my:Face YOUR IMPACT CRANIOFACIAL NEWSLETTER - SUMMER 2020

Changing Faces, Transforming Lives

THANK YOU FOR BRINGING ALONSO'S SMILE TO LIFE

Alonso is the youngest of a loving, close knit family of 5 who came to the US from the Dominican Republic in 2015 when he was just a baby. Born with Crouzon Syndrome, he was later diagnosed with Craniosynostosis - two craniofacial conditions that resulted in the bones of his face and skull not forming properly.

Knowing that the team at the myFace Center for Craniofacial Care would provide the best comprehensive care possible, Alonso's mom, Laryssel, knew that his future would be bright and filled with hope. In his just six short years, he has already undergone 18 surgeries - and is awaiting more.

Alonso recently graduated from kindergarten, and the myFace team couldn't be prouder of how far he has come.

As his mom says, "Alonso knows what he wants and he fights hard to get it." myFace has made a promise to fight hard for Alonso and his wonderful family. With your generous support, we can keep that promise.



Help children like Alonso by making a gift today! Your generosity transforms lives.

myFace.org/givenow

Alonso with David A. Staffenberg, M.D., D.Sc. (Hon), FACS Vice Chair of Pediatric Plastic Surgery, myFace Center for Craniofacial Care at NYU Langone Health "myFace has been a salvation for our family, they have been with us every step of the way through Alonso's care and treatment. We have met extraordinary people who have unconditionally loved Alonso as well as all our children. With myFace, we never feel alone. There are no words that express how grateful we are that we have been accepted as members of this community. myFace makes our children matter.

- Alonso's mother, Laryssel



BECAUSE OF

Within two weeks of the NY state pause order, the myFace team successfully launched the COVID19 Gift Card program on March 31. This initiative was created to provide a one-time \$100 Amazon gift card to craniofacial patient families hit financially by the crisis. We are delighted that to date, we have provided more than 190 gift cards to qualified "This Gift Card means so much to our family. Now we have the ability to purchase the most basic household supplies that otherwise wouldn't be possible without this extra help." - A grateful mom

families to allow them to purchase groceries and basic household supplies they may not otherwise have been able to afford. **This initiative was made possible because of your generosity.**

JOIN FAMILIES ACROSS THE NATION FOR THE MYFACE VIRTUAL SUMMER SERIES

On July 9th, myFace kicked off its new nationwide Virtual Summer Series with a Read Aloud Program featuring R.J. Palacio who shared her children's book *We're All Wonders*.

This inaugural program, which has already been viewed by thousands of children and families across the country, was the first of more than a dozen live virtual events scheduled over the next 2 months.

The **myFace Virtual Summer Series** program will help to provide compelling educational, creative, and community-building content for our patients, families and greater craniofacial community, as well as the general public. Most importantly, we will offer these programs at no charge to our participants. The series includes:

Read Alouds – Authors of popular children's books will read their books and offer a live Q&A.

Virtual Family Hours – Interactive programs are being created featuring NYC Kids Performance Group, The Paper Bag Players and interactive presentations by a magician and an artist.



All content centers around children with craniofacial and other differences by collaborating with partners, including authors, organizations, and artists, and live-streaming readings and performances to myFace's Facebook, YouTube, Twitter & Website.

Visit our website to subscribe to receive weekly emails with links to each live broadcast.

myface.org/summerseries

ASK THE EXPERT

Dr. Aileen Blitz, Team Psychologist, myFace Center for Craniofacial Care NYU Langone Health



Remember to consult your doctor and local regulations regarding leaving your home.

After many months of isolation, what advice do you have to stay calm and optimistic?

We are all facing a challenging time but the most important thing to do is keep perspective, this will not last forever, nothing does.

Reach out to friends, family, old friends you haven't spoken to, co-workers — stay connected every single day.

Try to go outside if you can to get some Vitamin D (sunshine) for at least 20 minutes a day. With summer in full swing around the country, there are many opportunities to get outside and take in the season with a whole new perspective.

It is important to keep a routine - of waking up and going to bed, of exercise - even if it is light stretching, a walk around your own house, etc.

Get creative: cook, bake, maybe adult coloring books, relax, jigsaw puzzles, learn to draw or paint, garden if you have outdoor space or try to create an indoor herb garden, rearrange your furniture—it might feel like you just redecorated.

What other ideas do you have about ways I can stay busy?

Have your kids participate in the **myFace Virtual Summer Series**! Or register a team for **Races for Faces**, a terrific way to give back and accomplish a specific goal during the summer months. Volunteering with myFace, you will feel less helpless. It will not only give you a sense of doing something worthwhile, but it will make a huge difference for the craniofacial community. It will also help you to lower your anxiety by distracting you from being overly focused on yourself and your worries. Other volunteer ideas might be to tutor a child online or do a cooking class on FaceBook. There are so many ways to help others and still be safe.

A PLACE FOR PATIENTS AND FAMILIES TO TURN WHEN THEY NEED IT MOST

WE COULDN'T PROVIDE THESE SUPPORT GROUPS WITHOUT YOU! THANK YOU.

Psychosocial care plays such a critical role in positive outcomes for those impacted by craniofacial differences. Dina Zuckerberg, Director of Family Programs, coordinates and co-leads emotional support groups that are designed to provide guidance, counsel and community for our patients, siblings and parents

Prior to the COVID19 outbreak, these myFace support groups were delivered as monthly in-person meetings. However, with the shelter-in-place restrictions in force, myFace needed to pivot and find a way to continue to provide this important resource. By quickly adapting to a virtual environment - thank you, Zoom! - everyone now has access to these groups from home or wherever they may be. In fact, attendance has almost doubled and the groups are meeting now 2-4 times a month!

"Being in a group like this just feels right and being surrounded by people who know, on the same level, what it means to have a facial difference and the daily struggle that comes with that is invaluable. Thank you for welcoming me with such open arms." - Kelsey, Moebius Syndrome, Alberta, Canada

With the launch of these online support groups, participants in the adult craniofacial group now reach beyond the New York Metro area, including Texas, Florida, Georgia, California, Ohio, New Hampshire and Rhode Island. We even have participants joining from Australia and Canada!

Since COVID19 restrictions began in March, Dina has led more than 40 online support groups, and counting. Our ability to provide important resources like this to the craniofacial community is only possible because of your generous support.



Participants at our Online Adult Support Group.

NOT JUST AN ORDINARY CAMP!

myFace is delighted to have joined forces with Harbor Camps - Camp Reflections - led by the founder, Nick Teich. The program is designed for children ages 7-13 living with a craniofacial difference. The group of fifteen children meet every other Wednesday for a one-hour session, with the program scheduled to run through the end of August.

"The Camp Reflections virtual meet ups are fun! I especially like the games and the counselors are nice! I like meeting other kids with facial differences like me!" - Emily, Age 10, Massachusetts



Participants at Harbor Camps in 2019.

It's a time for these kids to get together and have fun, and to just experience "being kids", which is unfortunately not always possible in today's world. They have experienced getting to know each other better and lots of laughing.

"I am having fun and meeting new people virtually at Camp Reflections!! Wednesdays are better with Camp Reflections and myFace!" - Panayioti, Age 8, New York

If you are interested in participating in any of our Support Groups or online meets, contact Dina Zuckerberg at Dina@myFace.org or 917-720-4701 ext. 160. You can also find out more information by visiting:

myFace.org/online-groups



WHEN:

September 26, 2020

WHERE:

We'll be online, you can be anywhere!

WHY:

By participating, you can help our patients like Jahzara get the quality comprehensive care and support they need to lead full and productive lives.

> Register Today: racesforfaces.org

JOIN US FROM WHEREVER YOU ARE

We weren't kidding when we said you can be anywhere for this year's **Races for Faces**!

Team Paprikás Csirke, led by myFace Star, Abby Rucker, is participating all the way from Romania. In fact, they are one of our **Races for Faces** Grand Marshals!



Abby Rucker (with hoodie) pictured with her family.



Jahzara, born with Goldenhar syndrome ckerberg, myFace Director of Family Programs

Please join myFace and Team Paprikás Csirke for this year's **Races for Faces** as we walk separately, but together in solidarity on September 26th.

SPECIAL THANKS TO OUR EVENT SPONSORS:





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

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