

# IMPACT STATEMENT 2015



Through research, education, and family support, we have

**ONE MISSION: END AHC**



# Momentum and Hope



Greetings! To all of our researchers, donors, volunteers, families, and friends: thank you for everything that you have done for the Alternating Hemiplegia of Childhood Foundation. Your continued support is the exact reason that we have come this far. We have accomplished so much in 22 years and this year is no exception. It is with great pleasure that we deliver our first Impact Statement.

As we look back on the fiscal year 2014/2015, we can all be proud of the amazing progress we have made in our quest to find the cause and treatment of AHC. Throughout the year, our foundation continued to support our AHC families and educate the medical community. Our momentum allowed AHCF to continue to raise funds and attract new donors in order to fund current and upcoming research projects.

We kicked off the year (July 1, 2014) still riding the high from our family meeting in Minnesota. The team of physicians and specialists who attended the workshop titled, “Achieving Consensus on Definitions and Outcomes for Natural History Studies and Clinical Trials in ATP1A3 Related Disorders” have been working hard to complete the paper. The foundation recognized \$454,129 in donations from our major donor contributors, the Wine Women and Shoes event, walk-a-thons, golf outings, honorariums, and additional donations! We funded the 3rd phase of the research grant at Vanderbilt and Northwestern Universities, which has resulted in potential compounds to test in mice models in 2015/2016. We created a new website and a new mission statement – “Through research, education, and family support, we have one mission: end AHC!”

Our work is not yet done, and we cannot stop now. This next year is an ambitious one. Besides the research projects, we have many projects that we believe will make a difference in the quality of life for our children. The foundation is full of positive energy, momentum, and progress. With such a remarkable team of researchers, donors, volunteers, families, and friends working together, I am confident that we will continue to work to improve the lives of all people with AHC and reach our ultimate goal of finding a cure. We will continue to have an Impact.

With appreciation and warm regards,

Handwritten signature of Lynn Egan in black ink.

Lynn MacDonald Egan  
AHC Parent  
AHCF President  
San Francisco, CA



# AHCF 20 Top Twenty

**1** Mission: END AHC

**11** newsletters published this year

**2** Major Donations totalling over \$156,000 received

**12** words to new mission statement:  
"Through research, education, and family support,  
we have one mission: end AHC!"

Phase **3** research grant fully funded at  
Vanderbilt and Northwestern Universities

**13** hundred dollars raised  
on adaptive bicycle raffle

**4** Top rated by  
Great Non-Profits  
years in a row

**14** th of February, 2014 launched the AHCF  
Giving Tree Campaign.

**5** part series written about being a  
parent of an AHC child

**15** seats on Board of Directors

June **6** th Wine Women & Shoes event raised  
over **\$80,000** for AHCF

**\$7,000** grant received from generous  
family foundation

**16** new articles added to  
AHCF bibliography

**8** % of AHC patients have G947R  
mutation discussed in AHCF  
sponsored Retrospective Genetic Study

**17** physicians plus 8 specialists  
attended the AHCF sponsored  
scientific workshop

**9** different countries represented  
at Minnesota Family Meeting

**18** holes of golf played at  
Michigan and Illinois events  
to benefit AHCF

**10** th Family Meeting scheduled for Indianapolis in 2016

**19** DNA kits were tested at no cost  
to AHC families

Over **20** years of services to the AHC community

# Family Support

A vital part of our mission is to support the AHC patients and their families

"...It wasn't until we came in contact with the AHCF that the feelings of loneliness and hopelessness slowly started to fade. We were able to have a support system of individuals who knew exactly what we were going through. Without them we wouldn't have had the opportunity for genetic testing that finally identified the mutation causing our son's disorder or known the treatment options available to our family.

The volunteers and individuals that make this foundation are amazing. They are proactive at increasing education and awareness, offer support, and truly care about all the children affected with the disease."

- SMG41 (user name)  
Great Non-Profits.org review

## Connected to families



AHC 365 on our website:  
<http://ahckids.org/ahc365/>



Facebook page:  
[www.facebook.com/AHCKids](http://www.facebook.com/AHCKids)



Twitter page: <https://twitter.com/AHCKids>



Yahoo discussion group:  
[groups.yahoo.com/neo/groups/afha/info](http://groups.yahoo.com/neo/groups/afha/info)



You Tube:  
[www.youtube.com/user/AHCPresident](http://www.youtube.com/user/AHCPresident)

## Worthy Notes ....

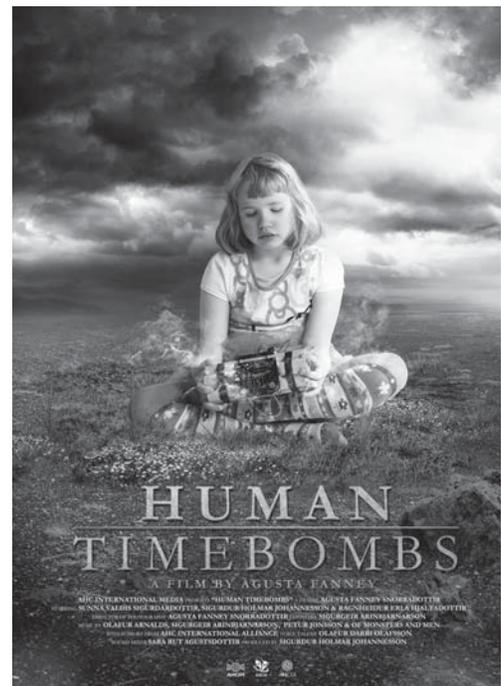
[www.AHCKids.org](http://www.AHCKids.org)

AHCF's new **website** went live in 2015 and provides up to the minute news and vast amounts of information relevant to patients and families with AHC. It will continue to add information in the coming months as a notable resource for the AHC community.

AHCF distributes a monthly **electronic newsletter** with information to keep the AHC community connected. You can find them here:  
<http://ahckids.org/community/ahcf-newsletters/>

AHCF has a **Coordinator** that is available to the families to answer questions or provide support through its network of experts whenever needed.  
[Sharon@ahckids.org](mailto:Sharon@ahckids.org)

AHCF financially supported and actively participated in the AHC Documentary and video library created by the AHC team in Iceland with Siggí Johannesson. The documentary premiered at the ATP1A3 Symposium in August of 2015.



# Family Meetings

One of the most important ways we support families is through our biennial Family Meetings.

The first Family Meeting was held over a weekend in 1999, in which 14 families participated with Dr. Ken Silver, the only AHC physician in attendance. Through the years we have held the meeting in Central Illinois, Salt Lake City, UT, Boston, MA, Chicago, IL, Raleigh, NC, San Francisco, CA and Minneapolis, MN. The idea of moving the family meetings around the country is that more families can participate, including those limited by mobility as well as cost.

It has grown to include families from across the Globe, with participation by the AHCF Board, AHCF Medical Advisory Board and numerous other AHC medical experts. In 2014, it was held in Minneapolis MN and was attended by 40 families from 9 different countries.



The Family Meeting is an incredible opportunity for parents to catch up with old friends, meet new ones, and connect with the largest gathering of AHC patients in the world. For the AHC “kids” it’s an opportunity to meet other kids with AHC and see that they are not alone. Many become lifelong friends.

During the conference, families have the opportunity to hear from researchers, chat with expert doctors, and hear from a variety of specialists that have an impact on living with AHC on a daily basis. They also have the opportunity to socialize and bond with other families facing the same challenges of raising an AHC child.

In the 3 days prior to the meeting, the Pediatric Motor Disorders Research Clinic Team led by Dr. Kathryn Swoboda, conducts AHC clinical appointments at no cost to the families.



**10th biennial Family Meeting  
Indianapolis, IN  
July 2016!**



Join us July 12 through July 17, 2016 in the family friendly city of Indianapolis, Indiana for our 10th AHC Family meeting. AHC expert physicians and scientists will discuss the most recent research findings, and answer parents’ medical questions. Specialists can advise families on important topics such as behavior, transitions, adulthood with AHC, diet, school, traditional and alternative therapies, and the psychological impact on the family members themselves.

# Research

"AHC is an amazing organization; they are a quality foundation run mostly by volunteers. They are 100% committed to all AHC kids and to funding valuable research. It is a testament to their commitment to end AHC-a majority of funds raised go directly to research. In addition to being on the leading edge of research, they are invaluable to AHC families! They have a long history of providing answers and help to families who often had nowhere else to turn."

- Laura

Great Non-Profits.org review

AHCF has funded

**\$1,816,332.97**  
of Research!

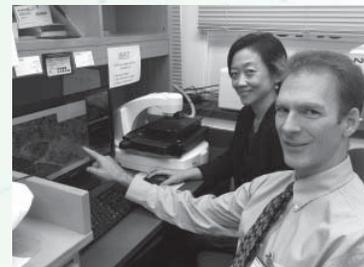
Look for additional project announcements later this year.

We are steadfastly dedicated to explore collaborative projects that will result in the advancement of understanding AHC and committed to finding a treatment and ultimately a cure.

## Funding Research



Dr. Alfred George, Jr.



Dr. Kevin Ess & Christine Simmons

### Research funded in 2014/2015 by AHCF

Molecular Physiology and Pharmacology of ATP1A3 Mutations in AHC

\$281,614.00 awarded to Dr. Kevin Ess at Vanderbilt University and Dr. Alfred George, Jr. at Northwestern University to continue their work to determine functional and biochemical consequences of the three most common gene mutations causing AHC. They will also continue to identify drugs or drug-like compounds through a drug screening program that are capable of restoring normal ATP1A3 gene function. Finally, they have made induced pluripotent stem cells (iPSCs) derived from AHC patients. These again include the three most common gene mutations causing AHC. These patient derived stem cells will be used to investigate electrophysiological abnormalities of neurons and to test whether compounds they have identified can restore ATP1A3 function.

For progress reports of this and past ongoing research grants, visit our research page:

<http://ahckids.org/research/researchprojects>



### AHCF Registry & Biobank

The foundation was founded in 1993 by parents of children with AHC. Five years later, in collaboration with top AHC researchers, the AHCF established an international registry and database to help document clinical outcomes and promote worldwide research efforts. Today the AHCF Clinical Research Registry and Biorepository is located at the Neurogenetics Program in the Center for Human Genetics Research at the Massachusetts General Hospital. It is the largest AHC database and DNA collection in the world under the direction of Dr. Kathryn Swoboda (pictured).

# Facilitating Collaboration

## Research Workshop

17 Physicians and 8 specialists attended an all day AHCF sponsored scientific workshop titled, "Achieving Consensus on Definitions and Outcomes for Natural History Studies and Clinical Trials in ATP1A3 Related Disorders." The workshop was held during the 2014 Family Meeting and was co-chaired by Dr. Kathryn Swoboda and Dr. Allison Brashear.

The primary purpose of the workshop was to bring together key stakeholders from diverse backgrounds to better educate the community about the diversity and complexity of neurologic phenotypes associated with mutations in ATP1A3, and to identify and prioritize key milestones for success in moving towards targeted therapies for ATP1A3 disorders.

A critical goal for this meeting includes working towards consensus on definitions and outcome measures that are both clinically meaningful to patients as well as practical to assess in the context of clinical studies and trials.



## Vanderbilt Clinic

Under the direction of Dr. Kevin Ess, the AHC clinic opened at Vanderbilt University in February 2014. The AHCF was proud to assist in the development of this clinic.

<http://www.childrenshospital.vanderbilt.org>

# Spreading Awareness



## Educating the Medical Community

AHCF was an exhibitor at The Child Neurology Society's 2014 annual meeting in Columbus, Ohio. We were represented by Mollie Erpenbeck (above right), Josh Marszalek (above left) and Cate Cohen from AHCF and Dr. Kevin Ess from Vanderbilt.

This is the largest annual gathering of Child Neurologists in the world, and connecting with these neurologists is invaluable. Answering questions, seeking out new AHC patients, learning the options for diagnosing AHC, and garnering support for referrals are the primary objectives of attending such a conference.

## ATP1A3 Symposia

AHCF has been a proud sponsor of the four ATP1A3 Symposia that have taken place yearly around the world, bringing interested researchers together to share the progress and move the research forward in hopes the collaborative effort will accelerate the road to a treatment and a cure.



# Financial Summary

"I have been involved with the foundation for the last 14 years and am constantly amazed at what a small group of people can achieve when they work together! AHC is not a popular disease, nor are there any famous people promoting our cause and yet year after year thousands of dollars are raised for research! ..."

- Carol

Great Non-Profits.org review

## Stewardship

The funds in stewardship by the AHC Foundation are raised entirely by private donors through extensive effort on their part and that of their families. Through careful deliberation and consultation with professionals, the AHCF allocates these funds to grants that have significant impact on the status of AHC research and its progress to a treatment or a cure for AHC. Good stewardship of donated resources is of the highest priority to the foundation. In that spirit, we thought you might like to know where funds are directed.



Official IRS filing information for non-Profits are called Form 990's, and they can be found at Guidestar.  
<http://www.guidestar.org>



## Raising Funds

Volunteers and private donations are the source of all the funds raised for research into Alternating Hemiplegia of Childhood. The AHCF has had great success in supporting individuals and families to raise funds on behalf of AHC Kids. The fundraising committee continually develops tools and resources for use by those who wish to join the effort to END AHC. By building on the experience of our volunteers in this way, future fundraisers are more effective and the momentum to a cure continues to build.

### 2014/2015 Actual

General Donations	\$144,151
Wine, Women & Shoes	\$135,925
Walk-a-Thon	\$51,170
Honorarium	\$41,820
Golf Outing	\$38,294
Hodes Dine-Dance	\$12,754
Family Fundraisers	\$8,186
Giving Tuesday	\$7,709
Infath Foundation Grant	\$6,500
Memorials	\$6,096
Charity Mania	\$810
United Way	\$714

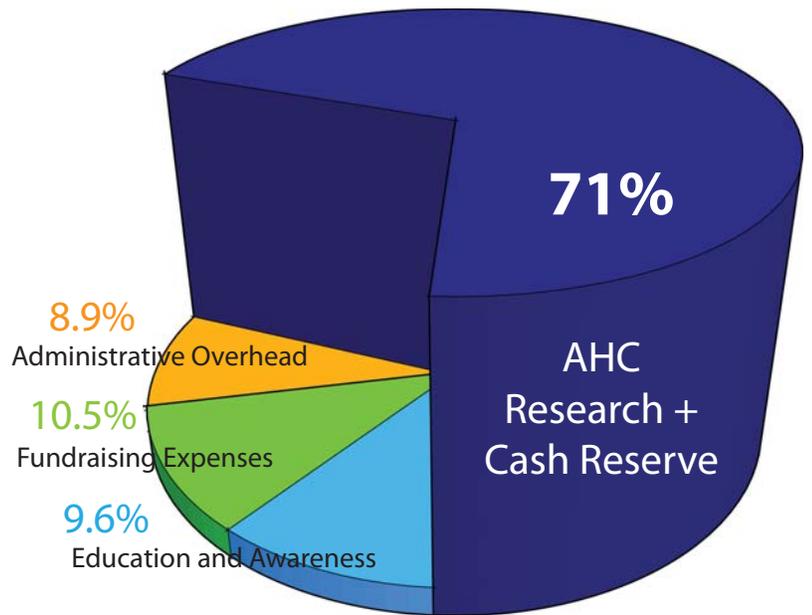
Total Donations \$454,129

## 2014/2015 Operating Expenses

Revenue		% of
Donations	\$454,129	Revenue
Other (Invest. & Misc.)	\$10,720	

Rent	\$1,049	0.2%
Non-profit fees	\$320	0.1%
Coordinator Pay	\$32,500	7.0%
Office & Invest. Fee	\$5,555	1.2%
Insurance	\$1,755	0.4%
Education & Awareness	\$44,639	9.6%
Fundraising Exp.	\$49,016	10.5%
<b>Research</b>	<b>\$263,491</b>	<b>56.7%</b>

<b>Total Spending</b>	<b>\$398,325</b>	<b>85.7%</b>
Added to Cash Reserve	\$66,524	14.3%



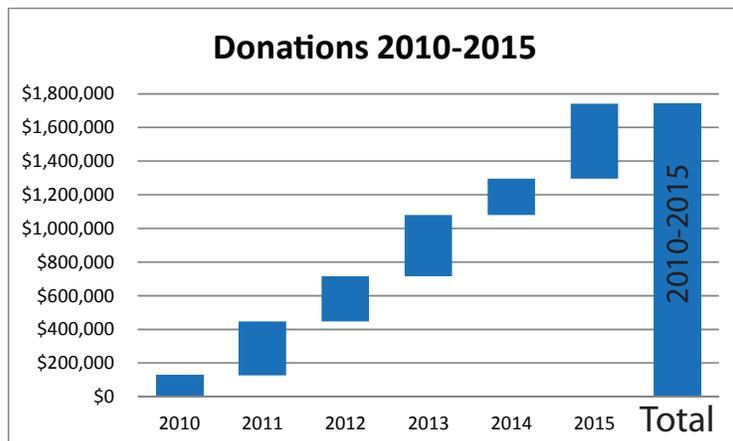
# Fund the Momentum!

AHCF accomplishments since 2010:

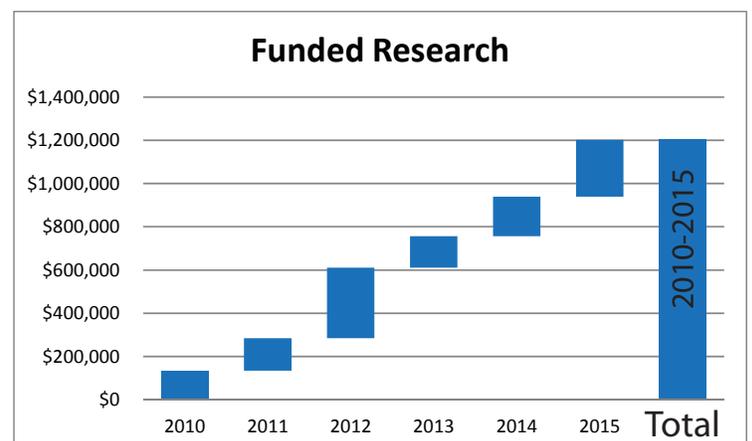
- Raised \$1.8 million in donations
- Funded \$1.2 million of research to find the causes/cure for AHC
- Funded medical conferences in the U.S. and Europe to promote collaboration among researchers and find the cure for AHC
- Funded events to bring families, doctors, and researchers together



The Chart below shows the growth in annual donations between 2010 and 2015



The Chart below shows the research funded annually between 2010 and 2015



# Moving Forward 2015

"My daughter was diagnosed with AHC in December 2012. We were scared, relieved, and confused. Doctors told us there was no real treatment and only about 300 cases in the US. We should contact AHC foundation for help. This foundation was all we had for support and answers. Everyone involved with this foundation has been so helpful and all are dedicated to find a treatment and hopefully a cure. I've met and spoke to other moms who know exactly what I've been through and can share my pain and frustrations. Our kids with AHC are one in a million and so is this foundation!!! With a little recognition and extra support this foundation would be unstoppable!"

Great Non-Profits.org review

## Contribute to END AHC



[www.AHCKids.org/contribute](http://www.AHCKids.org/contribute)

## Power of Progress

### Potential of our Future

The AHC Foundation is leading the fight with the AHC community to conquer the everyday battles of living with this disease. The foundation is committed to building on the tremendous progress seen in the last year and advancing our mission even further going forward.



## Progress through Research

### For Treatments and a Cure

Research holds the key to finding treatment options and a cure for AHC and ATP1A3 related diseases. Strengthening and supporting the research pipeline with creative and engaged scientists is essential to improving the quality of life of AHC families. Research planned for the next year includes:

- Funding Phase 4 of Molecular Physiology and Pharmacology of ATP1A3 Mutations in AHC study at Vanderbilt and Northwestern Universities
- Initiating an AHC Behavior Study
- Participating in a collaborative study with Wake Forest University and Rapid Dystonia Parkinsonism
- Participating in the Fourth Symposium on ATP1A3 in Disease

# Progress through Connection

## Making a Difference

The needs of families living with AHC are considerable and the AHC Foundation plays a vital role in keeping the AHC community connected. The foundation will continue to make a difference in the lives of AHC families by successfully executing our various programs. The planned initiatives include:

- Planning our 10th Biennial Family Meeting in Indianapolis, Indiana
- Connecting families by region after updating our family directory
- Expanding our website to include a physician directory and an “Ask an Expert” segment
- Supporting families at fundraising events while they support each other



# Progress through Success

## Lead the Momentum to a World without AHC

For over two decades, the AHC Foundation has funded research and provided steadfast support to the AHC community on a national and international basis. Going forward, the foundation will build on our success by boldly leading the fight against AHC and ensuring that the needs of AHC families around the world are met with expertise, consistency, and compassion.

# Progress through Education

## Engaging a Community

Providing current and credible information about a rare disease is essential to the AHC community. The AHC Foundation, in coordination with our Medical Advisory Board, collaborates with physicians and other professionals to strengthen our educational offerings. In addition to our monthly newsletters, the foundation’s educational efforts include:

- Developing a physician-to-physician guide to AHC with the assistance of NORD and our MAB
- Seeking out researchers at the beginning of their careers to foster an interest in AHC
- Begin addressing the needs of our adult population and engaging neurologists beyond the pediatric segment



[www.AHCKids.org](http://www.AHCKids.org)

*20years!*

Thanks to the families and our supporters,  
AHCF has provided over 20 Years of service  
to the AHC community!

ahcf

Alternating Hemiplegia  
of Childhood Foundation

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[www.AHCKids.org](http://www.AHCKids.org)

For more information about AHCF,  
including resources, genetic testing, research  
and general information, contact us!  
[info@ahckids.org](mailto:info@ahckids.org)