



# One Mission: End AHC

# INSIDER'S EDGE

YOUR ALTERNATING HEMIPLEGIA OF CHILDHOOD FOUNDATION NEWSLETTER [www.ahckids.org](http://www.ahckids.org)

AUGUST 2014

2000 Town Center ■ Suite 1900 ■ Southfield, Michigan 48075

Donors Confident AHCF is Most Trusted Nonprofit

## Website Guides Families to AHCF

Family and friends working to end AHC are a passionate group. We are on a mission to help where we can and make the biggest impact possible. Knowing how to do this important work has gotten more complicated over the last few years as new foundations are created and ask for your support.

- The U.S. is home to over 81,000 foundations
- 28% of foundations focus on health related issues
- Out of \$303.1 billion of private giving in the US, 72% comes from individual donors Foundation Center, "Key Facts on U.S. Foundations 2013 edition."

So, how do you determine which foundation to support? The best advice is to simply do a little homework. To make this process quick and easy for donors, GuideStar.org was created.



GuideStar gathers and disseminates information about IRS-registered nonprofit organizations. The information is provided so you can take the information and make an educated decision about how to donate your money.

Compare the AHC Foundation's GuideStar profile to others and you will see that our foundation has a long history of being a financially responsible organization dedicated to funding AHC research.

Even greater than providing data to assist in your decision making process is that of being a great resource to those with AHC and their families.

As the following comment from GuideStar demonstrates, the AHC Foundation continues to do this extremely well.

***"My 22 year old son has AHC. This foundation has been supportive to us since he was properly diagnosed at age 6. They have helped through offering advice and assistance. The people are awesome!!! We ask everyone to donate to this worthy cause."***

With your support we will continue to be the premier AHC foundation with a long history of helping AHC families end AHC.

### Upcoming Events

8/29/14

ATP1A3 in Disease 3<sup>rd</sup> Annual Symposium takes place in The Netherlands

9/1/14

Labor Day

9/8/14

Executive Committee Meeting

9/21/14

9<sup>th</sup> Annual Chicago Walk

9/22/14

Board of Directors Meeting

10/19/14 - 10/26/14

Child Neurology Society Annual Meeting

11/7/14

Dine & Dance to End AHC

### Alternating Hemiplegia of Childhood Foundation

#### GuideStar Summary

✓	GuideStar Exchange	Committed to transparency
✓	Registered with IRS	<a href="#">Legitimacy information is available</a>
✓	Financial Data	<a href="#">Annual Revenue and Expense data reported</a>
✓	Forms 990	<a href="#">2013, 2012, and 2011 Forms 990 filed with the IRS</a>
✓	Mission Objectives	<a href="#">Mission Statement is available</a>
✓	Impact Summary	<a href="#">Impact Summary from the nonprofit is available</a>
★★★★★		<a href="#">Average rating from 31 Personal Reviews   Write a Review</a>

**Your Dollars Matter Most.** Our foundation is 100% donor-supported. Help improve the quality of life of children with AHC today... with your donation. It's safe. It's fast. It's online. Look for the button...

[Donate Now](#)

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

Golfers T-Off Over AHC Disease

# \$23,000 raised to help AHC kids

- Record breaking attendance at August golf outings
- Battle Creek, Michigan family hosts 2<sup>nd</sup> annual golf scramble
- Grandparents host 3<sup>rd</sup> annual golf outing in Illinois



**The 3<sup>rd</sup> Annual Sharo Golf Outing** was held on August 1st by Terry and Barb Sharo. They raised over \$18,000 for the AHCF in honor of their granddaughter, Kiley Andrasco.

Kelly Andrasco, Kiley's mom, had this to say about the day, "I told my parents I had such a good feeling driving home that night. It was very heartwarming

to see the friends they grew up with and lots of family coming out to support AHC! It was just wonderful!"



**The 2<sup>nd</sup> Annual AHCF Golf Scramble** was held on August 3<sup>rd</sup> by Rik and Stacy Greenwood in Battle Creek, MI in honor of their son, Rory, they raised over \$4,400.

The Greenwood's wanted to do their part as an AHC family and reinforce that these children are not tragedies. They deserve to be understood and supported like any other child.

In Stacy's own words, "The community has not only stood behind our son, but embraced him as well.

The entire day felt like one big celebration and we were able to raise money for research in the process.

Seeing this small event grow is inspiring. By all accounts it was considered a great success. We look forward to doing it again next year and continue fundraising!"



First place team enjoys their victory



## AHC Mini Fact

The disease was first recognized as a distinct syndrome in 1971 in an article written by Verret & Steele.

However, in 1969, an article called, "Acute Hemiplegia in Infancy and Childhood" was authored by doctors Aicardi, Amsili & Chevrie.

These five doctors are credited with beginning the study of AHC some 45 years ago.

Thank you to all of the golf participants and sponsors for supporting these families and the AHC Foundation.

### Stay Connected



### Words of Wisdom

"Too often we underestimate the power of a touch, a smile, a kind word, a listening ear, an honest compliment, or the smallest act of caring, all of which have the potential to turn a life around." Leo Buscaglia



*Community Strikes Out AHC*

## AHC patients honored at N.Y. baseball game

On Sunday August 10th, the Renegades sponsored an AHC awareness night and honored Lisa Hodes. Not only was AHC mentioned in their promotional media, but Lisa's story was shared on their Facebook page. During the game the foundation was mentioned over their PA system as well as showing our logo on the scoreboard between every inning.

Lisa was joined by her buddy, Rascal the mascot, and threw out the first pitch of the game. Parents, Paul & Renee, were supported by many friends and co-workers as well as Lisa's teacher. We also had a surprise visit from another AHC family. The Caruso's, Louie, Adele and Louis (29) travelled 2 1/2 hours to join us! It was a great night for AHC and a lot of fun was had by all!

All this was made possible by Corinne Adams, Director of Marketing and Communications. We've worked very closely with Corinne over the last 4 years during our fundraisers and thank her for her support.



### VOLUNTEER

Your help is needed to end AHC.

The skills you have will help the foundation achieve our goal of ending AHC.

The amount of time you do have will make a difference in the lives of people with AHC.

Volunteering is as simple as saying, "I want to help!"

To volunteer email Lynn Egan at [lynn@ahckids.org](mailto:lynn@ahckids.org)

*Please give today.  
It's safe.  
It's fast. It's online.*

**Donate Now**

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

*AHCF Donors Have it All*

## 5 traits help raise major money

**Volunteers** have made the first 60 days of our new fiscal year a huge success. Several families built on the excitement from the Minneapolis AHCF Family Meeting and held fundraisers in the last two months. They included:

- BeneFEST (Massachusetts)
- Flower Power Fundraiser (National)
- Golf Outings (Michigan and Illinois)
- Macy's Shop for a Cause (National)
- Renegade's Baseball Games (New York)



While each of these host families is exceptional; so too are you. *The NonProfit Times* came up with some characteristics of major donors. Doesn't each of these traits sound just like you?

- Have strong values and deep beliefs
- Believe in people
- Desire to solve problems
- Respect knowledge and experience
- View giving as an investment



Now that you know you fit in with the AHC Foundation volunteers, join us during the next 60 days to raise even more money for **our mission to end AHC**.

### For More Information on How to Help

Contact:

Development Chair Mollie Erpenbeck at [mollie@ahckids.org](mailto:mollie@ahckids.org)

or

Fundraising Events Chair Vicky Platt at [vicky@ahckids.org](mailto:vicky@ahckids.org)

*AHCF Medical Advisory Board in Action*

## Access AHC specialists from anywhere

Everyone knows how difficult it is to get an appointment with a great doctor. Now imagine trying to get multiple doctors who specialize in epilepsy, dystonia, neurology, ahc, genetics, and pediatrics together in one place. The AHCF Medical Advisory Board did just that in Minneapolis, Minnesota this past June.

One exciting highlight from the meeting was the election of Dr. Matt Sweney to Chair the AHCF Medical Advisory Board (MAB). He has worked with AHC patients for many and is currently appointed as an assistant professor of pediatric neurology with special emphasis on epilepsy at the University of Utah.



With the assistance of the entire Medical Advisory Board, Dr. Sweney will actively engage in activities that promote education, awareness, and other activities that benefit the AHC Foundation and the entire community of AHC families. Welcome Matt!

*AHC Parents Care*

## Tips for living with AHC

Living with AHC can be so overwhelming at times that parents eliminate anything that distract from the direct care of their AHC child. Below are several tips to help remind parents to care for themselves while caring for someone with AHC.

- **Participate in the AHC community.** By joining organizations like the AHCF you can find support and information that helps deal with the challenges of AHC.
- **Exercise.** Maintaining your own health is a very important step in taking care of a loved one with any major health issue. Exercise helps reduce stress and if you get outside to do it, even better.
- **Keep good records.** There will be many changes in the life of a patient with AHC. Recording changes in medication, episodes, behavior, and quality of life issues will help during doctor visits and over the long-term medical history of your child.
- **Build a team of supporters** for your entire family. Family and friends often want to help, but just don't know how. Learn to be comfortable asking for help and allow your circle of supporters to be there for you.
- **Find time for yourself.** You may have to schedule it way in advance, but finding some time away from the stresses of a rare disease is crucial to maintaining your own health. You may only be able to be away for an hour or two at the beginning, but increasing the amount of time you can safely have some "free" time will pay off in the long run.

If the above five tips seem overwhelming, simply pick one that seems possible and give it a go. Remember, Dr. Sweney and the MAB are available to help. If you do have any questions, email Sharon Ciccodicola at [Sharon@ahckids.org](mailto:Sharon@ahckids.org), and she can help connect you with our excellent team of advisors.

**Donors:** Your gifts fund 100% of our effort to help children with AHC. It is our privilege to coordinate the support and services you find critical to improving their quality of life. Thank you for your steady support. Everything we achieve depends on you.

*Opportunities in Progress*

### Fun Ways to Help

(click on logos for more info)

#### Fall Flower Sale

Buy your fall bulbs and help the AHCF at the same time.

For every purchase made on this site, Flower Power Fundraising will give 50% back to Alternating Hemiplegia of Childhood Foundation.



When shopping on Amazon switch to **Amazon Smile** and 0.5% of your purchase can come to the AHCF.



Be sure to share these great sites with your friends and family to get them in on the fun as well.

Thank you for your help!



If you have any questions or comments about this newsletter, please contact Vicky Platt at [vicky@ahckids.org](mailto:vicky@ahckids.org)

[Donate Now](#)

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