OCTOBER 2024

CHARGE Accounts

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

Upcoming Events

10/10/2024
Ask the Expert: Behavior, Communication & Connections

10/19/2024
Birth-to-5 Year Parent Support Group

10/22/2024
Western Region CHARGE Syndrome Parent-to-Parent Call

10/24/2024
Familia CHARGE (Spanish-Speaking Families Support Group)

10/27/2024
Adults with CHARGE Virtual Social

The CHARGE Syndrome Foundation

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The Foundation Needs Your Help

As we enter the final few months of 2024, we reflect on the strides we've made together to support families affected by CHARGE syndrome. Through increased outreach efforts, more families than ever are finding their way to the CHARGE Syndrome Foundation.

The heightened awareness from events such as our CHARGE Syndrome Conference and our successful Walk and Roll has expanded our reach, but it has also led to an unprecedented demand for our programs and services. Families who might have once felt alone are now turning to us for assistance, and we are committed to answering that call.

This is where we need your help.

One of the Foundation’s proudest commitments is ensuring that every individual with CHARGE syndrome has the opportunity to attend Conference at no cost. We believe access to the valuable resources, connections, and support the Conference provides is essential—regardless of financial circumstances. To honor this commitment, we absorb those costs, and we need your help to ensure we can continue to offer this unique opportunity to families in need.

We’re asking every member of our CHARGE community to step up. Your end-of-year donation, no matter the size, will directly impact families who are counting on us. Your generosity helps us keep these vital programs running and ensures that we can continue to offer the support families desperately need.

By giving today, you help us ensure that every family facing CHARGE syndrome, especially those from underrepresented and underserved communities, receives the care and assistance they deserve. Together, we can make a difference in their lives.

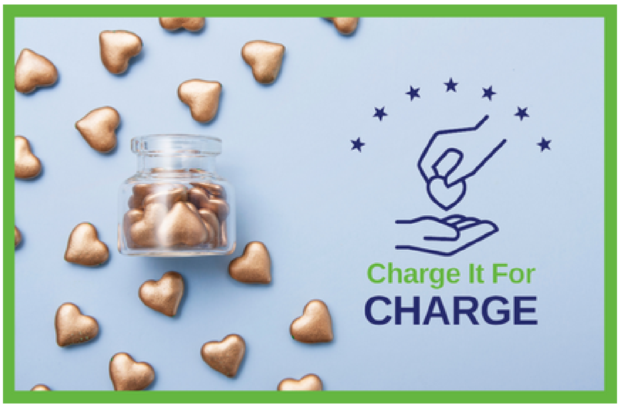
Donate now, and let’s continue to grow, support, and empower families as we wrap up this year. Thank you for your unwavering generosity and for being an essential part of our CHARGE community.

Become a Fundraiser

Charge It for CHARGE is our Foundation's year-round fundraising campaign, making it easy for YOU to raise money for the Foundation.

Money raised through your **Charge It for CHARGE** campaign helps the Foundation fund:

- Family Assistance Programs
- Conferences
- Outreach
- Research
- Interpreters for Educational Webinars



It is so easy to set up. Once you have created your personalized page you will have a link to share for any fundraising you choose to do throughout the year.

Your **Charge It for CHARGE** campaign can even be integrated into a Facebook fundraiser.

There are so many ways you can use your campaign, including:
- Sharing your family's story on social media or via email.
- Using it as a fundraiser surrounding an event - a birthday, holidays, graduation, or other milestone.
- Using the online platform to safely collect money raised before, during, and after your fundraising event so you don't have to worry about collecting cash and checks.

Help us continue our work to make the world a better place for all individuals with CHARGE syndrome and their families.

Click here to get started today!

Learn more about how your fundraising efforts can help. Read below for some recent stories from our Family Assistance Program recipients.

Family Assistance Program Spotlights

Participation in our Family Assistance Programs increases every year due, in large part, to our increased dedication to outreach, the incredible fundraising efforts of our community, and your participation in events such as the Walk and Roll for CHARGE, our biennial International CHARGE Syndrome Conference, the Charge It for CHARGE campaign, and by raising awareness by sharing your stories. We are proud of all the ways that we are able to help families and individuals affected by CHARGE syndrome, and enjoy hearing recipients' stories.

Hannah 's EWRAP Story

Hannah wanted a 3-wheeled bike for a long time, and was excited to finally receive one on her 19th birthday.

Hannah's family say, "We so appreciated the way you managed to coordinate this in such a short amount of time. We will always remember the meaning behind this amazing program and think of Ethan every time she rides her new bike. We cannot thank you enough for allowing Hannah to be a recipient of the Ethan Wolf Recreation Assistance Program. Please accept our sincere gratitude for making this possible."

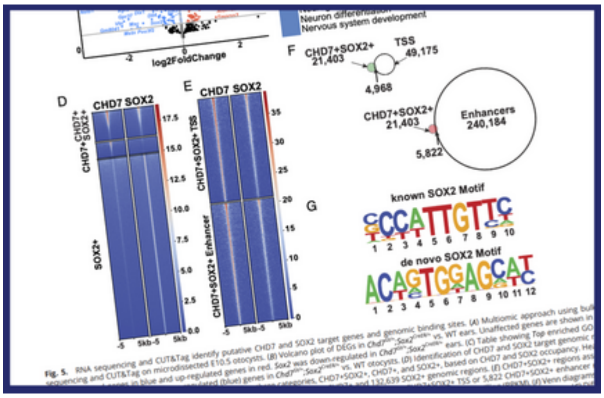
Click here to see more photos and a video of Hannah riding her bike.

Mateus' Medical Travel Story

"We are beyond grateful for the Medical Travel Assistance we've received through the CHARGE Syndrome Foundation. We live across the country, and this is the third time we are flying back to Cincinnati Children's Hospital for our son to receive the treatment he needs.

Lodging, meals, and transportation expenses can get overwhelmingly expensive. We feel very blessed to have such a wonderful and supportive program. The award we received helped alleviate some of our worries to allow us to focus on our child and family during these strenuous times." -Danielle, Mateus' Mom

New Research Paper Available



Many individuals with CHARGE Syndrome have changes in the gene CHD7 (Chromodomain helicase DNA-binding protein 7). Hearing loss and balance difficulties related to abnormalities in ear development are also common in CHARGE, but the type and severity of these abnormalities varies greatly. A recent publication entitled "CHD7 and SOX2 act in a common gene regulatory network during mammalian semicircular canal and cochlear development," from the laboratories of Donna Martin, M.D., Ph.D and Yehoash Raphael, Ph.D. (The University of Michigan) and Kelvin Kwan, Ph.D. (Rutgers University), begins to explain how this variability in hearing and balance abilities might occur. They report that CHD7 and SOX2 (a gene involved in many developmental processes) cooperate as the ear is forming in the embryo. CHD7 and SOX2 are both essential for forming hearing and balance structures in the ear, through binding to DNA and regulating expression of other genes. Findings from their study could help explain some of the variability in hearing and balance among individuals with CHARGE and may ultimately help develop therapies to treat them.

Click here to read the full article.

Scientific Research Grant Cycle Now Open

Thanks to the generosity of our donors, over the years the Foundation has been able to fund high quality CHARGE syndrome-related research projects. Many of our grant recipients have published their research in prestigious journals and have gone on to receive close to $12 million from the NIH and other government agencies.

The Foundation is proud to announce the opening of the 2025 Scientific Research Grant Cycle. Grants are available for up to $50,000 each, and proposals are due on December 15, 2024.

The purpose of these grants is to promote:

- New biomedical research into the etiology, genetic and molecular mechanisms and treatment of CHARGE syndrome, or
- New research into clinical and medical diagnosis and treatment of CHARGE syndrome.

Both established and new investigators are encouraged to apply. Proposals are for funding from April 1, 2025 to December 31, 2025 and may be in any area of basic, clinical, translational or epidemiological research. All proposals will be peer reviewed. Preference will be given to investigators who are new to CHARGE research and/or to new projects with clear potential to lead to future funding from other agencies.

Click here to learn more and submit proposals.

Research at Conference

The CHARGE Syndrome Foundation has a long history of providing opportunities for researchers to recruit participants and conduct their CHARGE syndrome-related research at Conference.

Applications will open in early 2025 for you to request to conduct your research at the July 2025 conference in Phoenix, AZ. If you have any questions, please email Tyler James, Ph.D. at jamesty@med.umich.edu.

Call for Conference Presentations

The CHARGE Syndrome Foundation is seeking proposals from professionals for its 16th International CHARGE Syndrome Conference, to be held in Phoenix, AZ:

- Thursday, July 24, 2025: Meg Hefner Professional Day
- Friday, July 25–Sunday, July 27, 2025: Family General Conference

This biennial event is the largest gathering of families and individuals with CHARGE syndrome in the world and is an extraordinary opportunity to meet and work with other professionals, as well as individuals and families affected by CHARGE syndrome, the leading cause of congenital deafblindness. Please consider sharing your expertise.

We are seeking proposals addressing the following topics:
Medical – neurology, genetics, gastrointestinal, immunology, endocrinology (growth and puberty), cardiology, psychiatry, audiology (BAHA, Cochlear Implant, etc.), ophthalmology (coloboma), pulmonology (secretion management, trach), feeding therapy, nutrition, etc.
Behavior –addressing social/emotional needs (self-esteem, body awareness), executive function, developing social stories, psychological treatment, OCD, etc.
Education – communication options, language development, assistive technology, IEP strategies and practical support, communication plans and therapies in educational settings, transition services, orientation and mobility, etc.
For Adolescents and Adults with CHARGE – adult services, puberty and sexuality, vocational rehabilitation, employment, independent living, transportation, social skills, etc.
Family – caregiver needs/self-care, stages of grief, coping strategies, sibling issues, relationship support for parents and extended family, financial planning and estate planning, etc.

Click here to submit your proposal. Deadline for submissions is December 2, 2024. Contact conference@CHARGEsyndrome.org with any questions.

Countdown to Conference

Sponsor and Exhibitor opportunities are available for the 16th International CHARGE Syndrome Conference in Phoenix, AZ, July 24-27, 2025. Your business or organization can be highlighted at this life-changing conference, which will be attended by over 1,200 individuals with CHARGE, their families, professionals, and researchers.

Click here to to sign up your business as a sponsor or exhibitor today. Deadline is June 1, 2025.

Click here to download our Exhibitor and Sponsor packet. Please forward to businesses, professionals or organizations that you think may be interested in participating.

For more info, contact us directly at conference@CHARGEsyndrome.org.

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.