

CHARGE Accounts

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

Upcoming Events

12/15/2024
**Deadline to Submit Research
Grant Proposals**

1/18/2025
**Birth-to-5 Year Parent Support
Group**

1/23/2025
**Familia CHARGE (Spanish-
Speaking Families Support
Group)**

Do you have a story, event, or news item that you would like to have included in the CHARGE Accounts newsletter? [Click here](#) to send submissions for review.

The CHARGE Syndrome Foundation

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The CHARGE Syndrome Foundation



@charge_syndrome_foundation



@chargesyndrome



President's Message



As we head into the new year, I'm excited to see the continued dedication and enthusiasm from our staff, board members, volunteers, and of course every one of you as we lead and partner to improve the lives of people with CHARGE syndrome locally, nationally, and internationally.

As we begin a fresh year, let's all renew our commitment to the Foundation. You can do this by volunteering your time, creating awareness, or raising funds for the Foundation. Let's leverage our collective strengths to make a meaningful impact on our community, while fostering a welcoming and supportive environment for all. Remember to actively participate in upcoming events and reach out if you have ideas to share – your involvement is vital to our success!

We had some major changes with our Board of Directors over the past few months. David Wolfe, who had been on the board for close to 20 years and was President since the summer of 2011, stepped down from the board. I would personally like to thank David and the entire Wolfe family for all of their hard work and dedication to the Foundation. As Vice President, I took over the position of President once again and Penni Echols has just been elected by our board as our new Vice President.

This summer we will bring our conference to the JW Marriott Desert Ridge Resort & Spa in Phoenix, Arizona from July 24 – July 27, 2025. I know many of you are wondering why we are going to Arizona with temps over 110 degrees that time of year. The summer months are the best time to get a discount. In an ongoing effort to keep costs affordable for families, we secured a room rate of under \$200 per night for our conference, a huge discount off the hotel's regular rate of over \$500 per night. Our conference will be fully indoors and there will be no reason to leave the hotel once you check in, unless you want to take advantage of the resort's many pools, water park, or lazy river. Our conferences are a great way to make new friends, rekindle old friendships, and of course learn as much about CHARGE as possible.

I look forward to seeing many of you at Conference next summer and hope that you will stay engaged with the Foundation through webinars, fundraising efforts, committee work, and parent-to-parent connections. I'm always available if you have questions or concerns. Please email me at neal@chargesyndrome.org.

From my family to yours, I would like to wish each of you a joyful holiday season and a happy and healthy new year!



Neal Stanger, President

Make a Difference

Thanks to your generosity, we raised over \$10,000 on Giving Tuesday. We are so THANKFUL for the support of our CHARGE community!

Missed Giving Tuesday? There is still time to make a difference before the end of the year! Visit our website to make a donation, set up your Charge It for CHARGE fundraising page, inquire about a matching gift with your employer, or set up a recurring donation.



Year-End Giving

With your donation, the Foundation:

- Provides families with direct support through our [Family Assistance Programs](#)
- Provides free [Conference](#) registration for every individual with CHARGE
- Funds groundbreaking [scientific research projects](#)
- Supports families through outreach, support groups, webinars, and conferences

[Click here to make a donation today.](#)

Employer Matching

Many companies offer matching gift programs to encourage employees to contribute to charitable organizations. Most of these programs match contributions dollar for dollar, and some will even double or triple the amount of your gift!

To make an even bigger impact with your donation, check with your employer's human resources department to see if they will match your gift. If not, you might want to ask your company to start a matching gift program.

Recurring Giving

By setting up your gift as a recurring donation, you give throughout the year without having to think about it. We offer monthly, quarterly, or annual giving options.

[Click here to set up your recurring donation.](#)

The 10th Annual Kinetic Cup Fundraiser by Jay Brandrup

The Kinetic Cup is a one-of-a-kind, quirky, annual wiffle ball rooftop golf tournament that is hosted by Jay Brandrup, whose daughter has CHARGE syndrome, and his company, Kinetic, in Birmingham, Alabama. The event is open to all friends of Kinetic, who attempt to log a qualifying score throughout the year. The winner hoists the Cup in a culminating shootout every October and 100% of all sponsorships and donations go to the CHARGE Syndrome Foundation.



The 10th Annual Kinetic Rooftop Shootout delivered big time! The wind was kicking, the beer was cold, and you couldn't have missed David Malone's grand entrance with his 2016 trophy even if you tried. After some impressively played rounds by the field, Fletcher Finch was crowned the youngest champion in Kinetic Cup history at 14! Past champion Hunter Finch proudly welcomed his son into the Hall of Fame, admitting that he hasn't been able to beat Fletcher at golf since he was 8.



Huge thanks to Michael Eady and Michael McGreevey for rockin' the mics as always, and all of our 2024 sponsors who made this record breaking year possible. We raised over \$35,000, with 100% of contributions going to our CHARGE Syndrome Foundation fundraiser. Cheers to 10 years of the Kinetic Cup!

[Click here to see more photos and a video from the event.](#)

Medical Travel Assistance - Peyton's Story

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

Here is Peyton's story:

Peyton and her family make multiple trips from Pennsylvania to Cincinnati for Peyton's medical needs. They have been lucky to get support from Angel flights and Ronald McDonald house, but sometimes things do not go as planned. They've had to find alternate accommodations, flights have been delayed, and they have to extend their stays. Our Medical Travel Assistance Program has helped with those unexpected expenses.



“Each time we travel there seems to be a little hiccup, and every time it happens I am so grateful for the Medical Travel Assistance Program. It makes the stressful situations just a little less stressful! We have food allergies and last minute menu changes at the Ronald McDonald House made us have to quickly scramble for other food options. It was SUCH a huge blessing to be able to pivot and to know that you all had us covered.



Peyton is a joy and a miracle all bundled into one! She just celebrated her 12th birthday. We are grateful for every single day we get to spend with her - each day is a gift! This journey is long and hard, but we get to have her with us, living and loving life, and we wouldn't have it any other way. Thank you so much for once again supporting us as we travel to get care for Peyton and for everything that you do.” - April, Peyton’s Mom

An Unforgettable Experience: My Participation in the Buenos Aires Marathon

CHARGE Syndrome Latin America, by Piero Franco Zapata

This year I had the incredible opportunity to be part of the Buenos Aires Marathon, one of the most well-known competitions in Latin America. What made this experience even more special is that I participated by making visible, socializing and above all representing all the people with CHARGE Syndrome in Latin America and the world. I was accompanied by wonderful people who shared with me every kilometer of this adventure.



The preparation

The previous weeks were a challenge not only physically, but also mentally and emotionally. The training consisted not only of exercises, but also the planning of every detail: food, hydration and rest, everything was essential to arrive in optimal condition on the day of the race. Of course, organizing my academic activities at the university was also key to being able to dedicate time to this preparation without losing sight of my studies.



The day of the race

September 22 dawned with vibrant energy. Buenos Aires was packed with runners, spectators and volunteers, all ready to give their best. Although I was pushed along the marathon route this time, I felt the same excitement and commitment as any other participant. Teamwork and coordination with those accompanying me was an essential part of enjoying the course and keeping up the pace. Every meter advanced was a shared victory.



Reflections on the journey

Throughout the marathon, I felt a lot of emotion representing people like me, with CHARGE Syndrome, and also gratitude for the support of my team, made up of my parents and my family, my friends and their families, members of the CHARGE community, and spectators. The encouragement and applause along the way reminded me that this was not just a race, but an opportunity to show that, with the right attitude and the necessary support, we can overcome any challenge. My participation in the marathon was a clear demonstration of how sport, beyond competition, can unite us and motivate us to give the best of ourselves and also be a tool to raise awareness of rare diseases.

The impact

The most beautiful thing about this experience was crossing the finish line and knowing that my participation in this marathon can inspire others not to give up, to find motivation in every obstacle and to trust in the strength of teamwork. Every race, every challenge, is an opportunity for growth and learning, and I can't wait to participate again next year.



Piero Franco Zapata is one of only 11 known people with CHARGE Syndrome in Peru. He is a clear example that family support is important in the full development of a person with a disability, since they have been by his side, motivating him to get ahead in every step of his life.

Currently, Piero is studying Public Health and Global Health at the Cayetano Heredia University, which he entered with the excellence factor. For Piero, disability is the understanding of being a human being who deserves to live a full and happy life. He likes to read and research, especially about rare diseases. His greatest aspiration is to make other people with this condition visible and support them.

Book Your Extended Conference Stay Now!

The 16th International CHARGE Syndrome Conference, “The Grand Adventure,” will be held at the JW Marriott® Phoenix Desert Ridge Resort & Spa, in Phoenix, AZ, July 24-27, 2025.

If you are making plans to extend your family’s stay either before or after Conference to enjoy all that the resort and surrounding area have to offer, we recommend booking now to take advantage of the special Conference room rate.



We have secured a room rate of \$192 per night plus tax (for up to 4 people per room), for the 16th International CHARGE Syndrome Conference. In addition to the conference dates, we have secured a limited number of rooms at the Conference rate for July 21 through July 29.

[Click here to reserve your room today.](#)

Countdown to Conference

The CHARGE Syndrome Conference is for the whole family! Having a brother or sister with CHARGE is not always easy. Sibshops provides siblings aged 8-13 a safe place to meet, share – and just have fun – with other siblings who know exactly how they feel.

Sibshops are held during the day at the same time as Conference sessions and camp. A sibling may attend one half-day Sibshops session.

Junior leaders are siblings 14 years and older who will assist the Sibshops facilitators. Priority is given to those who have attended Sibshops at a previous Conference.

SPACE IS LIMITED. Foundation Members have priority at registration for Sibshops.

[Click here](#) to become a member today!

