SPONSORSHIP GUIDE

Creating Connections



CACNAIA CONFERENCE JULY 18-20, 2024



GATHERING FOR FAMILIES. FOUNDATION CLINICIANS & SCIENTISTS





INTRODUCTION



On behalf of the CACNA1A Foundation, thank you for your interest in becoming a sponsor of our 2024 Creating Connections Family Conference and Research Roundtable on July 18th -20th, 2024. The CACNA1A Foundation is excited to host these events - the Research Roundtable is by invitation only and will take place at the NIH Neuroscience Center. The Family Conference will be a hybrid event, in-person at the Bethesda Marriott in Bethesda, Maryland, and virtually for those unable to attend in person.

The CACNA1A Foundation's Creating Connections Conference is the largest gathering of CACNA1A families worldwide. The event brings together patients, parents and caregivers, clinicians, and scientists to share updates on the latest research and best practices in education and therapies. It will be broadcast live to individuals around the world and, using Wordly's AI technology, can be translated into as many as 50 languages. The event allows our community to gather, learn, network, and socialize with old and new friends.

Your sponsorship is critical to helping us bring this event to fruition. There are a variety of levels of sponsorship, so please take a moment to look through this guide. All provide global visibility for your organization, and most importantly, our families, researchers, and clinicians are excited to connect with sponsors who share our hope for a better future for those with CACNA1A-related disorders. Thank you for considering sponsoring this year's event, and we look forward to seeing you in Bethesda!

The CACNA1A Foundation Board of Directors



ABOUT THE CACNAIA FOUNDATION



The CACNA1A Foundation is a US-based 501 (c)(3) nonprofit founded in 2020 by parents committed to finding treatments and cures for CACNA1A-related disorders.

Our **mission** is to find specific treatment options and a cure for CACNA1A patients by building a collaborative network of patients, families, clinicians, and scientists that will work together to raise awareness and accelerate the understanding, diagnosis, and treatment of CACNA1A-related diseases. Our **vision** is a world free of the debilitating effects of CACNA1A-related disorders.

The **priorities** of the Foundation are to advance research, support families, and raise awareness.

- We **support translational research** that holds the promise to improve the lives of individuals with CACNA1A-related disorders and their families by paving the way for clinical trials of life-changing treatments. Our goal is to have at least one treatment for the CACNA1A community in the pipeline within the next five years.
- We want families affected by CACNA1A-related disorders to know they are not alone. We **connect families** around the world and provide resources to make their journeys easier.
- We **raise awareness** about CACNA1A-related disorders among the general public and healthcare professionals to facilitate early diagnosis through genetic testing and to improve health outcomes.

WHAT IS CACNAIA?

CACNA1A-related disorders are rare neurodevelopmental disorders linked to mutations in the CACNA1A gene. CACNA1A encodes for the P/Q-type calcium ion channel Cav2.1, which is globally expressed in the brain and crucial for fast, presynaptic neurotransmission. A broad spectrum of neurological disorders is associated with variants in the gene and includes

- Seizures and epilepsy (ranging from absence epilepsy to intractable generalized epilepsy.) Both gain and loss of function variants are associated with Developmental epileptic encephalopathies (DEEs). Some patients, especially those with gain of function variants, experience status epilepticus, and many have refractory epilepsy.
- Hemiplegic Migraines (Spontaneous and Familial Hemiplegic Migraine Type 1)
- Ataxias Episodic ataxia type 2 (EA2), congenital ataxia, cerebellar ataxia, spinocerebellar ataxia type 6 (SCA6)
- Global developmental delay, intellectual disability, and Autism Spectrum Disorder.

To date, nearly 1700 CACNA1A variants are reported in ClinVar, with over 400 listed as Pathogenic or Likely Pathogenic.

The most severely affected patients are nonverbal, unable to walk independently, have limited self-care skills, and rely on a gastronomy tube (g-tube) for feeding.

2022 FIRST IN PERSON FAMILY CONFERENCE STATISTICS

- 100 attendees from all around the US and Canada, Australia, Europe and South America
- 75 people attended virtually, participating in real-time.
- 35 children enrolled in Camp CACNA1A
- YTD >275 visitors to the 2022 Conference webpage
- 16 renowned experts speak (including Drs. Wendy Chung (BCH), Henry Colecraft (Columbia), Al George (Northwestern), Ingo Helbig (CHOP), Dennis Lal (UT), Jen Pan (Broad), Aasef Shaikh (Case Western))

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\$10,000 Diamond Sponsorship

- Recognition at both the Science Meeting and the Family Conference
- · Logo in slideshow presentation during breaks and event recordings
- · Logo on event website and virtual platform
- Hyperlinked Logo on our website's homepage
- Pre-event promotion on all social media platforms (minimum 10)
- Logo on event signage and conference swag (item to be determined)
- Full-page ad in the conference brochure
- Opportunity to place items in our conference bags (literature, etc.)
- Tabletop exhibit for the duration of the conference
- Virtual booth for virtual attendees
- Opportunity to welcome the audience at the opening session
- After the event, listed as an event sponsor on the website conference page
- 5 complimentary conference registrations
- 10 additional 50% discounted conference registrations

\$5000 Platinum Sponsorship

- Recognition at both the Science Meeting and the Family Conference
- Logo in slideshow presentation during breaks and event recordings
- Logo on event website and virtual platform
- 5 social media pre-event promotions
- Logo on event signage and conference swag (item to be determined)
- Half-page ad in the conference brochure
- Opportunity to place items in our conference bags (literature, etc.)
- Tabletop exhibit for the duration of the conference
- Virtual booth for virtual attendees
- Chance to speak briefly during one of the large group sessions
- After the event, listed as an event sponsor on the website conference page
- 3 complimentary conference registrations
- 10 additional 50% discounted conference registrations

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\$2500 Gold Sponsorship

- Verbal recognition at Family Conference
- Logo in slideshow presentation during breaks and event recordings
- Logo on event website and virtual platform
- Logo on event signage and conference swag (item to be determined)
- 3 social media pre-event promotions
- Quarter-page ad in the conference brochure
- Opportunity to place items in our conference bags (literature, etc.)
- Tabletop exhibit for the duration of the conference
- Virtual booth for virtual attendees
- After the event, listed as an event sponsor on the website conference page
- · 2 complimentary conference registrations
- 5 additional 50% discounted conference registrations

\$1500 Silver Sponsorship

- Logo in slideshow presentation during breaks and event recordings
- Logo on event website and virtual platform
- Name listed in our conference brochure
- Opportunity to place items in our conference bags (literature, etc.)
- After the event, listed as an event sponsor on the website conference page
- 1 complimentary conference registration

\$1000 Bronze Sponsorship

- Name, business name and/or logo on the event website and virtual platform
- Name or business name displayed at the in-person conference
- Name or business name listed in the conference brochure
- Opportunity to place items in our conference bags
- After the event, listed as an event sponsor on the website conference page

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Sponsor Friday evening reception

\$7500.00 The Friday evening reception is an opportunity for CACNA1A parents, caregivers, adult patients, CACNA1A researchers, and clinicians to engage with each other in an informal setting.

Sponsor Researcher dinner

\$6000.00 - The Research Roundtable science meeting will be held on Thursday, July 18th at the NIH Neuroscience Center. Following the meeting, there will be a private dinner for all attendees.

Sponsor Saturday evening dinner dance

\$15,000.00 - This Saturday evening social event is a highlight for our families, especially the kids!

We'd love to chat about the opportunities outlined in this guide, or to discuss a custom solution that will meet your needs.

To make a payment by credit card, visit our <u>registration page</u>
https://cacnala.networkforgood.com/events/63570-creating-connections-community-conference
(scroll down to "sponsor our event" on the far right)



Lisa Manaster
Co-Founder & President
Lisa@cacna1a.org



Sunitha Malepati
Vice-President & Treasurer
Sunitha@cacna1a.org

The CACNA1A Foundation 31 Point Road Norwalk, CT 06854 203-969-6552 info@cacna1a.org www.cacna1a.org



