

CHARGE Accounts

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

Upcoming Events

03/27/2022
Adults with CHARGE
Social

04/12/2022
Autism or CHARGE
Identifying effective
educational and
behavioral
interventions

The CHARGE Syndrome Foundation

info@chargesyndrome.org

CHARGEsyndrome.org



The CHARGE Syndrome Foundation



@charge_syndrome_foundation



@chargesyndrome



New Board Members

Welcome Our New Board Members

Benedict (Ben) Daigle

Ben began volunteering as the Foundation's Connecticut State Family Liaison in January 2020. In November 2021, he was elected to the Foundation's Board for a first term starting in March 2022. To further the Foundation's mission while on the Board, Ben's goals include: 1) Supporting inclusive governance aligned with best practices, and 2) Collaborating to increase the racial and ethnic diversity of the Board and membership.

Ben has 15+ years' government, nonprofit, and civic experience, and currently serves as a public defense attorney representing people in Connecticut who are

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New Board Members (cont.)

indigent. In advancing social justice through public policy advocacy and direct client representation, he strives to practice humble leadership grounded in empathy, equity, and integrity. Ben and his family enjoy being engaged in their community and having outdoor adventures throughout the year.

Contact: Ben (at) chargesyndrome (dot) org.

Penni Echols

Penni and her husband Micah live in Las Vegas, Nevada with their six daughters. Their youngest, Martha was born in 2014 and the family connected with the CHARGE Syndrome Foundation during the difficult first years of her life. After reading handouts from the 2015 Conference while Martha was in the Pediatric Intensive Care Unit, Penni and Micah became members of the Foundation and have been engaged at various levels ever since.

Penni is employed by Nevada Hands & Voices as an Educational Advocate and Parent Guide for families with children who are Deaf or hard of hearing. She passionately believes that every child can communicate when they have the right support and a willing partner. She volunteers as the CSF Nevada Parent Liaison and looks forward to connecting families to one another, the Foundation and the larger Deafblind network as a member of the board.

Contact: Penni@CHARGEsyndrome.org

Medical Travel Assistance Program

The Medical Travel Assistance program was created to assist families with expenses related to medical travel needs. The funds may be used to cover transportation, meals, lodging, and parking for medical care that requires out of state/long distance travel. We hope this program will alleviate some of the financial burden.



For US families only.

Applications will be accepted on a rolling basis.

Visit our website to apply.

Solicitud disponible en español

Rare Disease Day 2022

Thanks to everyone who showed us their stripes for Rare Disease Day, Monday, February 28, 2022!

#ShowYourStripesForCHARGE

#ShowYourStripesForCHARGE



#ShowYourStripesForCHARGE



#ShowYourStripesForCHARGE



#ShowYourStripesForCHARGE



New State Family Liaisons

Welcome to our newest State Family Liaisons, Esther Owusu, Washington D.C., and Alexis Ramirez, Northern California!

Esther Owusu, Washington D.C.

Esther lives with her husband Eric Sr and four children, Aaron, Eric Jr, Alexander and "my princess" Lois. Esther and her family enjoy going for walks and worshipping at church every Sunday.

"We are family of six(6) and my oldest son has CHARGE Syndrome. For my first child to have this syndrome was heartbreaking, but my husband and I had to be strong. We got involved in his medical treatment while in the NICU for six month after birth, to learn about what CHARGE syndrome is, gather information and resources to help us care for our child and promote his quality of life.

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New State Family Liaisons (cont.)

As a family ,we work as a team to help Aaron reach his goals in life.

When asked "Why do you Volunteer with the Foundation?", Esther's response was:

I feel very blessed and privileged to be a volunteer with the CHARGE Syndrome Foundation. Through this, I will get the opportunity to empower other families who are going through challenges with their loved ones with CHARGE syndrome to best support them with their needs, mentally, emotionally and educationally to promote quality of life.

Esther and her family would also like to thank to MD/DC DeafblindProject and Connections Beyond Sight and Sound for their amazing support.

Alexis Ramirez, Northern California

Alexis Ramirez lives in East Bay Area of California with her husband, Cristian, daughter Mari (2), son Tayen (11m) who has CHARGE, and their labradoodle Luna.

Her family enjoys cooking, baking, singing and going for walks together. Alexis loves photography, books, podcast and various self care activity. Mari and Tayen love books, dancing, and getting into EVERYTHING

"My husband and I met in college, where I studied sociology and my husband was studying coding and web development. - I have been in the advocacy world since I was 19. - We are all learning ASL and our 2 year old currently knows more than anyone. -We're still learning but passionate about disability rights and advocacy."

When asked "Why do you Volunteer with the Foundation?", Alexis's response was:

My main reason is because advocacy is apart of who I am and I lost that for awhile when covid hit, after Tayen was diagnosed with CHARGE and I connected with other state liaisons I knew I wanted to support other families, especially ones who are just getting a diagnosis, who's world may feel a little upside down and may just need a little extra support.

Ask the Expert

Visit our Facebook page to view our most recent Ask the Expert Live videos!

Brenda Bujold - Intervener

Bethany Jung - Dietician

