CHARGE ACCOUNTS The latest news, events, and announcements from

The CHARGE Syndrome Foundation

Upcoming Events

12/6/2022 <u>Parent-to-Parent Support</u> <u>Meeting - Western Region</u>

<u>12/14/2022</u> <u>Grief Support for Families</u> <u>of Children with</u> <u>DeafBlindness</u>

<u>12/15/2022</u> Birth to 3 Parent to Parent Support Group

The CHARGE Syndrome Foundation

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#GI%INGTUESDAY[®]

#GivingTuesday Was a Success!

Thanks to our generous donors, we have exceeded our #GivingTuesday goal!

We raised over \$16,000 through our #GivingTuesday campaign page. In addition, we received many new and renewed memberships and donations through our website and Facebook. We are THANKFUL for the support of our CHARGE community!

Missed out on #GivingTuesday? It's not too late to make a year end donation, or set up a recurring donation for the new year. Make a difference in the lives of people living with CHARGE syndrome today!

Click here to donate now!

Year-End Gratitude

As 2022 comes to an end and we gather with friends and family to celebrate the holidays, we reflect on all we have to be grateful for this year.

As an organization, we have gone through many exciting changes this year. Perhaps the most exciting has been the opportunity to start planning for the return to an in-person conference for the first time in four years!



We truly could not do the things we do without the support of our community. With that, we would like to share our gratitude for:

Our Donors and Fundraisers

Our fundraisers and donors make everything we do possible. Because of their efforts and generosity, we were able to serve a record number of individuals with CHARGE and their families this year - and next year is already looking even better!

Our Members

In 2022, we gained 70 new members! A membership with the CHARGE Syndrome Foundation helps fund our initiatives, support our programming, and drive awareness in our community.

Our Volunteers and Liaisons

Our volunteers are one of the biggest strengths of our Foundation. We truly could not do it without them. This year, we tracked close to 4,000 volunteer hours. We are looking forward to many more in the coming months as we gear up for our 15th International CHARGE Syndrome Conference!

Our Board Members and Advisors

Their dedication, leadership, and hard work are what guide our direction and vision. We are forever grateful for this group's lasting contribution to the CHARGE Syndrome Foundation!

And YOU!

Whatever brings you here, whether you're an individual with CHARGE syndrome, a family member, friend, or a professional working with individuals with CHARGE, our community is truly the heart of this Foundation. Thank you for your continued support of our efforts to make the world a better place for individuals with CHARGE syndrome!

What Lifetime Membership Means to Me

Members are the lifeblood of the Foundation. By working together, we can create a better world for all individuals with CHARGE syndrome.

In addition to our Annual Memberships, there are four Lifetime levels available. Lifetime Members enjoy lifelong access to our suite of member benefits, as well as discounted Conference registrations. Every membership shows your support of the largest organization dedicated solely to making the world a better place for individuals with CHARGE syndrome.

Lifetime Diamond: \$10000
Lifetime Platinum: \$5000
Lifetime Gold: \$1000
Lifetime Silver: \$250
Annual Membership: \$30

Becoming a member, you will have a direct impact on increasing awareness, education, outreach and research.

See why others have decided to become Lifetime Members, and what their membership with the CHARGE Syndrome Foundation means to them.



"I've attended many CHARGE conferences over the years, both as a speaker and a Sibshop leader. All of the conferences included tracks for various family members. The Foundation has long recognized the unique needs of typically developing siblings. The sibling relationship is usually the longest-lasting one in the family and by providing support in childhood it increases the likelihood of the siblings staying lovingly involved as adults. Including siblings in conference programming benefits the entire family. Each conference I attended was an enriching experience

for me — and they were all lots of fun! There are many reasons I chose to become a Lifetime Member: the Foundation's work in family support and research, the opportunities to meet families from around the globe, the professionals who enriched my knowledge of academic issues, the friends I gained. But the best reason of all is that CHARGE sibs are some of the most amazing people I've ever met!" - Tina Prochaska

"Back in 1998 when our daughter Kennedy was born with CHARGE syndrome, the Foundation quickly became our lifeline. They provided us with resources, connected us with other families, and the conferences were life-changing experiences for us. The Foundation has continued to grow and develop even more support materials for families and professionals, funding



research, initiating new support programs such as EWRAP and more. I just can't say enough about the work that the Foundation does to support not only individuals and families but also to encourage all of our understanding of CHARGE around the world." -Lisa Weir

Lifetime Membership (cont.)

"I chose to be a lifetime member because I wanted to support the Foundation for all the help the members have given me over the years. I feel so thankful to the community and the Foundation for helping me to get through some tough emotional times of my life." -Chey McLaren, Adult living with CHARGE syndrome.



"Being a teacher is a critical role in the lives of so many students. Being a teacher of students who are DeafBlind, including students who have CHARGE syndrome, is special. Having taught for over 35 years and having students in my classes who have CHARGE syndrome throughout the years has piqued my interest in how best to teach these fabulous individuals. As I learned more about how to teach students with CHARGE syndrome and attended multiple conferences, I was able to learn new techniques, gather more information and meet so many children, teenagers

and young adults with CHARGE syndrome as well as their families. I want other teachers to have these same opportunities to learn and grow to become better teachers. Being a lifetime member of the CHARGE Syndrome Foundation is one simple way I can support the growth of others. This wonderful organization is dedicated to educating families and educational and medical professionals about CHARGE syndrome. Being a lifetime member helps support their mission to improve the lives of children with CHARGE and helps spread the word about CHARGE!" -Sharon Stelzer

"As an adult with CHARGE, the Foundation has given me an extended family. A community of people like me who understand the challenges I face and can support me through them, offer insight, and also share joy in accomplishments. Being a lifetime member of the CHARGE Syndrome Foundation gives me a chance to give back to the family that has enriched my life in so many ways." -Aubrey Williams

"Our family wanted to become lifetime members for a few reasons. First, CHARGE syndrome will be part of our forever and this is a way to acknowledge and celebrate its impact on our family unit. Second, we LOVE conference and the other opportunities afforded to us by the Foundation. We plan to go to continue taking advantage of those opportunities as long as we can and being Lifetime members demonstrates our support



for the Foundation and our desire for their important work to continue. And finally, remembering to renew annually is a pain — one and done is better and easier!!" - Kate Smith

Become a Lifetime Member Today!

Not ready to become a Lifetime member? <u>Click here</u> to lock in your Annual Membership!

CHARGE Holiday Gift Items

Shop Our CHARGE Syndrome Awareness Store for Great Holiday Gift Ideas!

Items are available in many different categories, perfect for family, friends, teachers, medical staff & stocking stuffers! Not sure what to buy? Gift certificates are also available!

Order by December 9th to receive in time for the holidays! <u>Click here to shop.</u>

US/Canada shipping only, calculated shipping rates apply.



Medical Travel Assistance Program Spotlight

The Medical Travel Assistance Program provides assistance to help to cover transportation, meals, lodging, and parking for medical care that requires out of state/long distance travel. The program is intended for families who would benefit from assistance to cover the cost for travel to receive medical care.



"We are so thankful for the CHARGE Syndrome

Foundation medical travel assistance program. We no longer have a pediatric ENT in our area so we have to travel out of state to receive ENT care. Our little guy handled the 6 hour car like a champ! The financial assistance helped ease the burden of having to travel for medical care. Thank you!" -Staci P.

To learn more about our Medical Travel Assistance Program, or to apply, <u>click here.</u>

Participate in CHARGE Research

Shelby Muhn, doctoral student working with Dr. Timothy Hartshorne in the CHARGE Syndrome Research Lab at Central Michigan University is investigating the prevalence of post-traumatic growth in parents of children with CHARGE syndrome. Through an online survey, we are seeking to better understand how factors such as coping styles, stress, and community support impact growth in parents.



What is this for? The purpose of this study is to explore the prevalence of post-traumatic growth in parents of children with CHARGE syndrome. Additionally, this study will assess the factors that are hypothesized to impact to growth, such as stress, coping styles, external support, and severity of their child's disability. The overall goal is to better support families and parents in raising a child with CHARGE Syndrome.

Participants must be:

- 18-years-old or older.
- Parent or legal guardian of an individual with CHARGE syndrome under the age of 18-years.
- Fluent in English.

To participate, please complete the online survey <u>HERE</u>. The online survey should take approximately 15-20 minutes:

Holiday Shopping with 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, but a portion of your purchases will be donated automatically to the charity of your choice.



For more information on how to use Amazon Smile, <u>click here.</u>

You can select us as your AmazonSmile charity by <u>clicking here.</u>