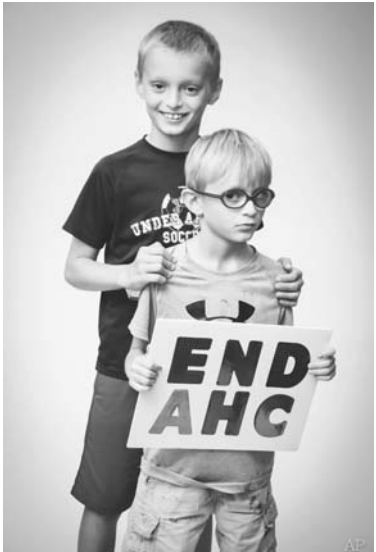


# IMPACT STATEMENT 2015/2016



Through research, education and family support, we have

**ONE MISSION: END AHC**



# Join our Momentum

I truly appreciate the opportunity to continue serving as the President of the AHC Foundation. It is my privilege to be associated with such a strong and vital foundation, which continues to grow in size and prominence each year. The AHCF is fortunate to have a strong Board of Directors and Medical Advisory Board. They are truly dedicated to moving the foundation forward with the ultimate goal of finding a treatment and cure for AHC.

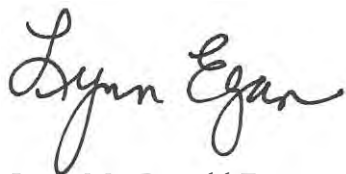
To our AHC families; you are why we exist. Your stories are why our board members and volunteers donate their time to achieving our One Mission: END AHC. You are inspirational, humble, and courageous in how you share your story with the community. Everyday can be a challenge for you and your child. And yet, you make up our incredible donors, volunteers and board members.

With your financial support, the AHCF has invested over \$2.2 million in research since we began in 1995. This past year our momentum continued as we realized over \$311,000 in donations and merchandise sales from our fundraisers and major donors. And, in collaboration with AHC Ireland, we funded the 4th phase of the Vanderbilt and Northwestern Universities grant, “Molecular Physiology and Pharmacology of ATP1A3 Mutation in AHC.”

During the next year, we will need ‘you’ to help accomplish the next breakthrough and push research even further. We invite you to join our movement and give hope to all children and adults fighting AHC. We are all in this to find a treatment and cure for AHC. So, with your participation, we know we will find the answers we seek.

This impact statement provides an overview of important accomplishments over the last 18 months and touches on the goals for 2016/17. Together, we have made these accomplishments possible and together we will ensure the momentum continues. Thank you for your support. We couldn’t have done it without you!

With appreciation and warm regards,



Lynn MacDonald Egan  
AHC Parent  
AHCF President  
San Francisco, CA



1 Mission: END AHC

2 nd Annual AHC Foundation Impact Statement

\$ 3 ,000 donated in 2015 to support the AHC Documentary "Human Timebombs"

4 th Phase of research funded at Vanderbilt & Northwestern Universities

Top rated by Great Non-Profits 5 years in a row

6 vetted projects waiting for funding

7 representatives and 3 advocate events supported (3 at Washington, D.C. ATP1A3 symposium, 3 Grand rounds, 1 Board Member speaking at Northwestern)

8 family run fundraisers = 65% of fundraising donations

9 newsletters published

10 th Anniversary of the Chicago Walk

# Family Support

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

"This organization works day and night to better the lives of those suffering from AHC. Our community grows each year because of the outreach done by everyone of the all volunteer staff and board members."

Great Non-Profits.org review

"AHC has been a lifesaver to me and my family! The tireless efforts to raise funds for research and raising awareness of the disorder speaks volumes about those involved in the foundation. Truly would be lost without them. We can SEE the progress they are making for our kids and adults with AHC!"

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)

Facebook Support Group:  
search "AHC Support Group" on FB.



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)

## The AHC Foundation

Building upon the past,  
thriving in the present  
and planning for the future

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 world-wide research efforts. Today this is the largest collection of AHC records and DNA samples in the world. For two decades the AHC Foundation has funded **research** and provided steadfast support to the AHC community on a national and international level.

AHC is a devastating disease that is difficult to diagnose and even more challenging to treat. We devote vigorous efforts to **education and increasing awareness** of AHC so that proper diagnosis may occur as early as possible. AHCF helped support the making of the AHC documentary "Human Time bombs" which brings AHC awareness to an international audience.

**Family meetings** are coordinated biennially by the foundation to provide AHC families with an incredible and unique opportunity. Patients from the United States and around the world have the chance to experience free medical appointments with a variety of AHC experts. During the conference, world renown physicians and specialists speak about the latest AHC research and topics that have an impact on living with AHC on a daily basis. Most importantly they have the opportunity to socialize and bond with other families facing the same challenges of raising an AHC child. Many AHC kids become lifelong friends.





# Family Meeting - Indy 2016

Our 2016 Family Meeting in Indianapolis, Indiana took place in July and featured an agenda that was developed with direct input from AHC families. It covered everything from the most up-to-date research findings, stress management techniques, and alternative therapy options.

In addition to generous sponsorship, we were awarded a grant from the rare disease advocacy organization, Global Genes. The grant allowed us to host live webinars of the presentations for the families who could not attend the meeting. We also created a phone app to keep everyone informed about the latest meeting news!

A workshop was held during the meeting to build on the work done at in 2014 with our Medical Advisory Board and other involved researchers and clinicians. A critical goal for this workshop included working towards consensus on definitions and outcome measures that are both clinically meaningful to patients as well as practical in the preparation of natural history studies and clinical trials.

Families learned about the latest research and how to manage some of the symptoms associated with AHC, but they also learned alternative therapies and how to care for themselves as the caregiver and shared their insights in the roundtables. They learned the importance of a Natural History Database for clinical trials while listening intently to the hard facts of what it will take to get there and everyone was invited to participate.

Starting with the Meet & Greet, through the Luncheon and finally the Ice Cream Social, the parents and kids got to know one another or reconnect with old friends.

The AHC kids got a special treat with live entertainment throughout the conference in the “kids” room including a magician who was a huge hit! We were surrounded by colorful posters of the kids as we were reminded to “Celebrate” them and their accomplishments throughout the meeting, and most importantly families were grateful for the opportunity to connect with others sharing the same experiences.



Volunteers played with the kids while parents attended sessions dedicated to improved care.



New friendships were made between kids and adults too.



AHCF presented lifetime achievement awards for the first time, honoring Dr Fred Andermann & Dr Ken Silver

## New Jersey June 2018!

Save the third week of June 2018 where we will meet you all in New Jersey for the 12th AHCF Family Meeting!

# Research

---

"I have only known about this great organization for a few years. But be assured that the Alternating Hemiplegia of Childhood Foundation (AHCF) does exactly what it claims to do.....help children with AHC and their families cope with the diagnosis, finding help amongst the AHCF community, raising awareness, and raising funds that almost entirely go toward research in finding a cure. I can't say enough positive things about the people who serve the cause and work so hard to make life better for those afflicted with AHC. They give a priceless gift to those children and their families... the gift of Hope."

Great Non-Profits.org review

---



# Funding Research



Dr. Kevin Ess, MD, PhD



Dr. Alfred Georg, MD

## **Molecular Physiology and Pharmacology of ATP1A3 Mutations in AHC (Phase 4) 2015-2016**

\$250,000 awarded to Dr. Kevin C. 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 have made induced pluripotent stem cells (iPSCs) derived from AHC patients. These cells will be differentiated to subclasses of neurons and tested for functional deficits. They will also be using a cell and computer-based screening process to identify drugs or drug-like compounds that are capable of restoring normal ATP1A3 gene function. Finally, they will investigate novel animal models of AHC to elucidate mechanisms of the disease and to test therapeutic strategies.

This grant was a collaborative effort between the AHCF and the Alternating Hemiplegia of Childhood Ireland.

For progress reports of this and past research grants, visit our research page: <http://ahckids.org/research/researchprojects>

---

AHCF has funded

**\$2,235,486.90 of Research!**

We are dedicated to exploring collaborative projects that will result in advancements to understanding AHC. We are devoted to finding a treatment and ultimately a cure. Look for additional project announcements later this year.

# Engaging Researchers and International Advocacy

Two symposiums attended by AHCF officers

The Symposium on ATP1A3 in Disease is organized by a coalition of organizations with the purpose of bringing researchers together to discuss all diseases associated with the ATP1A3 gene. During the last fifteen months, the foundation issued grants for researchers to attend the symposium, as well as representatives from the foundation.

At the Fifth Symposium on ATP1A3 in Disease, our own Vicky Platt represented the foundation in London, England. She spoke during the meeting and shared a parent's perspective to help keep the needs of AHC patients' front-and-center during the symposium.



Vicky Platt (AHCF Sec.) attended 5th ATP1A3 Symposium this summer in London.



Lynn Egan (AHCF Pres.), Mark Egan, Dominique Poncelin (AHC - FR), Dr. Kenneth Silver at 4th ATP1A3 Symposium.

President Lynn Egan traveled to Washington, DC in August 2015 to participate in the 4th Symposium in ATP1A3 in Disease. Presentations ranged from the explanation of how NIH funds are applied in rare disease, preparing for clinical trials, discussing different manifestations of AHC, engineering mouse models, and new phenotypes of novel ATP1A3 gene mutations.

It is not only important to attend and hear about the latest research, but to support the collaborative efforts of researchers working on AHC-related projects. Commonalities and overlaps in each ATP1A3-related disease mean that breakthroughs in any one of them could lead to advancements for all.

## Research Progress – Engaging the next generation!



Gene Andrasco spoke to Northwestern University Medical Students about AHC

Research holds the key to finding treatment options and a cure for AHC and ATP1A3-related diseases. This past year, our collaborative group of researchers and clinicians successfully taught many interested physicians, fellows and medical students about AHC. Their efforts helped strengthen and develop the research pipeline with creative and engaged scientists. Some of these young and energetic medical professionals are doing internships alongside the best AHC clinicians, writing their thesis on AHC, and working in research labs to gain an insight to a disorder they find intriguing.



# Financial Summary

Fiscal Year 7.01.15 thru 6.30.16

"This wonderful organization makes a difference. The focus is truly on the kids and their families and they emphasize results, including funding the exciting discovery of the gene that causes the disorder. My niece and her family also rely on the support community to stay strong and manage incredibly difficult daily challenges. AHCF impacts their life every-day."

Great Non-Profits.org review

## Stewardship

Through careful deliberation and consultation with professionals, the AHCF allocates funds to grants that have significant impact on the status of AHC research and make progress towards a treatment, or 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.



In the United States, the Internal Revenue Service requires a Form 990 to provide the public with financial information about a nonprofit organization. The AHCF files their 990's on Nov. 15th of each year, and they can be found on Guidestar within 2 months of filing. [www.guidestar.org](http://www.guidestar.org).

## Raising Funds

With the needs of the AHC patients in mind, the AHCF works tirelessly to raise funds through the generosity of private donations. We mentor those individuals and families who raise money on our behalf and work to build on this momentum every year.

The AHCF had another successful year of fundraising. Through a combination of a major donor grant, family run fundraisers, family honorarium pages on our website, and other events we raised \$297,464.

The major donor donation of \$125,000 came from the Jake and Nina Kamin Foundation and it is the first half of their very generous grant. We are honored that they committed to help fund critical research.

We had 8 family run fundraisers that brought in almost \$115,000. These events included golf outings, dinners, walks, and a pumpkin fest.

The generosity of our donors has enabled the Foundation to continue on the path to a cure. Here are some of major initiatives we were able to fund:

- We funded Phase 4 research at Vanderbilt & Northwestern (\$250,000)
- Sponsored the International AHC Symposium for the 4th consecutive year
- Funded the 2016 Family Meeting
- Maintained a strong cash position to help Fund Phase 5 research in next year (\$250,000)

### 2015/2016 Actual

General Donations	\$147,976
Golf Outing	\$42,824
Walk-a-Thon	\$30,092
Family Fundraisers	\$29,230
Honorarium	\$18,943
Hodes Dine-Dance	\$13,984
End of Year Campaign	\$5,280
Wine Women & Shoes	\$4,375
Memorials	\$1,705
Charity Mania	\$1,680
Network for Good	\$730
United Way	\$644

Total Donations \$297,464



# Keeping up the Momentum!

## AHCF accomplishments since 2010:

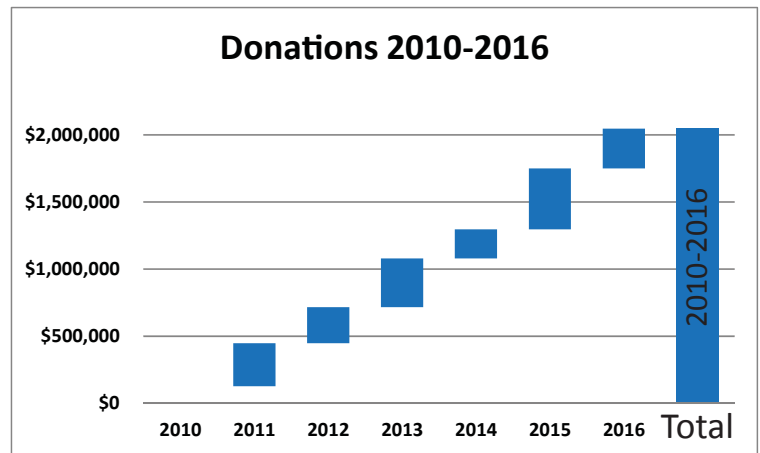
- Raised \$2.0 million in donations
- Funded \$1.5 million of research to find the causes/cure for AHC
- Increased our reserves by 25% to help fund future research
- Funded medical conferences in the US and Europe to promote collaboration among researchers
- Funded events to bring families, doctors, and researchers together

- Reduced fixed overhead costs by aligning our spending on items that support our mission to End AHC
- Rent, insurance, and taxes down 85%
- Investment fees brought down 35%

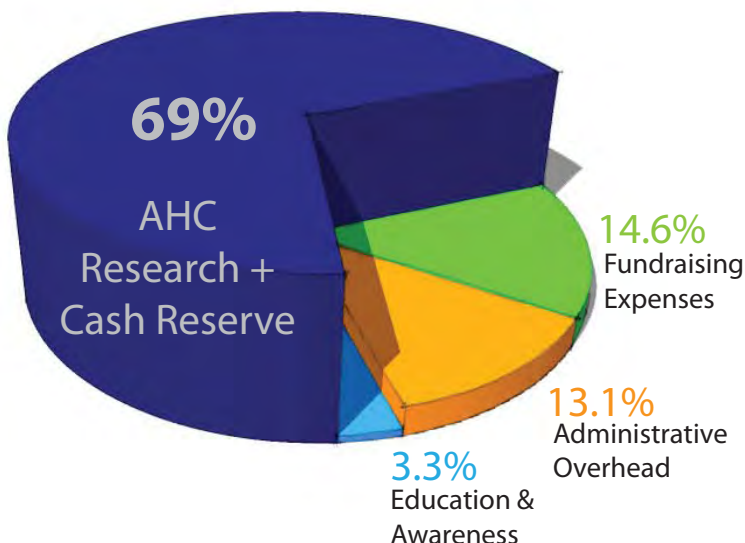
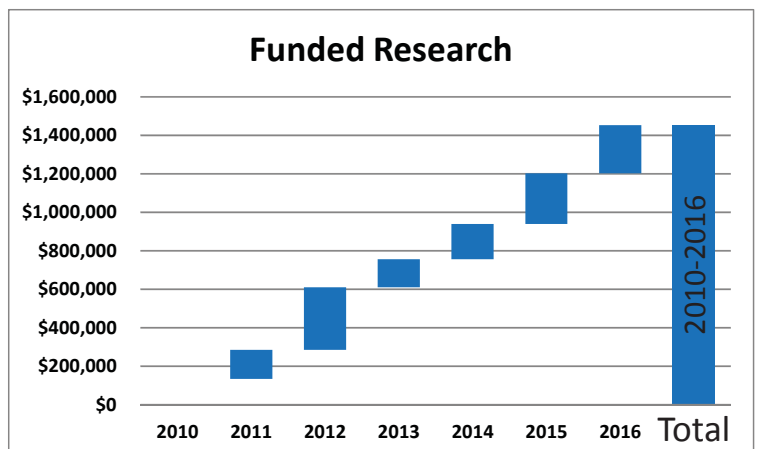
## 2015/2016 Condensed Income Statement

Revenue		% of
Donations	\$297,464	Revenue
Other Misc.	\$13,559	
<b>Rent</b>	<b>\$990</b>	<b>0.3%</b>
<b>Non-profit fees</b>	<b>\$320</b>	<b>0.1%</b>
<b>Coordinator Pay</b>	<b>\$32,500</b>	<b>10.4%</b>
<b>Office &amp; Invest. Fee</b>	<b>\$6,004</b>	<b>1.9%</b>
<b>Insurance</b>	<b>\$909</b>	<b>0.3%</b>
<b>Education &amp; Awareness</b>	<b>\$10,404</b>	<b>3.3%</b>
<b>Fundraising Exp.</b>	<b>\$45,404</b>	<b>14.6%</b>
<b>Research</b>	<b>\$250,000</b>	<b>80.4%</b>
<b>Total Spending</b>	<b>\$346,531</b>	<b>111.4%</b>
Added to Cash Reserve	(\$35,508)	-11.4%

The Chart below shows the growth in annual donations between 2010 and 2016



The Chart below shows the research funded annually between 2010 and 2016



# Moving Forward 2016



## Looking Ahead

AHCF will continue to lead the fight against AHC, ensuring that the needs of AHC families around the world are met with expertise, consistency, and compassion! Our planned initiatives for 2016 - 2017 include:

Updating the AHCF Family Directory, enabling us to have an accurate count of AHC patients in the U.S. and the ability to connect with each family and encouraging them to connect with each other.

Expanding our website with new and timely information will be helpful to the AHC community and especially the newly diagnosed patients.

Providing families an opportunity to share their story in our ever expanding network of rare disease partners. And, continuing to explore and evaluate opportunities to collaborate with our global partners.

Continued collaboration with Wake Forest University for the ATP1A3 - RDP/AHC study.

As our AHC population ages, we will work towards developing strategies that focus on their needs to achieve an optimum quality of life.

## Potential Research Projects

We have six projects vetted by the Medical Advisory Board and the Board of Directors waiting for funding...

COST	RECIPIENT	UNIV. / LOCATION	FOCUS
\$150,000	Dr. Kenneth Silver	Univ. of Chicago	Pharmaceutical Treatment
\$130,000	Dr. Alfred George	Northwestern Univ.	Develop Mouse Models
\$120,000	Dr. Kevin Ess	Vanderbilt Univ.	Accelerate Treatment Research
\$50,000	Dr. Kathryn Swoboda	Harvard Univ.	Database for Drug Trial Preparation
\$50,000	AHC Episode Tracker	International	Improve Quality of Life
\$10,000	Alice Belgrade	U.S. based	Behavior Study

**\$510,000 Total**

The AHCF is always looking for more ways to further collaboration and encourage progress while being good stewards of our resources.

# Thank you for your support

The Board of Directors extends its sincere thanks to those who have given their time and treasure for over 20 years to further the mission of this foundation and of the whole AHC community...

## END AHC



Lynn Egan - President  
Joshua Marszalek - Vice President  
Vicky Platt - Secretary  
Gene Andrasco - Treasurer  
Sharon Cicodicola - Medical Liason  
Shannon Berta  
Bill Gerber  
Rik Greenwood (NP)  
Renee Hodes  
Mario Merida  
Carol Presunka



# ahcfcf

Alternating Hemiplegia  
of Childhood Foundation

2000 Town Center, Suite 1900  
Southfield, Michigan 48075  
[www.AHCKids.org](http://www.AHCKids.org)

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

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