2025 Impact Statement

Alternating Hemiplegia of Childhood Foundation

Connecting the Community

Delivering Research, Support, & Education that Leads to a Cure

Greetings from the President

Celebrating 30 Years of Commitment to the AHC Community

Thirty years ago, we began the AHC journey filled with uncertainty and hope. In 2025, we celebrated not just time, but the incredible strength, courage, and love that carried us forward. Together, we turned challenges into progress, discovered the gene responsible for AHC, built bridges of understanding, and created a global community united by compassion and determination.

Results through the Power of Community

This milestone was not just about years-it was about the lives touched, the voices amplified, and the breakthroughs made possible through your strength and advocacy. We witnessed the power of community and the strength of purpose. Every step we took on our AHC path brought us closer to transforming lives affected by this terrible disease.

Through groundbreaking research, unwavering advocacy, and compassionate support, we not just imagined a better future—we helped make it a reality. With you at the heart of our mission, we advanced bold research projects, expanded access to critical support programs, hosted an amazing family meeting, and launched an international awareness campaign.

2026 and Beyond – Unwavering Commitment to You

The journey is far from over, but with your continued support, we will push boundaries, challenge limitations, and ensure that no one faces AHC alone. Projects under development for the community include:

- Developing a framework to understand and treat anxiety and depression in AHC,
- Establishing regional site visit locations for AHC research appointments and,
- Creating and distributing guides to better understand AHC.

With Gratitude to All AHC Volunteers

Thank you for three amazing decades of resilience, gratitude, and unwavering commitment to the Alternating Hemiplegia of Childhood community. Here's to the next chapter: stronger, larger, and more united than ever!

With gratitude,

Victoria Platt

Vicky Platt
President, Alternating Hemiplegia of Childhood Foundation

AHCF – Research, Support, and Partnership

Cate Cohen, Secretary

For three decades, the AHC Foundation has stood at the center of a powerful movement—uniting families, researchers, and partners in the urgent pursuit of answers for AHC. As we marked this milestone in 2025, our mission remained at the forefront of everything we did.

Celebrating 30 Years of Accomplishments

- Provided $4,260,264 in funding for over 17 projects to help find a cure.
- Translational research projects included gene discovery, genetic mechanisms, pharmacology, gene edit/replacement, and animal models. We funded programs as a foundation and provided joint financial assistance with AHC Europe, Cure AHC, For Henry, and Rare Hope.

Supporting Families Across the World

- Personal assistance from our experienced parents, handling hundreds of requests and facilitating connections for families across the U.S.
- Heping families in Malaysia, Brazil, Sweden, Canada, France, U.K., Serbia, China, New Zealand, Australia, French Polynesia, Hungary, Greece, Saudi Arabia, South Africa, Denmark, Pakistan, Japan, Spain, Croatia, Columbia

Community Commitment – Our Focus

We stand for joining anything related to helping your family with AHC.

- Join everything you can. Learn everything you can. We support and recommend that you use the resources of AHCF, AHC Europe, Cure AHC, Rare Hope, and others.

We stand for family support.

- Our network of parents and volunteers offers a warm voice and fully understands the challenges of AHC. They are an incredible wealth of knowledge. Our support includes connection, advocacy, and resources.

We stand for participating in anything that will help your family live and thrive with AHC.

- We are active participants in the global AHC community and seek out opportunities to share our experiences with our families.

We remain a highly funded foundation seeking a cure for AHC. Last year **100%** of our donations went directly toward research, education, and family support.

2025 Top Highlights

Sharon Ciccodicola, Director

Each year brings new momentum to our mission, and this one was no exception. Across research initiatives, family support programs, educational outreach, and administrative achievements, we continued to drive meaningful progress that strengthens our community and expands what's possible for those living with AHC.

Multiple Research Initiatives

- Directly or jointly funded 10 research initiatives. Three of the most recent projects are:
    - Cerebellum Study (NIH): Understanding what causes the sudden attacks of paroxysmal symptoms in AHC.
    - Natural History Study (Harvard/MGH): Identifying measurable markers of AHC progression to prepare for future clinical trials.
    - Spreading Depolarization Study (Leiden University): Co-funded international study about abnormal waves of electrical activity in the AHC brain.
- Supported the International AHC Research Consortium's ongoing technology expenses.
- Selected to participate in the Orphan Disease Center JumpStart Program

Family Support

- Worked directly with domestic and international families.
- Hosted a monthly Family Circle Support group meeting.
- Biennial family meeting held in Cincinnati, Ohio (upcoming in Houston, Texas, June 2027).
- Created awareness campaigns for funding needs and to help us unite as a community.
- Awarded multiple family grants.
- Expanded organizational relationships to include the Child Neurology Foundation, Epilepsy Alliance of America, Orphan Disease Center, and Rare Epilepsy Network.

Education and Communication

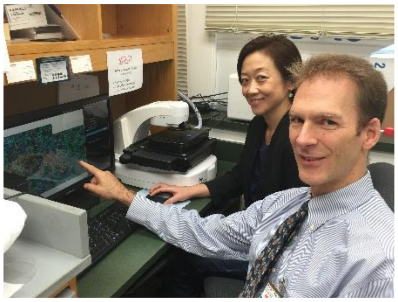
- Initiated monthly webinars for education, research information, and daily living.
- Continued to update our website with the most thorough information on AHC.
- Quarterly newsletters shared.
- Social media groups

Foundation Honors

- Earned the Great Non-Profits Badge for 2025, continuously for 13 years!
- Received a three-star rating with Charity Navigator, the largest and most-utilized, free independent evaluator of U.S.-based nonprofits.
- Gained Candid Gold Status, which shares financials and leadership demographics to gain funders' trust and support.

AHCF Research

AHCF funds research directly and partners with other foundations including AHC Europe, Cure AHC, For Henry, and Rare Hope. The foundation uses a formal process to assess a research proposal to ensure the optimal use of funding. Our Medical Advisory Board provides feedback on all proposed projects.



100% of donations go to program services and research

Advancing Research Through Strategic Funding in 2025

In 2025, AHCF made a decisive investment in the future of medical innovation by funding research programs that address some of the most pressing challenges in our community. This commitment was not just financial—it was a pledge to accelerate discovery, foster collaboration, and deliver hope to families who have long awaited answers.

Our Approach

Through these initiatives, we enabled scientists to pursue groundbreaking studies, explore novel therapies, and leverage innovative technologies. Our funding supported multi-disciplinary teams, strengthened global partnerships, and opened doors to clinical trials that bring us closer to effective treatments.

$4,260,264 in funding for over 17 projects to help find a cure

Impact in Action

The results speak for themselves: new insights into disease mechanisms, promising therapeutic targets, and a growing pipeline of potential interventions. Beyond the science, this investment represents something even more profound—a lifeline for the AHC community, and a clear signal that innovation and compassion can work hand in hand.

Investing in research isn't just funding science- it's funding possibility.

For families facing AHC, research is the difference between living in uncertainty and moving towards answers, treatments, and hope. Every discovery begins with someone who believes progress is possible. Donors make that belief real.

AHCF Research - Looking Ahead

As we look to 2026, our commitment remains unwavering. By continuing to prioritize research funding, we are shaping a future where breakthroughs are not the exception but the expectation. Together, we are building a world where knowledge leads to cures, and hope becomes reality.

Research Innovation in 2026

Advancing AHC Science

- Harvard University - Dr. Sharma's natural history study to identify quantifiable measures of AHC disease
- Leiden University (Europe) - Dr. Arn van den Maagdenberg's international co-funded cortical spreading depression project
- National Institute of Health (NIH) - Dr. Sietam's cerebellum changes in AHC mice.
- Northwestern University - Dr. Leite's postdoctoral fellowship

Advancing AHC Therapies

- Sorbonne Univ. (Paris) - Dr. Flammand-Roze's continuation of the co-funded international clinical trial of high-flow oxygen
- Harvard Univ. - Dr. Gupta -funded AHC wearables study

Collaborative Partnerships in 2026

Academic Genetics Programs

- Case Western Reserve - AHC quality of life genetic survey with Rae Dwyer
- Orphan Disease Center, University of Pennsylvania JumpStart program participant

Domestic Organizations

- CNF - Child Neurology Foundation member
- Epilepsy Alliance America member
- NORD – National Organization for Rare Diseases member
- REN - Rare Epilepsy Network member
- US AHC - U.S. AHC patient advocacy group research council member

Industry / Pharmaceutical Companies

- Aspartes Pharmaceuticals - AHC advisory board member
- Mahzi Therapeutics & Global Genes 2026 RAD Brain Workshop participant

International Organizations

- AHC Europe co-funding international projects (France & The Netherlands)
- ATP1A3 Symposium meeting funding support
- International AHC Research Consortium funding support

AHCF 2025 - Family Support

Heather Gates, Director

Whether a family member was recently diagnosed or you have been on the AHC journey for years, AHCF Family Support volunteers are here for you.

Our team consists of experienced parents of individuals with AHC who understand what you are going through. Connecting with our AHC community becomes an extension of your family. We share in the daily trials of this complex and unpredictable neurological disorder and are here to encourage you on your journey.

When you register with AHCF, you become part of the AHCF family.

Support can include:

- Chatting with an experienced parent
- Learning about resources for daily living
- Receiving guidance throughout all stages of your family's journey
- Applying for a family grant
- Connecting with experienced AHC clinicians
- Sharing your AHC story in awareness campaigns

When you become part of the AHCF family, connecting in community activities can include:

- Joining Zoom group calls and educational webinars
- Attending our family meeting in person or virtually
- Participating in a Valentine’s Day card exchange
- Signing up for clinical studies
- Relating to families and their AHC Journeys on the AHCF website

When you connect with the community you can:

- Receive emergency support
- Access care resources
- Navigate complex medical needs

> “This community has changed everything for me. Here, I’m never alone.”
>
> Jessica H.

AHCF 2025 Family Meeting

Kelly Andrasco & Heather Gates, Chairs

An important part of our mission is to support AHC patients and their families. One of the ways we do this is through our biennial Family Meetings. In June 2025, our 15th AHCF Family Meeting took place in Cincinnati, Ohio.

When at an AHCF Family Meeting, families were able to:

- Socialize with AHC families from around the world
- Speak with AHC physicians & specialists
- Attend research sessions from leading AHC investigators
- Join AHC kids for live entertainment, ice cream socials, and lots of fun activities

Cincinnati was Incredible Because, Families got to:

- Attend a meeting where you as a parent and your child are not alone.
- Discuss, compare, cry, challenge, and vent with each other.
- Catch up with old friends.
- Share your day-to-day trials, fears and sometimes, despair.
- Form new connections & friendships that stretch across the country and the world.
- Share a meal with doctors, clinicians, experts, and therapists and look forward to joining up in Houston, Texas in June 2027.

International Advocacy & Research Partners

Beto Duarte, Director

We remain deeply committed to working with the entire AHC community and numerous research partners. AHCF continues to collaborate directly with the research community as well as co-funding initiatives with AHC Europe, Cure AHC, For Henry, and Rare Hope.

We are proud to recognize our partners' invaluable contributions to advancing science and improving patient outcomes.

Current Research Partners:

- Boston Children’s Hospital (BCH)
- Broad Institute
- Brown University
- Case Western Reserve
- Child Neurology Foundation
- Global Genes
- Harvard University
- International AHC Research Consortium
- Jackson Laboratories
- Leiden University (The Netherland)
- Massachusetts General Hospital
- NORD
- National Institute of Health
- Northwestern University
- RareX
- Rare Epilepsy Network (REN)
- Sorbonne University (France)

Previous Research Partners:

- AxosLabs
- Cleveland Clinic
- Duke University
- Flufarma IHC
- Janvier Labs (France)
- Montreal Research Symposium (Canada)
- Porsolt (France)
- Radboud University Nijmegen (The Netherlands)
- Seattle Research Symposium
- SomaLogic
- The Jackson Laboratories
- University of Leeds (England)
- University of Seattle
- University of Utah
- University of Texas Southwestern Medical Center
- Vanderbilt University
- Wayne State University

AHCF 2025 Financial Summary

Gene Andrasco, Treasurer

For the Fiscal Year ending June 30, 2025,

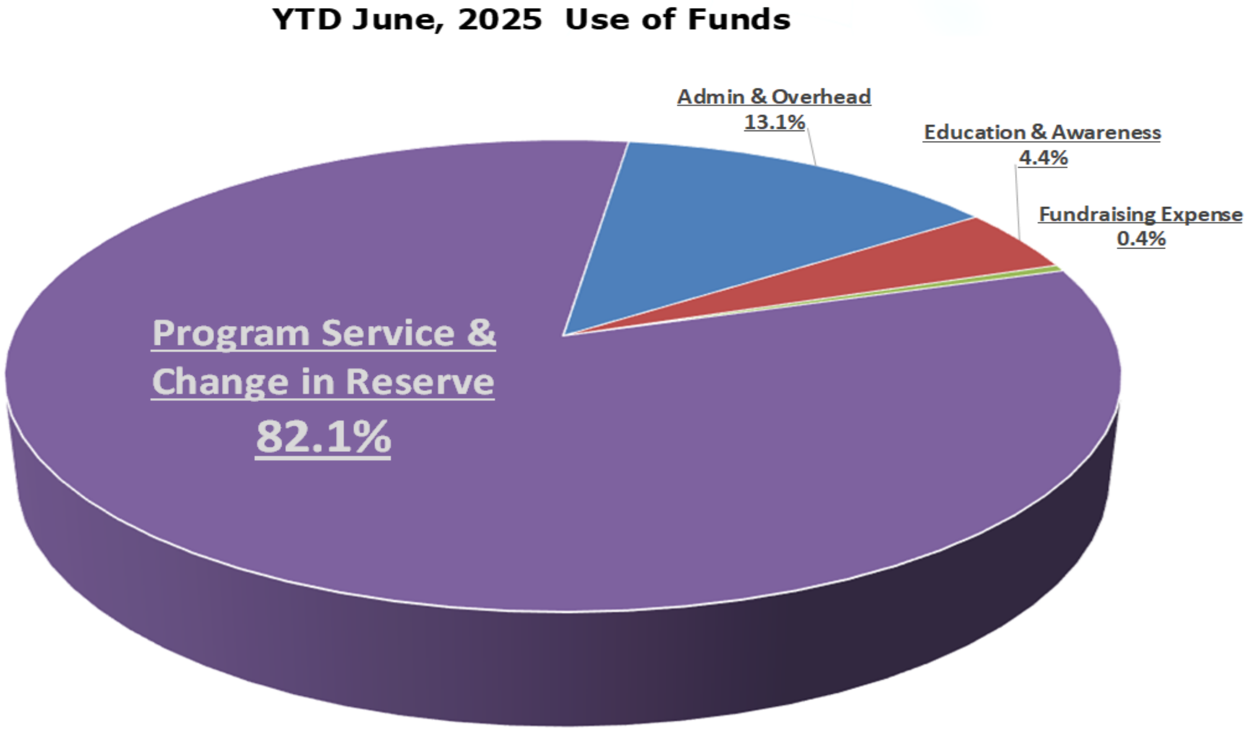
our revenue exceeded expenses, which continued to build on our strong financial foundation.

Donations were driven by the Foundation's yearend campaign, family fundraisers / honorarium pages, and sponsors for our family meeting.

Our investment income exceeded our overhead & 100% of donations went to programs & research

Condensed Financial Report
Fiscal Year End June 30, 2025

		% of
Revenue		**Revenue**
Donations	$195,616	69.0%
Investment income	$83,143	29.3%
Other Misc	$4,575	1.6%
Total Revenue	**$283,334**	**100.0%**
Expenses		
Admin & Overhead	$47,575	16.8%
Education & Awareness	$15,815	5.6%
Fundraising Expense	$1,570	0.6%
Investment Fee	$15,466	5.5%
Program Service/Research	$120,568	42.6%
Total Spending	**$200,994**	**70.9%**

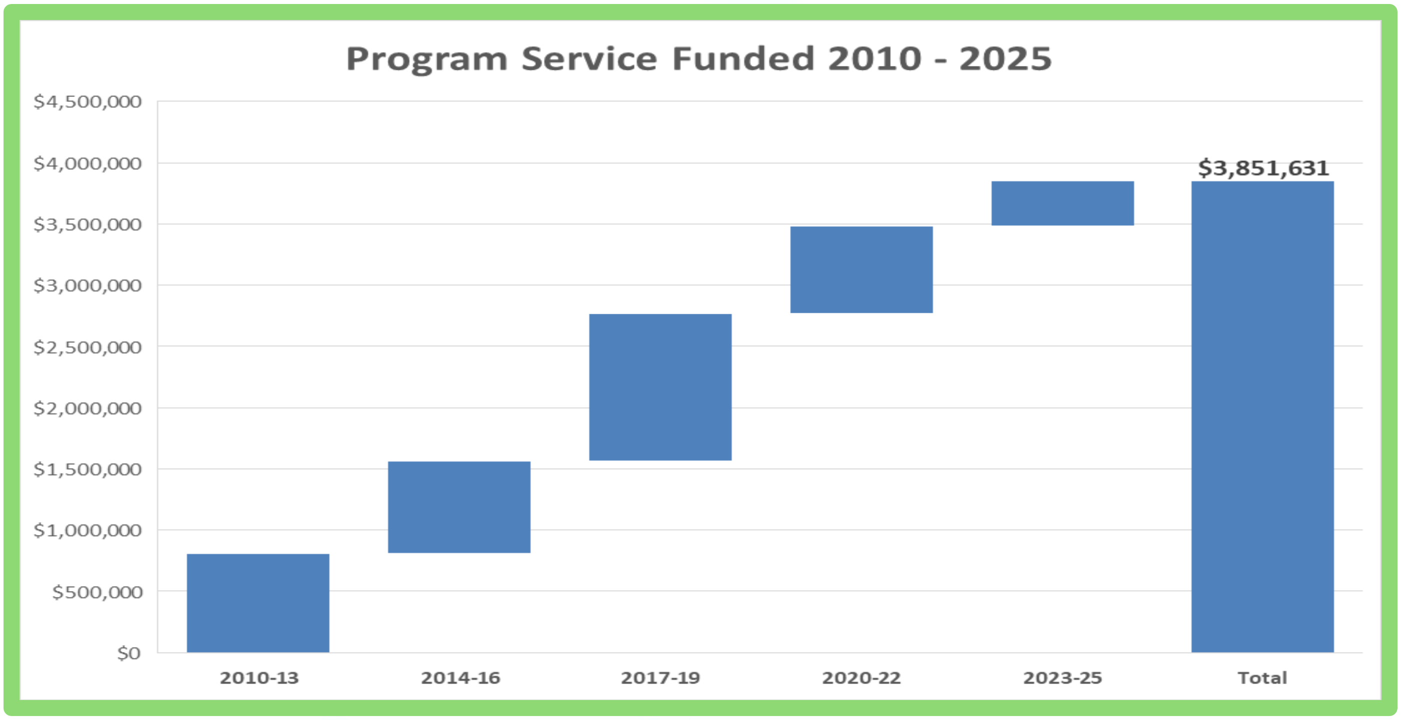


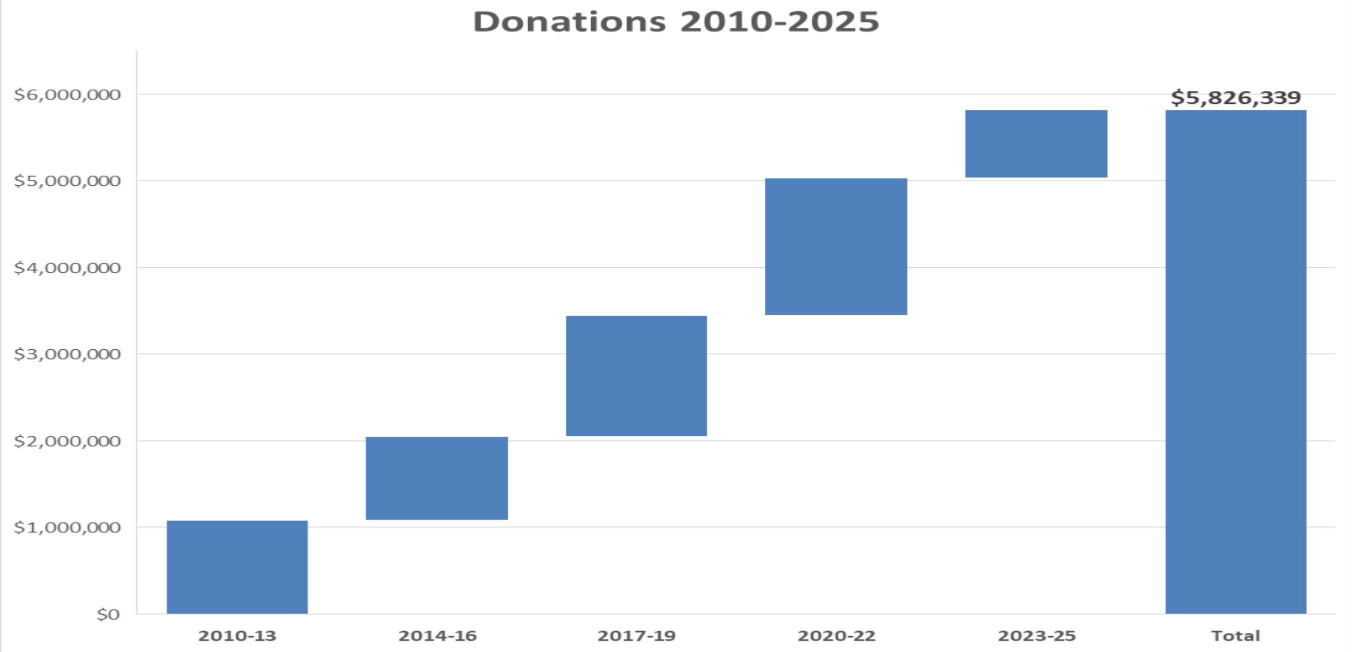
Note: Investment income funded 100% of Operating Expenses

AHCF 2025 Financial Summary continued. . .

Bill Gerber, Director

Since 2010 the AHCF has raised almost $6 million in donations, which has enabled us to fund almost $4 million in research, medical conferences, family meetings, and provide support to families in times of need.





Community Commitment Means Everything!

Our work is powered not only by vision and determination, but by the extraordinary *people who choose to give their time, energy, and compassion* to this mission.

Volunteers are the lifeblood of the AHC Foundation—champions who show up, lift others, and make progress possible in big and small ways. Their dedication strengthens families, accelerates research, and keeps hope moving forward.

AHCF Medical Advisory Board (MAB)

The AHCF MAB is a distinguished team of qualified healthcare professionals who provide expert guidance to the foundation.

Please join us in thanking our current MAB for their service.

Matthew Campbell PhD, FTCD - Professor in Genetics and Head of Department at the Smurfit Institute of Genetics in Trinity College Dublin, Ireland.

Suzanne D DeBrosse, MD. - Clinical geneticist in the Center for Human Genetics at University Hospitals Cleveland Medical Center, and Associate Professor of Genetics and Genome Sciences, Pediatrics, and Neurology at Case Western Reserve University in Cleveland, Ohio.

Kevin C. Ess, MD., PhD - Chief of Child Neurology at the University of Colorado, Anschutz Medical Campus in Denver, Colorado USA, and the Ponzio Family Chair of Pediatric Neurology at Children's Hospital Colorado.

Andrew Landstrom, MD., PhD - Inaugural Director of Translational Research at Children's Hospital of Philadelphia's Cardiovascular Institute.

Laurie Ozelius, PhD - Associate Professor of Neurology, Harvard Medical School Associate Neuroscientist.

Hendrik Rosewich, MD. - Associate Professor and Assistant Medical Director in the Department of Pediatrics and Adolescent Medicine, Division of Pediatric Neurology at the University Medical Center at Georg August University in Goettingen, Germany.

Terence Sanger, MD., PhD - Professor of Electrical Engineering at the University of California Irvine (UCI), Vice Chair of Research, Pediatrics, (UCI) Director of the Pediatric Movement Disorders Clinic and Deep Brain Stimulation Program at Children's Hospital of Orange County (CHOC), and the Vice President, Chief Scientific Officer at CHOC.

Masayuki Sasaki, MD. - Director, Tokyo Children Rehabilitation Hospital, Japan, clinical child neurologist at NCNP.

Community Commitment Means Everything!

Kathy Sharo, Director

AHCF Medical Advisory Board continued . . .

Kenneth Silver, MD., MSc, F.R.C.P. - Pediatric neurologist at Shriners Children's Chicago and co-director of the muscular dystrophy MDA-affiliated clinic at the Shriners Children's Chicago.

Marcio A. Sotero de Menezes, MD. - Director, Pediatric Neurology and Epilepsy Swedish Neuroscience Institute, Pediatric Neuroscience Center and Genetic Epilepsy Clinic Swedish Medical Center, Clinical Associate Professor, the University of Washington Department of Neurology.

Matthew T. Sweney, MD., M.S. - Pediatric neurologist and epileptologist who focuses on the diagnosis and treatment of drug-resistant pediatric epilepsy. He is the Medical Director of the Comprehensive Pediatric Epilepsy Program at Primary Children's Hospital.

Kathryn Swoboda MD. - Neurologist, geneticist and clinical neurophysiologist, and the former Katherine B. Sims M.D. Endowed Chair in Neurogenetics, Massachusetts General Hospital and Harvard Medical School.

Sho Yano, MD., PhD - Pediatric neurologist and medical geneticist who is doing research to understand why people with different genetic changes in ATP1A3 can have different symptoms.

Mary Zupanc MD. - Former Clinical Professor of Pediatrics and Neurology at the University of California-Irvine and Co-Medical Director of the Children's Hospital of Orange County Neuroscience Institute.





AHCF Board of Directors – AHC Volunteers, Parents, Caregivers, & Friends

Vicky Platt - President and parent
Gene Andrasco - Treasurer and parent
Heather Gates - Vice President of Family Support & Education and parent
Cate Cohen - Secretary, Communications Chair, and parent
Sharon Ciccodicola - Director, Foundation Coordinator and Family Meeting Co-Chair
Adalberto Duarte - Director, Webinar Coordinator, and parent
Lynn Egan - Director, Family Support, and parent
Bill Gerber - Director, Finance Team, and parent
Kathy Sharo - Director, Website, and aunt

Help Us Make a Difference - Volunteer Today!

Lynn Egan, Director

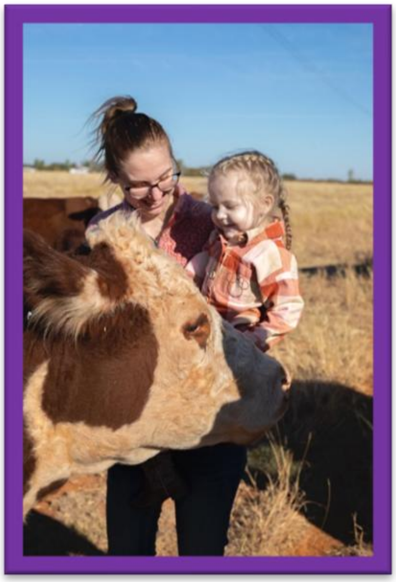
The AHCF volunteer network brings people together to help make the AHC community stronger. With a wide variety of opportunities, there are numerous ways to help. Your contributions as a volunteer will also provide an opportunity to meet other like-minded volunteers who will be here to support you every step of the way.

Email us at **ahcfoundation@ahckids.org** to volunteer for any of the areas below.

- Assisting families
- Supporting research efforts
- Participating in a fundraising event (live or virtual)
- Writing or editing content
- Helping with the website
- Volunteering at a fundraising or awareness events
- Coordinating family meetings
- Utilizing graphic design skills
- Sharing tech support talents
- Participating in legislative advocacy
- Photography / Videography

As we look to the future, we do so with deep gratitude for every volunteer who stands with us. Their generosity fuels our momentum, and their spirit reminds us why this work matters. Together, we are building a brighter path for everyone living with AHC.

Thank You to Everyone Who Supports Finding a Cure for Our Families



Be Sure to Join us
in Houston, Texas
June 2027
for the 16th
AHCF Family Meeting
Bigger in Texas - Stronger Together

Alternating Hemiplegia of Childhood Foundation
ahcfoundation@ahckids.org
www.ahckids.org
313-663-7772
2000 Town Center, Suite 1900, Southfield MI
Non-profit # is 38-3225425