

# CHARGE Accounts

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

## Upcoming Events

**8/8/2024**

**CHARGE Syndrome  
Awareness Day**

**8/17/2024**

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

**8/22/2024**

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

**8/27/2024**

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

## The CHARGE Syndrome Foundation

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The CHARGE Syndrome Foundation



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## CHARGE Syndrome Awareness Day



The first CHARGE Syndrome Awareness Day will be held internationally on August 8th, 2024. This marks the anniversary of the publication of the first paper on the discovery of the CHD7 gene by Professor Conny van Ravenswaaij-Arts (August 8, 2004). This day aims to raise awareness of the variability of CHARGE syndrome to help improve diagnosis and access to best practice interventions.

This year's theme is CHARGE: How do you spell it? The goal is to present the word 'CHARGE' in a variety of ways to show the variability of CHARGE syndrome.

Here are some ways that you can participate using this year's theme:

- Spell the word CHARGE by using a variety of materials or methods.

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- Use Lego bricks or Scrabble tiles; get some friends to form human letters; write it in the sand or even in the sky; fingerspell it or fingerprint it; crochet it or knit it; bake the letters or write them on a cake; or have CHARGE lit up in lights or hoisted up a flagpole.
  - Be creative! Take a photo of your creation and share it on social media to show how different CHARGE can look around the world.
  - Use the following hashtags when sharing your story on social media:  
#CHARGESyndromeAwarenessDay #CHARGEHowDoYouSpellIt  
#CHARGENoTwoPeopleAreTheSame #CHARGEMoreThanAnAcronym
  - Follow the CHARGE Syndrome Awareness Day Facebook Page: [CHARGE-Syndrome Awareness Day](#).
  - Join the CHARGE Syndrome Awareness Facebook Group: [CHARGE-Syndrome Awareness Day – International Group](#)
  - Show your support by wearing CHARGE syndrome apparel. [Click here to shop our Awareness Store](#).

Join us on August 8, 2024 to raise awareness of CHARGE syndrome around the world!

## Theo's EWRAP Story

Theo is a recent recipient of the Ethan Wolfe Recreational Assistance Program (EWRAP). Thanks to EWRAP, Theo is participating in 1:1 swim lessons. According to his mom, Alexis, “Theo is absolutely thriving in his swimming lessons and it makes him so happy!



“When we first started, I wasn’t sure how it would go, he was really nervous, but now we can barely get him out of the water. Theo has been through so much and is really struggling with anxiety - it is so amazing to see him jump right in and be really happy without reservation.”

The Ethan Wolfe Recreational Assistance Program (EWRAP) provides individuals with CHARGE syndrome the opportunity to participate in recreational activities. To learn more about EWRAP and apply, please [click here](#) to visit the EWRAP section of our website.

# DBI CHARGE Network Webinar: What About the Dads?

The DBI CHARGE Network invites its members to a webinar on Monday September 9th, 2024, where Jerry Petroff, Ph.D, Professor at The College of New Jersey, will be sharing his research on fathers' roles in families with infants and young children with CHARGE: **What About the Dads? Fathers' Involvement in the Care, Development and Education of their Children with Deafblindness.**



Recent decades have brought increased research on fathers' roles in families and their contributions to children's development and education, but what about the unique features of fathers of children with vision loss and additional health and development challenges? Research tells us that educators, health professionals, therapists and others need to take special and deliberate steps to ensure that fathers are actively involved in the habilitation and education of their children. Therefore, consideration and training in varied styles of communication, demonstrating flexibility to support father involvement and developing approaches to heighten a gender-balanced climate may lead to fathers' effective and consistent participation.

This session will frame the issues and offer practical guidelines to involve fathers of infants and young children with deafblindness/CHARGE syndrome. It should be noted that everyone is welcome to participate (e.g. fathers, mothers, professionals).

There will be two webinars on the same topic, presented at different times. Multiple language interpretation will be offered, so participants can choose the time and language that best suits their needs.

**Session 1: September 9, 2024, Central European Summer Time 10 am to 11 am**

**Session 2: September 9, 2024 Central European Summer Time 8 pm to 9 pm**

Central European Summer Time is 6 hours ahead of U.S. Eastern Time.

To register for this webinar please email Hannah Fletcher at [Hannah.t.fletcher@seashelltrust.org.uk](mailto:Hannah.t.fletcher@seashelltrust.org.uk)

For more information or to watch recordings of any of our past webinars, [click here](#) to visit the webinars section of our website.



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# Deafblind Awareness Week Stories

DeafBlind Awareness Week, which took place during the last week of June, helped raise public awareness about individuals who have combined hearing and vision loss, to promote a better understanding of the challenges they face, and to celebrate their unique abilities and contributions to society.



We used this week to help raise awareness for those individuals in the CHARGE community living with deafblindness, including the challenges they face every day, by sharing your stories on our social media and website.

Thank you to everyone who shared stories of their loved ones that live and thrive with deafblindness. To read their stories, please [click here](#).

## Planning Has Begun for Our 16th International CHARGE Syndrome Conference

This month kicked off the official planning of our 16th International CHARGE Syndrome Foundation Conference. Our board met at the JW Marriott Desert Ridge in Phoenix, AZ to get a first hand glimpse of our accommodations, Conference facility, and activities offered.



With less than a year until Conference, you will soon start to hear more about the program; volunteer, sponsorship, exhibitor and presenter opportunities; activities; and all that Conference has to offer! Be sure to follow us on [Facebook](#) for all of the most up-to-date information.

# Crocker Barker Sibling Scholarship 2024

We wish all of our Crocker Barker Sibling Scholarship recipients the best of luck as they embark this Fall on their continuing education journeys!

To learn more about the Crocker Barker Sibling Scholarship and to see a list of the recipients, [click here](#).



## Countdown to Conference

There is a place for everyone at Conference! We are proud to offer a camp program for individuals with CHARGE and their siblings, providing fun, entertaining activities for the kids while their adults attend Conference sessions. Arts and crafts, magic shows, and petting zoos have been part of the camp program during prior conferences.



- There will be a professionally-staffed calm room containing sensory items and a soothing atmosphere, which will be available if campers need a space/time to calm down.
- Camp is free for all individuals with CHARGE but all campers must be registered.
- Registration for camp will open in Spring 2025.
- Your caregiver may attend camp with your child. The caregiver must be registered for conference.

To learn more, [click here](#) to visit the Conference page of our website.

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.