

CHARGE Accounts

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

Upcoming Events

4/16/2024

**Ask the Expert - Intervener
Series Part 1**

4/20/2024

**Birth-to-3 Year Parent Support
Group**

4/21/2024

**Adults with CHARGE Virtual
Social-Email to Register**

4/22/2024

**Crocker Barker Sibling
Scholarship Deadline**

4/23/2024

**Western Region CHARGE
Syndrome Parent-to-Parent
Call**

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The CHARGE Syndrome Foundation

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Crocker Barker CHARGE Sibling Scholarship Opens



Crocker Barker CHARGE Sibling Scholarship

We are now accepting applications for the 2024 Crocker Barker CHARGE Sibling Scholarship. The Crocker Barker CHARGE Sibling Scholarship was created, thanks to a generous donation from the Barker Family, to help siblings of individuals with CHARGE syndrome fund their post high school education – including trade school, community college, or university.

Siblings of individuals with CHARGE are lifelong champions and supporters of their brothers and sisters. We want to recognize these siblings by providing an opportunity for them to continue their education post high school.

Scholarships are awarded based on merit and financial need.

Upcoming Events Continued

4/25/2024

Familia CHARGE (Spanish-Speaking Families Support Group)

4/30/2024

Ask the Expert Intervener Series Part 2

5/14/2024

Ask the Expert Intervener Series Part 3

5/18/2024

Walk and Roll for CHARGE

Past recipient Chanel says, "I am so honored to have this opportunity and I am so grateful for this amazing organization that has done so much for my brother. Thank you for all of your help!"

[Click here](#) to apply now. Deadline is April 22, 2024.

Thank You Walk and Roll for CHARGE Sponsors

By sponsoring the Walk and Roll for CHARGE, these organizations are helping to support our community through direct assistance, research, and outreach. These organizations have a special connection to our community and we are grateful for their support.

Learn more about our Walk and Roll for CHARGE sponsors:

- [Rady Children's Center for CHARGE Syndrome](#)
- [Perkins School for the Blind](#)
- [Miles to Row](#)
- [Freedom Concepts, Inc.](#)

There is still time to show your support by becoming an event sponsor!* [Click here](#) for more information.

[Click here](#) to register for Walk and Roll for CHARGE.



**Sponsors must be registered by April 13, 2024 in order for names to appear on the official Walk and Roll for CHARGE t-shirt design.*

Walk and Roll for CHARGE Fundraisers

In addition to sharing your story, emailing supporters, and connecting your page to Facebook, consider doing a fundraiser to raise money for your Walk and Roll for CHARGE campaign. See what some of our top fundraiser teams are doing:

CHARGE on 4 Tucker's Bowling Fundraiser

"Friends and family gathered at a local bowling alley to raise money for our Walk and Roll for CHARGE team, CHARGE On 4 Tucker. We sold about 30 tickets (There's only 6 lanes at this bowling alley, so 30 was the max we could sell!). Families came out to bowl, there was a bake sale, 50/50, basket raffle, and CHARGE themed jewelry for sale. We had several people who couldn't join the actual event stop in to buy raffle tickets and baked goods.

Hunter was very excited to help raise funds and awareness in honor of his brother. He made sure 'Tucker Bear' met everyone, and helped pick winners for the different drawings."

-Amanda K, Tucker's Mom



Team Rhett's CHARGE Bracelet Fundraiser

"When thinking of ways to raise money for the CHARGE Syndrome Foundation, I wanted to do something that others would be excited about and something I haven't seen done before. Beaded friendship bracelets are so popular right now, but I wanted to make one to stand out. I found the ASL I love you bead, and I knew I had to make a bracelet with that. ASL is Rhett's language, so the I love you sign means so much to me personally. I knew it would have a lot of significance to others as well, and I was more right than I could have imagined! So many CHARGE families and friends have purchased bracelets to support those they love with CHARGE. Thank you to everyone for your support in making this fundraiser so successful!!

We are so thankful to everyone who has contributed to our fundraiser through the purchase of a bracelet or donation!"

-Anna M., Rhett's Mom



If you are interested in purchasing a bracelet, contact Anna at mommyinchargeblog@gmail.com.

Scientific Research Grants

Thanks to the generosity of our donors, over the years the CHARGE Syndrome Foundation has been able to fund high quality CHARGE syndrome-related research projects. Many past recipients have published their research in prestigious journals and have gone on to receive over \$11,500,000 from the NIH and other government agencies.



We are pleased to announce the awards for the 2024 Scientific Research Grants to the following:

- Albert Basson of University of Exeter, UK and Stefano Espinoza of University of Eastern Piedmont, Italy.
- Dr. Rosanna Weksberg at The Hospital for Sick Children in Toronto

Our next Scientific Grant Cycle will be opening in Winter 2024.

Profiles in CHARGE - Meet Tyler

Tyler Criswell, 19, lives in the San Francisco Bay area of California and enjoys spending time out with family and friends like Grayson Rago, who also has CHARGE syndrome.



In addition to his human friends, Tyler also has a special bond with his K-9 Buddy, Yosemite. Tyler received Yosemite, a yellow lab, on February 16, 2024 from the Guide Dogs for the Blind K-9 Buddy Program, which is available to people with any type of vision impairments. Prior to taking Yosemite home, Tyler and his family had a 3 hour training on the program's campus in San Rafael, CA. This is Tyler's second dog and this time Tyler is older and has taken on a bigger role in the care of Yosemite.



Tyler's mom, Victoria, says, "It is so cute to see him interact with Yosemite. Tyler has even slept with him, which shocked us! Tyler doesn't like furry things, but he has really connected with Yosemite and wanted to sleep next to him."



Have the Best Summer Ever with EWRAP!

As summer approaches, many parents are left wondering how to keep their children engaged during the school holiday. There are many recreational and social opportunities for people with CHARGE syndrome, from camps, to recreational classes and programs.

Whatever you choose to do this summer, the Ethan Wolfe Recreational Assistance Program (EWRAP) can help! EWRAP provides individuals with CHARGE syndrome the opportunity to participate in recreational activities. [Click here](#) to learn more and to apply today.



Below are some ideas of fun summer activities. To explore options in your specific area please consult with your child's school, developmental disability service office, and special recreation departments.

- Camp Abilities Brockport is a one-week educational sports camp for children and teens who are blind, visually impaired, and deafblind with the motto – Believe You Can Achieve! Registration is currently open for this summer's session, June 30-July 6. [Visit the Camp Abilities website](#) for more information and to register.

- Hippotherapy refers to how occupational therapy, physical therapy, and speech-language pathology professionals use evidence-based practices and clinical reasoning in the purposeful manipulation of equine (horse) movement to engage sensory, neuromotor, and cognitive systems to achieve functional outcomes. In conjunction with the affordances of the equine environment and other treatment strategies, hippotherapy can be part of a patient's integrated plan of care. Visit the [American Hippotherapy Association](#) for more information and to find a program in your area.
- Music Therapy uses music within a therapeutic relationship to address physical, emotional, cognitive, and social needs of individuals. Research in music therapy supports its effectiveness in many areas such as: overall physical rehabilitation and facilitating movement, increasing people's motivation to become engaged in their treatment, providing emotional support for clients and their families, and providing an outlet for expression of feelings. Visit the [American Music Therapy Association](#) for more information and to find a program or therapist near you.
- Art therapy is a mental health profession that enriches the lives of individuals, families, and communities through active art-making, creative process, applied psychological theory, and human experience within a psychotherapeutic relationship. Learn more and find a program near you by visiting the [American Art Therapy Association](#).

Ask the Expert: Intervener Series

We are happy to present an Ask the Expert Intervener Series, taking place over three webinars this spring. Each webinar will take place at 6:30 PM CT on the following dates, and will last for 1 hr and 15 minutes (45 minutes of content followed by a question and answer session).

Click on the titles to register, and download the [IEP Discussion Guide](#) prior to the start of the webinars.



Part One: April 16 - Deafblindness and its Impact on Learning: Key Resources for Families and Educational Teams

Does your IEP team understand what your child who is deafblind may need as a result of their combined vision and hearing impacts? Join us for this webinar where we will provide an overview of deafblindness and its impact on learning, and share resources that will help you and your IEP team plan better educational programs for your child.

Part Two: April 30 - Educational Accommodations and Modifications: Improving Your Child's Routines

A continued discussion around educational planning using resources presented in session one for children with deafblindness, including those children with more complex needs. Accommodations and modifications that can be included in your child's daily routines and IEP will be shared.

Part Three: May 14 - The Nuts and Bolts of Interveners: What, Why, How, and When

What is an intervener? How is an intervener different from a paraeducator? How can an intervener or staff trained in deafblindness help support your child's learning? Join us to learn about current services and supports across the country that can be considered when planning your child's IEP. Key resources will be shared to increase your knowledge about interveners and their role in education now and in the future.

Sessions will be lead by Dr. Kristi Probst, the Interveners and Qualified Personnel Initiative Lead for the National Center on Deafblindness. She is a National Leadership Consortium in Sensory Disabilities scholar. She holds licensures in Special Education for the Deaf & Hard of Hearing, Low Vision & Blindness, Learning Behavior Specialist, Elementary Education, and Early Childhood Education. Her undergraduate and graduate degrees focused on the education of students with sensory disabilities (deaf/hard of hearing and visual impairment), while her doctoral studies concentrated on the area of special education, specifically educating students who are deafblind. She has worked as a teacher both for students with sensory impairments and students with learning disabilities, early interventionist, sign language interpreter, and university professor. Kristi uses her personal and professional experiences to inform her work, research, writing, and presentations.

CHARGE Syndrome Represented at the EHDI National Conference

Members of the CHARGE community, Iris Filkins, CO Family Liaison, Penni Echols, NV Family Liaison and Foundation Board member, and Staci Petralba, NV, presented at the EHDI (Early Hearing Detection and Intervention) National Conference in Colorado, March 18-20. Their presentation, **Family Perspectives on Navigating a CHARGE Syndrome Diagnosis**, shared their

personal stories on when they received their diagnosis, the challenges of trying to navigate the health system, and what resources contributed to building a network of support. The group also shared resources offered by our Foundation and connected to other parents and providers. [Click here](#) to view the recording.



Countdown to Conference

The 16th International CHARGE Syndrome Conference is an opportunity to learn from medical professionals, researchers, educators, and other specialists that work in the field of CHARGE.

Conference includes a top notch program with a 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. There will be something for everyone!



For an idea of at what to expect at Conference, [click here](#) to check out the Agenda from our most recent Conference this past July. For a comprehensive look at all that Conference has to offer, [click here](#) to watch our Ask the Expert webinar. Save the date for July 24-27, 2025.

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.