DECEMBER 2023

# CHARGE Accounts

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

## *Upcoming Events*

**12/6/2023**
**Grief Support for Families of Children with Deaf-Blindness**

**12/10/2023**
**Adults with CHARGE Social - Email to Register**

**1/18/2024**
**Birth to Age 3 Parent-to - Parent Support Group**

**1/23/24**
**Western Region CHARGE Syndrome Parent to Parent Call**

**5/18/2024**
**Walk and Roll for CHARGE**

### The CHARGE Syndrome Foundation

info@chargesyndrome.org
CHARGEsyndrome.org
The CHARGE Syndrome Foundation
@charge_syndrome_foundation
@chargesyndrome

## Board President's Message: Another Year of Opportunity

At this time of year, I always spend time reflecting on the past year, while also looking forward to the future. As we celebrated our 30th Anniversary in May, and began our 31st year, I am thankful for all of you that have supported the Foundation, attended our events, and utilized the many resources and programs we offer. I am also encouraged by how hard our professional staff has worked to get to know our community, refine and improve our programs, and become an integral part of our CHARGE family. Our future is bright!

But what will that future for the Foundation really look like? How do we evolve and grow more over the next 30 years than we did in the first 30 years? When will there be medical breakthroughs for better treatment of CHARGE? How do we help create a better future for all individuals with CHARGE? The answers to these questions will depend on the joint effort of all of us. Will we all continue to donate and fundraise to the best of our ability, work together to create and prioritize new programs to fill the needs of our CHARGE community, and give generously with our precious time? As I look to the future, I am confident that the answer to all these questions is a resounding YES.

As we turn the page to 2024, I hope you will continue to make the Foundation a top priority. Every donation counts. Every fundraising event and membership matters. Every idea you have for the Foundation and our programs is worth mentioning. It is only when we all work together that we can truly create a better world for all individuals with CHARGE syndrome. Together it can be done!

Happy Holidays and best wishes for a happy and healthy New Year.

David Wolfe, Board President

## Giving Tuesday and Year End Giving

We raised over $8,000 through our Giving Tuesday campaign. In addition, we received many donations through our website and Facebook. We are THANKFUL for the support of our CHARGE community!

Your support helps us continue to make the world a better place for people with CHARGE syndrome through our Family Assistance Programs, Outreach, CHARGE Research, and Conferences.

Missed Giving Tuesday? There is still time to include the Foundation in your year-end giving plans. Donate here today!

Checks can be mailed to: CHARGE Syndrome Foundation, 318 Half Day Rd., #305, Buffalo Grove, IL 60089

.

# 2023 Impact Statement

The Foundation has accomplished so much this year. Our Family Assistance Programs helped families fund recreational, medical travel, and scholarship needs. We funded pilot research grants, spread awareness of CHARGE syndrome, and offered support to thousands of families.

Perhaps our biggest achievement this year was our 15th International CHARGE Syndrome Conference.

It was truly a monumental success, with the Foundation hosting over a thousand family members, professionals, individuals with CHARGE, and volunteers in Orlando for our first in-person Conference in 4 long years. The Foundation continued to demonstrate its commitment to ensuring individuals with CHARGE always attend at no cost - this year we supported 227 individuals with CHARGE at conference. Thanks to the generosity of our donors, we also awarded over $40,000 in Conference scholarships, ensuring that 86 families could participate and benefit from this invaluable, life-changing experience. We are already counting down the days to our next Conference!

Click here for our full 2023 Impact Report.

# Support the Foundation While You Shop this Holiday Season

There are many ways to support the Foundation while you shop for the special people in your life this holiday season!

Choose the CHARGE Syndrome Foundation as your charity of choice on the following sites and the Foundation will receive a percentage of your purchase as a donation. You can shop and support the Foundation at the same time!

- Shop Gift Cards from over 550 retailers at RaiseRight
- Make your online shopping purchases through GoodShop or iGive

You can also shop for CHARGE syndrome items at our Awareness Store.

# Raising CHARGE Awareness in Latin America

Piero Franco Zapata works with people with CHARGE syndrome in Peru and Latin America, providing knowledge about the syndrome and emotional support. He recently received recognition from the Government Palace on Peru's "Day of the Person with Disabilities," for being an example of struggle, improvement, and resilience. Piero's dedication and effort demonstrates the potential that lies in all individuals with CHARGE, and is an inspiration as we work towards creating a more inclusive world.

Piero Franco Zapata trabaja con personas con Sindrome de Charge en Perú y Latinoamérica brindando conocimientos y soporte emocional sobre el sindrome así como concientizando en sus redes sociales sobre el mismo. Piero recibió un reconocimiento de parte de Palacio de Gobierno, en el día de la persona con discapacidad, por ser un ejemplo de lucha, superación y resiliencia, demostrando que con esfuerzo y dedicación son la clave para alcanzar las metas, superar barreras y crear una sociedad más inclusiva.

# EWRAP Gives Everyone the Chance to Play

**Gannon's Story**

"We were amazed to receive the news that EWRAP could provide an adaptive bike for Gannon. Until he received this bike, he was using one that was very run-down and did not fit him well at all.

Gannon says, "it's easy to drive and I like that I can be more independent with biking," even though Mom is never far behind. Seeing Gannon safely navigate the terrain up and down sidewalks and roads has been such a relief. We have been able to use this bike as a tool for learning road safety including looking and listening for cars. This bike also has hand breaks which is helping to increase Gannon's fine-motors skills. Keeping with the fun, Gannon makes sure to bring his baby along on the back of his bike!

Gannon has been honored to share Ethan's story when telling others about his bike. What a tremendous honor it is for Gannon to be a part of Ethan's legacy! Thank you EWRAP for enriching Gannon's life!"

**Sami's Story**

"Sami was born with a cleft lip and palate, leading the doctors to begin checking for other abnormalities. They found she had multiple congenital heart defects and a heart that 'has all the right parts but not in the right places,' deafness, colobomas affecting the optic nerve and retina in both eyes, inner ears that are not correctly formed, no inner circular canals for balance, brain atrophy, dysphasia, unilateral choanal atresia, olfactory deficiency, sleep apnea, and asthma. She later developed seizures. We were told she would never see, hear, learn more than 20% of what other kids learn, read, and might not walk. We learned later that some of her specialists didn't expect her to live and, if she did, thought she would be a 'vegetable.' Fourteen years and 23 surgeries later, Sami is thriving! She learns at her own pace, loves to read, hears with cochlear implants, sees with her right eye, and dances! Her seizures have halted! Her sleep apnea and asthma are both now mild. After more than 10 years on a feeding tube due to swallowing difficulties and silent aspiration, she has learned to eat by mouth! But one thing she could not manage was to ride a bike.

A couple of years ago Sami was given a beautiful bicycle from a friend. She tried so hard to balance on it, but, even with training wheels, it was impossible. Thanks to the Ethan Wolfe Recreational Assistance Program (EWRAP) Sami is now able to find joy in riding her brand new three wheeled bike! Like other kids her age, she loves the feeling of independence and the mobility. For kids like Sami, every single accomplishment is a reason for celebration and this is no exception! Sami and her parents appreciate Jody and David Wolfe and EWRAP so much! Thank you for the chance to do 'normal.' Thank you for finding such a wonderful way to remember Ethan. He lives on in our hearts and through the joy you are bringing to other kids with CHARGE."

Click here to learn more about the Ethan Wolfe Recreational Assistance Program (EWRAP).

# Scientific Research Grants Application Deadline Approaching

Thanks to the generosity of our donors, the Foundation is able to fund high quality CHARGE syndrome-related research projects. Our research grant recipients have gone on to receive over $11,500,000 from the NIH and other government agencies, and many have published their research in prestigious journals.

If you are a researcher or know anyone who would be interested in this opportunity, please see the below scientific research grant program details. Grants are available for up to $50,000 each.

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. 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.

Applications are due December 31, 2023. Please click here to learn more.

# Correction - Cole Wins at Conference

In last month's newsletter article about Cole, we used the last name Gannon. Cole's last name is Honore. And the quote, attributed to Lois Gannon, was from his grandmother, who entered the raffle. Congratulations to Cole!

Please click here to read the entire updated story here.

Do you have a story, event, or news item that you would like to have included in the CHARGE Accounts newsletter? Send submissions for review to **torrie@CHARGEsyndrome.org**