

CHARGE Accounts

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

Upcoming Events

2/17/2024

Birth to Age 3 Parent-to -
Parent Support Group

2/25/2024

Adults with CHARGE Virtual
Social-Email to Register

2/27/24

Western Region CHARGE
Syndrome Parent to Parent
Call

2/28/2024

Grief Support for Families of
Children with Deaf-Blindness

5/18/2024

Walk and Roll for CHARGE

The CHARGE Syndrome Foundation

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The CHARGE Syndrome Foundation



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5th Annual Walk and Roll for CHARGE



Walk and Roll for CHARGE

Join us for the 5th Annual Walk and Roll for CHARGE on May 18, 2024. Gather together in person or virtually with family and friends to walk/run a 5K, take a stroll, or even hop on a bike...the options are limitless! No matter how or where you gather, the goal is the same: to be active while raising critical funds for the Foundation and awareness for CHARGE syndrome. Register as an individual or family, create your own team, or join an existing team. All funds raised will help support individuals with CHARGE and their families through direct assistance, research, and outreach.

[Click here](#) to register today and be a part of creating a better world for people with CHARGE syndrome!

T-Shirt Design Winner

Voting for this year's t-shirt design took place on social media last month and we are excited to announce the winner, chosen by you!

This year we will also be offering the opportunity to be featured on the back of the official Walk and Roll for CHARGE t-shirt, either as a business sponsor or as a top fundraiser.



Sponsorship deadlines are April 13, 2024. [Click here](#) for additional information on sponsorship and fundraising.

T-shirts are available for purchase at the time of [registration](#), or by clicking the [store link](#) on our [Walk and Roll for CHARGE event webpage](#). You can order as many t-shirts as you would like under one registration, so order for the entire family! Only one registration required for each family or group.

Orders must be received by Friday, April 13, 2024* in order to guarantee delivery by the walk date, May 18, 2024.

**Delivery not guaranteed by event date when ordering outside of the US.*

Become a Walk and Roll Sponsor

Show your support for the Foundation by having your business sponsor this year's Walk and Roll for CHARGE.

Benefits include:

- Company logo on the back of our official Walk and Roll t-shirts*
- Recognition on our social media platforms and support groups (9,000+ reach)
- Featured on our website (10,000+ monthly visitors)
- Inclusion in our monthly newsletter (4,500+ subscribers)
- Company logo featured on the official event website



The cost for a sponsorship is \$1,000. [Click here](#) to submit a Sponsor Profile.

*All sponsorship materials must be received by Friday, April 13, 2024 to be included on the official Walk and Roll for CHARGE t-shirt

Individual and Team Fundraising Rewards

New this year - raise \$1,000 or more as a team or individual and you will receive recognition for your hard work!

Reach the \$1,000 fundraising milestone and receive:

- Individual or team name on the back of the official Walk and Roll t-shirts*
- Recognition on our social media outlets, website, newsletter, and event fundraising website
- Receive one Stanley Cup with Foundation logo per team or individual

*\$1,000 must be raised by Friday, April 13, 2024 to be featured on our official Walk and Roll for CHARGE t-shirt.



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 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 community, and all of those individuals affected by rare diseases – including the unique challenges we face every day.



SHARE YOUR STORY

The zebra is the official symbol of rare diseases in the United States. Because every stripe has a story, we want to hear yours!

- Share your story and show your stripes! Fill out [this form](#) and [send a photo](#) for a chance to be featured on our Facebook page
- Show your unique stripes on social media by using #ShowYourStripesForCHARGE
- Share the link to the [Rare Disease Day website](#) on your social media
- Change your profile picture to our [CHARGE Awareness graphic](#)
- Print and have your child [color the rare disease zebra](#) to show their stripes
- Start a [Charge it for CHARGE campaign](#) in honor of the day

Countdown to Conference: About the Venue

It's not too early to start planning! 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.

This gorgeous resort includes luxurious, newly transformed, family friendly guest rooms and suites. Enjoy a tranquil stay with breathtaking views of the lush resort grounds, mountains, or Wildfire Golf Club. It will be a spectacular backdrop for an unforgettable Conference.



Located at the heart of Phoenix, North Scottsdale, Cave Creek and Desert Ridge Marketplace, infinite pathways for entertainment, exploration, dining and rejuvenation come together at the newly transformed JW Marriott Phoenix Desert Ridge Resort & Spa. From the serenity of their Revive Spa to championship golf, an expansive pool complex with four swimming pools, and six on-property restaurants, every element needed for an unforgettable experience is yours to explore.

From open-air shopping to hiking and horseback expeditions, there are many opportunities to explore in the resort’s surrounding area as well.

We look forward to another amazing International CHARGE Syndrome Conference and providing our community with the opportunity to learn, connect, and grow together in Phoenix in 2025!

Family Liaison Highlight - Takrima Sandikot

Takrima Sandikot is our Family Liaison for Kansas. She is enthusiastic about helping families and building partnerships with her State Deafblind Project. She has collaborated with them for some of their events and ensures our families know of every opportunity.

Many exciting things have happened with our families in Kansas since Takrima started her role.

For example, a family in Kansas was gifted a Lifetime Silver Membership by an anonymous donor. This donor pledged to donate one Lifetime Membership every December. This is an excellent way for families to have a long-term connection with our Foundation's CHARGE community. We cannot wait to see the impact Takrima's dedication to helping more Kansas families will have in the future. Thank you, Takrima!



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.