



2025 AHC Family Meeting

Hot Topic: *Oxygen and Dystonic
Attacks in AHC*

Join us for the 2025 AHCF Family Meeting this summer as Dr. Flamand-Roze shares information on a current research study involving high flow oxygen and its effect on AHC episodes.

Meeting information can be found below.

[Register for 2025 AHCF Family Meeting](#)

[Check Out Dr. Flamand-Roze's Bio](#)

RESEARCH

Funding AHC PostDoc

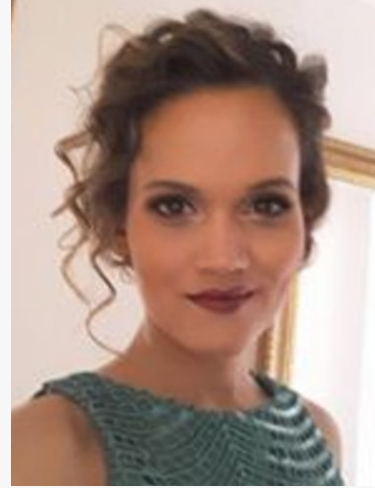


The AHC Foundation is honored to help fund Dr. Jacqueline Leite's fellowship with Dr. Al George at Northwestern University. Dr. Leite is a visiting doctor from Brazil and will be working with Dr. George on a number of AHC-related projects starting this April.

Dr. Leite is currently an Adjunct Professor of Pharmacology at Universidade Federal de Goiás in Brazil with AHC experience from

her work with Brazilian families. With this training, Dr. Leite plans to build a biorepository of PBMCs and iPSC lines from AHC patients in Brazil. This could be a valuable resource with which to investigate genetic and phenotypic diversity of AHC in a non-European and non-U.S. population.

Join us in welcoming Dr. Leite to the U.S. and we look forward to hearing more from her in the near future.



Critical Events in AHC Study



A new article is now available from Dr. Mikati, Dr. Landstrom and a team of doctors from Duke University. The article is titled, Critical Events in Patients With Alternating Hemiplegia of Childhood: A Cohort Study Subgroup Analysis. It was published by American Association of Nurse Anesthesiology in February 2025.

People with alternating hemiplegia of childhood undergoing general anesthesia are at risk for severe complications including critical bradycardia and hemiplegic incidents. They performed a 10-year historical cohort study of patients who specifically underwent general anesthesia. Patients with ATP1A3 positive variants were compared with those without such variants.



The 14 patients reviewed underwent general anesthesia a combined total of 39 times. Two patients had a short QTc documented prior to anesthesia and presented with bradycardia in the recovery room. Two other patients experienced a suspected seizure and hemiplegic incident; one of those patients received no facility-administered medications prior to experiencing a hemiplegic incident, and the other experienced a hemiplegic incident on emergence from anesthesia with subsequent cardiac arrest and successful resuscitation.

No apparent association was identified between type of anesthesia and the development of bradycardia or hemiplegic incidences. Of the four patients experiencing critical events, three had the ATP1A3-D801N



variant. Although additional research is necessary to confirm such associations, patients with alternating hemiplegia of childhood, specifically the ATP1A3-D801N variant, appear to be at elevated risk for complications associated with general anesthesia, suggesting the need for an increased anticipation of complications for this population.

[Abstract Link](#)

From Insight to Action – Research Update

The AHC community is fortunate to have a large number of highly talented and experienced professionals helping to find answers to many AHC questions. The help comes in various formats and is in different stages of development. Here are some highlights on the amazing research efforts taking place in the U.S. and Europe.

Dr. Anne Hart – Brown University

Dr. Hart is continuing her work on developing *C.elegans*, or worm, models of AHC to understand the mechanisms underlying AHC and nervous system function.

This work is important because *C. elegans* pass through several distinct phases of life which can be observed physiologically and genetically. Phase two of her work is nearing completion and we look forward to hearing more from her efforts.

Dr. Emmanuel Roze – France

The high flow oxygen trial is underway in France and is hoping to be an efficacious treatment for limiting paroxysmal symptoms in AHC. Dr. Roze has authored two articles on the use of oxygen in treating AHC and is scheduled to speak at the June 2025 AHCF Family Meeting.

As this trial could serve as a prototype for future trials of other therapies, it is important work for our community. Come listen to Dr. Roze update us on his work and learn more about high flow oxygen.

Dr. Al George – Northwestern University

With several AHC-related projects underway at his lab, Dr. George's continued dedication to the AHC community is in full swing. He is half-way through a five-year NIH grant which is benefiting our community in numerous ways. Dr. George is not only an active AHC researcher, but an active collaborator with other AHC researchers.

He will be giving an update on AHC research at the family meeting this summer, so keep an ear out for more information.

Dr. Alison Brashear – University at Buffalo

Dr. Landstrom – Duke University

Dr. Cat Lutz and Markus Terrey - The Jackson Laboratory

Dr. Brashear continues to lead a trusted team of renowned medical experts in expanding the world's knowledge of ATP1A3-related disorders.

She is studying patients diagnosed with AHC, as well as other disorders, to find new treatments and more ways to diagnose these conditions.

This is a multiple year study and one we look forward to learning more about upon its completion.

If you've read any of the articles on AHC and cardiology (or anesthesia), then you've seen the hard work of Dr. Landstrom in action.

He is a physician scientist who specializes in the care of children and young adults with arrhythmias, inheritable cardiovascular diseases, and sudden unexplained death syndromes.

The work is challenging and will be featured at the AHCF Family Meeting. Come ask Dr. Landstrom questions and learn about these new discoveries in person.

As a nonprofit organization, the team at JAX is continuing outstanding work on numerous AHC-related projects.

The primary research goals of the Lutz lab involve developing preclinical mouse models of neurodegeneration to test therapeutics and inform clinical trials.

The commitment to collaborative AHC research is evident in everything done by Cat, Markus and the entire JAX team.

Come meet part of the JAX team at the family meeting in June and hear more about their amazing work.

FAMILY SUPPORT

Advocacy Resource

Keep your child's medical information in a comprehensive toolkit. Download or print to take to a new neurologist visit or other medical professional.

Get Toolkit

AHCF Resource Guide

Do you know we have a new resource guide on our website? Check out links to find what you need or just to browse. Equipment, education, emergency medical, nutrition, and financial planning resource links are here.

See Research Guide Here

AHC Family Circle

Want to share the day to day challenges with parents who get it? Need a good listener who understands this AHC life? We are here!

If you have questions, please email Heather Gates at Heather@ahckids.org.

Join Zoom Meeting:

Sign up for text message reminders for AHCF Family Circle at:
<https://www.remind.com/join/ahcfamily>

Join Zoom
Meeting

FUNDRAISING & DONATIONS



Who Wants a Cure to End AHC? How're We Gonna Get There?

So often we see our AHC families frustrated, asking for a cure to end AHC. We see the suffering within our families. We see the missed milestones. We see the tears and hear the “why?” We see what our friends and neighbors get to do that we don’t. We see the “missing out” in general.

A cure to End AHC requires a lot of money. Researchers don’t solely fund their own research. AHCF contributes! Where does AHCF get the funds to contribute? From donations! Have you fundraised for us? If not now, then when? If not you, then who?

Fundraising doesn’t have to include a big effort. Please. Just share our donation link with your circle. Ask them to share it with theirs. We all need to pitch in if we ever hope to see an end to this disorder.

I want to help end
AHC!

AHCF Board of Directors: Gene Andrasco, Sharon Ciccodicola, Cate Cohen, Lynn Egan, Mollie Erpenbeck, Heather Gates, Bill Gerber, Vicky Platt, and Kathy Sharo



[Unsubscribe](#) | [Update Profile](#) | [Constant Contact Data Notice](#)



Try email marketing for free today!