

CHARGE Accounts

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

Upcoming Events

11/12/2024

Familia CHARGE (Spanish-Speaking Families Support Group)

11/16/2024

Birth-to-5 Year Parent Support Group

11/17/2024

Adults with CHARGE Virtual Social Email to Register

11/21/2024

Ask the Expert: Supporting Adult Needs in CHARGE

12/2/2024

Deadline to Submit Conference Presentation Proposals

The CHARGE Syndrome Foundation

info@chargesyndrome.org

CHARGEsyndrome.org



The CHARGE Syndrome Foundation



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A Season of Gratitude



As we enter the holiday season, we would like to take a moment before the hustle and bustle begins to express our gratitude for you, our community. We see the support you give to each other in our Facebook Support Group, in online support groups, and at events throughout the year. You generously answer questions, welcome new families, and share your stories. This all means so much to others in similar circumstances. The Foundation's work is all for you, yet ironically we couldn't do it without you!

Also, we are endlessly grateful for our fundraisers. Those of you who raise money throughout the year with your Charge It for CHARGE campaigns, Facebook fundraisers, events in your community, and Walk and Roll for CHARGE - you are what keeps our Foundation going!

Upcoming Events cont.

12/3/2024
Giving Tuesday

12/15/2024
**Deadline to Submit Research
Grant Proposals**

In addition to fundraising, so many of you donate your valuable time volunteering for the Foundation. We are especially grateful to our Family Liaisons who not only support and provide information to the families in their state, but also provide us with new and important information. Whether it is being a part of a workgroup, helping to plan Conference, or simply sharing your story, photos, or videos for a social media post, every bit helps. Volunteers will become more important than ever as we enter another Conference year in 2025. [Click here](#) if you are interested in learning more about volunteering before or during Conference.

And we can't forget our small but mighty staff! Each one of our three staff members wear many hats throughout the year and work hard to keep the Foundation running. We are so grateful to them for their dedication.

We also take a moment to thank David Wolfe for his years of hard work dedication to the Foundation as volunteer, fundraiser, board member, and President, and wish him well in all his future endeavors.

Finally, and perhaps most importantly, the Foundation would not be where it is today without our Board of Directors, Advisors, and Professional Advisory Board. They selflessly dedicate their time and expertise to guide the direction of the Foundation every day, truly making the world a better place for people with CHARGE syndrome.

Be a Part of Something Great

Be a part of something great by becoming a member of the CHARGE Syndrome Foundation. Becoming a member is easy and impactful. As a member of the CHARGE Syndrome Foundation, you will enjoy the power of connection, support, and shared knowledge.

If you are already a member, renewing or upgrading your membership can do even more to strengthen our community and show your support for the Foundation.

Support Critical Research & Family Assistance Programs

Your membership directly supports research initiatives and programs that improve the lives of individuals with CHARGE syndrome.



Voting Rights & Surveys

As a member, you'll have the privilege to vote in board elections and participate in member surveys, giving you a voice in the Foundation's future direction.

Exclusive Resources & Content

Unlock access to specialized webinars, workshops, and in-depth materials to help you stay informed about CHARGE syndrome.

Conference Benefits

All members have priority access to Sibshops. In addition, Lifetime members enjoy discounted registration.

Members make it all possible! [Click here](#) to become a member today* and show your commitment to making the world a better place for individuals with CHARGE syndrome.

If you are currently a member and interested in upgrading, [click here](#) to learn more about the different levels of Lifetime Memberships we offer.

*Annual Memberships will be valid from date of purchase to December 31, 2025.

Ask the Expert - Supporting Adult Needs in CHARGE

Our next Ask the Expert webinar, entitled "Supporting Adult Needs in CHARGE," presented by Kasee Stratton-Gadke, PhD, will take place November 21st, 2024, 7:00 - 8:00 pm EST.

This presentation will briefly review results of a survey from adults with CHARGE syndrome regarding their most pressing concerns and needed supports. The discussion will include potential ways to prepare for the transition into adulthood including transition plans in high school, post-graduation, mental health support and physical/health needs in adulthood.

[Click here](#) to register.

**ASL and Spanish interpretation is available at all of our Ask the Expert Webinars.*



Giving Tuesday

Giving Tuesday is a global generosity movement with a simple idea behind it: a day that encourages people to do good. Since its inception in 2012, it has grown exponentially and inspires people around the world to give, collaborate, and celebrate generosity.



We hope you will participate in the Giving Tuesday movement and support the CHARGE Syndrome Foundation's "Rising from Challenges Together" campaign. Please consider making a gift to the Foundation.

Your gift will help our community Rise from Challenges Together by:

- Ensuring that individuals with CHARGE continue to be able to attend Conference at no cost
- Sponsoring Cutting Edge Research
- Supporting our families through our Family Assistance Programs
- Helping to grow our community through outreach and engagement
- Helping to award close to \$200,000 in scholarships for families to attend conference, to help fund the postsecondary education of siblings of individuals with CHARGE, and to send up-and-coming professionals to Conference

Together we can help more families. Please watch your email and the Foundation's social media channels in the coming weeks for the link to our Giving Tuesday campaign.

Holiday Gift Ideas

Items from our CHARGE Syndrome Awareness Store make the perfect gift for family, friends, teachers, and medical staff. And we have some great stocking stuffers! Be sure to check out our special limited time Winter 2024 design - chosen by your votes on our Facebook page!

[Click here](#) to shop now.

Shipping takes 2-3 weeks (available in the US only), so be sure to order early to have in time for the holidays!



Call for Conference Presentations

The CHARGE Syndrome Foundation is seeking proposals from professionals for its 16th International CHARGE Syndrome Conference, to be held in Phoenix, AZ.

We are seeking proposals addressing the following topics:

- Medical
- Behavior
- Education
- For Adolescents and Adults with CHARGE
- Family Support



[Click here](#) to learn more about these topics and [click here](#) to submit your proposal. Deadline for submissions is **December 2, 2024**. Contact conference@CHARGEsyndrome.org with any questions.

Book Your Room Now for Conference

Book your room now for The 16th International CHARGE Syndrome Conference, “The Grand Adventure,” to be held at the JW Marriott® Phoenix Desert Ridge Resort & Spa, in Phoenix, AZ, July 24-27, 2025.



[Click here to reserve your room today.](#)

We have secured a room rate of \$192 per night plus tax, for up to 4 people per room. The room rate is available for extended dates before and after Conference, but are filling up fast! Make plans to extend your family’s stay and enjoy all that the resort and surrounding area have to offer. If you would like to book over the phone (480-293-5000), please let the hotel know that you are with the CHARGE Syndrome Foundation. If booking more than one room you will need to make two separate reservations. You can request connecting rooms by adding the request on your reservation, or you can call the hotel about 10 days prior to arrival. Questions email conference@CHARGEsyndrome.org.

Countdown to Conference

There are so many ways that you can volunteer both before and during Conference. See below for the many opportunities that are available then [click here](#) to complete the interest form or email Conference@chargesyndrome.org.

PRE-CONFERENCE WORKGROUPS – November 2024 to June 2025

- Silent auction/basket raffle item soliciting
- Solicitation of sponsors and exhibitors
- Scholarship evaluation subcommittee
- Evening event planning subcommittee

PRE-CONFERENCE SET-UP – July 19-24

- Assist in all areas with pre-conference setup (moving tables, supplies, and signage)
- Unload boxes from storage (some may be heavy)
- Assemble attendee bags
- Organize conference materials
- Set up signage
- Arrange tables

DAY CAMP – July 25-27

- Assist campers with crafts and other activities
- Assist with the set-up and monitoring of the sensory room
- Help reach parents attending sessions if their child at camp requires attention
- Familiarity with children with deafblindness preferred
- ASL knowledge is highly desirable



SILENT AUCTION & BASKET RAFFLE

- Solicit items to be donated in advance of conference ([click here](#) for more information and to submit donations)
- Assemble baskets and deliver to the conference
- Organize donated items at the conference and prepare for event
- Set up and assist with evening events

GREETER – July 23 & 24

- Welcome attendees in hotel lobby
- Assist attendees in finding conference center
- Direct attendees to registration tables

REGISTRATION – July 22-25

- Assist staff with final preparation of attendee materials
- Welcome attendees and assist in conference check-in
- Direct attendees to staff with questions
- Assist in distribution of attendee badges
- Assist with final exhibitor set-up
- Guide attendees to research areas
- Assist research teams in connecting with attendees as needed

**Camp volunteers must be 18 years or older. A background check will be required for all camp volunteers.*

MEALTIME BADGE CHECKER – July 24-27

- Arrive 10 minutes before scheduled food service begins
- Greet attendees and ask them to show badges before entering the food service area
- Direct attendees with previously arranged dietary needs to staff for assistance

SALES TABLE – July 23 -27

- Morning set up of sales table materials
- Process sales of items
- Evening tear down

INTERPRETER/INTERVENER/ TRANSLATOR – July 25-27

- Volunteer ASL Interpretation of live events
- Volunteer 1:1 Intervener for Individuals with CHARGE syndrome
- Volunteer English/Spanish Translation

EVENING EVENTS – July 24-26

- Volunteer in workgroup (monthly meetings and individual planning assignments)
- Assist in soliciting items for art show
- Prepare media presentations for evening events
- Prepare items for events in advance of conference
- Set up and operate activity stations
- Welcome attendees at events
- Assist with activities for children



EVENT VIDEOGRAPHY & PHOTOGRAPHY – July 24-27

- Assist Foundation's Communication Specialist in documenting conference
- Use video and photos to capture the emotions and key moments of the event
- Volunteer in four to six-hour shifts to take photos and/or videos of all conference events
- Volunteers will use personal camera equipment
- Foundation will provide SD cards for daily use
- All images will be property of the Foundation

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.