CHARGE Accounts

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

Upcoming Events

6/15/2024
<u>Birth-to-3 Year Parent Support</u>
<u>Group</u>

6/24-6/30/2024 Deafblind Awareness Week

6/25/2024 Western Region CHARGE Syndrome Parent-to-Parent Call

6/27/2024 Familia CHARGE (Spanish-Speaking Families Support Group)

The CHARGE Syndrome Foundation

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The CHARGE Syndrome Foundation



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Deafblind Awareness Week



Deafblind Awareness Week is an annual event that takes place during the last week of June. This coincides with the birthday of Helen Keller on June 27, 1880. This national advocacy campaign has been held each year since 1984, when the then-President Ronald Reagan issued a proclamation in recognition of this special week. The purpose of Deafblind Awareness Week is to raise public awareness about individuals who have combined hearing and vision loss. Today, there are 2.4 million people who are deafblind in the United States.

The awareness week aims to promote a better understanding of the challenges faced by deafblind individuals and to celebrate their unique abilities and contributions to society. During this week, various organizations and advocates host events and activities to increase public awareness and promote inclusivity and accessibility for deafblind individuals.

We use this week to help raise awareness for those in the CHARGE community that are deafblind – including the unique challenges they face every day.

Here are some ways that you can help raise awareness

- 1. Share your story with us! Fill out <u>this form</u> to have your story featured on our Facebook and Instagram.
- 2. Send us a "Day in the Life" video to share on our TikTok channel.
- 3. Start a Facebook Fundraiser in honor of the week.

Walk and Roll for CHARGE 2024 Recap

Thanks to you, this year's Walk and Roll for CHARGE was the biggest and best yet! Over \$85,000 was raised for the Foundation, and more than 540 people participated across the world. Your efforts will increase awareness of CHARGE syndrome and help to support our community through outreach, research, and direct assistance.

This was our largest event ever with participation in all 50 states and 4 countries! We loved seeing your photos and videos from far and wide. <u>Click here</u> to see a montage of the fun events around the world.

Shout out to Team Deafblind for being at the top of our leader board. Their 41 teammates raised over \$7,000!



Other top teams include Team Cyrus Wolf, raising over \$6,000; Team Ahana, raising over \$5,000, and Team CHARGE on for Cole, raising over \$4,800.

A special thank you to our top individual fundraisers, Jigisha Tamakuwala, raising over \$3,300; Hunter Katzura, raising over \$2,700; and Norine Kobes, raising \$1,500!

Want to make a difference but were unable to participate in Walk and Roll for CHARGE? <u>Fundraising</u> will remain open until June 30, 2024.

Shop for Summer with the CHARGE Syndrome Awareness Store

One of the best ways to spread awareness is by shopping at our CHARGE Syndrome Awareness Store! We have many items perfect for the summer, from tank tops to tote bags, picnic blankets and beach towels to water bottles, we have something for everyone.

Check out our limited edition 4th of July CHARGE syndrome design - available in adult and youth t-shirts, tanks, and baby onesies! Shipping can take up to 2-3 weeks so order today to have for the holiday!



One of our current best sellers is the I Love You ASL tote bag, perfect to pack up for a trip to the pool or beach. This design is also available in a t-shirt and beach towel. Proceeds from each sale benefit the CHARGE Syndrome Foundation.

<u>Click here</u> to see all of the items we have to offer and shop today.

Spanish Translations Available

¿Hablas español? Did you know that we have a <u>Spanish section</u> on our website? We are constantly working towards expanding our reach by offering Spanish versions of this newsletter, important documents, information, and applications; translation services during webinars and at Conference; and a support group for Spanish speaking families - <u>Familia CHARGE</u>. Our



Outreach Manager, Lourdes Quintana is also bilingual and available to assist when needed.

Visit our website to learn more.

Countdown to Conference

The International CHARGE Syndrome Conference is the largest worldwide gathering of individuals with CHARGE, their families, professionals and experts on CHARGE syndrome, but who exactly attends Conference and what can they do there?

Individuals with CHARGE and their Families

We will have a top notch program a with wide variety of speakers who are the leading experts in CHARGE syndrome. The four general theme areas under which most sessions are organized include: behavior, education, adult issues, and medical.

We are pleased to offer a camp program for individuals with CHARGE and their siblings. Our onsite camps and will provide fun, entertaining activities for the kids while the adults attend conference sessions. Arts and crafts, magic shows, and petting zoos have been part of the camp program during prior conferences.

Having a brother or sister with CHARGE is not always easy. Sibshops provides siblings aged 8-13 a safe place to meet, share – and just have fun – with other siblings who know exactly how they feel. Junior leaders are siblings 14 years and older who will assist the Sibshop facilitators.

Professionals

The CHARGE Syndrome Conference is unique in that experts in the field are available to speak with families throughout the weekend. The respect is mutual. Professionals learn as much from families as families do from them.

Save the date to join us in Phoenix, AZ, July 24-27, 2025 for the 16th International CHARGE Syndrome Conference. <u>Click here</u> to learn more.

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