

Changing Faces, Transforming Lives

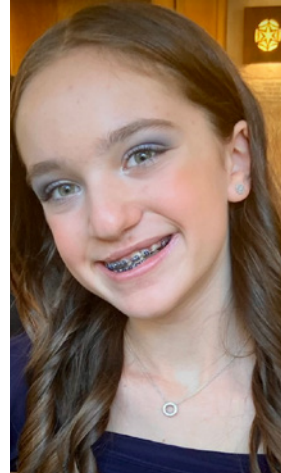
OY TO THE WORLD A MITZVAH PROJECT TO HELP FAMILIES IN NEED

Meet Emily. She's a smart and talented 7th grader. Her favorite subject is math and she loves to sing in her school's musicals and acapella group.

What also makes Emily special is her unbeatable smile, regardless of being born with a cleft lip and palate. Approximately 1 in 700 babies in the world are born with a cleft each year, which can cause difficulties eating, breathing, hearing, and speaking. Emily was fortunate to have had her surgeries performed by Dr. David Staffenberg - first when he was part of the team at the **Children's Hospital at Montefiore** (CHAM), and then later when he moved to the **myFace Center for Craniofacial Care** at NYU Langone Health - where she continued her care. And while now all that remains is a barely visible scar above her lip, she recalls her mom telling her how the specially designed cleft bottles she used to feed Emily during the first year of her life made all the difference in the world.

Now that she's 12 years old and becoming a Bat Mitzvah, Emily wanted to do something deeply personal and meaningful, and give back to the community that helped her and her family when they needed it most.

Knowing that compassion, giving to those in need, and making the world a better place is a "mitzvah," Emily was inspired to dedicate her Mitzvah Project to support myFace.



She found that the **myFace Newborn Craniofacial Care Kit** program was a perfect project as it helps families with limited financial resources receive the items they need to care for their babies born with a cleft. The kits include everything needed for the first month of a baby's life, including those specially designed bottles that helped Emily and her parents twelve years ago.

So far, Emily has raised close to \$1,400 from family and friends who were inspired to support her efforts - enough to provide 8 newborn care kits! She told us that even people that she didn't know directly were moved by her story and wanted to help by making a donation.

Mazel Tov, Emily! We applaud your thoughtfulness and compassion, and your desire to do what you can to make this world a better place.

If you are planning a Mitzvah Project of your own or a special fundraiser, please contact Karen Lazarus at 917-720-4715. To learn more about the **myFace Newborn Craniofacial Care Kit Program**, use the QR Code here.



myFace Celebrates... is back!

Save the Date:
**MONDAY
MAY 15
2023** The Edison Ballroom
240 West 47th Street, NYC

In-person benefit, cocktail party & dessert reception
and livestream broadcast

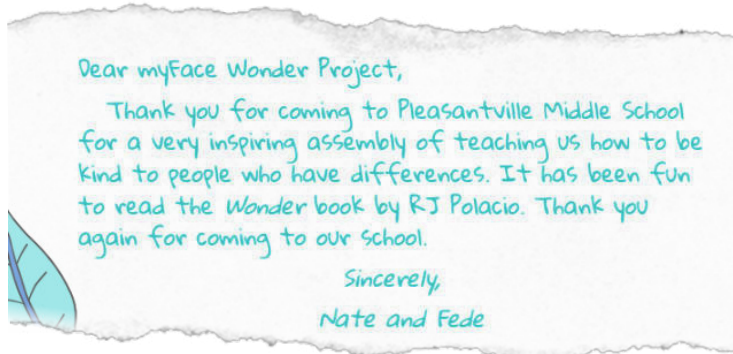
Join us as we share messages of
hope, resilience and community
through musical performances and storytelling
to benefit the craniofacial community.

THE MYFACE WONDER PROJECT

INSPIRING A NEW GENERATION AT PLEASANTVILLE MIDDLE SCHOOL

Each year, myFace brings the **Wonder Project** to thousands of students across the country (both virtually and in person) to spread messages of kindness and how to be an Upstander against bullying.

A recent **Wonder Project** assembly was particularly special for Dina Zuckerberg, myFace Director of Family Programs, who was invited to meet 150 5th grade students at Pleasantville Middle School. She was invited by Colleen Sullivan, president of the school's Special Education PTA (SEPTA); and parent of Aidan, now 21, who was born with Goldenhar Syndrome and developmental delays. Aidan has been a patient at the **myFace Center for Craniofacial Care** at NYU Langone Health since birth.



Colleen was thrilled when her younger daughter Kaylee read R.J. Palacio's book WONDER when she was a student at Pleasantville, the book on which the **Wonder Project** is based. The book's main character, Auggie, was particularly special for Kaylee, as he gave her a deeper understanding of her brother's experiences. Seeing firsthand how the book's themes of compassion, empathy, acceptance and inclusion affect readers, Colleen was eager to bring WONDER to a new generation of Pleasantville students.

"I wanted Dina to come to our community and share her journey with the kids, and talk about the obstacles that she and other people with craniofacial differences - like my son - must navigate and overcome on a daily basis. The myFace Wonder Project helps students, like my daughter, take the lessons from the book and apply them in real life. It was a pleasure and honor to bring this program to my community's school!" - Colleen

ASK THE EXPERTS: Q & A

From left to right: Randall A. Bly, MD and Aijiana Zanders, AuD, CCC-A, (Seattle Children's Hospital); and Courtney and Austin Cole, who provided the parent and patient perspectives



In October 2022, myFace presented a webinar on "Management of Hearing Loss Associated with Cleft Lip/Palate and Other Craniofacial Conditions" as part of our free **Transforming Lives** series:

My son doesn't want to wear his hearing aid. Do you have any suggestions to help overcome this?

Dr. Zanders: We see this a lot, as kids often don't want to stand out or appear different. It may be helpful for him to meet another child who wears a hearing aid, and shares similar experiences. Ask your audiologist if they have a social/support group or family gathering. Also, it may help for the audiologist to demonstrate to him that he is able to hear better with his hearing aid versus without it. I also encourage families to make using a hearing aid a positive experience, and give their child some ownership over their hearing aids. It can also be great to connect with the school teacher and/or audiologist to provide additional support for their child as well.

Courtney: We had this experience with Austin. We tried to be positive and encouraging, rather than getting on his case about it. For example, we would let him know that he was missing out on fun things - like invitations to parties - because he couldn't hear those conversations if he wasn't wearing his hearing aid. That helped. And once he started using the Frequency Modulated (FM) system, he actually began to appreciate his assistive listening devices.

Courtney: What factors tipped your decision towards undergoing surgery?

Courtney: Even with the hearing aid and FM system, Austin was still missing out on a lot. After investigating different surgical options, we sat Austin down and said "This is what we're thinking - how do you feel about this?" We had developed a lot of trust in Dr. Bly. Austin had to undergo 2 major surgeries, but his hearing was dramatically improved by this approach.

Dr. Bly: I try to give families the information they need about available hearing devices and implants - as well as potential surgical options - so that they are empowered to make the best decision for their child. A lot of hearing devices are FDA approved for

Continued on the back page

MYFACE'S ANNUAL HOLIDAY PARTY

WHERE KIDS GET TO CELEBRATE BEING THEMSELVES

For most kids, the idea of going to see Santa Claus is what dreams are made of. But for children with facial differences, going to a mall to sit on Santa's lap means getting stared at and often feeling like an outsider.

That is why myFace hosts an annual holiday party for our children and families - to provide a safe and festive place to celebrate together - but more importantly, a place where each and every member of the craniofacial community can celebrate their unique selves.



On December 8th, nearly 200 members of the myFace Family gathered together, including kids with facial differences and their families, medical and dental students, staff, our Board of Trustees, and of course, Santa! It was such a heartfelt community event, and we are so thankful to everyone who helped make it so special. Like our friends Nikki and Ben Kaufman - parents of a child with a craniofacial condition - who generously hosted our party at their Columbus Circle CAMP store and provided fun arts and crafts activities. Thanks to Michael Muoio of Villa Rustica Pizzeria and Trattoria (who also has a child with a facial difference), the families dined together before meeting Santa.



Because of the outpouring of volunteer support, each child took home a wrapped present to put under their tree. Special thanks goes to Massimo Sheinin, a 14-year-old from NJ born with a cleft lip; NYU Medical Student Sofia Perez Otero;

students from NYU Dental School; members of the Oral Maxillofacial Surgery Society; fellow nonprofit UNITY SME; and the CARES Committee at The Kips Bay Towers - home of myFace headquarters! We are still feeling warm and fuzzy over a month later, and will continue to reflect on the generosity of our community until we gather together again next year!

To see photos of the event, visit myFace.org/gallery/holidayparty2022.

THE MYFACE FAMILY APARTMENTS

JUST ONE OF THE MANY RESOURCES WE OFFER TO OUR COMMUNITY



Meet Dara, a 4th grader from CT who loves doing gymnastics, playing the bass, telling knock knock jokes, and studying science (specifically geology). Dara was also born with a cleft lip and palate, and has been a patient at the **myFace Center for Craniofacial Care** at NYU since she was just four days old.

Dara and her parents recently stayed at the **myFace Family Apartments** when she came to NYC to undergo closure of a fistula (an opening) in her palate - a complication sometimes associated with cleft palate repair. Over the years, Dara has grown to be very confident and talkative. She has learned how to advocate for herself; and readily explains her condition to classmates when asked.

Dara's mother, Ann-Marie, encourages other members of the craniofacial community to take advantage of all of the resources myFace has to offer, saying:

"Although having a child with a craniofacial condition may be challenging at times, it is important to remember the tremendous array of resources we have through myFace. The apartments are just one of them. myFace has truly been there every step of the way - providing both physical and emotional support - which has empowered and prepared Dara and our family to tackle anything that comes our way."

Ask the Experts, continued from page 2

ages 5 and up, so age 5 is the time when we order a computerized tomography (CT) scan and start to consider the various options.

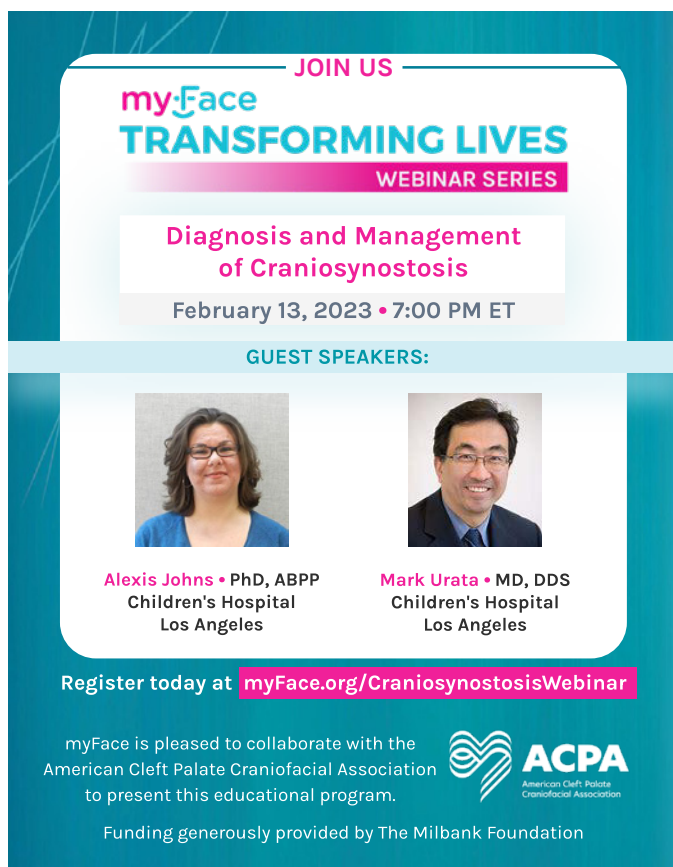
Courtney – what have you done to advocate for Austin?

Courtney: We started Early Intervention as soon as possible, in Austin's Pre-K program. We also set up an Individualized Education Program (IEP) plan as soon as possible. This included some self-advocacy goals for Austin, so that he could learn to advocate for himself. I've also worked hard to build a good relationship with his school.

Austin – how was your hearing improved by the surgery?

Austin: After taking just a step outside, I felt like a new person! I could hear things the most clearly I ever have. I felt like the world just said "hello" to me, and welcomed me in.

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



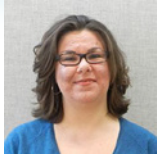
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TRANSFORMING LIVES
WEBINAR SERIES


Diagnosis and Management of Craniosynostosis

February 13, 2023 • 7:00 PM ET

GUEST SPEAKERS:




Alexis Johns • PhD, ABPP
Children's Hospital
Los Angeles



Mark Urata • MD, DDS
Children's Hospital
Los Angeles

Register today at myFace.org/CraniosynostosisWebinar

myFace is pleased to collaborate with the American Cleft Palate Craniofacial Association to present this educational program.



ACPA
American Cleft Palate
Craniofacial Association

Funding generously provided by The Milbank Foundation

THE FIGHT FOR ELSA WILL CONTINUE IN 2023



myFace, along with a broad coalition of 70+ national health care professional and patient advocacy organizations, took part in a number of advocacy initiatives led by the National

Foundation of Ectodermal Dysplasias (NFED) throughout 2022 to advocate for the passage of an important piece of legislation: the **Ensuring Lasting Smiles Act (ELSA)**.

Unfortunately, despite being passed in the House of Representatives with 310 votes on April 4th, 2022 - and gaining 62 sponsors/cosponsors in the Senate - **ELSA** was not ultimately passed into law in the 117th Congress that ended on January 3rd, 2023.

The goal of **ELSA** is to close health insurance loopholes that currently prevent individuals born with congenital and craniofacial anomalies from getting the coverage they need for medically necessary treatments and procedures, and to guarantee comprehensive coverage for these individuals from birth through adulthood. This piece of legislation would be a game changer for individuals with facial differences and their families, and myFace will not stop fighting until it is passed into law.

Although we are disappointed with this outcome, our work on this front will continue. We made a lot of progress building bipartisan support for **ELSA** this year, which we hope to expand upon in 2023. We are so grateful to each and every one of you who joined in our advocacy efforts throughout the past year, and will be in touch again soon with further updates as the fight for **ELSA** continues!

To join our advocacy efforts, visit myFace.org/ELSA



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

333 East 30th Street, Lobby Office, New York, NY 10016 • myFace.org • 917.720.4701

myFace is a non-profit organization dedicated to changing the faces - and transforming the lives - of children and adults with facial differences.