

Changing Faces, Transforming Lives

MEET EMILY.

A SPIRITED "WARRIOR" AND PASSIONATE ADVOCATE FOR THE CRANIOFACIAL COMMUNITY

Emily is not your ordinary 24-year-old. In fact, she's quite extraordinary.

Emily was born with a rare craniofacial condition called Apert Syndrome causing her facial, skull bones and digits to fuse together too early in development.

She's had so many surgeries to date she doesn't even remember all of them. Emily acknowledges her life has not been easy, dealing with all the obvious physical struggles and the many psychosocial and developmental challenges as a result of her condition. However, she feels they have made her tougher and stronger, and the spirited "warrior" she is today.

Emily has worked hard to get to where she is. She is currently studying at Nassau Community College earning her degree in Administrative Business Technology and works part-time at an agency that helps provide services for people with intellectual and developmental disabilities.

For Emily, giving back is part of her core, and one of the reasons she has become an active part of myFace, especially through her participation in the **Adult Support Group** and **myFace, myStory Broadcast Series**, where she has a platform to share her voice, her story and be an advocate for others like her.

Emily wants people to know that "no matter what kinds of obstacles life may throw at us, we must always remember to keep moving forward and never give up on something that we really want to see ourselves accomplish."

Bravo, Emily, for all you do and for all you fight for. You are an inspiration to us all.



"What I mostly admire about being a part of myFace is getting the opportunity to be an advocate for others like me by sharing my story and letting them know it's okay to embrace your differences. Because what you think about yourself is more important than what a stranger walking on the other side of the street thinks of you."



On Sunday, September 19th, close to 300 individuals and 46 teams came together across the nation for our **9th Annual Races for Faces Virtual Kickoff Celebration**, celebrating differences, promoting acceptance and bringing awareness to the craniofacial community.

With your support, we raised over \$200,000!

Thank YOU for making this possible.

Visit RacesForFaces.org to view the virtual broadcast.



A SAFE HAVEN FOR PATIENTS AND FAMILIES

GENEROUS DONATIONS MAKE IT POSSIBLE FOR MYFACE TO PROVIDE FREE ACCOMMODATIONS

Laura and Malcolm Beeler are so grateful to myFace for being able to stay in the myFace apartments over the years while they've sought treatment for their daughter, Ava. Now 18, Ava was born with Pfeiffer Syndrome and a cloverleaf skull, a rare and complex craniofacial condition which presented a host of medical problems that required many trips for surgeries and treatment to the myFace Center for Craniofacial Care at NYU Langone Health.

Living in northern CT, the Beelers are too far away to make day trips back and forth when Ava needs an extended stay. The apartment has enabled them to focus on getting care for their daughter without the worry or expense of staying in a hotel in NYC.

"Having the apartment across the street from the hospital has been incredibly convenient. My husband and I can take turns sleeping at the hospital with Ava while getting a good night's rest in the apartment. Everything is provided for, even things for siblings. We can bring food in or cook if we want, and we can take a nap there anytime. It's helpful to Ava because she can sleep there the night before surgery and not have to stress about being late or traveling." - Laura Beeler



If you are a craniofacial patient and/or family coming to NYC for treatment and are in need of accommodations, contact John Hume at John@myFace.org. myFace is here for you!

ASK THE EXPERTS

On August 10, 2021, myFace presented a free educational webinar as part of our *Transforming Lives* series focused on helping parents create the building blocks for a successful school year, home life, and social interactions for children with craniofacial diagnoses. Below are some of the questions posed during the live Q&A to three expert pediatric psychologists.



Pictured from left to right: Dr. Marik, Dr. Johns, and Dr. Magee

Q for Dr. Patricia K. Marik, PsyD, Children's Wisconsin: "My 5-year-old is very worried about his upcoming surgery. How can I help him prepare for it?"

A: "There are a number of things that children may find helpful when preparing for surgery: (1) Watch a cartoon about surgery, engage in medical play with dolls to rehearse the procedure, and/or do a pre-surgical hospital tour; (2) Be involved in the planning process by figuring out what to bring for their hospital stay (e.g., stuffed animals, toys, pajamas, movies, etc.); (3) Emotional regulation tools such as relaxation breathing may also help reduce anxiety."

Q for Dr. Alexis Johns, PhD, ABPP, Children's Hospital of LA: "My child was cyberbullied on social media and is now asking to be home-schooled. What do you recommend?"

A: "Although it may be tempting to protect your child from negative experiences that can happen at school through homeschooling, this can also do your child a disservice as school provides a valuable opportunity to learn coping and other "real life" skills. Working with school administrators to address cyberbullying can often be a good first step. You can also explore the many useful resources on [Stopbullying.gov](https://www.stopbullying.gov). It is important to give your child lots of support so they feel confident remaining in school, and to ensure that they have many positive social experiences outside of school."

Continued on the back page

AN IMPORTANT LESSON ON GETTING YOUR CHILD'S CONFIDENCE TO SHINE THROUGH

Kelly Vurinaris is an international, bestselling children's book author. But first and foremost, she is mom to beautiful 6-year-old daughter, Zoe, who was born with Treacher Collins Syndrome, a rare craniofacial syndrome that affects the formation of the ears, eyelids, cheek bones, and jawbones. Because Zoe was also born with microtia and atresia, her ears are underdeveloped and she has to wear a cochlear hearing aid.



"Everyone has a difference. Some you see and some you don't, but everyone deserves the same respect and love." I thought if this book helped my daughter, it could help others."

While Zoe has a lot to deal with and may look different from other kids, she is just like anyone else her age. Kelly shares that Zoe is "as smart as a whip," and the most "caring, empathetic, strong, brave, and awesome girl ever!" She loves to play with her friends and is always making new ones. She loves to sing, dance, play the piano, and dress up as Elsa from *Frozen*!

It's no wonder that Zoe inspired her to write her first children's books, *Hi, I'm Me* and *Hi, I'm Me in Kindergarten*, where Kelly shares the experiences her daughter and family go through in their everyday life and the lessons they've learned along the way. Whether it's dealing with someone staring in the store, or interacting with classmates at school; as a mom, you want to be there to protect your child, even though that's not always possible.

That's why Kelly believes in teaching kids that if you use your voice, your undiscovered confidence will shine through. Kelly saw the transformation firsthand with Zoe and how, by learning to use her voice, she could control the outcome of a situation and be the confident, outgoing and empowered little girl she is - and that all kids deserve to be.

To see Kelly read from her book during the myFace **Virtual Summer Series**, visit bit.ly/KellyVurinarisVSS.

MYFACE, MYSTORY A CONVERSATION WITH SISTERS

myFace launched a new monthly podcast in June 2021 hosted by Dina Zuckerberg, Director of Family Programs. The series - **myFace, myStory: Voices from the Craniofacial Community** - aims to inform and educate the general public about craniofacial differences and the issues that individuals and families of the community face; with each episode sharing a different personal journey and perspective. The third episode, "A Conversation with Sisters," featured best-selling author, comedian, and internet sensation, Sarah Cooper, and her sister, Charmaine Cooper, an accomplished nurse practitioner. Charmaine was born with Treacher Collins Syndrome and deafness, and in this episode, she offers her firsthand experience living with a facial difference, while Sarah provides a heartfelt sibling perspective.

Sarah felt that the podcast offered the opportunity to ask her sister questions about her facial differences that she had never asked before, saying, "I'm 43 and she's 50 now and we're having the conversations that I wish we had had when we were a lot younger."

When asked what advice she would give her younger self, Charmaine answered, "Ask for help and tell people how you feel. I'm not sure I ever communicated how I feel."

Sarah asked her sister, "When you meet someone, would you want someone to ask about it? How do you feel about being asked about [your facial difference]?" Charmaine responded that while there is a time and place for curiosity, "If it comes from a good place, ask me! It's okay to ask because if you don't know, knowledge is power."

This conversation has so many moments of genuine sisterly love, humor, and heart. In case you missed it, visit bit.ly/myfacemystoryCooperSisters to learn all the ways to watch/listen!



CAMP REFLECTIONS GIVES KIDS WITH DIFFERENCES A SUMMER THEY WON'T FORGET

myFace is delighted to have joined forces once again with Harbor Camps/Camp Reflections in New Hampshire, led by founder, Nick Teich. The week-long program is designed for youth, ages 8-16, living with a craniofacial difference and their siblings, providing them a safe, non-judgmental environment where they can simply be themselves. The camp encourages interaction the old-fashioned way - lots of crafts, games and activities - including fun, late-night cabin talks - that encourage camaraderie and promote understanding. Through your support, you enabled 7 campers to attend and have a very special, memorable summer experience. Just hear what some of the kids had to say:

"I participated in Camp Reflections because this was a safe place for me. I don't see people like me a lot back home, so this was a great place for me to express myself and be myself."
- Hector

"As a sibling, I chose to go to Camp Reflections because it's cool to learn about other people's stories that are almost identical to my brother's. It really helps me understand where my brother is coming from." - Gino

"Going to Camp Reflections made me feel loved and welcomed. It's an amazing place where I can be myself." - Jocelyn

Thank you, Nick Teich, and the staff at Camp Reflections for giving these kids a summer they won't forget.



ASK THE EXPERTS

Continued from page 2

Q for Dr. Leanne Magee, PhD, Children's Hospital of Philadelphia: "As parents, we spend a lot of time tending to the medical needs of our child with a craniofacial condition, and his unaffected sibling is becoming jealous. What can we do to prevent our other child from feeling neglected?"

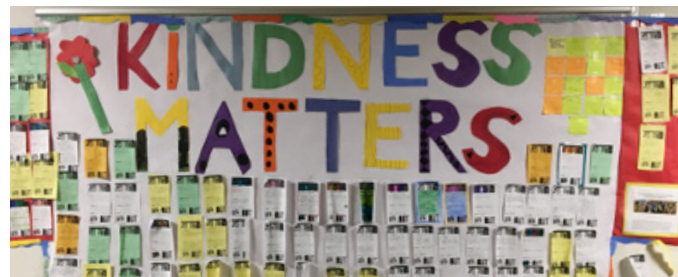
A: "Children with medical needs sometimes do get more time and attention from parents than their unaffected siblings. To provide balance, it can help to make sure that each child gets their own designated, special time with parents. However, if that is not enough to restore family functioning, family counseling may be effective. Also, some hospitals offer support groups for siblings to discuss their unique issues and to connect with other siblings."

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



Bring the myFace Wonder Project & Assembly to your school so students can learn the importance of celebrating differences, choosing kindness and being an "Upstander" against bullying.

Visit myFace.org/wonder or email Dina Zuckerberg at Dina@myFace.org for more information.



For more information or to learn more about the ways you can support myFace, please visit myFace.org/waystogive

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All donations are tax-deductible in accordance with IRS regulations.

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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.