JUNE 2022

CHARGE Accounts

The latest news, events, and announcements from The CHARGE Syndrome Foundation

Upcoming Events

6/26/2022 Adults with CHARGE Virtual Social

7/8/2022 Cincinnati Children's CHARGE Conference 2022

The CHARGE Syndrome Foundation

info@chargesyndrome.org
CHARGEsyndrome.org
The CHARGE Syndrome Foundation
@charge_syndrome_foundation
@chargesyndrome





Our Best Walk and Roll Yet

Thanks to our community's fundraising efforts, we raised over \$51,000, making it our most successful Walk and Roll yet! The money raised will allow us to to help support our families through direct assistance, outreach, and research.

Team Perkins Deafblind Program topped our leader board, with their 30 teammates raising an impressive amount at over \$8,000!

Other top teams included Team Michigan, raising over \$4,000; and NY CHARGE Families, CHARGE on for Cole, and Team Beach Chargers each raising over \$3,000.

Top individual fundraiser included, Iris Filkins, raising over \$3,000, and Sheri Stanger and Kate Stone, each raising over \$2,000!

<u>Click here</u> to see a video of all of our CHARGE families and friends walking and rolling together!

New Outreach and Engagement Manager

We are excited to announce a new addition to our Foundation! Please join us in welcoming Outreach and Engagement Manager, Lourdes E. Quintana Baez.

In her position, Lourdes will be responsible for building a supportive and connected community for individuals with CHARGE syndrome, their families, and the professionals with whom they work. This will be accomplished by connecting families with resources, developing supportive relationships with members and professionals, and supporting our network of State Family Liaisons.

Lourdes is bilingual and is available to communicate in English and Spanish.

Lourdes habla español, lo cual facilitara la comunicación con familias de habla Hispana.



Learn more about Lourdes by <u>clicking here</u> to read her bio.

You can contact her via email at lourdes@chargesyndrome.org.

Fundraising with Facebook

Fundraising with Facebook is a great way to let your friends and family know that The CHARGE Syndrome Foundation is important to you!

Facebook fundraisers can be set up any time or used to highlight a special occasion, such as a birthday, graduation, or to bring attention to an awareness day, week, or month.



Setting up and sharing a Facebook fundraiser is quick and easy. <u>Click here</u> to learn how to set up your own Facebook Fundraiser today.

Sibling Spotlight



The Bohon family consists of mom Christine, dad Rob and 14-year-old twin girls, Katie and Sarah. They are an ASL family and the girls enjoy playing board games, cards and Roblox together. Katie has always been one of Sarah's biggest supporters and advocates.

Recently, Katie, was assigned a project for health class to write about something that has affected their family. She chose to write about CHARGE syndrome and her twin sister, Sarah.

"I am beyond proud of both of my girls. CHARGE not only effects Sarah, but our entire family. The Foundation has been a wonderful asset to us throughout the years and we are forever grateful," says Christine.

Click here to see Katie's project.

Important Dates

- June is National Child Vision Awareness Month. <u>Learn more</u> <u>here.</u>
- June 15th Crocker Barker Sibling Scholarship application deadline. To learn more and to apply, please <u>click here.</u>
- June 26 July 2 Deafblind Awareness Week. The focus this year is Diversity and Inclusion: Creativity and innovation are built upon a diverse group of perspectives. Who better to help initiate that innovation than the DeafBlind community, a group of people whose lives are driven by the pursuit of change and innovation? The CHARGE Syndrome Foundation would like to share your stories on our social media during this awareness week. If you have a story of diversity, inclusion, creativity, and innovation that you would like to have featured, please send it to

torrie@CHARGEsyndrome.org

Ask the Expert

In May, we held an Ask the Expert webinar with Lily Slavin.

Lily is a 5th year doctoral candidate in the school psychology PhD program at Central Michigan University. She has been a member of the CHARGE syndrome research lab at CMU since 2016, where she has conducted research on the educational experiences of students with CHARGE with Dr. Tim Hartshorne. She developed the Educational Checklist for students with CHARGE, which outlines common educational needs of students with CHARGE and ways school teams can begin to address these needs at school.

You can watch the recorded Ask the Expert webinar with Lily Slavin <u>here</u>.

You can find all previous webinars here.



We will be taking a break from webinars for the summer months, but would love to hear from you what topics you would like to see discussed in the future. To submit suggestions, or to offer your services as an expert in the CHARGE field, please send an email to <u>torrie@CHARGEsyndrome.org</u>_

Do you have a story, event, or news item that you would like to have included in the CHARGE Accounts newsletter? Send submissions for review to <u>torrie@CHARGEsyndrome.org</u>