

# CHARGE Accounts

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

## Upcoming Events

**3/14/2024**

**Ask the Expert en español-  
Síndrome de CHARGE:  
conociendo sus desafíos y  
oportunidades**

**3/16/2024**

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

**3/24/2024**

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

**3/26/2024**

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

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## The CHARGE Syndrome Foundation

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CHARGEsyndrome.org



The CHARGE Syndrome Foundation



@charge\_syndrome\_foundation



@chargesyndrome



## Walk and Roll Across America



## Turn the Map Green

This year, one of our goals for the Walk and Roll for CHARGE is to have participation from every state. So far, we have participants and teams registered from the states in green on our map. Register today and help us turn the whole map green! Here are some ways you can help:

- Plan an in-person event in your area. Pick a location (a park, neighborhood, hiking trails, etc.) and spread the word to family and friends.
- Tell us about your event! Large or small...or something in between. Send us a quick 10-15 second video with your name, state, and a description of your event so we can help spread the word!
- Share your stories - tell your supporters why you Walk and Roll for CHARGE!
- Post your photos on the day of the event using the hashtag #WalkandRoll4CHARGE

## Upcoming Events Continued

**3/28/2024**

**Familia CHARGE (Spanish-Speaking Families Support Group)**

**5/18/2024**

**Walk and Roll for CHARGE**





# Fundraising is Off to a Great Start!

Fundraising for the 5th Annual Walk and Roll for CHARGE is off to a great start. Our goal is to raise \$50,000. Funds raised will help support our community through direct assistance, research and outreach. So far this year we have raised \$4,100!





This year, individuals and teams that raise \$1,000+ will have their names on the back of our official Walk and Roll for CHARGE t-shirts\* and will receive a CHARGE Syndrome Foundation special edition Stanley cup. Sponsorships are also available, [click here](#) to learn more.

Congratulations to our current top fundraising individuals and teams:

## Top Fundraising Individuals

 <b><u>Hunter Kutzura</u></b> <b>\$644</b> of \$500 Reached <a href="#">View</a>	 <b><u>Foster Family</u></b> <b>\$200</b> of \$500 Reached <a href="#">View</a>	 <b><u>Suzanne Chen</u></b> <b>\$150</b> of \$500 Reached <a href="#">View</a>	 <b><u>Laurie Suter</u></b> <b>\$125</b> of \$500 Reached <a href="#">View</a>
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## Top Fundraising Teams

 <b><u>Zach Attack the Whole Snack</u></b> <b>\$700</b> of \$2,000 Reached <a href="#">View</a>	 <b><u>CHARGEon4Tucker</u></b> <b>\$644</b> of \$5,000 Reached <a href="#">View</a>	 <b><u>Massachusetts and New Hampshire Families CHARGE On Together</u></b> <b>\$325</b> of \$3,000 Reached <a href="#">View</a>	 <b><u>Victoria Strong</u></b> <b>\$220</b> of \$500 Reached <a href="#">View</a>
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*\*\$1,000 must be raised by April 13, 2024 in order for names to appear on the official Walk and Roll for CHARGE t-shirt design.*

# Spread Awareness with CHARGE Syndrome Awareness Items

One of the best ways to spread awareness, while supporting the Foundation, is by shopping at our CHARGE Syndrome Awareness Store! From clothing to tote bags, beach towels to water bottles, we have something for everyone.

Our current best sellers include our CHARGE Forward t-shirt and our I Love You ASL design, available as a t-shirt or tote bag.



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

## Welcome to the Board Sara Espanet

We would like to welcome Sara Espanet to the CHARGE Syndrome Foundation Board of Directors.

Sara is a Supervising Practitioner for teachers at Perkins School for the Blind in the Deafblind Program. She started working at Perkins School for the Blind in 2008 as a teaching assistant and in 2015 she became a classroom teacher after receiving

her Masters in Severe Special Education from Bridgewater State University. At Perkins, Sara works with students who are deafblind and multimodal learners. As a classroom teacher, Sara worked with many students who have CHARGE Syndrome and has experience working with students' families and collaborating with the whole team to ensure the success of each of her students.



Sara participated in the Sandra Davenport Fellowship Program in 2015 and was a mentor for the program in 2019 and 2023. Her favorite part of attending the CHARGE conferences is connecting with families and working with the Fellows program to support new professionals in the field of CHARGE. Sara has also been a consistent fundraiser for the Foundation since 2017, most recently helping to lead the Perkins School for the Blind Walk and Roll team. Sara Espanet is honored to join the Board and looks forward to continuing her work to support individuals with CHARGE Syndrome and their families.

# Simplified Program Applications Now Available

Applying for our Family Assistance Programs is now easier than ever! We listened to your suggestions and have simplified the application processes to our [EWRAP](#) and [Medical Travel Assistance](#) programs.

The Ethan Wolfe Recreational Assistance Program (EWRAP) provides individuals with CHARGE syndrome the opportunity to participate in recreational activities. This program is need based and funded through a generous gift from the Wolfe family and friends. Together with the CHARGE Syndrome Foundation, they wish to honor their son Ethan's memory by providing other individuals with CHARGE with fun recreational activities and equipment.



The Medical Travel Assistance Program provides financial assistance for families in the United States who are traveling long distances for medical care. The program helps cover costs of transportation, meals, lodging and parking. Applications for both EWRAP and Medical Travel Assistance are accepted year-round.

## Ask the Expert en español - Síndrome de CHARGE: Conociendo sus desafíos y oportunidades

Join us March 14, 2024 at 7:00 PM ET for our first Ask the Expert en español.

Silvia Zapata, mother of an adult with CHARGE syndrome, will share her story of how she has navigated the health system in Peru, despite little information about the syndrome. She will also share how she has managed to turn many challenges into opportunities for Piero.



Piero Franco Zapata is an adult with CHARGE syndrome who will share his experience growing up and developing independently. Piero has started many initiatives to help other families in Latin America.

English interpretation will be provided. [Click here](#) to register.



# Support for Spanish-Speaking Families

We are thrilled to announce new initiatives tailored for Spanish-speaking families in the US and around the globe. Due to overwhelming demand, we are providing a platform for you to connect, share resources, and support each other.

Join us for an evening of connection and support at our monthly support group in Spanish, every fourth Thursday of the month at 7:00 PM ET. Connect with Spanish-speaking families in the US and from all corners of the world. Share your experiences, challenges, and victories in your preferred language and form bonds with other families facing similar situations. Let's navigate this journey together!

Once you register, you will receive the zoom link for the meeting. You only need to register once; the meeting link will remain the same. [Click here](#) to register.

Encourage others in your network to join – let's strengthen our community!  
¡Únete a nosotros y comparte en familia!

For more information and updates, contact [Lourdes@chargesyndrome.org](mailto:Lourdes@chargesyndrome.org)  
Uniendo Familias – Fortaleciendo Lazos, Compartiendo Experiencias.



## Share Your Expertise

We are currently looking for guest speakers for our Ask the Expert webinar series. Participants with knowledge about a specific topic that would benefit our community are encouraged to participate. Interested experts in the field of CHARGE syndrome, parents, siblings, caregivers, or individuals with CHARGE can email [info@chargesyndrome.org](mailto:info@chargesyndrome.org) for more information.



# Countdown to Conference

The theme for the 16th International CHARGE Syndrome Conference is “The Grand Adventure: Rising from Challenges Together.”

Past attendees have compared Conference to a family reunion, a life-changing experience, and equated it to coming home. At Conference, we have the chance to come together to share experiences and challenges, learn from one another, make lifelong friendships, experience a sense of belonging unlike any other, and hear from the world’s top experts in CHARGE syndrome. Start planning now to join us on this “Grand Adventure”!

The 16th International CHARGE Syndrome International Conference will be held at the JW Marriott Phoenix Desert Ridge Resort & Spa, in Phoenix, AZ, July 24-27, 2025. To learn more about what to expect by reading through information about past Conferences [click 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.