JANUARY 2025

# CHARGE Accounts

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

### Upcoming Events

1/10/2025 <u>See's Candies Fundraiser</u> <u>Begins</u>

1/18/2025 <u>Birth-to-5 Year Parent Support</u> <u>Group</u>

1/20/2025 Conference Scholarship Applications Open (check your emails later this month for more info)

1/23/2025 <u>Familia CHARGE (Spanish-</u> <u>Speaking Families Support</u> <u>Group)</u>

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#### The CHARGE Syndrome Foundation

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# Looking Forward to 2025

2025 is a big year, bringing lots of exciting opportunities surrounding our <u>16th Annual CHARGE Syndrome</u> <u>Conference</u>, in Phoenix, AZ, July 24-27!

Parents often describe the Conference as a transformative experience—a rite of passage, a family reunion, and a unique opportunity to connect with others navigating similar challenges. It's a chance to learn from leading professionals in medical, clinical, and educational fields, participate in CHARGE research, and gain valuable insights to better support your child. We hope you'll take advantage of everything the Conference has to offer this July in Phoenix!

If you are not familiar with our conferences and all that they include, check out the <u>Frequently Asked Questions</u> on our website.

# Upcoming Events cont.

1/26/2025 Adults with CHARGE Virtual Social <u>(email to register)</u>

1/28/2025 Family Liaison Meeting

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

7/24-27/2025 <u>16th International CHARGE</u> <u>Syndrome Conference</u> Here are some things that you can do now and some key dates to put on your new calendars:

- Conference hotel rooms are available now! We have secured a room rate of \$192 per night plus tax (for up to 4 people per room), for the 16th International CHARGE Syndrome Conference. If you're interested in extending your stay either before or after Conference, we have secured a limited number of rooms at the Conference rate for July 21 through July 29. Book ASAP as these extended dates are filling up fast. <u>Click here</u> to secure your room now.
- <u>Applications to conduct research</u> at Conference are now being accepted
- Applications are now being accepted for the <u>Sandra</u> <u>Davenport Fellowship</u> for professionals early in their careers who have shown a commitment to CHARGE syndrome (learn more below)
- January 20 Foundation Supported Conference Scholarships For Families applications open
- February 3 Deadline to apply to conduct research at Conference (for professionals)
- February 14 Scholarship application deadline
- February 28 Scholarship recipients will be notified
- March 1 Conference registration opens (see below for pricing structure. This is also when you will be able to register for camps)
- March 3 Sandra Davenport Fellowship Application Deadline
- April 11 Sandra Davenport Fellows will be notified
- May 31 Early Bird Registration pricing ends
- June 1 Deadline to sign up as a Conference Exhibitor or Sponsor

Below are the registration pricing and dates. Register by May 31 for the best deal!

#### Early Bird Registration (through 5/31/2025):

- Adults (13 and over): \$399
- Children 12 and under, attending camp: \$ 399
- Children 12 and under not attending camp: \$299
- Individuals with CHARGE: FREE!
- Meg Hefner Professional Day (Thursday) only: \$250
- Meg Hefner Professional Day & Conference: \$649



#### Registration 6/1 – 6/30/2025:

- Adults (13 and over): \$449
- Children 12 and under, attending camp: \$449
- Children 12 and under not attending camp: \$349
- Individuals with CHARGE: FREE!
- Meg Hefner Professional Day (Thursday) only: \$300
- Meg Hefner Professional Day & Conference: \$699

#### Registration 7/1/2025 – Start of Conference:

- Adults (13 and over): \$499
- Children 12 and under, attending camp: \$499
- Children 12 and under not attending camp: \$399
- Individuals with CHARGE: FREE!
- Meg Hefner Professional Day (Thursday) only: \$350
- Meg Hefner Professional Day & Conference: \$749

#### Would you like to help with Conference? Here are some ways that you can get involved:

- <u>Volunteer</u> before or during Conference
- Donate a basket or auction item for our raffle and silent auction
- <u>Become a Conference Exhibitor</u>
- Become a Conference Sponsor

# Volunteer at Conference

We would not be able to accomplish all that we do at Conference without our amazing volunteers! There are so many ways to volunteer at Conference - from being a part of a pre-Conference workgroup, to assisting with camps, or donating a basket or item for our silent auction. Please <u>click here</u> to see all of the positions that we are looking to fill.



"Working with the kids at the CHARGE Syndrome Conference was an absolute joy. Their smiling faces made the already meaningful experience more amazing," said Elijah, who volunteered (and posed as Spiderman) at the 2023 Conference.

# **Conference Sponsorship**

The CHARGE Syndrome Conference provides an outstanding opportunity for organizations to reach hundreds of professionals, families, and individuals with CHARGE syndrome by becoming a sponsor. Organizations can increase their market outreach while supporting the only national organization dedicated solely to serving individuals with CHARGE syndrome.



This year's Conference promises to be something truly special. We're expecting over 1,200 people to join us for a life-changing and affirming weekend of learning, collaboration, support, and fun! Please share this opportunity with organizations that you think would be a good fit for sponsorship. For more information, <u>click here</u> to download the Sponsorship Packet, or contact us directly at <u>Conference@CHARGEsyndrome.org</u>.

# **Research Opportunities at Conference**

The CHARGE Syndrome Foundation has a long history of providing opportunities for researchers to conduct their CHARGE syndrome-related research at Conference. With more than 1000 attendees, including more than 200 individuals with CHARGE, the International CHARGE Syndrome Conference presents a unique opportunity for research.



If you are interested in conducting research at the 16th International CHARGE Syndrome Conference, July 24-27, 2025, please <u>click here</u> to complete the application.

The application asks for information about the study principal investigator, methods, and logistical needs. We will be accepting submissions until Monday, February 3, 2025. If you have any questions, please contact Dr. Tyler G. James at <u>tyler@chargesyndrome.org</u>.

## Sandra Davenport Fellowship Opportunity

The CHARGE Syndrome Foundation is committed to nurturing and educating professionals who have shown a commitment to CHARGE syndrome. The Davenport Fellowship program brings professionals (clinical, research, therapeutic, educational) early in their careers to the International CHARGE Syndrome Conferences, where they have the opportunity to learn more



about CHARGE, interact with one another, and get to know individuals with CHARGE and their families.

The program is named in honor of Sandra Davenport, MD, a medical geneticist with expertise in sensory deficits who was a founding member of the CHARGE Syndrome Foundation. Dr. Davenport set the tone for conferences from the beginning – making sure medical and educational professionals interact with one another and ensuring that the conference is a family-friendly place. Her expertise in sensory deficits and deafblindness influenced a generation of CHARGE professionals.

<u>Click here</u> to learn more about this year's information and expectations, and to apply.

# New Vice President of the Board -Penni Echols

We are pleased to announce that Penni Echols has been elected as the new Vice President of the CHARGE Syndrome Foundation.

Penni and her husband Micah live in Las Vegas, Nevada with their six daughters. Their youngest, Martha, was born in 2014 and the family connected with the CHARGE Syndrome Foundation during the difficult first years of her



life. After reading handouts from the 2015 Conference while Martha was in the Pediatric Intensive Care Unit, Penni and Micah became members of the Foundation and have been engaged at various levels ever since. Professionally, Penni has worked as a fierce advocate for families with children who are deaf or hard of hearing. She passionately believes that every child can communicate when they have the right support and a willing partner.

Penni enjoys connecting families to one another, the Foundation, and the larger Deafblind network. She represents the Foundation as a Nevada Family Liaison, spends countless hours volunteering at our conferences and hosting parent support groups, and has been a member of the board since 2022.

# **Sweets for CHARGE**

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 with our See's Candies Fundraiser!

The fundraiser will be open now through January 31. <u>Click</u> <u>here</u> to shop.

\*US Shipping only



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.