

# This is myFace



FY 17|18

# This is myFace

This fall, we launched a special public awareness campaign, **This is myFace**. Our faces tell only part of our story; our experiences tell the other. This is even more so for the craniofacial community. By reaching beyond the faces of our patients and hearing their stories, we delve into their hearts and souls and discover who they are, and what they have overcome. Celebrating their uniqueness, while promoting acceptance of our differences.

**This is myFace** also highlights the highly skilled and compassionate team of medical professionals whose unique approach provides a very specialized level of care that is often hard to find. It further recognizes that none of what we do would be even remotely possible without the support of our staff, Board of Trustees and donors like you.

**This is myFace** is not just a campaign. It's our story.

In the U.S., approximately **600,000 INDIVIDUALS** have been diagnosed with a craniofacial condition.

## OUR MISSION

myFace is a non-profit organization dedicated to **transforming** the lives of patients with facial differences.

With a special focus on children and their families, myFace funds medical, surgical, dental, speech, and psychosocial services as well as research and public awareness.



Akemi before cleft surgery

# This is myFace

## Meet Gospel.

Gospel is a beautiful, vibrant and determined 13-year-old – wise beyond her years. Her home is in Kingston, Jamaica, but she spent the last couple of years in the US living with a host family so that she could undergo the special reconstructive surgeries she desperately needed to correct her cleft lip and palate that couldn't be done back home.

## Gospel's Journey.

While she missed the support of her extended family in Jamaica, she acknowledged that she had to "move away to try to better myself."

Gospel has had 5 corrective surgeries to date – a lot for a young girl, but through her resiliency, determination and support from her host family, she has persevered with a bold, can-do attitude. When asked how she feels now, she proudly stated,

*"My confidence is very high and I don't have low self-esteem anymore. I think what stands out the most is my personality."*

Gospel recently returned back home to Jamaica. She wants everyone to know that she wouldn't be smiling as much as she is today if it weren't for the amazing support and care from myFace.



Gospel before cleft surgery

## OUR SERVICES



Shelley Cohen, MA, CCC-SLP  
Speech Pathologist, myFace Center for Craniofacial Care,  
Hansjörg Wyss Department of Plastic Surgery, NYU Langone Health



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.



**7,000+**  
Patient Consultations  
& Procedures



Located in the myFace Center, the team at Newman includes a: Social Worker • Clinical Psychologist • Geneticist • Nurse Practitioner  
Speech Pathologists • Nutritionist • Family Program Coordinator

### FY 17|18 IMPACT



**192**  
Nutrition  
Consultations



**174**  
Social Work  
Evaluations



**1,077**  
Speech  
Consultations



**458**  
Psychosocial  
Consultations

### SOCIAL & PSYCHOLOGICAL SERVICES INCLUDE:



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



Emotional, behavioral,  
developmental, family  
& genetic counseling



Networking of  
families & patients



Hospital admittance,  
bedside, waiting room  
& discharge support



Speech therapy,  
medical assistance  
& referrals to local  
professionals

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*"Without the support from myFace, we would not be able to have this unique team that's all together in one place for all of our families any time they come in."*

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Pat Chibbaro has nearly 30 years of experience as a nurse practitioner caring for children with craniofacial differences. In this critical role, she serves as the liaison among the patient, the family and all of the health care providers involved: the surgeons, orthodontics team, speech therapists, psychologist, social worker, nutritionist and geneticist. For her, it is about the patient's complete and total care; she often likens it to a "journey." And what a journey it can be! Pat had the honor of attending the bris, bar mitzvah and wedding of one of her patients, bringing that journey full circle. Just as she is an intrinsic part of their lives, she is certainly an intrinsic part of ours.



Hannah & Family | Born with Treacher Collins Syndrome

Margy Maroutsis  
Administrative Manager of Plastic Surgery,  
myFace Center for Craniofacial Care,  
Hansjörg Wyss Department of Plastic Surgery,  
NYU Langone Health

# This is myFace

When Margy Maroutsis first started working at the myFace Center for Craniofacial Care, she was the youngest on the team. Now, thirty-six years later, still nothing is able to slow her down. Day in and day out, as the Administrative Manager of Plastic Surgery, Margy devotes her life to the clinical staff and tirelessly provides compassion to the patients and families we serve. Regardless of the type or severity of the anomaly, the length of treatment, or the family's ability to afford care, she does everything she can to help each patient who walks through the door.

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*Margy will never forget the story of a young boy with a cleft lip and palate she saw decades ago. Thirty years later, his daughter was also born with a cleft. With tears in his eyes, he said to her, "I'll never forget what you did for me and for my family, and now you're going to do the same for my daughter."*

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Patricia Chibbaro RN, MS, CPNP  
Pediatric Nurse Practitioner, myFace Center for Craniofacial Care,  
Hansjörg Wyss Department of Plastic Surgery, NYU Langone Health

Maia | Born with Apert Syndrome

# OUR PROGRAMS



2017 Family Holiday Party

## TRAVEL ASSISTANCE & HOUSING FOR OUT-OF-TOWN FAMILIES

myFace provides three 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.

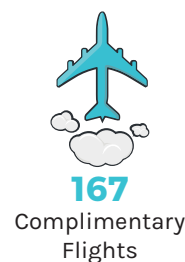
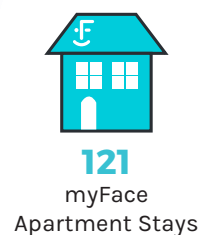
## FAMILY SUPPORT GROUPS & WORKSHOPS

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.

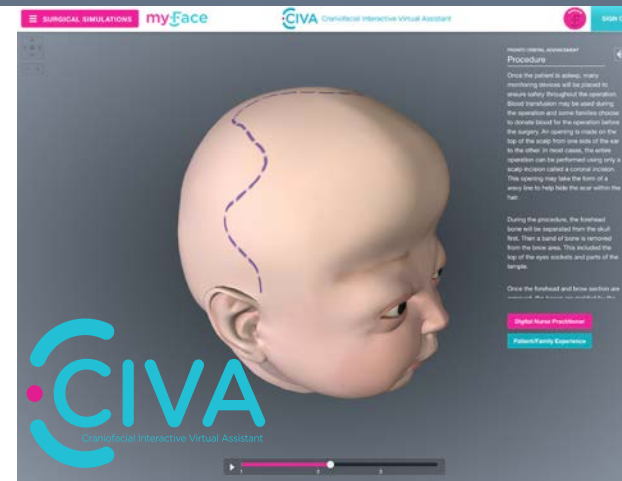
### Groups & Workshops include:

- Parent Group
- Teen/Adult Group
- 10-14 Year-Old Group
- Sibling Group (ages 10-17)

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## THE CRANIOFACIAL INTERACTIVE VIRTUAL ASSISTANT



myFace seeks to relieve the stress and anxiety surrounding craniofacial surgery by providing thorough details on the three stages of the process: pre-operative, surgical and post-operative. CIVA allows you to see and interact with the discrete steps of a specific craniofacial procedure.

CIVA also includes a Nurse Practitioner Consultation portal which speaks directly to any additional technical and medical questions and a Patient Experience portal where a patient or family member describes his/her experience with the specific craniofacial procedure.

CIVA Pro is an online tool designed to educate reconstructive surgeons, fellows and residents by explaining the ten most common craniofacial surgical procedures. Surgeons and medical professionals are now utilizing the technology to better prepare for surgery.



Partnering with Sprigeo and Facing History and Ourselves, myFace developed an English Language Arts curriculum based on the best-selling book *Wonder* by RJ Palacio to raise community awareness of the social stigma surrounding facial difference. The overarching goal of **The myFace Wonder Project** is to promote empathy and kindness, teach acceptance for those with craniofacial differences, and combat the all-too-common issue of bullying. 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.

TO LEARN MORE, PLEASE VISIT [MYFACE.ORG/THE-MYFACE-WONDER-PROJECT](http://MYFACE.ORG/THE-MYFACE-WONDER-PROJECT)

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# This is myFace

## Meet Ofelia.

Ofelia was born in a small town in Mexico. She, along with her grandmother, mother, and sisters were all born with a syndrome called Crouzon - a condition resulting from the premature fusion of the skull. However, in Mexico, no one could diagnose their condition.

Ofelia and her family even traveled hundreds of miles to Mexico City from their remote village where a doctor gave the family special pills thinking it would cure them. Unfortunately, the pills did not work. Ofelia had bulging wide-set eyes, one of the most common characteristics of Crouzon Syndrome, and was teased and bullied a lot as a child.

## Ofelia's Journey.

When she was 15, her parents heard about an organization in the United States that specialized in treating this craniofacial condition. That organization was myFace. When they contacted us, we stepped in to arrange transportation and accommodation for Ofelia to stay in New York City and receive the medical care she desperately needed. It was Dr. Joseph McCarthy, the head, at the time, of the Institute for Reconstructive Plastic Surgery, who operated on her. Ofelia was the first one in her family to have surgery. And it completely changed her life.

Ofelia recalled how every morning the doctors would visit her in her hospital room to see how she was doing. They gave her so much support and encouragement. While it was a very painful and long recovery, she knew that this would only be temporary. Her new face would last a lifetime.

*"I owe so much to myFace for providing me and my family with the life-changing surgery and care we would have otherwise never received. You've not only changed my face, but you've given me a new life."*

When Ofelia looked at herself in the mirror, she realized how her new face gave her so much self-confidence, and, as a result, she enjoyed going out, making new friends and meeting new people. New York City became her home, and she soon met her husband with whom she has 2 children.

As fate would have it, both of her children were born with Crouzon Syndrome. But luckily, they are also being treated at the myFace Center, where they are receiving the expert, comprehensive care that will not only change their faces, but transform their lives, just as it did for Ofelia almost 15 years ago.



Ofelia, with Her Son, Gabriel | Born with Crouzon Syndrome



Ofelia before surgery



Ofelia | Participating in a myFace Teen/Adult Support Group



David A. Staffenberg, MD, DSc (Hon)  
Vice Chairman for Pediatric Plastic Surgery,  
myFace Center for Craniofacial Care,  
Hansjörg Wyss Department of Plastic Surgery, NYU Langone Health

Giuliana | Born with Craniosynostosis

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"We have a rich history and culture of innovation and tackling the toughest of the tough. And because of that, people continue to come to us from all over the United States and all over the world for care. No one has been able to reproduce the level of comprehensive care we provide."

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Dr. Roberto Flores is a very special surgeon and individual. He has an unmatched devotion to our pediatric patients, providing them with an unsurpassed level of care. He serves as the Joseph McCarthy Associate Professor of Reconstructive Plastic Surgery at the Hansjörg Wyss Department of Plastic Surgery and is the Director of the Cleft Lip and Palate Program. He has helped so many children like Bobby in the photo below, giving them the chance they may otherwise never get to lead a full and productive life.

# This is myFace

Dr. David Staffenberg is a renowned pediatric plastic surgery expert and serves as the Professor of Plastic Surgery and Vice Chair for Pediatric Plastic Surgery at the Hansjörg Wyss Department of Plastic Surgery. He may have many roles, but has one true passion: helping others. For him, craniofacial surgery is the subspecialty that makes the most dramatic and immediate difference for patients. He is not only a brilliant surgeon who can transform a face, he transforms their lives. He gets to know his patients which allows him to tailor his surgery to them, making his approach to each patient a singular special endeavor.

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Dr. Staffenberg acknowledges that the "biggest secret sauce" they have at the craniofacial center is myFace. "It's sort of like the nuclear power that keeps everything together. And it keeps us performing at the level that the babies and children demand of us."

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Roberto Flores M.D.,  
Director of Cleft Lip & Palate Program  
myFace Center for Craniofacial Care,  
Hansjörg Wyss Department of Plastic Surgery, NYU Langone Health

Bobby | Born with Treacher Collins Syndrome

*"The generous services I've received through myFace have enabled me to resume daily activities and functions I have been incapable of doing for more than a decade of my life."*

In August 2015, Patrick Hardison received the most extensive face transplant in the world. He was a volunteer firefighter from Senatobia, Mississippi and suffered severe facial burns in responding to a house fire in 2001. He lost his face - his ears, lips, eyelids, and most of his nose. Dr. Eduardo Rodriguez, the Chair of the Hansjörg Wyss Department of Plastic Surgery at NYU Langone Health, worked tirelessly to offer Patrick the chance at a new face, performing procedures never been done before, and ultimately exceeding all expectations.

myFace has played a critical and integral role in Patrick's journey, providing transportation and housing throughout his treatment, as well as access to comprehensive dental and psychosocial care, essential to his physical and emotional recovery.



Pradip R. Shetye, DDS, BDS, MDS  
Director, Craniofacial Orthodontic Dental Center, myFace Center for Craniofacial Care,  
Hansjörg Wyss Department of Plastic Surgery, NYU Langone Health

# This is myFace

The role of the orthodontist is absolutely vital to a patient with a craniofacial condition. myFace is lucky to work with one of the best, Dr. Pradip R. Shetye, who, as the Director of the Craniofacial Dental Center, offers all phases of comprehensive orthodontic treatment for children, teens and adults. Good pre and post surgical orthodontics ensures better surgical outcomes and can potentially reduce the number of surgeries needed. Craniofacial patients often require significant orthodontics care throughout their life, and myFace's support of this discipline is critical, as the cost will easily exceed any dental insurance benefit.

*Dr. Shetye is proud of the fact that myFace ensures "all patients, irrespective of their financial resources, get the quality treatment they deserve."*



FY 17|18 IMPACT

  
**5,108**  
Dental and  
Orthodontic Procedures

Dental insurance covers approximately \$1,000-2,000 lifetime benefit. Orthodontics for these patients far exceeds the amount of coverage. myFace steps in to support patients for this care.



# RACES FOR FACES



# FINANCIALS

## STATEMENTS OF FINANCIAL POSITION

SEPTEMBER 30

| ASSETS  | 2017                 | 2016                 |
|---|----------------------|----------------------|
| Cash and case equivalents                               | \$ 195,383           | \$ 170,416           |
| Investments   | 20,823,317           | 20,343,026           |
| Pledges receivable - Net                                | 48,932               | 276,594              |
| Prepaid expenses and other assets                       | 49,693               | 239,951              |
| Property and equipment, net of accumulated depreciation | 1,857,229            | 1,916,447            |
| <b>TOTAL ASSETS</b>                                     | <b>\$22,974,554</b>  | <b>\$22,946,434</b>  |
| <b>LIABILITIES AND NET ASSETS</b>                       |                      |                      |
| <b>LIABILITIES</b>                                      |                      |                      |
| Accounts payable and accrued expenses                   | \$ 131,043           | \$ 91,714            |
| <b>TOTAL LIABILITIES</b>                                | <b>131,043</b>       | <b>91,714</b>        |
| <b>CONTINGENCY AND COMMITMENTS</b>                      |                      |                      |
| <b>NET ASSETS</b>                                       |                      |                      |
| Unrestricted  | 13,949,590           | 12,296,245           |
| Temporarily restricted                                  | 6,493,921            | 8,158,475            |
| Permanently restricted                                  | 2,400,000            | 2,400,000            |
| <b>TOTAL NET ASSETS</b>                                 | <b>22,843,511</b>    | <b>22,854,720</b>    |
| <b>TOTAL LIABILITIES AND NET ASSETS</b>                 | <b>\$ 22,974,554</b> | <b>\$ 22,946,434</b> |

## STATEMENTS OF ACTIVITIES

|   | FOR THE YEAR ENDED SEPTEMBER 30, 2017 |                        |                        |                      | FOR THE YEAR ENDED SEPTEMBER 30, 2016 |                        |                        |                      |
|---|---------------------------------------|------------------------|------------------------|----------------------|---------------------------------------|------------------------|------------------------|----------------------|
|   | Unrestricted                          | Temporarily Restricted | Permanently Restricted | Total 2017           | Unrestricted                          | Temporarily Restricted | Permanently Restricted | Total 2016           |
| <b>SUPPORT AND REVENUE:</b>   |                                       |                        |                        |                      |                                       |                        |                        |                      |
| Contributions and grants  | \$ 1,016,065                          | \$ 155,000             | \$ -                   | \$ 1,171,065         | \$ 3,049,406                          | \$ 995,354             | \$ -                   | \$ 4,044,760         |
| Special events (net of direct benefit costs of \$171,048 in 2017 and \$214,666 in 2016) | 300,705                               | -                      | -                      | 300,705              | 468,787                               | -                      | -                      | 469,787              |
| Investment income   | 1,917,287                             | 189,653                | -                      | 2,106,940            | 1,390,061                             | 87,243                 | -                      | 1,477,304            |
| Donated goods and services  | 414,052                               | -                      | -                      | 414,052              | 145,401                               | -                      | -                      | 145,401              |
| Other income  | -                                     | -                      | -                      | -                    | 2,042                                 | -                      | -                      | 2,042                |
| Total public support and revenue before release of restrictions                         | 3,648,109                             | 344,653                | -                      | 3,992,762            | 5,055,697                             | 1,082,597              | -                      | 6,138,294            |
| Net assets released from restrictions   | 2,009,207                             | (2,009,207)            | -                      | -                    | 910,129                               | (910,129)              | -                      | -                    |
| <b>TOTAL PUBLIC SUPPORT AND REVENUE</b>   | <b>5,657,316</b>                      | <b>(1,664,554)</b>     | <b>-</b>               | <b>3,992,762</b>     | <b>5,965,826</b>                      | <b>172,466</b>         | <b>-</b>               | <b>6,138,294</b>     |
| <b>EXPENSES:</b>  |                                       |                        |                        |                      |                                       |                        |                        |                      |
| Program services  | 2,910,394                             | -                      | -                      | 2,910,394            | 2,908,534                             | -                      | -                      | 2,908,354            |
| Administrative support  | 841,966                               | -                      | -                      | 841,966              | 420,253                               | -                      | -                      | 420,253              |
| Fundraising   | 251,611                               | -                      | -                      | 251,611              | 361,443                               | -                      | -                      | 361,443              |
| <b>TOTAL EXPENSES</b>   | <b>4,003,971</b>                      | <b>-</b>               | <b>-</b>               | <b>4,003,971</b>     | <b>3,690,230</b>                      | <b>-</b>               | <b>-</b>               | <b>3,690,230</b>     |
| <b>CHANGE IN NET ASSETS</b>   | <b>1,653,345</b>                      | <b>(1,664,554)</b>     | <b>-</b>               | <b>(11,209)</b>      | <b>2,275,596</b>                      | <b>172,468</b>         | <b>-</b>               | <b>2,448,064</b>     |
| <b>NET ASSETS - BEGINNING OF YEAR</b>   | <b>12,296,245</b>                     | <b>8,158,475</b>       | <b>2,400,000</b>       | <b>22,854,720</b>    | <b>10,020,649</b>                     | <b>7,986,007</b>       | <b>2,400,000</b>       | <b>20,406,656</b>    |
| <b>NET ASSETS - END OF YEAR</b>   | <b>\$ 13,949,590</b>                  | <b>\$ 6,493,921</b>    | <b>\$ 2,400,000</b>    | <b>\$ 22,843,511</b> | <b>\$ 12,296,245</b>                  | <b>\$ 8,158,475</b>    | <b>\$ 2,400,000</b>    | <b>\$ 22,854,720</b> |

For the last 7 years, myFace has hosted Races for Faces, a fun-filled family day, including carnival activities for our families and a walk to raise awareness for the craniofacial community.

# This is myFace

## Meet Jahzara.

Jahzara is a spirited 10-year-old living in New York City. She was born with Goldenhar Syndrome, making her lower mandible life-threateningly small. Before age one, she had already had three radical surgeries with metal pins hanging from her face. Although she has many scars, she has always embraced them, and doesn't seem to let anything stop her. One of her many passions is music, and, in fact, she has already composed four songs on the piano. Her music teacher, and those who hear her play, are in awe of her talent.

Jahzara recognizes that she wouldn't be where she is today without the help of myFace, whom she considers her extended family.

***"Someone told me at a myFace meeting; you're not different, you're special."***

And she certainly is.



Jahzara before surgery

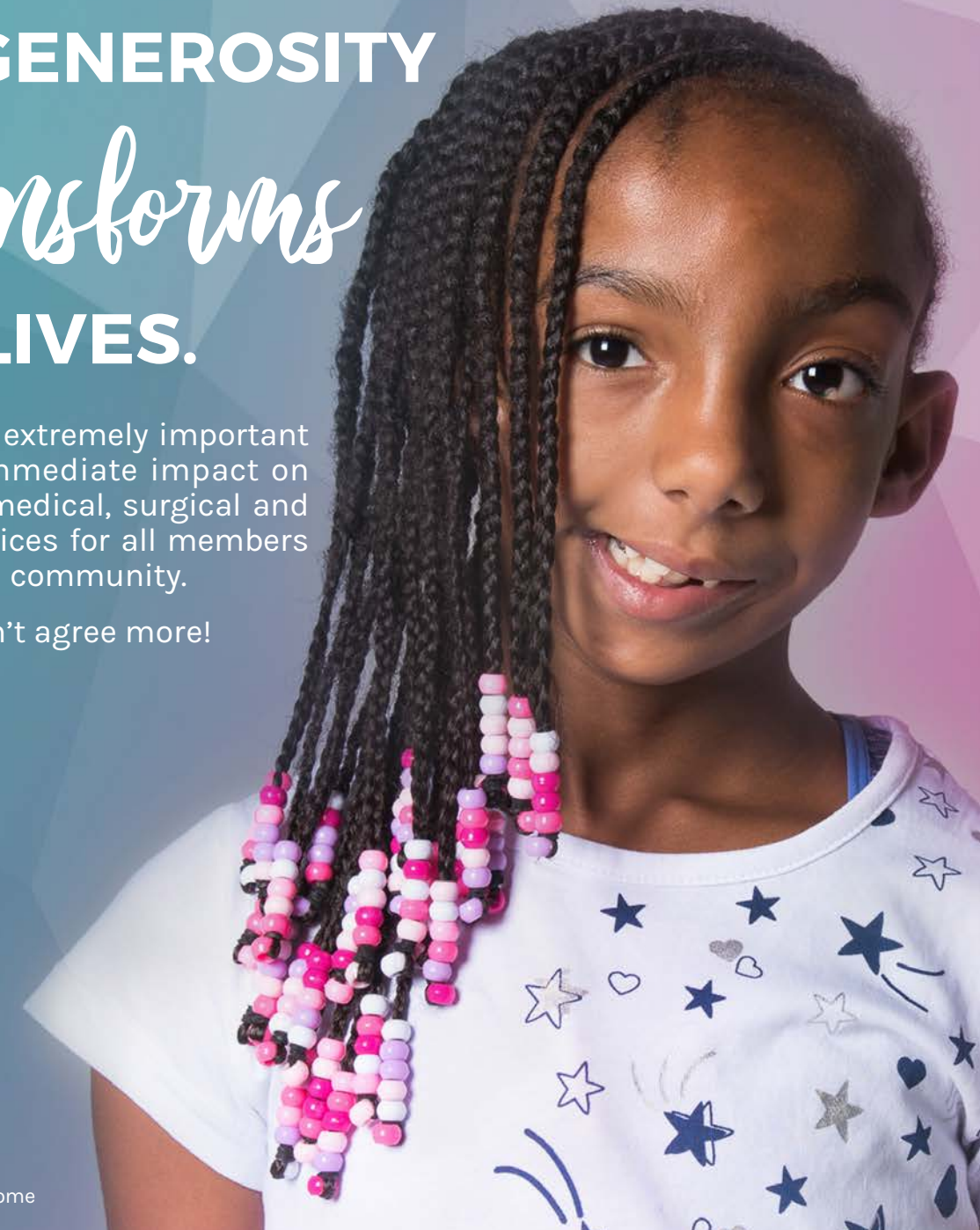
## YOUR GENEROSITY

# Transforms

## LIVES.

Your support is extremely important and makes an immediate impact on urgently needed medical, surgical and psychosocial services for all members of our craniofacial community.

Madison couldn't agree more!



Madison | Goldenhar Syndrome

**myFace extends our heartfelt gratitude to the following Foundations and Corporations who made an outstanding investment in our patients and families this past year:**

The Achelis and Bodman Foundation  
Ada Lieb Goldstein Foundation  
The Ambrose Monell Foundation  
The Arthur Loeb Foundation  
Billy Rose Foundation, Inc.  
The Edouard Foundation  
Footprints in the Sand  
KLS Martin, L.P.  
L and L Foundation  
Lebensfeld Foundation

The LeRoy Schecter Foundation  
Midtown Tennis Club  
Milbank Foundation for Rehabilitation  
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The logo for myFace, with 'my' in pink and 'Face' in teal, where the 'y' and 'F' are connected.

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### PHOTOGRAPHY |

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