CHARGE Accounts

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

Upcoming Events

2/11/2025 Parent-to-Parent Virtual **Support Meeting**

2/13/2025 Parent-to-Parent Virtual **Support Meeting**

2/14/2025 **Conference Scholarship Application Deadline**

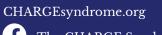
2/15/2025 Birth-to-5 Year Parent Support <u>Group</u>

2/23/2025 **Adults with CHARGE Virtual** Social (email to register)

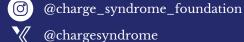
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The CHARGE Syndrome Foundation

info@chargesyndrome.org CHARGEsyndrome.org



The CHARGE Syndrome Foundation







6th Annual Walk and Roll for CHARGE

Saturday, May 17, 2025 is our 6th Annual Walk and Roll for CHARGE. All across the country, members of the CHARGE syndrome community will gather their friends and families in neighborhoods, parks, tracks, community centers, and shopping malls to fundraise for the Foundation and help spread awareness of CHARGE syndrome.

Last year's Walk and Roll for CHARGE was our biggest and best yet, with over \$86,000 raised for the Foundation and more than 540 participants across all 50 states (and 4 countries). This year we want to level up! Help us turn the map green by having participants and getting donations from all 50 states.

Upcoming Events cont.

2/27/2025
<u>Familia CHARGE (Spanish-Speaking Families Support Group)</u>

3/1/2025 16th International CHARGE Syndrome Conference Registration Opens

3/24/2025 Crocker Barker CHARGE Sibling Scholarship Applications Open

5/17/2025 6th Annual Walk and Roll for CHARGE

7/24-27/2025 16th International CHARGE Syndrome Conference Registration for this year's Walk and Roll for CHARGE will open February 15th. Get your team together and start planning your event now.

To make fundraising even more exciting, the first 30 individuals or team leaders that raise \$1,000 will earn a special edition Walk and Roll for CHARGE Stanley cup. Plus, if you raise \$1,000 or become a Walk and Roll sponsor by April 13th, your name will appear on the back of our official Walk and Roll for CHARGE t-shirts!

We would love to hear what this event means to you! Sharing your story helps spread awareness and encourages others to sign up. Send us a short video, or a photo and a quote, telling us why you Walk and Roll for CHARGE!

Whether it's a large state-wide gathering or a small family stroll through the neighborhood, the goal remains the same: to be active while joining together to create a better world for people with CHARGE syndrome.

Share Your Story for Rare Disease Day

The last day of February is World Rare Disease Day, an annual event that gives us the chance to come together, show our stripes, and raise awareness for more than 300 million people affected by rare disease globally.

We use this day to help raise awareness for the CHARGE syndrome community, and all of those



individuals affected by rare diseases - including the unique challenges we face every day.

Fill out this form to have your story featured on our website and social media.

New Parent-to-Parent Support Meetings

We are thrilled to announce our new Parent-to-Parent Virtual Support Meetings, open to parents and caregivers of individuals with CHARGE syndrome. These meetings will be held on the second Tuesday and Thursday of each month. The first meetings will be Tuesday, February 11 and Thursday, February 13.

PARENT-TO-PARENT
SUPPORT MEETINGS

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CHARGE
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FOUNDATION

To accommodate families across different time zones, we will offer the following meeting times:

- Tuesday sessions at 6:00 pm PT, 7:00 pm MT, 8:00 pm CT, and 9:00 pm ET
- Thursday sessions at 4:00 pm PT, 5:00 pm MT, 6:00 pm CT, and 7:00 pm ET

These meetings are designed to be a welcoming and safe space where families can:

- Share experiences and offer mutual support
- Exchange valuable tips and strategies for caregiving
- Learn from guest speakers who will provide expert insights and guidance

Most importantly, this is a space where we can come together as a community to support each other on this unique and meaningful journey.

<u>Click here</u> to register, and you will be sent the Zoom link before the meeting. We look forward to connecting with you!

Conference Sponsorships Available

The CHARGE Syndrome Conference provides an outstanding opportunity for your business to reach hundreds of professionals, families, and individuals with CHARGE syndrome. Increase your market outreach while supporting the only national organization dedicated solely to serving people affected by CHARGE syndrome. Become a sponsor for our 16th International CHARGE Syndrome Conference in Phoenix, AZ, July 24-27, 2025.



The 2025 Conference is expected to attract more than 1,200 people, including individuals with CHARGE, their families, and the professionals who work with them...all seeking community and information. Sponsorships offer your business the opportunity to impact:

- Individuals with CHARGE syndrome
- Family members and caregivers
- Teachers of Students who are Deaf and/or Visually Impaired
- Orientation & Mobility Specialists
- Physicians
- Physical & Occupational Therapists
- Audiologists
- Speech Language Pathologists
- CHARGE syndrome researchers
- Representatives from organizations, schools and government agencies who support people affected by deafblindness ...and more

Becoming a sponsor for our International CHARGE Syndrome Conference comes with lots of great perks! See below for the different levels of Sponsorship available and <u>contact us</u> to learn more.

Diamond \$25,000

- Podium Opportunity at Opening Reception
- Premier Stage Signage
- 4 Conference Registrations
- 8 Tickets to Donor
 Reception
- Company Logo featured on all Conference signage
- Table signage at events and meals
- Logo featured on website
- Logo displayed on Conference App and all digital displays
- Advertising space on
 Conference App.
- Logo printed on Conference Bag
- Logo on all attendee lanyards
- Premium Exhibitor Space
- Sponsor acknowledgment in Newsletter

Sponsorship Levels



Custom sponsorship packages also available.

For more info email

Conference@CHARGEsyndrome.org

Platinum \$10,000

- Stage Signage
- 2 Conference
 Registrations
- 4 Tickets to Donor Reception
- Logo featured or website
- Logo placed on Conference Welcome
- Logo displayed on Conference App
- Advertising space on
 Conference App.
- Logo printed on Conference Baa
- Two exhibit spaces
- Sponsor acknowledgment in Newsletter

Gold \$5,000

- 2 tickets to Donor Reception
- Logo featured on website
- Logo placed on Conference Welcome Sign
- Logo displayed on Conference App
- Advertising space on Conference App
- Logo printed on Conference Bag
- One exhibit space
- Sponsor acknowledgment in Newsletter

Silver \$2,500

- 1 ticket to Donor Reception
- Logo featured on website
- Logo displayed on Conference App
- Logo printed on Conference Bag
- One exhibit space
- Sponsor acknowledgment in Newsletter

We Need Your Help!

Our Basket Raffle and Silent Auction are always among the highlights of the CHARGE Conference festivities – and they'll be back again this year to raise money for the Foundation!

For the Basket Raffle, we need donations of themed baskets with a value of at least \$75. Think dinner and a movie, family movie night, day of beauty,



sports collectibles, games, coffee lovers, chocolate fanatics, wine aficionados, baskets showing off your hometown or state. Get creative!

For the Silent Auction, we need donations of higher-ticket items such as sports tickets and memorabilia, timeshares or condos, fine jewelry, and electronics.

Please help us by soliciting from businesses, friends, family, and colleagues, giving them the opportunity to support the Foundation's good work. <u>Click here</u> for the solicitation letter template. <u>Click here</u> to access the online donation form (and be sure to write a great item description so the item really sells!). Contact <u>Conference@chargesyndrome.org</u> for more information. Thank you!

Call for Conference Panelists

We are looking for participants for our CHARGE Sibling* and Adults with CHARGE panels, that will take place during General Sessions at the 16th International CHARGE Syndrome Conference.

Please click on the links below to fill out an interest form. We will have limited space, so participation is not guaranteed. Presenters will be live on stage at



Conference, so should be comfortable sharing their story in front of a large audience.

CHARGE Sibling Panel

Adults with CHARGE Panel

*CHARGE Sibling panelists preferred to be aged 16+. Adults with CHARGE panel includes individuals 21+.

Conference Family Checklist

Our 16th International CHARGE Syndrome Conference will be here before you know it! Here are some things you can do now, and some dates to keep in mind:

May 31 - Early Bird registration ends

Book your hotel room and make travel arrangements
Fill out the Volunteer Interest Form
<u>Donate an auction item</u>
February 14 - Deadline to submit <u>Conference Family Scholarship</u> a
March 1 - Conference registration opens



The 16th International CHARGE Syndrome Conference, "The Grand Adventure," will be held at the JW Marriott Phoenix Desert Ridge Resort & Spa, in Phoenix, AZ, July 24-27, 2025. <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? Fill out this form to submit submissions for review.