

my Face our stories your impact

Rafi born with Goldenhar Syndrome

myFace is dedicated to

transforming

the lives of patients with facial differences. With a special focus on children and their families, myFace funds medical, dental, speech and psychosocial services as well as research and public awareness.

**Jahzara** born with Goldenhar Syndrome



-Award's

"myFace makes this journey less difficult by providing the resources, education, love and support necessary for us to prioritize our son and his development." - Erin, Edward's mom

Edward was born with a bilateral cleft lip and palate. His parents, Erin and EJ found out about his condition during a sonogram when Erin was 20 weeks pregnant. While the news was shocking at first, they were immediately reassured by Cleft Team Coordinator, Shelley Cohen, MA, CCC-SLP at their pre-natal appointment that when they held their baby for the first time, Edward's cleft wouldn't matter.

Shelley was always available to answer any questions - day or night - give advice and be a tremendous advocate for little Edward, especially during the more challenging times. And thanks to a grant myFace received, they were able to attend a special speech workshop led by Shelley that focused on pre-surgery speech and sound stimulation. While Edward was too young to realize the benefits of this workshop, his parents walked away feeling more knowledgable and empowered to more effectively play, converse and interact with him.

Edward, before surgery

Edward may not yet be able to fully express himself with words, but his ear-to-ear smile says it all.

"We are a strong family as a result of being supported by this amazing organization, and we will be forever grateful for all that myFace has provided us with."

Morgan's

"Even though someone might look different, never judge them because there is so much more to them than what meets the eye."

Morgan is a very confident, outgoing and determined young woman. But that wasn't always the case. Morgan was born with a very rare condition called Apert Syndrome, which affected the development of her face and skull, as well as her hands and feet.

Because she looked different, she was teased a lot while growing up. She was bullied and called all sorts of names to make her feel bad about herself.

However, she considers herself lucky to have 3 sisters who have always stepped in to protect and stand up for her when she could not. Morgan explained that her sisters always believed in her and never treated her any differently. They pushed her to do everything they did. As a result, she continues to excel in school and is a decorated athlete. And it is because of them that she is a stronger person today.

What makes Morgan so special is her desire to give back and help others who might be going through the same journey and challenges that she faced growing up. This summer, Morgan signed up to be a counselor at a camp for craniofacial patients and their siblings. myFace sent 7 kids to this camp where she served as a role model and showed them that it is okay to be different.

"I want to be the one who people can look up to and know I have their back and their best interest at heart. myFace has shown me that I am not the only one battling this battle, and that there are other people just like me."

In the U.S., more than half a

'lillion

individuals have been diagnosed with a craniofacial condition.



## The my face Center

The myFace Center for Craniofacial Care at the Hansjörg Wyss Department of Plastic Surgery at NYU Langone Health is a world-class medical facility. The myFace Center provides integrative, highly specialized, and personalized team care to all those who request treatment, regardless of the type or severity of the anomaly, the length of treatment, or the family's ability to afford care.

The myFace Center is staffed with leading experts in every facial anomaly all under one roof. Embracing a team approach, specialists meet regularly to evaluate patients with complex problems and formulate comprehensive treatment plans. It is this comprehensive and holistic approach that makes the myFace Center one-of-a-kind and the gold standard for craniofacial care.

Left: David A. Staffenberg, MD, DSc (Hon) Vice Chairman for Pediatric Plastic Surgery myFace Center for Craniofacial Care Hansjörg Wyss Dept. of Plastic Surgery, NYU Langone Health Alonso, born with Crouzon Syndrome & Craniosynostosis

## The Newman Family Support Center

Located within The myFace Center, The Newman Family Support Center includes the most comprehensive psychosocial team of any craniofacial center in the U.S.

### The team at Newman includes a:

- Social Worker
- Clinical Psychologist •
- Geneticist
- Nurse Practitioner
- Speech Pathologists
- Nutritionist
- Family Program Coordinator

### **OUR PSYCHOSOCIAL SERVICES**



Pre and post-natal counseling, feeding & home care instruction



Emotional, behavioral, developmental, family & genetic counseling



Hospital admittance, bedside, waiting room & discharge support



Speech therapy, medical assistance & referrals to local professionals



Networking of families & patients

### **YOUR IMPACT**

Because of your generosity, we were able to support:



Patient Consultations &

**INCLUDING:** 



232 Surgeries Performed



Dental & Orthodontic Procedures



382 Nutrition Consultations



1.300 **Speech Consultations** & Therapy Sessions







Psychological **Evaluations** 



"I want everyone to know that I am more than just my facial difference. I am Mason."

Mason is a little kid with a big personality. It could be because he's a 3rd grader, or because he lives in Queens, NY or because he's already had one surgery for almost every year of his life. Or maybe it's because he's had a very special person in his life (other than his mom, dad, brother and sister!) who has impacted him in a very important way, giving him the confidence to be the special boy he is.

Mason was born with a cleft lip and palate and, at 8 years old, has already had 7 surgeries. While he seems to love everyone at The myFace Center for Craniofacial Care who has played a role in his care and treatment, he has a special fondness for Dr. Etoile LeBlanc, speech pathologist extraordinaire. His mom is convinced she's not any ordinary speech pathologist, but rather someone with superpowers she keeps a secret. Dr. LeBlanc was able to connect with Mason right away and get him to sit through speech therapy lessons. Not only did she make it fun and effective, she made sure he knew how much she genuinely cared about him.

"Dr. LeBlanc showed me that I can do anything I try hard for. Now I speak better and my friends at school can understand me."

When asked what advice he would give to someone else with a craniofacial difference, Mason explained:

"We are all born with differences, some you can see and some you can't, so don't be embarrassed about yours - it makes you special."

### "myFace has been there for our family every step of the way."

- Mason's mom, Alyssa

From the moment they found out about Mason's cleft during Alyssa's pregnancy until now, their family has benefitted from the psychosocial services at The myFace Center. Jennifer Russell, Senior Social Worker, is their go-to person that helps them figure out who to contact and what steps to take whenever they have an issue with Mason. Jenn helps to navigate a process that can be overwhelming when you try to do it alone.

Alyssa and her family are also grateful for the counsel they receive from Dr. Aileen Blitz, Clinical Psychologist, who's given them advice on how to handle the different psychological aspects that come with raising a child with a facial difference. When Mason started looking in the mirror and noticing his scars, Dr. Blitz came to the rescue with resources to help Mason understand what he was feeling.



Mason and his mother, Alyssa.



Etoile LeBlanc, PhD-CCC and Mason.



Jennifer Russell, LCSW, working with Mason and his family at one of our support groups.

## OUR PROGRAMS & OTHER SERVICES

"There is power in the shared story, knowing you are not alone and that someone understands." - Dina Zuckerberg, Director of Family Programs

Many of our patients and their families are reminded of this power when they attend our support groups. Our goal is to empower them to share their stories in these groups. We also want to inspire them to share their stories in their communities to give hope to others and educate the public so no one is teased or excluded because of their differences.

# SUPPORT GROUPS & WORKSHOPS

myFace organizes family support groups and workshops that provide needed guidance and support for our patients, their siblings, and their parents. We also host a variety of networking events and therapeutic and educational programs.

These groups are open to everyone within the craniofacial community and include ones for:

- Parents
- Adolescents
- Pre-Teens
- Siblings
- Adults



"myFace has allowed me to start and co-lead adolescent support groups for youth with craniofacial conditions. It's provided an outlet for these individuals and allowed them to express themselves in ways that they had never experienced before with individuals from similar backgrounds. Being able to co-lead these groups and watch and learn from these kids has been one of the most rewarding experiences of my life." - **Eric,** born with Crouzon Syndrome



"Something I find very helpful is being able to participate in the myFace 'kids' group' where I can freely express myself without being judged and feel safe around others." - Emily, born with Hemifacial Microsomia, Microtia and Microphthalmos

# TRAVEL & HOUSING

myFace provides 3 apartments for out-of-town families and patients undergoing surgery and treatment, as well as complimentary round trip tickets through Southwest Airlines' Medical Transportation Grant Program.

# EDUCATION & PUBLIC AWARENESS

myFace has developed a pro-compassion English Language Arts Curriculum based on the best-selling book, *Wonder*, by R.J. Palacio, to educate students on the importance of having compassion, celebrating uniqueness and always choosing to be kind. The team at myFace also delivers powerful anti-bullying presentations to schools throughout the country. By learning about myFace's work and connecting it to the character of Auggie Pullman, students learn how important it is to be an Upstander and not a bystander.



A school presentation moderated by Dina Zuckerberg, Director of Family Programs

## YOUR IMPACT

Because of your generosity, we were able to support:







**281** One-way Flights





"December 29, 1995 was the day my face changed."

aren's

Karen suffered a traumatic car accident at age 18 where she broke most of the bones on the right side of her face, and lost her right eye. By the time Karen had come to myFace, she already had had close to two dozen surgeries, but this time she was in need of very highly specialized care that only the surgeons at The myFace Center for Craniofacial Care at NYU Langone Health could provide.

Karen lives in California and was afraid that getting this care from some of the top craniofacial surgeons in the country would simply be out of reach. myFace was able to make sure that it wasn't.

"My 22nd procedure took place on June 18, 2019.

The travel and lodging costs would have been exorbitant and put these world-class surgeons out of my reach."

"myFace provided me with an apartment for 1 week and round-trip tickets on Southwest Airlines. I couldn't have received the surgeries I needed at NYU without the help of myFace."

Karen is proud to exclaim that "at age 41, I would say I am the most comfortable I have ever been in my own skin since that fateful day over half a lifetime ago."

ameron's Storv

At 26, Cameron was given a new face and a second chance at life after surviving a gunshot wound to his face which nearly took his life.

Under the leadership of Dr. Eduardo D. Rodriguez, MD, DDS, Chair of the Hansjörg Wyss Department of Plastic Surgery at NYU Langone Health, Cameron underwent a face transplant considered to be the most advanced in the world. Dr. Rodriguez and the surgical team masterfully reconstructed his jaw, teeth, gums, mouth, cheeks, nose and nasal passages so he could begin living life again.

myFace supported Cameron by providing travel for his many trips back and forth between his home in California and NYC, as well as more than 150 nights of free housing for him and his family while on extensive stays in NYC for pre-surgery, surgery, recovery and follow-up.

"myFace is huge. If it weren't for the flight vouchers to get us here, and the apartments

### where we stay, we wouldn't be coming nearly as often as we needed to."

Additionally, myFace was instrumental in supporting Cameron's rehabilitation, by providing speech therapy, orthodontic treatment, nutrition counseling and psychological support services.

"For me, myFace was a great facilitator in taking the burden off of our shoulders as well. It doesn't feel like when we sit down I have to feel like I'm some sort of therapist. [Cameron] doesn't need that from me. He just needs his brother. So thank you, myFace, for that."

- Aaron, Cameron's brother

a while, for a while

## This is my Face TALENT SHOW Featuring our myFace Stars?

'Everyone in the world should get a standing ovation at least once in their life.' - Auggie Pullman, Wonder

The myFace Talent Show showcased the skills of 14 myFace Stars – twelve performers and two artists whose work was displayed and raffled off. The stars included Logan, who performed "Perfect Symphony" by Ed Sheeran and Andrea Bocelli on the piano, Harborfields High School freshman, Wyatt, who sang "Vienna" by Billy Joel, and Grace, who came all the way from Westlake, Texas to perform "Gavotte" by Johann Sebastian Bach.

"These kids are often teased or excluded for their facial difference, so to be recognized and applauded for their talent was truly empowering for them."

- Dina Zuckerberg, Director of Family Programs







In honor of Craniofacial Acceptance Month, myFace hosted its 7th annual Races for Faces walk and carnival on Sunday, September 15, 2019 to raise funds and awareness for the craniofacial community. This year, we had over 600 walkers and 50+ teams the most ever! We couldn't have done it without the support and participation of our myFace Stars, their families, our Grand Marshals - the Capobianco Family - and all the walkers, supporters, sponsors and volunteers who came together to make the day a success.











"If you're not familiar with how they change lives, you should be. The children they help are truly heroic." - Joe Graf, Jr.

The myFace staff had the honor of meeting the Graf family last December: Joe Sr., Nancy, Andreah and Joe Jr. To say they left an impression on us is an understatement.

They came to the myFace offices to present us with a generous donation, specifically from Joe Jr. and his sister, Andreah, who both have a level of empathy and maturity well beyond their years.

Andreah, now a freshman in college, was born with hemifacial microsomia, Goldenhar syndrome and single-sided deafness. She has been a patient of Dr. David A. Staffenberg at The myFace Center for Craniofacial Care for many years; she and her family are grateful for the exceptional quality of care she received. Because of her personal connection to having a facial difference, she formed her own foundation to help raise money and awareness for others like herself. Her goal is to help them achieve "acceptance, greater self-esteem" and feel "empowered to achieve their dreams."

It was Andreah who told her brother, Joe Jr. about myFace and how impressed she was with the medical and psychosocial care we provide so that patients, like herself, can live full and productive lives.

Joe Jr. was taken by her commitment and passion for our cause and decided that he too would offer his support. It is important to note that Joe Jr. is not only a sophomore at NYU with a 3.8 GPA, but also a professional NASCAR race driver with 70+ victories under his belt.

In addition to the \$20,000 Andreah helped raise for myFace through her foundation, Joe Jr. thought it would be a "fantastic idea" to donate \$10,000 of his race winnings from the 2018 season. He also arranged a special, once-in-a-lifetime event for a group of our myFace Stars at Pocono Raceway in July where they met Joe Jr., toured the garage, got into the pitbox on the track and witnessed a real live car race for the very first time. It was a day they will never forget.

Joe Jr. speaks of how much of an impact the book and movie, *Wonder*, had on him. He understands that the emotional challenges that children like Auggie face can be heartbreaking.

"I just hope that more children can experience the acceptance Auggie ultimately gets in *Wonder*. That is really the goal Andreah and I have in mind. Help these children have greater self-esteem and greater acceptance from their peers." - Joe Graf, Jr. Andreah and Joe are articulate and thoughtful individuals whose commitment to giving back and helping others is simply part of the family values they all share.

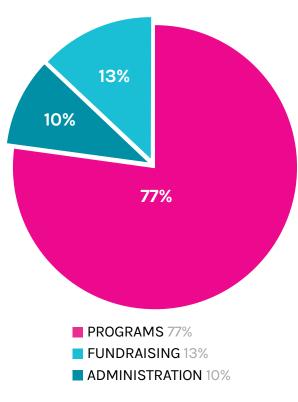
We owe a special thanks to the Graf family for their unwavering commitment, compassion and generosity. And for putting a smile on the faces of so many of our patients, just the same way they've put one on ours!



Joe Graf Jr. and some of our myFace Stars at the Pocono Raceway on July 26, 2019.

## We're proud of how we spend your money.

myFace spends more than 3/4 of its total budget on programs that directly impact our patients and families. (Based on our 2018 Audited Financials.)



We've earned a Platinum Seal of Transparency from Guidestar, their highest ranking and an "exceptional" 4-star rating from Charity Navigator, the largest independent charity evaluator in the United States.





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### 2018 Financial Statements

STATEMENTS OF FINANCIAL POSITION		SEPTEM	1BER 30		
ASSETS	20	018	20	2017	
Cash and case equivalents	\$	292,458	\$	195,383	
Investments		20,337,732		20,823,317	
Pledges receivable - Net		49,798		48,932	
Prepaid expenses and other assets		150,906		49,693	
Property and equipment, net of accumulated depreciation		1,798,337		1,857,229	
TOTAL ASSETS	\$	22,619,231	\$	22,974,554	
LIABILITIES AND NET ASSETS					
Accounts payable and accrued expenses	\$	114,676	\$	131,043	
TOTAL LIABILITIES		114,676		131,043	
CONTINGENCY AND COMMITMENTS NET ASSETS					
Unrestricted		15,410,424		13,949,590	
Temporarily restricted		4,694,131		6,493,921	
Permanently restricted		2,400,000		2,400,000	
TOTAL NET ASSETS		22,504,555		22,843,511	
TOTAL LIABILITIES AND NET ASSETS	\$	22,619,231	\$	22,974,554	

#### STATEMENTS OF ACTIVITIES

	FOR THE YEAR ENDED SEPTEMBER 30, 2018			FOR THE YEAR ENDED SEPTEMBER 30, 2017				
	Unrestricted	Temporarily Restricted	Permanently Restricted	Total 2018	Unrestricted	Temporarily Restricted	Permanently Restricted	Total 2017
SUPPORT AND REVENUE:								
Contributions and grants	\$1,082,880	\$260,644	-	\$1,343,534	\$ 1,016,065	\$ 155,000	\$ -	\$ 1,171,065
Special events (net of direct benefit costs of \$171,048 in 2017 and \$214,666 in 2016)	\$354,698	-	-	354,698	300,705	-	-	300,705
Investment income	1,619,967	301,719	-	1,921,686	1,917,287	189,653	-	2,106,940
Donated goods and services	198,788	-	-	197,788	414,052	-	-	414,052
Other income	111	-	-	111	-	-	-	-
Total public support and revenue before release of restrictions	3,255,444	562,363	-	3,817,807	3,648,109	344,653	-	3,992,762
Net assets released from restrictions	2,362,153	(2,362,153)	-	-	2,009,207	(2,009,207)	-	-
TOTAL PUBLIC SUPPORT AND REVENUE	5,617,597	(1,799,790)	-	3,817,807	5,657,316	(1,664,554)	-	3,992,762
EXPENSES:			-					
Program services	3,189,579	-	-	3,189,579	2,910,394	-	-	2,910,394
Administrative support	419,325	-	-	419,325	841,966	-	-	841,966
Fundraising	547,859	-	-	547,859	251,611	-	-	251,611
TOTAL EXPENSES	4,156,763	-	-	4,156,763	4,003,971	-	-	4,003,971
CHANGE IN NET ASSETS	1,460,834	(1,799,790)	-	(338,956)	1,653,345	(1,664,554)	-	(11,209)
NET ASSETS - BEGINNING OF YEAR	13,949,590	6,493,921	2,400,000	22,843,511	12,296,245	8,158,475	2,400,000	22,854,720
NET ASSETS - END OF YEAR	\$12,410,424	\$4694,131	\$2,400,000	\$22,504,555	\$ 13,949,590	\$ 6,493,921	\$ 2,400,000	\$ 22,843,511

### Your generosity

myFace extends our heartfelt gratitude to the following foundations and corporations who made an outstanding investment in our patients and families this past year.

## my:Face

333 EAST 30TH STREET, LOBBY OFFICE NEW YORK, NY 10016 info@myface.org • 917.720.4701 myFace.org

### Matilda born with a Unilateral Cleft Lip and Palate

Access Capital Foundation Allergan Foundation Ambrose Monell Foundation Andrew and Dana Stone Family Foundation

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#### PHOTOGRAPHY

Ewan Burns: 15, 16 Katie Currid: 11 Robert DiScalfani: 3, 14 (middle) Rick Guidotti: Cover, 1-3, Back cover Mary Spano: All before images - 4,3, 7 Barry Williams (New York Daily News): 12 Reiko Yanagi: 4, 7, 9 (bottom), 13, 14 (top, bottom)

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