

CHARGE Accounts

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

Upcoming Events

11/9/2022

**Grief Support for Families
of Children with
DeafBlindness**

11/19/2022

**Birth to 3 Parent to Parent
Support Group**

11/20/2022

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

11/29/2022

**Parent-to-Parent Support
Meeting - Western Region**

The CHARGE Syndrome Foundation

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Holiday Gift Pre-sale

It's never too early to start your holiday shopping!

We are taking pre-orders for our popular full zip sweatshirts, in Youth, Women's Fit and Adult Unisex sizes. Items for pre-order are only available until Friday, November 11, so don't miss out on this opportunity! [Click here](#) to place your pre-order.

In addition to the pre-sale items, we have lots of great awareness products that would be perfect gifts for family, friends, teachers or medical support team.

[Click here](#) to visit our store.

Worldwide delivery is available, calculated shipping rates apply. All in-stock merchandise will be shipped with your pre-order and should be received in time for the holidays.

Giving Tuesday

Save the date for Giving Tuesday, November 29, 2022.

#GivingTuesday is a global day of giving. You can be a part of the CHARGE Syndrome Foundation's *Together Again* campaign when you join the #GivingTuesday movement.

Your donation can provide direct assistance to our entire community:

- Families caring for those with CHARGE
- Individuals with CHARGE
- Professionals who work directly with the CHARGE Community
- Researchers who gather new and exciting information related to CHARGE syndrome

Mark your calendar and spread the word to family, friends and followers.

The #GivingTuesday campaign will go live on November 28, 2022. Please check your emails for the link on that day to start your campaign. [Click here](#) to be added to our mailing list.



Black Friday - Amazon Smile

Your holiday shopping can help support the CHARGE Syndrome Foundation, at no additional cost to you!

When you shop at smile.amazon.com, or in the Amazon app with AmazonSmile turned on within Settings, you'll find the same products and same low prices as the Amazon you already know - plus, they donate a portion of your purchases to your chosen charity.

For more information on how to use Amazon Smile, [click here](#).

[Click here](#) to select us as your AmazonSmile charity.



Welcome New State Liaisons

This month we welcome to new State Liaisons, Sharren Foster from Massachusetts, and Amanda Kutzura from Pennsylvania.

Sharren Foster lives with her family, husband Bob and daughters, Kaitlyn and Molly (their "CHARGE rockstar"), both 11, in Newburyport about an hour north of Boston, and just a few miles from the beach.



Molly's favorite activity is swimming and she stays busy with aquatic therapy, t-ball, and Special Olympics track and soccer. Molly also loves the Christmas season ... especially the lights and Santa! Molly is a happy little girl and makes everyone smile with her laugh. Kaitlyn is in 5th grade and loves art, tumbling, cheer, and learning to play the flute. She is the best sister to Molly.

They love spending summers with family and friends in Old Orchard Beach, Maine. Most weekends you can find them at their camper enjoying the pool, bands, golf cart rides and s'mores around the campfire. The girls love to swim, go to the beach, and visit the amusement park. The rides are Molly's favorite!

When asked why she volunteers, Sharren says, "The journey of having a child with CHARGE can be scary at first and even isolating. I want to share my experiences with others and let them know they are not alone. I hope I can connect others to the wonderful CHARGE community and help them learn about all the CHARGE Syndrome Foundation has to offer. I want to provide support, resources and, most importantly, hope to other families who are embarking on or are in the midst of this crazy journey."



New State Liaisons (cont.)

Amanda Kutzura lives in Pennsylvania with her husband; and their sons, Hunter (4) and Tucker (1), who has CHARGE. Amanda is a teacher of students with visual impairments and a Certified Orientation and Mobility Specialist. Although new to the parent role, she has worked with students with CHARGE for the past 14 years.

They are a very outdoorsy family and enjoy camping and fishing. Hunter and Tucker love catching frogs and crawfish. They also enjoy geocaching as a family. Hunter does karate and Jeremy enjoys hunting.

Amanda chose to volunteer because, "We were fortunate that I already knew what CHARGE was when Tucker was diagnosed. I want to help support families who don't have the background that we do and help them through the tough times."

The State Family Liaison Project is a model of collaboration to improve the Foundation's outreach to both families and professionals at the national level. The position will be used to build relationships, network, collaborate and disseminate information.

To find your liaison, or for more information on how to become a State Liaison, [click here](#).



Birth to 3 Parent-to-Parent Support Group

We are excited to introduce a new parent-to-parent support group for parents of children with CHARGE aged newborn to 3 years of age. The group will meet monthly via zoom and the hope to build a community where parents feel supported and validated in a safe space, with others in the same stage of their journey with CHARGE.

[Click here](#) to register.



2022 Marcus Velázquez Service Award

Meg Hefner has been named the recipient of the 2022 Marcus Velázquez Service Award!

Meg Hefner is a genetic counselor with more than 35 years of experience with CHARGE syndrome. She co-founded the CHARGE Syndrome Foundation in 1993 and has been a member of the Missouri Deaf-Blind Advisory Board since 2005. Meg is one of the editors of

the book CHARGE Syndrome; the first edition was released in 2010 and the second edition in 2021. In the forward Foreword to the 2021 edition, Dr. Daniel Choo writes that Meg is a “world-renowned expert on CHARGE.”



The Marcus Velázquez Service Award is presented by the Deaf-Blind Advisory Committee to an individual or organization that has made a significant contribution to improving the quality of life for individuals with deaf-blindness and their families in the state of Missouri.

Born in 1970, Marcus Velázquez was deaf and had a degenerative eye disease, retinitis pigmentosa that would eventually leave him severely blind — both conditions are a part of a disorder called Usher’s Syndrome. He also had autism and Tourette’s Syndrome. All of this never stopped him. He wanted to do all the things everyone else did. So, he learned to swim, went to church and even tried to drive the family car (thankfully, no one was hurt). Among his other solo adventures: Riding Chicago’s EL Train and taking a bus in Mexico to a mall where he could get a McDonald’s “hamburguesa” (burger). He moved through the world with his cane in hand and a fanny pack fastened to his waist, filled with the essentials for adventure and independence: His ID, money and a reporter-sized notebook and pen to communicate with the non-deaf world. He preferred to express his thoughts through tactile sign language.

Marcus learned many of these life skills during the two years he spent learning at Helen Keller National Center (HKNC) in Sands Point, New York. He went to HKNC after graduating from Missouri School for the Blind, an institution where his teachers nurtured his desire for knowledge and independence. His education and growth was made possible through the efforts of the Missouri DeafBlind Task Force, his family, and countless advocates who believed in Marcus. Upon his return from HKNC, Marcus lived and worked independently in St. Louis. At 26, Marcus learned he had cancer. He died two months later, on July 4, 1997

Bill McCarthy Memorial Golf Tournament

On September 25th, the inaugural Bill McCarthy Memorial Golf Tournament was held at Normanside Country Club in Delmar New York. Bill's grandson Will has CHARGE, and since Will's birth Bill Sr. was a source of love and unending support.



Bill's wife Maureen was joined by Will's parents Bill Jr. and Mary McCarthy, Will's Uncle John McCarthy as well as almost 100 golfers to celebrate Bill's memory on the course. The weather in Upstate New York cooperated, and golfers were able to finish 18 holes and gather at the bar afterwards for anecdotes, an auction, and prizes for the top teams.

The event was a fun day for all, and organizers are proud to send \$10,000 contribution to the CHARGE Syndrome Foundation. Stay tuned for more details on next year's event!



4to24 App: Transition Guidance for Parents

By: Karla Antonelli & Anne Steverson, Mississippi State University

If you're traveling new ground, guideposts from a friend who has been there can be invaluable. Many families of a child who has CHARGE syndrome may find themselves in this situation, having new territory to navigate. The hearing and vision impairments associated with CHARGE syndrome are defined by the Individuals with Disabilities Education Act (IDEA) as low incidence disabilities – meaning that personnel with highly specialized skills and knowledge are needed for children with those impairments to receive early intervention services or a free appropriate public education.* A low incidence disability also means that resources and information for families can often be limited or hard to find.



With this in mind, the National Research and Training Center on Blindness and Low Vision created an app for parents of children with both hearing and visual impairments called 4to24. As the name suggests, it is for parents whose child is between ages 4 and 24. Its purpose is to provide information, resources, and suggested activities that parents can use to help plan for and navigate their child's transition from youth to adulthood and all that that entails.

Before creating 4to24, we met with some parents of youth who are deaf-blind – some of whom had additional disabilities – and asked about their current sources for transition information and the overall idea of the app. We learned that most of these families felt unsupported and lacked information or guidance about what to do after their child graduated high school. One parent commented, “Really, we don't have any transition planning right now.” Others reported that if they did have information, it was from their own research, “We're the ones that have had to seek it out.” For these families, the concept of 4to24 would be a resource to help them brainstorm how to help their child prepare for the next stages of life, whatever that may look like.

Armed with this information, we partnered with experts in the education and transition fields for deaf-blind youth, who wrote the content for the app. We then asked a different set of field

4to24 App: Transition Guidance for Parents (cont.)

experts to review and validate the content. Parents receive this expert-vetted content in modules that arrive over time based on the youth's age so that information is compatible with the child's current life stage. Each module's activities are flexible for ability level so that all families can benefit from the information. Content touches on topics like how to develop and support communication, ideas for documenting and advocating for the youth's personal preferences and strengths, and building skills in areas like mobility and dexterity. 4to24 also emphasizes building community supports and engagement and planning for the future. In an early test of the app with parents, one parent said about 4to24: "It's a cool resource, and we hadn't found anything out there like this in the past... that provides information like this for families with children who have these complex medical issues."

The 4to24 app is a free resource for parents in the Google Play and Apple stores. It is also available as a web application at 4to24.org.

*Individuals With Disabilities Education Act, 20 U.S.C. § 1400 (2004).

CHARGE Research

Great research continues by our friends in the Netherlands. Monica Wong, a PhD candidate in Conny van Ravenswaaij's group at University of Groningen, has completed her dissertation "Underexposed features of CHARGE syndrome: Immunological, Adrenal, and Scapular Function" and is due to defend this month.

[Click here](#) to view the flipbook if you're interested in learning more.



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