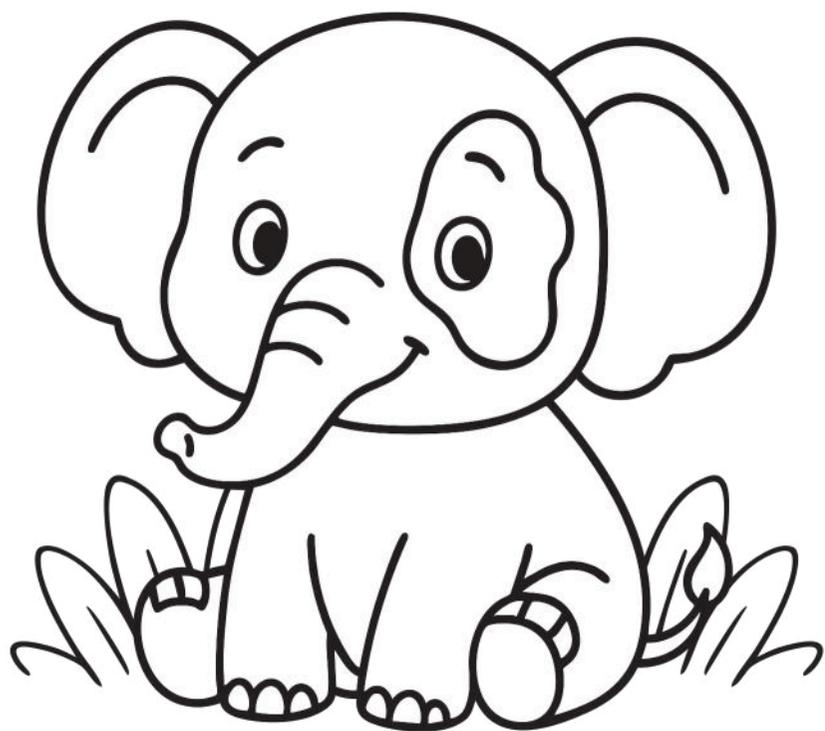
On December 21st, myFace Chicago enjoyed a festive afternoon at JoJo’s Shake Bar in River North, where Halle, Emily, and Rena, Senior Program Officer, came together for a cozy holiday gathering. The ladies enjoyed sipping their milkshakes, chatting and painting holiday ornaments. While the busy travel season meant others had to raincheck, the intimate gathering underscored how meaningful even small moments of connection can be. Events like these create space to simply be, strengthening community and fostering a sense of comfort and belonging.



Kid's Corner

C K R S F R I E N D
 O O I U H T H O W I
 N S M N N A E O Z F
 F B T M D I R A P F
 I R A O U N Q E M E
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|------------|------------|-----------|
| confidence | difference | community |
| kindness | unique | smile |
| brave | listen | care |
| story | team | share |
| friend | heart | hope |
| | | art |



the myFace
wonder
 project
 Kindness Program

**What If KIND
 Was Your School's
 Superpower?**

Inspired by the book
Wonder by R.J. Palacio

Bring
 the myFace
wonder
 project
 Kindness Program
**to your
 school**

Scan to Learn More
www.myface.org/wonder

Upcoming Events:

Creating Community Through Shared Moments

Join us in creating memories, making connections, and celebrating what makes our community unique

Make sure to follow us on social media and keep an eye on your inbox for registration details and updates!

January 23rd

Zoom: Virtual Game Night
8:00 pm ET

January 24th

Different by Design: Building
Confidence Through STEAM
For Children Ages 7-14 and Their Caregivers
12:00 - 4:00 pm
Chicago

January 30th

Fireside Chat with Felicia Rosario
12:30 - 2:30 pm
New York

February 5th

An Evening of Magic with Ben Jackson
For Adults and Kids 13+
6:00 - 7:30 pm
New York

February 12th

ACPA Webinar: Preparing Parents for Their
Child's Surgery – A Comprehensive Approach
Presented by Patricia Chibbaro, RN, MS, CPNP
6:00 - 7:30 pm ET

February 15th

Galentine's Day Celebrations
New York & Chicago

February 23rd

Zoom Panel: Empowering our Kids by Advocating for
Inclusion, Support and Success in School
Liliana Diaz-Pedrosa, Director AFC Parent Center,
Suzanne Orlando, LCSW & Dina Zuckerberg
6:00 - 7:30 pm ET

March 12th

Zoom Panel: Advocating for Your Child
in the Hospital Setting
7:00 pm ET

March TBD

Fireside Chat with Dr. Becky Clark
12:30 - 2:30 pm
New York

July 5th-10th

Camp Boggy Creek Camper Week
Ages 5-17
Eustis, Florida

September 18th-20th

Camp Boggy Creek Family Weekend
Ages 4-17
Eustis, Florida



September 27th

Races for Faces
9:00am - 1:00pm
Pier 62
New York

October 16th-18th

Victory Junction Family Camp Weekend
Ages 4-17
Randelman, North Carolina

November 6th-9th

Family Weekend
The Painted Turtle
Ages 4-17
Lake Hughes, California





Ask Pat!

Concerns about baby?
Feeling overwhelmed?
Questions about feeding?

♥ You are not alone.

Patricia Chibbaro, CPNP,
Pediatric Nurse Practitioner

Pat a nurse practitioner with over 30 years of experience at the myFace Center for Craniofacial Care at NYU Langone Health, is continuing to help our community by addressing questions from the craniofacial families on our myFace YouTube channel.

Some topics Pat has addressed:

- What is craniofacial microsomia?
- Do kids with cleft lip and palate need special dental care?
- How can I help manage the stress that I am feeling as a parent with a craniofacial condition?
- Why do some patients with craniofacial conditions need jaw surgery?
- Will the same craniofacial team be able to take care of my child throughout their life?

myFace

tinyFaces

Have Questions? Need to talk?

Patricia Chibbaro, RN. NP.
patricia@myface.org
917.720.4712



Scan Here to Catch up on Ask Pat Videos

myFace

Support Groups

Created for craniofacially affected individuals and their families, our myFace virtual support groups offer a safe, welcoming space to connect with people who truly understand your experiences.

Please note: These are peer support groups, not clinical therapy sessions.

TEEN & ADOLESCENT SUPPORT GROUPS

PARENT SUPPORT GROUPS

ADULT SUPPORT GROUPS

SPANISH-SPEAKING PARENT SUPPORT GROUP/
GRUPO DE APOYO PARA PADRES



SCAN HERE TO LEARN MORE!

MOMS OF myFace

Moms of myFace is a safe, supportive sisterhood for mothers of children with craniofacial differences and complex medical needs—an essential lifeline when the journey feels isolating, overwhelming, and hard to navigate alone.

We're here to connect you—to one another, to community, and to yourself—filling a gap too often left unspoken.

More than a network—it's a movement. Join us, experience the sisterhood, and help build something that grows with you—and because of you.

- Reclaim the **joy and celebration** of motherhood.
- Honor the **strength and courage** of raising a child with craniofacial differences or complex medical needs.
- Feel truly **seen, heard and supported** by those who get it.

LEARN MORE HERE:



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myFace



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