

CHARGE Accounts

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

Upcoming Events

9/21/2024
Birth-to-5 Year Parent Support Group

9/21/2024
A Day to Remember

9/24/2024
Western Region CHARGE Syndrome Parent-to-Parent Call

9/26/2024
Familia CHARGE (Spanish-Speaking Families Support Group)

9/30/2024
Ask the Expert: What Topics Do You Want to See at Conference?

The CHARGE Syndrome Foundation

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A Day to Remember



On September 21, the CHARGE community will take a Day to Remember and honor those individuals with CHARGE who have passed away.

During the week leading up to September 21, we ask you to perform an act of kindness and share it on social media using the hashtag #ADayToRemember.

We love seeing the CHARGE community share their many wonderful acts of kindness and remembrances. From treating teachers, classmates, or important people in your community to lunch or goodies, to donating books and meals, helping a neighbor, or sending a note or e-mail of encouragement to a friend or stranger, there are so many ways we can be kind to each other.

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- [Click here](#) for some ideas of things that you can do.
 - [Click here](#) to print out a Day to Remember sign.
 - [Click here](#) to watch videos from past years.

Those that we have lost will always remain in our hearts. If you are dealing with a loss in your life, please [visit our Grief Support Page](#) for resources that may help.

17th Annual Charge It for CHARGE

[The 17th Annual Charge It for CHARGE](#) campaign will open October 1, 2024 and we need YOU to fundraise!

Our Charge It for CHARGE campaign is one of the primary ways our Foundation raises money for Conference, outreach, research, and Family Assistance Programs. This platform is open year round to make it easier for you to raise money with fundraisers big and small to help support the Foundation.



There are so many ways you can use this tool to your advantage and make your campaign great!

- Use as a fundraiser surrounding an event - a birthday, holidays, graduation, or other milestone
- Raise money through a fundraising event - some ideas include hosting a bowling night, golf tournament, or lemonade stand
- Share your story on social media or via email

It is quick & easy to set up your fundraising page. Help us continue the work to make the world a better place for all individuals with CHARGE and their families - watch your emails and our social media for a link to set up your campaign on October 1.

For more information about how to set up your campaign, [click here](#) to watch our instructional video. For fundraising ideas, [click here](#) to visit the fundraising section of our website.

Bowling for CHARGE

Earlier this year, our Wisconsin Family Liaison, Brooke Fula, and Aimee Gruber, along with their families, hosted their annual Bowl 4 CHARGE event to raise funds for the CHARGE Syndrome Foundation.



The event brought together many supporters from their community for an afternoon of fun, while raising money for CHARGE syndrome.

Thank you to Aimee and Brooke for your continued dedication to the Foundation!

Hosting a fundraising event in your community is a great way to raise money for the Foundation and contribute to your annual Charge it for CHARGE campaign. Wondering how you can fundraise too? [Click here](#) to visit our website for fundraising ideas.

Ask the Expert: What Topics Do You Want to See at Conference?

Join us Monday, September 30 at 7:00 pm EST for an Ask the Expert webinar: What Topics Do You Want to See at Conference?



[Click here to register.](#)

The panel will include Lisa Cunningham (Executive Director), Sara Espanet (board member), Joanne Lent (board member), and Lily Slavin (board member).

For this month's Ask the Expert, we want to hear from you! When you register via zoom, you'll have a chance to send us your conference-related questions, session topic requests, and ideas for activities. Can't join us for the webinar? No problem, we'll upload the recording [HERE!](#)

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.

Family Assistance Program Spotlights

Rachel's Birthday Bike

The Ethan Wolfe Recreational Assistance Program (EWRAP) provides individuals with CHARGE syndrome the opportunity to participate in recreational activities.



Just three days before Rachel's 21st birthday, she received a new Freedom Concepts Bike, thanks to EWRAP.

"It was so exciting to see that giant semi-truck and trailer circle around our little cul-de-sac and stop in front of our house. The driver lowered a huge wooden crate wrapped in plastic and everyone cheered! Rachel took an inaugural spin around the cul-de-sac while grinning ear to ear.

"Thank you so much for making this possible!" -The Gaudin Family

Goldie's Summer on Stage

This summer, EWRAP helped Goldie attend a summer arts theater camp. Her first performance was in *The Music Man*, followed by *The Wizard of Oz*.



"She is having such a wonderful time and I think it is incredible for her self-confidence. Thank you again for the scholarship and enabling Goldie to have a wonderful summer!" -Sabrina, Goldie's Mom

Back to School Resources

As we head into a new school year, you may find it useful to view some of our past webinars from experts in the field:

- [How CHARGE Syndrome Impacts Participation at School and Home](#)
- [Bridging the Gap between Home and School](#)
- [Educational Experiences of Individuals with CHARGE and the Checklist of Educational Needs for Individuals with CHARGE Syndrome](#)



Countdown to Conference

Our Conference hotel room block is now open!

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

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.**



We have secured a room rate of \$192 per night plus tax, for up to 4 people per room, for the extended dates of July 18 through July 30. 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](tel: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. If interested in booking a suite, please contact Neal@CHARGEsyndrome.org.

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 restaurants, 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.