

CHARGE Accounts

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

Upcoming Events

2/8/2023

Grief Support for Families of
Children with DeafBlindness

2/18/2023

Birth to Age 3 Parent-to -
Parent Support Group

2/19/2023

Adults with CHARGE Virtual
Social - Email to Register

2/27/2023

Ask the Expert Webinar -
Transition

2/28/2023

Parent-to-Parent Support
Meeting - Western Region

The CHARGE Syndrome Foundation

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 The CHARGE Syndrome Foundation

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Become a Recurring Donor in February and Receive a Free Annual Membership

In celebration of the CHARGE Syndrome Foundation's 30th anniversary, set up a recurring monthly or quarterly donation of \$30 or more during

February and you will receive a FREE annual membership!*



Become a Recurring Donor

Since its beginnings in 1993, the CHARGE Syndrome Foundation has evolved into an internationally known and respected organization that supports thousands of individuals with CHARGE, their families, and the professionals who serve them every year. Our members are the lifeblood of our organization!

Your donation demonstrates that YOU support the largest organization dedicated solely to CHARGE syndrome. Together, we can create a better world for individuals with CHARGE syndrome.

CLICK HERE to set up your recurring donation today!

**All new recurring donations of \$30 or more established in the month of February 2023 will receive one Foundation membership, valid from February 2023 to December 2023.*

Show Your Stripes for Rare Disease Day

The last day of February is World Rare Disease Day, an annual event that gives us the chance to come together, show our stripes, and raise awareness for more than 300 million people affected by rare disease globally.

We use this day to help raise awareness for the CHARGE community, and all of those individuals affected by rare diseases - including the unique challenges we face every day.

The zebra is the official symbol of rare diseases in the United States. Every stripe has a story, here are some ways that you can share yours!

1. Share your story with us! Fill out [THIS FORM](#) and send a photo to have your story featured on our Facebook page
2. Show your stripes on social media by using #ShowYourStripesForCHARGE
3. Change your profile picture to our CHARGE Awareness graphic - [CLICK HERE](#) to download
4. Print and have your child color the rare disease zebra to show their stripes - [CLICK HERE](#) to download
5. [CLICK HERE](#) to start a Facebook Fundraiser in honor of the day



RARE
DISEASE
DAY 2023



THE
CHARGE
SYNDROME
FOUNDATION
Since 1993
Celebrating 30 Years



AmazonSmile to End February 20

Thank you for your support over the years while shopping AmazonSmile for CHARGE Syndrome Foundation. Unfortunately, AmazonSmile is closing Feb. 20.



Fortunately, we are already set up with a great alternative! [CLICK HERE](#) to join iGive today (it's free). When you login and shop their 2,000+ stores (think Chewy, Walmart, Expedia and so many more), we'll earn at least TWICE what was donated through AmazonSmile. The average donation through an iGive store is about 3%, with some offering 25% or higher! Make it all automatic. [CLICK HERE](#) to download the iGive button and turn your browser into an automatic donation generating machine!

Sharing Love for Our Volunteers

This month is all about spreading the love and, with that in mind, we would like to share our love for our volunteers!

In 2022, volunteers logged a total of 3,072 hours and with the upcoming 15th International CHARGE Syndrome Conference in July, we expect that number to increase dramatically for 2023. We already have dozens of volunteers working behind the scenes to get ready for Conference, from helping plan the agenda, to procuring items for our silent auction and basket raffles.

Our Board and Advisory Committee, Family Liaisons, workgroup members, and more are all volunteers. They attend meetings, plan events, and help our families in countless ways. Without them we would not be able to achieve all that we do as a Foundation and for that we are eternally grateful.



Funding Options for Your Family to Attend Conference

Need help finding funding sources for your family to attend the upcoming 15th International CHARGE Syndrome Conference? We have scoured the internet to find alternative sources of funding that you and your family may be able to use! There are a number of organizations that may offer grants to individuals and to families of children with developmental disabilities.

[CLICK HERE](#) for our Conference Funding Guide.



Earn one free Conference registration for every \$3,000 raised by April 1, 2023. [CLICK HERE](#) to set up your Charge it for CHARGE fundraiser today. This Conference fundraiser ends soon!

Reserve Your Conference Hotel Room Today

We are thrilled to be returning to the gorgeous Rosen Shingle Creek Hotel in Orlando for our 15th International CHARGE Syndrome Conference, July 20-23. The hotel is a fantastic meeting and vacation destination, conveniently located near Orlando International Airport, Disney World, Universal, and Sea World. Families will love the spacious and comfortable



guest rooms with mini refrigerators and complimentary Wi-Fi, the four shimmering heated pools, a golf course and spa, the numerous options for meals and snacks, and the many other amenities the hotel offers.

Conference hotel reservations are now open and rooms are filling up fast! Hotel Rooms are \$169 per night + tax for a standard room with 2 queen beds that will sleep up to 4 people. The rate is also available 3 days before and 3 days after Conference if you would like to extend your stay.

[CLICK HERE](#) to reserve your room today.

Please contact the hotel directly at 1-866-996-6338 for suite upgrade rates and other information. **[CLICK HERE](#)** to view suite details and rates. Special requests, including king beds, connecting rooms, etc. are not guaranteed and will be granted based on availability on the day of arrival. Be sure to let them know you are part of the CHARGE Syndrome Conference.

If you have any additional questions please **[email Neal Stanger](#)**.

Conference registration will open early March 2023.

Conference Scholarships Coming Soon

The Foundation is pleased to offer a limited number of Conference scholarships. Please watch your inbox and our social media this month for links to the application.

First-time conference attendees can apply for the Norbury Scholarship, a tribute to Marion Norbury, a founder of the CHARGE Syndrome Foundation, and her husband Lee, who supported her work. The Norbury Scholarship covers up to 3 conference registrations.



The CHARGE for Connor Scholarship was created in memory of Connor Logsdon by his family. The scholarship supports families who need help with hotel costs.

The Emma Bluestone Scholarship was created in memory of Emma Bluestone, a grandmother of Zachary, an individual with CHARGE. Repeat attendees can apply for this scholarship to cover up to 3 conference registrations.

Only Foundation members may apply for scholarships. [CLICK HERE](#) to become a member by April 1, 2023 to become eligible for a scholarship.

Ask the Expert Webinar - Postsecondary Transitions

On February 27, we will be hosting an Ask the Expert Webinar on Postsecondary Transitions.

The panel will include:

- Jodie Beavers, the proud mother of a 20 year old son with CHARGE Syndrome named Nolan. She has been a Special Educator for 21 years and is now the MTSS Coordinator for Shepherd Public Schools in Michigan. She also serves as the Michigan State Liaison for the CHARGE Syndrome Foundation.

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Ask the Expert Webinar (cont.)

- Joanne Lent, the CHARGE Syndrome Foundation secretary. Her son Eddie, 23, recently aged out of school and now lives in a group home in New Jersey.
- Minnie Lambert, mother to Andrew, who attends Perkins School for the Blind in MA. Minnie serves as the South Carolina State Liaison for the CHARGE Syndrome Foundation.
- Nancy Salem-Hartshorne, Ph.D., Professor of Psychology at Delta College and a Nationally Certified School Psychologist. She has authored numerous articles and book chapters about developmental outcomes for individuals with CHARGE syndrome. Her son Jacob, 34, is a positive influence on all those who encounter him. He is DeafBlind, has CHARGE syndrome, lives in his own home, and is integrated into his home community through individualized supported work and community engagement. Nancy is an advocate for individuals with disabilities, teamwork, thorough planning, and forward thinking for quality life outcomes for all individuals.

[CLICK HERE](#) to register.

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