JANUARY 2024

CHARGE Accounts

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

Upcoming Events

1/10/2024
Grief Support for Families of Children with Deaf-Blindness

1/18/2024
Birth to Age 3 Parent-to - Parent Support Group

1/23/24
Western Region CHARGE Syndrome Parent to Parent Call

1/30/24
Ask the Expert: How CHARGE Syndrome Impacts Participation at School and Home

5/18/2024
Walk and Roll for CHARGE

The CHARGE Syndrome Foundation

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

Start the New Year Off Right with a Charge it for CHARGE Campaign

"Charge It for CHARGE" is the primary online fundraising campaign of the CHARGE Syndrome Foundation. There are so many ways that you can use your campaign throughout the year!

- Share your story with family and friends
- Link your campaign to a Facebook fundraiser in honor of a special event, birthday, or graduation
- Host a fundraiser in your community and use your Charge it for CHARGE campaign to collect donations (click here to see ideas from past fundraisers)

Set a goal and challenge yourself to see how far you can take your fundraising efforts this year!

By raising money through your Charge it for CHARGE campaign, you are helping to support our Family Assistance Programs, Outreach, educational webinars, Conference, and ground-breaking research.

We acknowledge all of our top fundraisers with a token of our appreciation and recognize them at our biennial Conference.

Click here for a quick tutorial on how to set up your fundraising page.
Click here to set up your fundraising campaign today.

Together, we can make a difference in the lives of people with CHARGE syndrome!

Sweets for CHARGE Returns

Our most popular fundraiser is back, just in time for Valentine's Day!

Treat yourself and all the special people in your life to the yummiest candy on earth! Support The CHARGE Syndrome Foundation's Family Assistance Programs with our See's Candies Fundraiser!

The fundraiser will be open from January 10 through January 26. Orders ship immediately.

Please look for the link in your email and on our social media channels.

Sibling Spotlight - Hunter Kutzura

In May of 2023, Hunter Kutzura was really excited for the the Walk and Roll for CHARGE. He wanted to make CHARGE on for Tucker, the team in memory of his brother, the top fundraiser for the event. When he realized that he wouldn't hit that goal, he set a new goal: to be the top kid fundraiser. He was recognized for achieving this goal at the 2023 International CHARGE Syndrome Conference.

Hunter did his best to help spread awareness for CHARGE syndrome, raise funds, and keep his brother's memory alive. Way to go Hunter!

Our 5th Annual Walk and Roll for CHARGE

In celebration of our 5th Annual Walk and Roll for CHARGE, we have some fun new ideas and contests planned for you, your family, and friends! We hope to “walk and roll around the world” by having registered teams in every state and beyond! You'll also have the chance to secure a spot for your team, family name, or company on the back of our official Walk and Roll t-shirt through fundraising goals or sponsorship opportunities. Be sure to check your emails and keep an eye on our social media channels for more information.

Save the date - Saturday, May 18, 2024 - and start thinking about who you will ask to join your team and where you will be walking this year. Whether you walk or run a 5K, take a stroll with a group of friends, or bike the neighborhood with family, the goal is the same: to be active while raising money for the Foundation and raising awareness of CHARGE syndrome.

Click here for information on our previous Walk and Roll for CHARGE events.

Share your reason for participating in Walk and Roll for CHARGE with a short video. Click here to send it to our Marketing Department.

Birth to 3 Parent-to-Parent Support Group

Join us for the first Birth to 3 Parent-to-Parent Support Group of the year, at a new time: Saturday, January 20, 7:00 PM ET.

On the third Saturday of every month, the CHARGE Syndrome Foundation hosts a virtual support group for families with children aged birth – 3 years. We recognize that this group goes through so much in the first 3 years of life and it can often feel isolating or overwhelming. We want to offer a safe place where families can get together to connect, share, ask questions and get support from other families. A Zoom link is sent out monthly to registered participants.

Click here to register.

Family Liaison Highlight - Katie Schneeberger

Katie Schneeberger is the Foundation's Family Liaison for Ohio. She and her family decided to move to this state so they could be closer to the CHARGE Clinic at Cincinnati Children's Hospital, since the team there has taken such great care of their daughter, Lilly. Katie now helps other families who visit the CHARGE clinic as they navigate through that process, ensuring that they feel at ease and welcome during their stay. She has helped facilitate connections between families who visit the clinic at the same time so they can support each other. Katie enjoys meeting families while they are in town for their appointments and has even donated some of her personal items to help those families.

We are very lucky to have Katie on our Family Liaison team and we appreciate her for always going above and beyond for our families!

The Family Liaison Project is a model of collaboration to improve the Foundation's outreach to both families and professionals at the national level. The position will be used to build relationships, network, collaborate, and disseminate information.

The primary function of a Family Liaison is to:

- Share the latest CHARGE resources with the State Deaf-Blind Projects and the families in their state
- Assist in helping both the Foundation and the State Projects in identifying families
- Update the Foundation on available state resources
- Promote connections among the CHARGE families in the state

Click here to find your state's Family Liaison. If you are interested in becoming a Family Liaison, please email our Outreach and Engagement Manager, Lourdes Quintana at Lourdes@CHARGEsyndrome.org.

Do you have a story, event, or news item that you would like to have included in the CHARGE Accounts newsletter? Click here to send submissions for review.

Ask the Expert: How CHARGE Syndrome Impacts Participation at School and Home

Join us for an Ask the Expert webinar on January 30, 2024, 7:00 - 8:00 PM ET: How CHARGE Syndrome Impacts Participation at School and Home.

Presenters include Alysha Croke, PT, DPT, PCS; Catherine Murphy, PT, DPT; Emily Weber, PT, DPT; Lauren Kling, PT, DPT; and Michelle Sousa, PT, DPT from Perkins School for the Blind in Massachusetts.

Alysha, Catherine, Emily, Lauren, and Michelle are physical therapists working in the Deafblind Program at Perkins. They have the pleasure of working with many individuals with CHARGE syndrome. The PT team members love to design fun activities that are motivating for their students while encouraging the development of gross motor skills. They take a team approach that includes collaboration with the student, the family, and other providers to get the best outcomes for the students. Each physical therapist brings experience, passion, and knowledge to the field of deafblind physical therapy.

Click here to register.

Help Spread Awareness

The best way to help spread awareness about CHARGE syndrome is by sharing your story!

Despite seemingly insurmountable obstacles, children with CHARGE syndrome often far surpass their medical, physical, educational, and social expectations. Parents of children with CHARGE are often heard talking about the indomitable spirit, the humor, and the compassion of their children. We would like to help share these stories, as well as stories about special sibling bonds, fundraising successes, your work volunteering with the Foundation, and more, on our website, newsletter, and social media.

Click here to submit your story.