



One Mission: End AHC!



YOUR ALTERNATING HEMIPLEGIA OF CHILDHOOD FOUNDATION NEWSLETTER

November 2016

2000 Town Center ■ Suite 1900 ■ Southfield, Michigan 48075

AHCF in Action

Thanksgiving message from Lynn Egan

As Thanksgiving approaches, we would like to take the time to express how **thankful we are for all of our family, friends, donors, scientists and researchers.**

Thanksgiving is a time to reflect upon the many blessings for which we are so grateful. Your trust and support to the foundation are greatly appreciated.

You continue to inspire us to work even harder to not only support each of you but to push forward the research that will get us closer to a treatment and ultimately a cure!

The Board of Directors and I wish you and your family a wonderful Thanksgiving.



DOUBLE the FUNdraining

AHC answers are waiting for us and your help is needed

List of potential projects waiting for funding

\$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

It is very exciting times in terms of research.

Right now we have the problem of how to raise enough money to fund it all of the potential projects that have been put in front of the foundation.

We currently have **\$510,000 in research grant requests** that we can't afford to fund.

Our end of year goal is to raise \$150K that will help us begin to fund these projects.

Doctors are excited about the discovery of the ATP1A3 gene and we want to ensure we act upon that excitement. If we don't fund the research when they have time, we will lose valuable **opportunities to End AHC!**

Our year-end campaign has kicked off and needs your help! Step Up to END AHC is a call to action for families to raise, not donate, money to fund research that will help to End AHC. We made it easy to raise as much or as little money as you can while sharing your own AHC story at the same time.

When you support the **Step Up to End AHC** campaign, you are **helping the AHCF achieve its mission** to fund research, promote year-round education, and provide families with much needed support.

www.ahckids.org

PATH to a CURE **AHC campaign underway**

Be part of the movement and join our **Step Up to END AHC** campaign! All funds raised in this campaign will go directly to research that will not only benefit your child but the entire AHC community!



All of your efforts will directly affect the future of every person living with AHC.

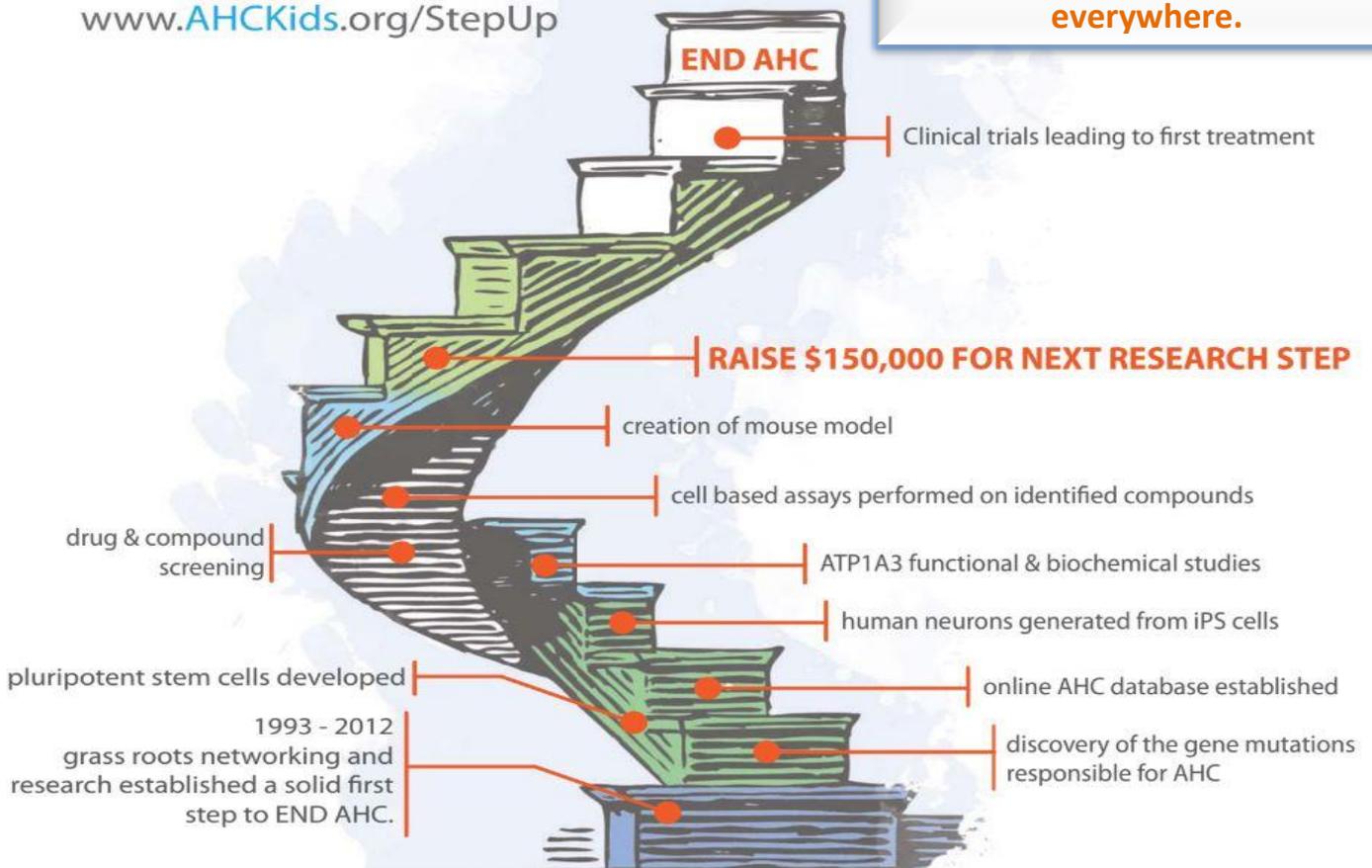
Your contributions can help create treatments for AHC episodes, prepare our community for clinical drug trials and develop tools to improve the quality of life of all AHC patients.

The AHC Community is a small and industrious group that has achieved great success when presented with a challenge.

The test now for us is to find new ways to support the projects waiting for funding.

With your help, we can take advantage of these new opportunities which can bring real solutions to AHC patients everywhere.

www.AHCKids.org/StepUp



To join in the campaign, see the next pages for instructions and ideas!

PATH to a CURE

Joining the AHC campaign is simple and fast for everyone

To take the next steps to a treatment, we are asking for your help.

Go to <http://www.firstgiving.com/AHCF/step-up-to-end-ahc>

Click on **FUNDRAISE** and **create a personal page or join a team**

Create a personal fundraising page - This is your personal page where you can tell your story. You are encouraged to share the ups and downs of living with AHC. Really let people know why it is important to end AHC!

Add a photo and set a fundraising goal. **You can add a goal** for your team or leave it blank and each person who becomes part of your team set's their goal.

When people ask to join your team, remember to send them the **link to your team page**. This is where it will ask them to 'join team' and they will need to also create an account, join your team. They don't need to tell a story unless they want to, but if left blank, there is a generic one that populates.



FirstGiving
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Warriors for Kathryn
Step Up to End AHC



Warriors for Kathryn raise funds for research into Alternating Hemiplegia of Childhood (AHC) on behalf of Kathryn and AHC kids everywhere. These funds will allow research teams to continue their momentum to finding a treatment or a cure for this debilitating rare disease. While there is much work to do, these teams are on the path, with hope that they will achieve the unthinkable...a normal quality of life for Kathryn. AHC is a disease in which half or all of the body becomes paralyzed periodically. Trapping the otherwise conscious person in their bodies with painful contractions. Additionally, between these episodes AHC kids have an underlying lack of muscle control. Much like a pilot driving a poorly functioning robot. While the pilot is aware and intelligent and learns, the robot body does not work well with the pilot. Warriors for Kathryn aggressively raise funds to END AHC.

46 Days 9 Hours 16 Minutes
 left to give

[Join Team](#)

[Donate](#)

\$5,000
goal

\$4,245
raised

85%

Email Share Tweet Share

Like Be the first of your friends to like this.

ALTERNATING HEMIPLEGIA OF CHILDHOOD FOUNDATION INC

Through research, education and family support, we have ONE MISSION: END AHC

[See Nonprofit Page](#)

21 Oct Step Up to End AHC
[See Event Page](#)

0 Comments Sort by **Oldest**

Add a comment...

Facebook Comments Plugin

This is an existing team page. You can customize one for your family, set you own goals and tell your own story.

Joining us is easy. Go to <http://www.firstgiving.com/AHCF/step-up-to-end-ahc>

www.ahckids.org

www.ahckids.org

www.ahckids.org

***DOUBLE the FUN*draising** **3rd Annual Dine and Dance to End AHC a Huge Success**

On Friday, November 4th, in Jefferson Valley, New York, the **3rd Annual Dine and Dance to End AHC** event was a huge success.

The dance was **hosted by Renee and Paul Hodes** in honor of their daughter, Lisa. In addition to tasty food and great friends, wonderful raffle items kept everyone **coming back for more fun.** Paul said, “Okay Folks! We Dined we Danced I am happy to say we raised over \$13,000 and counting.”



The best part of the evening was when a few words were shared by the guest of honor, Lisa Hodes. She said,

“Thank you for coming to support me and my friends.
I appreciate it.

Remember the cause. ONE MISSION: END AHC.”

Great job Lisa! We couldn't have said it better.

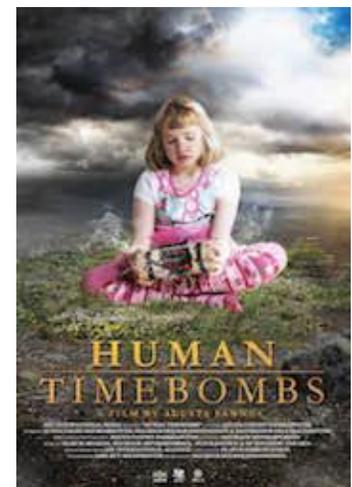
Thank you to everyone whom volunteered, donated and attended the 2016 Dine and Dance.

AHCF in ACTION **Grant awarded to support documentary**

In August 2015, the AHC documentary, **Human Timebombs** was completed by AHC International Media under the leadership of Siggie Johannesson and Augusta Fanney.

The documentary was created in order to **explain AHC to family, friends and doctors.** Now available in a variety of formats, the documentary has gone on to **win a number of accolades and acknowledgements all over the world.**

Until a cure for AHC is found, plans to further the reach of this documentary are moving forward in a variety of ways.



The AHC Foundation is pleased to support these efforts and **awarded a \$7,000 grant** in October to AHC International Media. AHCF President Lynn Eagan said, “We are honored to help increase awareness of AHC in the global community while continuing to support this wonderful documentary.”

Through research, education and family support, we have ONE MISSION: END AHC!

AHCF in ACTION

Learn how to engage potential donors!

Board member Bill Gerber is hosting a webinar titled, "**How to Create Exponential Engagement for Fundraising Efforts**," with speaker Andrea Boccard, a digital marketing specialist.

It will take place on Monday November 21st at 7:30 PM EST.

The webinar will help you engage potential donors for the **Step Up to END AHC** campaign as well as for future fundraisers.



Give Thanks.
Give Hope.
Give Generously.

Andrea Boccard is a **digital marketing expert** with over a decade of experience spanning many industries and marketing disciplines. Throughout her career she has spearheaded national and regional general marketing and **major social media campaigns**, comprehensive content marketing plans and viral marketing initiatives for major brands, has managed multi-million dollar paid search campaigns and advertising budgets, writes and ghost writes extensively on many topics, and is obsessed with all things inbound marketing, social media and SEO.

Everyone is invited to attend whether you already have a page or are planning to set one up.

Join us in reaching our campaign goal of \$150,00! To register, please go to the site:

<https://attendee.gotowebinar.com/register/366457708574650628>

INFO EXCHANGE

Share with your friends the easiest AHC fundraising ever

As you and your family enjoy the upcoming holiday shopping season, there is a super **easy way to help raise money for AHC research**. And, it won't cost you a dime.

When you **shop online, consider using AmazonSmile (smile.amazon.com)**. It is the exactly the same as Amazon.com, but the AmazonSmile Foundation will donate 0.5% of the price of eligible purchases to the AHC Foundation.

On your first visit to AmazonSmile (smile.amazon.com), you need to **select the organization of your choice. Please select the Alternating Hemiplegia of Childhood Foundation** to receive donations from eligible purchases before you begin shopping. They will remember your selection, and then every eligible purchase you make at smile.amazon.com will result in a donation.

It is that easy. Simply go to smile.amazone.com, select AHC Foundation, and make your purchases. **Amazon does the rest and you can be proud to have just helped raise money for AHC research.**

<h1>Thank You</h1>		<p>I just supported Alternating Hemiplegia of Childhood Foundation Inc at AmazonSmile. I shop. Amazon gives.</p> <p><small>When you shop at AmazonSmile, Amazon donates to...</small></p> <p><small>SMILE.AMAZON.COM</small></p>	<h1>Thank You</h1>
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Your Dollars Matter Most. Our foundation is 100% donor-supported. Help improve the quality of life of children with AHC today...with your donation.