

CHARGE Accounts

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

Upcoming Events

5/11/2024

Birth-to-3 Year Parent Support Group

5/14/2024

Ask the Expert Intervener Series Part 3

5/18/2024

Walk and Roll for CHARGE

5/19/2024

Adults with CHARGE Virtual Social-Email to Register

5/23/2024

Familia CHARGE (Spanish-Speaking Families Support Group)

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The CHARGE Syndrome Foundation

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The CHARGE Syndrome Foundation



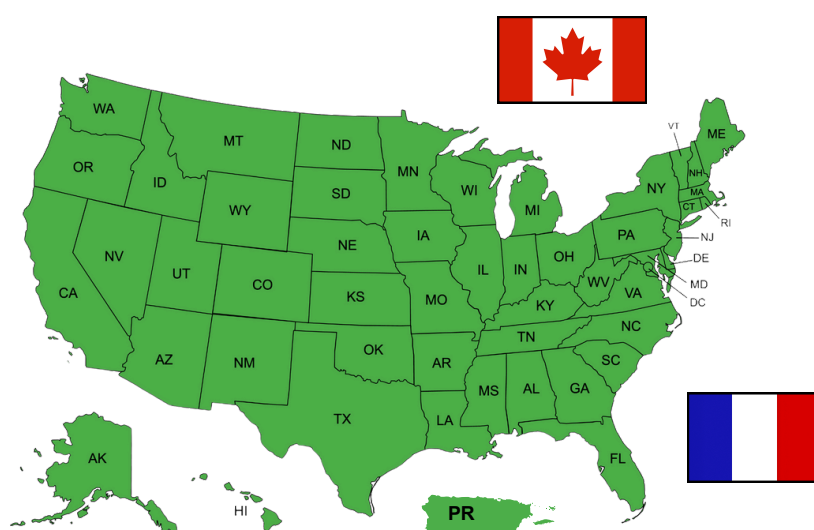
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@chargesyndrome



Our Biggest Walk and Roll for CHARGE Yet!



This year, for our 5th annual Walk and Roll for CHARGE, we set some pretty high goals. We wanted to “Walk and Roll across America,” with participants in every state — and we met our goal! Not only will we have participation in every state plus Puerto Rico, we have also expanded our event to include participants in France and Canada.

The states that currently have the most participants are Missouri (55 participants), Massachusetts (50 participants), New York (31 participants), California (20 participants) and Florida and Texas (19 participants each). This year's event is poised to be the largest Walk and Roll ever!

The 5th annual Walk and Roll for CHARGE has also

Upcoming Events Continued

5/28/2024

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

6/4/2024

**Ask the Expert: Take CHARGE
with Total Communication!**

resulted in the best fundraising participation in the history of the event!

We currently have sixteen teams and six individuals that have raised over \$1,000 for the event. Individuals and teams that reach the \$1,000 fundraising mark will earn a special edition CHARGE Syndrome Foundation Stanley Cup, while supplies last.

[Click here](#) to see our top fundraising teams.

[Click here](#) to see our top fundraising individuals.

With just about two weeks left until the event, there is still plenty of time to join the fun and show your dedication to individuals with CHARGE!

[Click here](#) to register, fundraise, plan your own event or join a Walk and Roll team! If you are interested in meeting up with others in your state, reach out to Lourdes@CHARGEsyndrome.org to find an event in your area.

We look forward to seeing everyone walking and rolling on May 18! You can download a sign to show who you walk and roll for [here](#). On the day of the event we ask you to post photos and videos using #WalkandRoll4CHARGE or email them to our [Marketing Department](#).



Congratulations to the 2024 Crocker Barker CHARGE Sibling Scholarship Recipients

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.

Congratulations to our 2024 recipients: Andre Zimmer, Kathryn Echols, Elizabeth Echols, Mary Catherine Young, Mallorie Beavers, Joseph Gaudin, Olivia Bowdoin, Kylie Steinhauser, Amaya Davis, Jadyann Rivera, Trinity Swanson, Kaylanna Dedman, and Caleb Teed.

We wish you the best of luck as you continue your education and cannot wait to see what the future brings!

Everyone Deserves the Chance to Play

The Ethan Wolfe Recreational Assistance Program (EWRAP) provides individuals with CHARGE syndrome the opportunity to participate in recreational activities, including camps, adaptive bikes, swimming lessons, music classes, and so much more.

Charlotte T. is a recent recipient of support from the EWRAP program, helping her attend therapeutic horseback riding lessons.

Her mom, Mia, says, “This is amazing and we are so, so grateful. Charlotte is all smiles when she is there.”

Jack S. is also enjoying therapeutic horseback riding sessions thanks to EWRAP.

Jack’s mom, Mariah, says, “This has brought us such joy. It is so incredibly special that you do this in Ethan's name and that you are spreading joy to other CHARGE children by giving them the opportunity to participate in all kinds of different recreational activities.”

With help from the program, Kaylee C. recently received a Freedom Concepts adaptive bike with a special EWRAP license plate. Her family did the big reveal at Kaylee's school, where classmates, friends, and a local paper were there to witness the exciting event.

Kaylee’s mom, Becky, says. “Thank you so much. We went out four times today. She is really loving it!”

For more information on the program and to apply, [click here](#) to visit the EWRAP page on our website.



Show Your Support this Summer

One of the best ways to spread awareness is by shopping at our CHARGE Syndrome Awareness Store! We have many items perfect for the summer, from tank tops to tote bags, picnic blankets and beach towels to water bottles, we have something for everyone.

One of our current best sellers is the *I Love You ASL* tote bag, perfect to pack up for a trip to the pool or beach. This design is also available in a t-shirt and beach towel. Proceeds from each sale benefit the CHARGE Syndrome Foundation.



[Click here](#) to see all of the items we have to offer and shop today.

Ask the Expert: Intervener Series

The Ask the Expert Intervener Series continues into May with Part 3, The Nuts and Bolts of Interveners: What, Why, How, and When at 7:30 PM ET on May 14.

During this session you will learn: 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. Family perspectives will also be shared for all to gain insight from their journey!

[Click here](#) to register.

Each session is 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.

Recordings of Part 1 and 2 are now available to watch on our YouTube channel. Click the links below to view.

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

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

Download the **IEP Discussion Guide** prior to the start of the webinars.

Ask the Expert: Take CHARGE with Total Communication!

Join us June 4 at 7:00 PM ET for Ask the Expert: Take CHARGE with Total Communication! [Click here](#) to register.

Presenters, Kathryn Bleczynski, Christine Cammisa, Neha Sharma, and Amber Skerry are Speech-Language Pathologists (SLPs) in the Deafblind Program at Perkins School for the Blind in Watertown, MA. They specialize in addressing the complex communication needs of students with CHARGE syndrome, deafblindness, Autism Spectrum Disorder, and those with significant global challenges due to complex diagnoses. The SLP team is passionate about providing therapeutic services via a Total Communication approach to facilitate the development of receptive and expressive communication. They value an interdisciplinary approach to encourage generalization of skills across the school day, at home, and in the community.

Total Communication is an approach that uses a **combination** of verbal speech, sign language, symbols (e.g., photo/picture symbols, tactile symbols), meaningful use of whole objects, gestures, actions, facial expressions, communication devices, etc. This approach exposes students to multiple modalities to support both receptive and expressive language. A student may communicate using one or a combination of modalities, and we honor and shape all modes. During this presentation, we will discuss the benefits of using a Total Communication

approach with our students who are diagnosed with CHARGE. We will discuss the possible ways communication can develop along with the strategies we have implemented to facilitate communication growth. Overall, we use creativity to individualize equipment and accommodations to optimize access to communication. We work together as an interdisciplinary team to implement each child's educational program and incorporate a developmental approach. The development of language and communication through individualized instruction is paramount. Attendees will leave our presentation with the knowledge and tools necessary to support students with CHARGE and implement various communication strategies at home.

Countdown to Conference

The 16th International CHARGE Syndrome Conference will be at the JW Marriott Phoenix Desert Ridge Resort & Spa, in Phoenix, AZ, July 24-27, 2025. We have secured a room rate of \$192 per night plus tax, for up to 4 people per room, from July 21 until July 29th. Make plans to extend your family's stay and enjoy all that the resort and surrounding area have to offer. Keep an eye out for more details on room reservations...coming soon!



The luxury resort offers a wide range of experiences, from pickleball facilities, tennis courts, yoga classes, and two champion golf courses for the sports enthusiasts, to a spectacular pool area featuring five pools, a lazy river, three new multi-story water slides, cabana cottages, and pool suites for those looking for some fun in the sun. You can also find your zen with a relaxing treatment at Revive, the hotel's spa, and you won't have to leave to eat - the hotel boasts six restaurant, including celebrity chef Angelo Sosa's newest addition, Tia Carmen.

Located at the crossroads of Phoenix, North Scottsdale, Cave Creek, and Desert Ridge you will find many opportunities to explore the area outside of the resort. You can find open-air shopping, hiking and horseback expeditions, wildlife and nature preserves, an aquarium, local sports teams, and more.

We have partnered with Visit Phoenix to help make planning your trip as seamless as possible. [Click here](#) to view some day trip itineraries they have put together and [visit their website](#) for more ideas on activities, sites, and dining in the area.

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.