

CHARGE Accounts

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

Upcoming Events

1/16/23
**See's Candies Fundraiser
Opens**

1/21/2023
**Birth to Age 3 Parent-to -
Parent Support Group**

1/24/2023
**Parent-to-Parent Support
Meeting - Western Region**

1/25/2023
**Grief Support for Families
of Children with
DeafBlindness**

The CHARGE Syndrome Foundation

info@chargesyndrome.org

CHARGEsyndrome.org

 The CHARGE Syndrome Foundation

 @charge_syndrome_foundation

 @chargesyndrome



A Message From Our Executive Director

A new year brings new beginnings, fresh perspectives, and ambitious resolutions. Personally, I've resolved to maintain my various inboxes better, cleaning out the embarrassingly large number of emails I've collected over the past few years by deleting the trivial and archiving the important.

Ironically, it's forced me to spend far more time in the past than I typically indulge in as I launch into a new year. But this time spent is no less valuable, as I reflect and wonder how in the world I got on so many mailing lists.

As we kick off our 30th Anniversary year, we're spending lots of time reflecting at the Foundation, too. What was started in 1993 by a small group of professionals who saw a significant need for information and understanding about a rare and at-the-time confusing condition, has evolved into an internationally known and respected Foundation that supports thousands of individuals with CHARGE, their families and the professionals who serve them every year. The best part of this anniversary is we get to celebrate with all of you at our 15th International



30th Anniversary (cont.)

Conference in just 188 days! We'll party like it's 1993...honoring how far the Foundation, medical and clinical advancements, and best of all, YOU have come.

There is still more we want to accomplish in the coming days, months, and years. We're excited to take you all along for the ride as we work to make the world a better place for every individual with CHARGE syndrome.

Cheers to our 30th!



Lisa Cunningham
Executive Director



Conference Presentations Submission Deadline Approaching

The January 31st deadline is fast approaching for the submission of Conference presentations.

The CHARGE Syndrome Foundation is seeking proposals from professionals for the 15th International CHARGE Syndrome Conference. This biennial event is the largest gathering of families and individuals with CHARGE in the world. It is an extraordinary opportunity to meet and work with other professionals, as well as individuals and families affected by CHARGE Syndrome. Please consider sharing your expertise with our community.



Call for Presentations (cont.)

When:

- Thursday, July 20, 2023 – Professional Day and Family Reception
- Friday, July 21–Sunday, July 23, 2023 – General Conference

Where:

- Rosen Shingle Creek, Orlando, Florida

We are seeking proposals addressing the following topics:

- Medical – neurology, genetics, gastrointestinal, immunology, endocrinology (growth and puberty), cardiology, psychiatry, audiology (BAHA, Cochlear Implant, etc.), ophthalmology (coloboma), pulmonology, feeding therapy, nutrition, etc.
- Behavior –addressing social/emotional needs (self-esteem, body awareness), executive function, developing social stories, psychological treatment, OCD, etc.
- Education – communication options, language development, assistive technology, IEP strategies and practical support, communication plans and therapies in educational settings, transition services, etc.
- Adolescent/Adulthood – life planning, adult services, puberty, managing sexuality, vocational rehabilitation, employment, independent living, transportation, etc.
- Family – caregiver needs/self-care, stages of grief, coping strategies, sibling issues, relationship support for parents and extended family, financial planning, etc.

PROPOSALS DUE JANUARY 31, 2023

To submit a proposal, please click below.

[SUBMIT A PROPOSAL](#)

Please share this information with colleagues or other professionals who might be interested in presenting.

For more information or questions, please contact:

Joanne Lent

CHARGE Syndrome Conference

2023 CHARGE Syndrome Conference Program Chair

Sandra Davenport CHARGE Syndrome Fellowship

The CHARGE Syndrome Foundation is committed to supporting and educating professionals who have shown a commitment to CHARGE syndrome. The Davenport Fellowship program brings professionals (clinical, research, therapeutic, educational) early in their careers to the International CHARGE Syndrome Conferences, where they have the opportunity to learn more about CHARGE, interact with one another and get to know individuals with CHARGE and their families.



The program is named in honor of Sandra Davenport, MD, a medical geneticist with expertise in sensory deficits who was a founding member of the CHARGE Syndrome Foundation. Sandra set the tone for conferences from the beginning – making sure medical and educational professionals interact with one another while ensuring that the conference is a family-centered place. Her expertise in sensory deficits and deafblindness influenced a generation of CHARGE professionals.

Please see below for information on applying for Fellowship at the **15th International CHARGE Syndrome Conference**, July 20–23, 2023 in Orlando, Florida.

What do Davenport Fellows do?

- Attend Professional Day Conference (Thursday July 20)
- Attend International CHARGE Syndrome Conference (evening of Thursday July 20 through noon on Sunday July 23)
- Get matched with a family with a child with CHARGE
- Volunteer for ½ day in Camp, with the child from your family match (this requires a background check)
- Participate in daily sessions with the Fellowship advisors and other Fellows
- Write up observations, experiences, and/or highlights for the CHARGE Accounts newsletter

Sandra Davenport CHARGE Syndrome Fellowship (cont.)

Who is eligible to apply for a Davenport Fellowship?

Students or early career professionals with interest in and some experience with CHARGE syndrome or deafblindness, including—but not limited to—those in the fields of:

- Education/special education
- Deafblindness
- Genetic counseling
- Medicine
- Psychology
- Providers (e.g., audiologists, occupational therapists, physical therapists, speech and language pathologists, etc.)

What does the fellowship cover?

- Registration for Professional Day (Thursday July 20)
- Registration for International Conference (evening of Thursday July 20 through noon on Sunday July 23)
- Hotel costs for shared room for four nights (check in on Wednesday July 19; check out on Sunday July 23)
- Travel stipend between \$300–\$750, depending on travel distance and availability of funds.

2023 Application Information

For complete application instructions [**CLICK HERE**](#). When you are ready to complete your application (including your essay and CV), click [**SUBMIT APPLICATION**](#).

You letter writer should submit your letter of recommendation to [**lily@chargesyndrome.org**](mailto:lily@chargesyndrome.org). Deadline for completed applications (including the letter of recommendation) is April 3, 2023.

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**](mailto:torrie@CHARGEsyndrome.org)

Sweets for CHARGE

Just in time for Valentine's Day!

Treat yourself and all the special people in your life to the yummiest candy on earth! Support The CHARGE Syndrome Foundation's Family Assistance Program with our See's Candies Fundraiser!

The fundraiser is now open! [Click here](#) to treat yourself or someone you love now.

Orders ship immediately.* The fundraiser ends on January 27, 2023.

**US Shipping only*



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 live in Tampa, FL and travel to Cincinnati Children's for the majority of our 2 year old daughter Sienna's care. Sienna recently needed surgery and a couple follow-up appointments within the span of a month. We applied for the Medical Travel Assistance Program to help us with airfare for the three times we had to travel in a short period of time. The process was easy and really helped us financially! We are so grateful for this program and encourage other families to apply!" -Lindsay Y.

To learn more about our Medical Travel Assistance Program, or to apply, [click here](#).