myFace

CHAMPIONS

CARE COMPASSION COMMUNITY

2016: A YEAR IN REVIEW

OUR MISSION

myFace is dedicated to transforming the lives of patients with facial disfigurement. With a special focus on children and their families, myFace funds medical, surgical, dental and psychosocial services as well as research and public awareness.

"Hello, we're the Encarnacion / Lalane Family!
We are proud parents of three beautiful children, Gabriella, Amanda and our warrior, Alonso. Alonso was diagnosed with Crouzon Syndrome and Craniosynostosis.

ALONSO HAS UNDERGONE MORE THAN 10 SURGERIES WHICH HAVE GREATLY BENEFITED HIM AND AFFORDED HIM A BETTER QUALITY OF LIFE.

In each surgery, Alonso demonstrates unwavering strength and perseverance. We are so grateful for the unconditional support of myFace. They have facilitated every challenge and become our family. We feel blessed to be a part of this unique organization that has been a lifeline for our children."

- **Laryssel**, Mother of Alonso

On the cover:
Alonso *(Crouzon Syndrome & Craniosynostosis)*

EACH YEAR, APPROXIMATELY
250,000 CHILDREN
ARE BORN IN THE UNITED STATES WITH CRANIOFACIAL CONDITIONS.
THE FACES OF ANOTHER 100,000 INDIVIDUALS
ARE DISFIGURED THROUGH ACCIDENT OR DISEASE.

Benjamin *(born with Cleft lip & Palate)*

myFace CHAMPIONS CARE

myFace funds the craniofacial program at the Hansjörg Wyss Department of Plastic Surgery at NYU Langone Medical Center. Due to the complexity of craniofacial conditions, treatment requires a multidisciplinary, collaborative team approach.

The team is comprised of reconstructive plastic surgeons, an orthodontic team, a medical photography team, speech therapists, a psychologist, a geneticist, a social worker and a nutritionist.

Neurosurgeons, ENTs and other pediatric specialists join the craniofacial team to meet with patients and their families in weekly Conferences. The team reviews the patient's medical history, photographs and MRI/CT results to create a comprehensive treatment plan that best fits the individual needs of the patient.

Conference also offers the patients and their family a unique opportunity to address questions and concerns to all of the specialists involved in their child's care.

Patricia Chibbaro, RN, MS, CPNP
Pediatric Nurse Practitioner
Hansjörg Wyss Department of Plastic Surgery

Anderson *(Goldenhar Syndrome)*

The Newman Family Support Center

ADDRESSES THE PSYCHOSOCIAL NEEDS

of our patients and their families including:

- Speech evaluation and therapy
- Nutrition counseling
- Genetic counseling
- Pre and post-natal counseling, feeding, and home care instruction
- Psychological and therapeutic support

% INCREASE FROM 2015

38%	Speech Sessions
83%	Psychosocial Consultations
95%	Diagnostic Speech Procedures

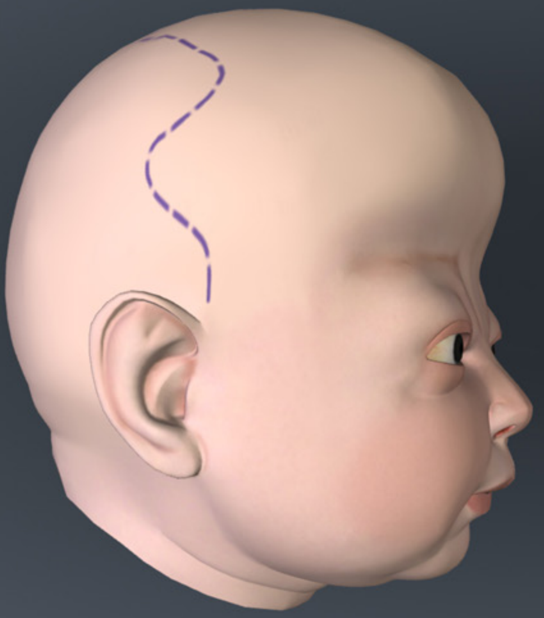
Deborah Malkoff-Cohen
Registered Dietitian
MS, RD, CDN, CDE
Hansjörg Wyss Department of Plastic Surgery

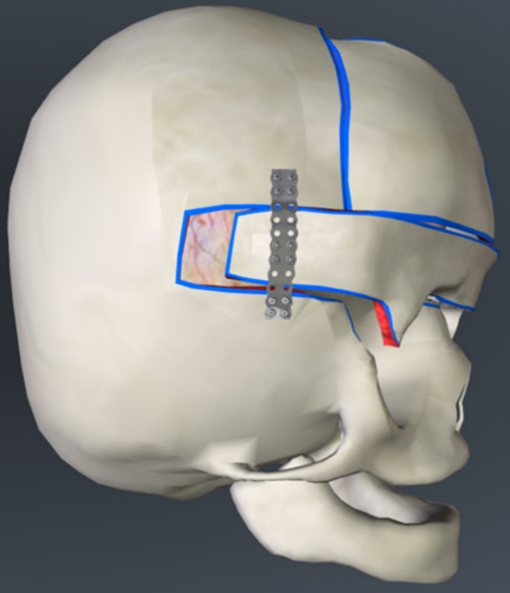
Tiffany *(born with Cleft lip & Palate)*

CIVA
Craniofacial Interactive Virtual Assistant
PRO

Over the past two decades, myFace and the pioneers at the Department of Plastic Surgery have partnered with BioDigital to create CIVA Pro, a craniofacial surgical simulator.

CIVA Pro is designed to educate reconstructive surgeons, fellows and residents by explaining the ten most common craniofacial surgical procedures.



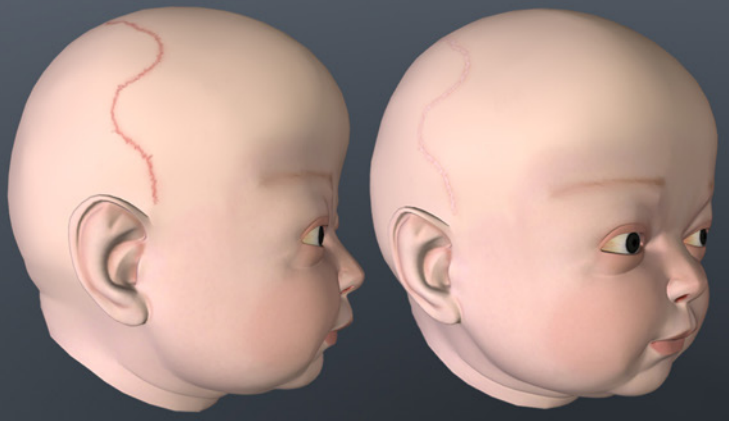


This cutting edge technology provides

INNOVATIVE METHODS OF TEACHING TO EMPOWER THE NEXT GENERATION OF SURGEONS.

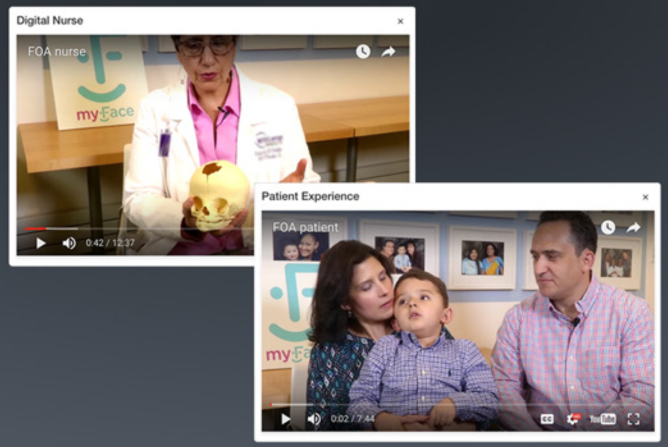
In 2016, surgeons and medical professionals in 74 countries and in 19 institutions in the U.S. alone have recognized CIVA Pro's potential and are now utilizing the technology to better prepare for surgery.

Following the success of CIVA Pro, myFace launched CIVA to offer interactive technology to patients and families. myFace's Craniofacial Interactive Virtual Assistant serves to relieve the stress and anxiety surrounding a child's craniofacial surgery.



CIVA
Craniofacial Interactive Virtual Assistant

Families can now fully understand the pre-operative, surgical and post-operative stages of their child's procedure.



The Nurse Practitioner Consultation and Patient/Family Experience portals address any additional questions, both medical and personal.

Thanks to a generous grant from Southwest Airlines' Medical Transportation Grant Program, we provide

COMPLIMENTARY ROUNDTRIP AIRFARE

to our families in need.

We also have four beautiful apartments across from the Department, which are offered to all out-of-town myFace families free of charge.

Viktor (*Goldenhar Syndrome*)

> "I will never forget what the wonderful myFace organization did for me, my son Viktor and my whole family. I will always think of them as members of my own family. When my son Viktor had two serious jaw surgeries, they offered us their beautiful and comfortable apartment where we felt at home. Their kindness and support touched me to the bottom of my heart. Thank you so much for everything.
>
> -Tanja, Mother of Viktor"

A DAY IN MY LIFE

"Yeah, the whole staring thing.
And name calling. And teasing. And bullying.
Everyday, at some point, someone will do those
things to me. Both kids and grown-ups.
I mean, how many kids do you know that
grown-ups tease or point at?"

**"I'D LIKE TO SEE ANYONE WHO
TEASES ME LIVE MY LIFE FOR A DAY."**

"I bet they wouldn't tease anyone else ever again.
I wonder if they ask themselves why
they're teasing someone."

**"THIS IS MY NORMAL.
I LIVE LIKE THIS EVERY SINGLE DAY."**

"I get no time-outs from it. I never get to wake up
without the food tube or without my Trach.
I never go into the bathroom and look in the
mirror and see my mouth and cheeks and eyes
and ears all the right size and in the right place.
No matter how hard I ask and no matter
how many times I wish for it on my birthday."

Stories like Anibel's
compelled myFace
to create

**THE *WONDER*
PROJECT**

Anibel (*Nager Syndrome*)
The 2015 Mary Ross Holiday Party

myFace CHAMPIONS COMPASSION

myFace School Visit

In the Fall of 2016, we officially released THE MYFACE *WONDER* PROJECT based on the New York Times Best Seller, *Wonder*, by R.J. Palacio.

Wonder, a young adult novel, tells the story of Auggie, an ordinary boy with an extraordinary face. myFace developed the *Wonder* Curriculum, an intensive classroom tool focused on empathy and acceptance, based upon this incredible book.

The curriculum is enhanced by videos of our patients telling their personal stories. The goal of the *Wonder* Project is to educate children and young adults on the importance of having compassion, celebrating uniqueness and always **choosing to be kind.**

SCHOOL OUTREACH

As young leaders in their respective communities, students have the power to raise awareness and spread kindness. Through compassion, commitment and perseverance, students can achieve unparalleled results and take part in fostering a more respectful, empathetic, and accepting society.

myFace offers students the opportunity to:

- Raise awareness about myFace and the craniofacial community through a class project or presentation
- Create a myFace Student Club
- Organize a myFace bake sale, social event, or toy drive

Reese (on the right, born with *Cleft lip & Palate*) hosting a lemonade & bake sale to benefit myFace

myFace launched its first **crowdfunding platform** to

EMPOWER MYFACE SUPPORTERS

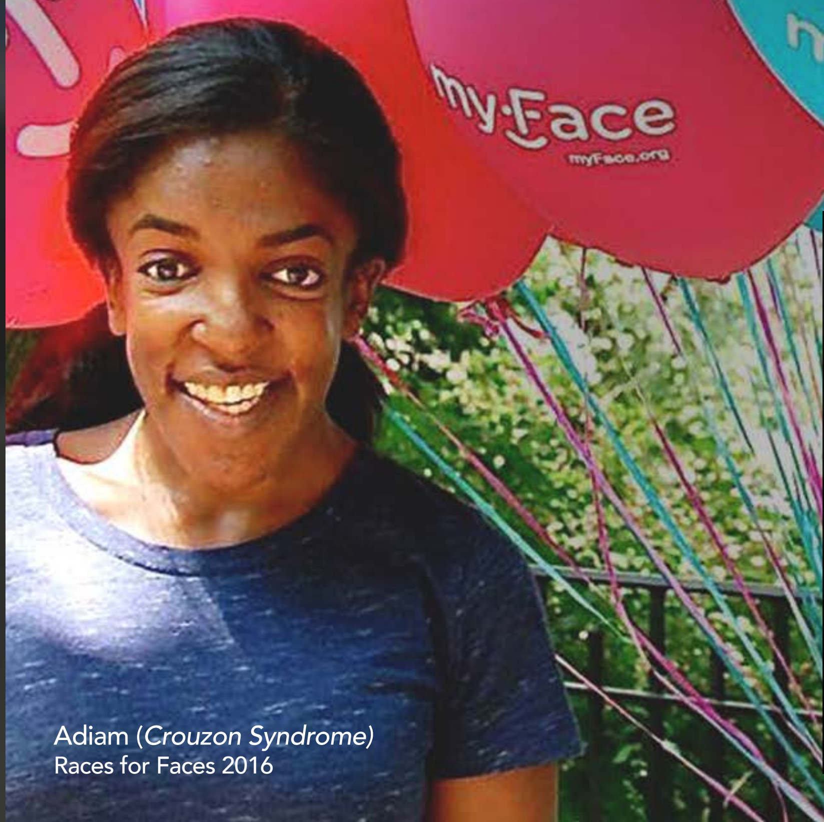
with the tools to share their personal stories and become **advocates** for the craniofacial community.

CELEBRATIONS
Ask for donations in lieu of gifts for your birthday, graduation, wedding or Bar/Bat Mitzvah

SPORTS
Take part in a 5k, compete in a marathon, walk or other athletic event

IN HONOR OF
Commemorate a loved one by raising money in their honor

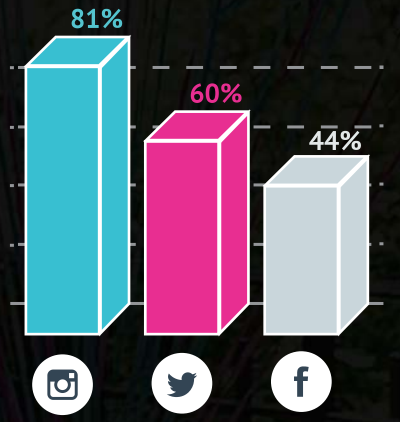
Find more ideas & start your fundraiser today by visiting crowdrise.com/myface



Adiam (*Crouzon Syndrome*)
Races for Faces 2016

SOCIAL MEDIA GROWTH

myFace has raised significant awareness in 2016



myFace CHAMPIONS COMMUNITY

myFace recognizes the critical need for family support groups designed to provide much-needed guidance and support for our patients, siblings and their parents. The groups serve as a place to share, find support and mentor others.

OUR SUPPORT GROUPS ADDRESS THE FOLLOWING ISSUES:

- relationships
- fear and anxiety
- transitions and fitting in
- functional challenges
- sibling rivalry and guilt
- teasing and bullying
- recognizing self-worth
- empowerment

Teen & Adult Support Group

myFace hosts a variety of events for our families

BRINGING OUR COMMUNITY TOGETHER

and facilitating networking with others living with craniofacial differences. We offer quarterly bowling parties, The Mary Ross Holiday Party, and theatre workshops in partnership with the Turtle Bay Music School.

> “Before we didn’t feel that we fit into any community and now we do, so thank you!
> - Hilda, Mom of Ali”

Ali *(Parry Rhomberg Syndrome)*

> “myFace is the light in our long journey through the darkness. For Hadi it was a miracle, a smile so bright, nothing could wipe it off his face. For that, our whole family thanks myFace for all the joy they brought to us!
> - Rabah, Mom of Hadi”

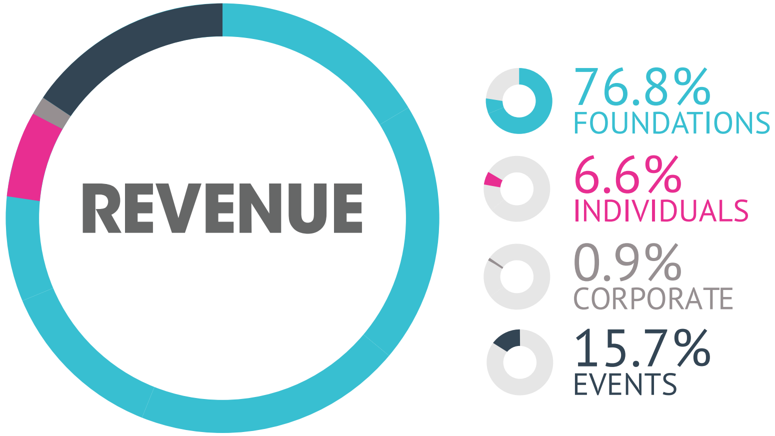
Hadi *(born with Cleft lip & Palate)*

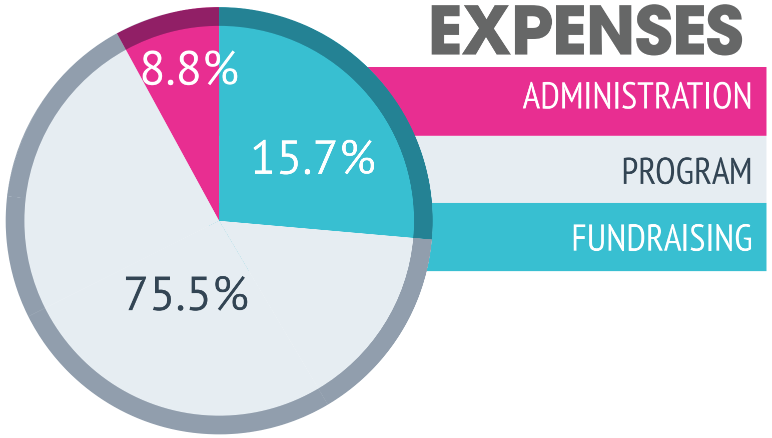
Claudia *(Amniotic Band Syndrome & Adams-Oliver Syndrome)*
myFace Bowling Party at Brooklyn Bowl

For the last 5 years, myFace has hosted Races for Faces, a fun-filled family day in Riverside Park. This annual walk provides a day of summer fun and carnival activities for our families while raising awareness for the craniofacial community.

All proceeds from Races for Faces are dedicated to funding the psychosocial services offered by the Newman Family Support Center.

Anibel *(Nager Syndrome)* & Taina *(born with Cleft lip & Palate)* along with Taina's family at Races for Faces 2016





100% OF ANNUAL APPEAL DONATIONS WILL BE USED FOR PATIENT SUPPORT

*myFace supports full disclosure of our financial information. To learn more, please visit: myFace.org/Financials

Please Save the Date for the Inaugural myFace Panel Luncheon

INNOVATION IN RECONSTRUCTIVE PLASTIC SURGERY AND ITS IMPACT ON COSMETIC PLASTIC SURGERY

Monday, March 6th, 2017 • 12:00 PM - 2:00 PM
564 Park Avenue - New York City (North West corner of 62nd Street and Park Avenue)

Join us for an informative panel discussion with exclusive access to the world renowned team of craniofacial surgeons and medical professionals from The Hansjörg Wyss Department of Plastic Surgery at NYU Langone Medical Center.

The Panel will address the truths, misconceptions and latest advancements in the field of reconstructive and cosmetic craniofacial plastic surgery, with a special focus on cleft lip and palate.

Hear directly from the experts at The Hansjörg Wyss Department of Plastic Surgery

David A. Staffenberg, MD, DSc (Hon)
Vice Chairman and Chief of Pediatric Plastic Surgery

Roberto Flores, MD
Director of the Cleft Lip & Palate Program

Aileen Blitz, PhD
Clinical Psychologist

Patricia Chibbaro, RN, MS, CPNP
Pediatric Nurse Practitioner

Etoile LeBlanc, PhD
Speech Pathologist

Moderator

Dr. Eduardo Rodriguez, MD, DDS
Chair of the Hansjörg Wyss Department of Plastic Surgery

For ticket information, please contact Chloe Harrouche at Chloe@myFace.org

---

PLEASE SAVE THE DATE FOR THE MYFACE GALA
AT PIER SIXTY, CHELSEA PIERS ON WEDNESDAY, MAY 10, 2017

LEADERSHIP

BOARD OF TRUSTEES

In loving memory of

Whitney Burnett McLeod

For many years, Whitney worked tirelessly as Executive Director for myFace and remained an Advisor when she retired. She will always remain in the hearts of the thousands of less fortunate souls whose lives were changed because of her altruistic efforts.

YOUR GENEROSITY TRANSFORMS LIVES:

- Make a contribution
- Include myFace in your Will or Trust
- Engage your company
- Volunteer your time or expertise
- Become a myFace ambassador

Thomas *(Crouzon Syndrome)*

Dear myFace Friends,

A true **champion** is someone who overcomes challenges, someone who wants to make a difference, who never gives up and who gives everything s/he has no matter what the circumstances are. Our brave and courageous patients are true champions, our team of surgeons and psychosocial providers are true champions and you, our donors, are true champions.

"A champion is an optimist, a hopeful spirit. Someone who plays the game, even when the game is called life. There can be a champion in each of us if we live as a winner, if we live as a member of the team, if we live with a hopeful spirit, for life."[1]

myFace champions care, compassion and community each and every day and we ask that you join us by making a gift today. Your donation is extremely important since it makes an immediate impact on urgently needed medical, surgical and psychosocial services for all members of our craniofacial community. Every dollar donated supports our unique and critical mission.

With heartfelt gratitude,

Carolyn Spector

Carolyn Spector
Executive Director

---

[1] Mattie Stepanek

myFace extends our **HEARTFELT GRATITUDE** to the Foundations and Corporations who made an outstanding investment in our patients and families in 2016:

The Achelis Foundation

The Ambrose Monell Foundation

The Arthur and Eileen Newman Family Foundation

Barbara Hope Foundation

Billy Rose Foundation, Inc.

Carey Ramey Estate

The Columbus Foundation

The Edouard Foundation

KLS Martin L.P.

Lavelle Fund For the Blind, Inc.

The Lebensfeld Foundation

Mary Ross Estate

Milbank Foundation for Rehabilitation

Mortimer J. Harrison Trust

The New York Community Trust

Park Foundation

RBC Foundation

The Sence Foundation

Virginia B. Toulmin Foundation

Virginia Rudat Estate

West End Collegiate Church

Kiran (*Goldenhar Syndrome*)

myFace

333 East 30th Street, Lobby Office, New York, NY 10016
P. 212.263.6656 F. 212.263.7534
myFace.org

Carolyn Spector
Executive Director

Lin-En Chen
Web & Marketing Manager

Chloe Harrouche
Director of Development

Denise Maldonado
Creative Director

Savannah Mazda
Development and Events Manager

Eddie Plata
Office Manager

Dina Zuckerberg
Director of Family Programs

Photography:
Mary Spano: pages 2-5, 18
Denise Maldonado: Inside cover, pages 7-9
Domenica Comfort: pages 1, 11, 23, 24
Cecilia Maronilla: Cover, pages 15-17
Griselda Barrera: pages 12, 13