

CHARGE Accounts

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

Upcoming Events

9/7/2022

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

9/18/2022

**Adults with CHARGE
Virtual Social - Register**

9/18/2022

**2022 Conference
Scarlett's Park:
Presentation on Deaf
and Hard of Hearing
Children with CHARGE
syndrome**

The CHARGE Syndrome Foundation

info@chargesyndrome.org

CHARGEsyndrome.org



The CHARGE Syndrome Foundation



@charge_syndrome_foundation



@chargesyndrome



15th Annual Charge it for CHARGE Now Open

The 15th Annual Charge It for CHARGE campaign is now open. Charge it for CHARGE is the online fundraising campaign of the CHARGE Syndrome Foundation. Every dollar donated helps fund research, outreach, conferences, and our family assistance programs.

[Click Here](#) to start fundraising!

Fundraiser How To's

- Getting started is quick and easy! [Click Here](#) for a short tutorial on how to set up your fundraising page.
- You can now set up your campaign and link it directly with your Facebook page! This will expand your reach for donations by allowing people to share.
- There are so many easy ways to use CIFC to raise money for the Foundation. [Click Here](#) for some great ideas.

15TH INTERNATIONAL CHARGE SYNDROME CONFERENCE INCENTIVE

ATTEND CONFERENCE FOR FREE!



THE CHARGE SYNDROME FOUNDATION
15th International CHARGE Syndrome Conference
July 20-23, 2023 | Orlando, FL

Earn one free Conference Registration for every \$3,000 raised through April 1, 2023. Limit 4 Registrations.*

*Does not include Professional Day

If not needed, your free registrations can be donated to the Conference Scholarship Fund.



Save the Date for a Day to Remember

On September 21, 2022 we will come together as a community to honor the memory of those individuals with CHARGE who passed away with A Day to Remember.

On September 21, which is also the International Day of Peace, we ask everyone to perform an act of kindness and share it with us on social media using #ADayToRemember. The goal is to spread as much kindness as possible throughout the day. It could be something as simple as sending an encouraging e-mail, making a donation, or spending time with loved ones. These kind acts show our solidarity as a CHARGE community and signify to the families who have lost their loved ones that we will ALWAYS REMEMBER.



Click on the [here](#) to see photos of joy and kindness from previous years.

If you are dealing with a loss, please visit our [Grief Support page](#) for available resources.

Lily Slavin, PhD Joins the Board of Directors

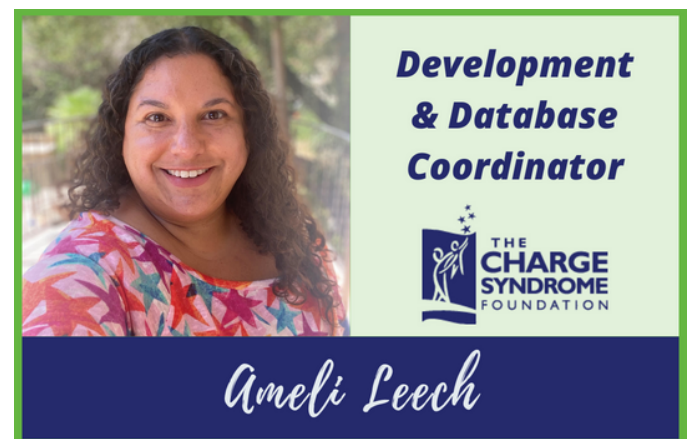
Lily Slavin earned her PhD in school psychology from Central Michigan University (CMU) in 2022. She has been a member of the CHARGE Syndrome Research Lab at CMU working with Dr. Tim Hartshorne since 2016. After attending a Michigan CHARGE family picnic that year, she knew she wanted to continue studying CHARGE in graduate school. Lily's research focuses on educational needs and support for students with CHARGE. She published an [educational checklist](#) for students with CHARGE and has presented her research at CHARGE conferences around the world, and to DeafBlind projects across the country.



Lily has also written several book chapters on CHARGE. Lily's favorite aspect of researching CHARGE is the tight knit community of professionals, family members, and individuals with CHARGE. She greatly looks forward to CHARGE conferences where she gets the opportunity to reconnect with this amazing community! Lily is honored to join the Board.

Ameli Leech Joins the Foundation as the Development & Database Coordinator

Ameli has over 15 years of experience working in the nonprofit sector and carries a strong background in communications, fundraising, and database management. After earning her Bachelor of Arts from Texas A&M University, College Station, TX, Ameli began her nonprofit career managing a collection of historic artifacts for a sister museum to the Alamo. From there, Ameli's passion for supporting nonprofit organizations developed and has guided her career path ever since.



Outside of the office, you can find Ameli spending time with her family which includes her husband, two children, four dogs, a cat, and a handful of fish.

Profiles in CHARGE - Shannon's Story

Meet Shannon Boelter. Shannon, who is from Minnesota, has CHARGE syndrome and uses American Sign Language as her first language. She works at a Deaf school in Minnesota and loves travel, hiking, trivia, and history, particularly history related to the 50 U.S. states.

You may have seen some of Shannon's hiking photos in the CHARGE Facebook group. Shannon says she started hiking in 2018 but has always enjoyed walking. "Nowadays, I try to go on long and challenging hikes. I walk in snow, rain, and on dry land," Shannon says. At first, she notes, she worried about her balance challenges. "I learned to control my fear and know my own limits. Now I go out with a few friends and hike more. They encourage me and are very supportive. I use walking poles and it is helpful to feel like I can do it on my own independently.

"CHARGE syndrome is a challenge for me, but I am proud to be a person with CHARGE. It is who I am," Shannon adds. She notes that while her low vision and balance challenges can sometimes get in the way at work or in everyday life, she doesn't let them stop her. For example, once when Shannon was hiking, she came across some rocks — a challenge with her balance. But she took her time, considered where to step, and made it across the rocks safely. "When hiking, know your own limits and take your time," Shannon advises.

"Don't let people put you down," she adds. "Don't let people say 'You can't' because you never know what you or your child can succeed at! Some people said they couldn't invite me to go hiking because of my balance and vision. I told them, 'How do you know I can't do it?' Always know your or your child's limits, but don't let that make you feel they can't necessarily do something. Just try. If you succeed, awesome! If not, it's okay; keep smiling!"



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