



# One Mission: End AHC! INSIDER'S EDGE

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

JANUARY 2015

2000 Town Center ■ Suite 1900 ■ Southfield, Michigan 48075

*End-Of-Year Campaign is Wildly Successful*

## AHC community gets one step closer to possible treatments with your help!



*Thank you for being awesome.*

How beautiful a day can be, when kindness touches it. George Elliston

**Thanks to you, we were able to fully fund phase three of the Northwestern University and Vanderbilt University research grant.**

It's moments like this, when the AHC community comes together to take action that proves our power to make a huge difference in the lives of people suffering from AHC. With every dollar you give, you are helping us give children with AHC a chance to find viable treatment options.

Our 2014 end-of-the-year goal was to raise at least \$140,000 to finish funding the \$280,000 grant we began funding in September 2014. **Because of you, we raised over 134% of that goal.**

Thank you for funding phase three and getting this year started off with a bang!

**You are awesome!**

**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)

*Board of Directors News*

## Marszalek Elected Secretary

On January 19<sup>th</sup>, Josh Marszalek was elected by the Board of Directors to the office of Secretary for a three year term.

President, Lynn Egan commented, "Josh brings a wonderful perspective to the board as well as many talents. We are fortunate to benefit from his addition to the Executive Committee."

Please join us in thanking Josh for his willingness to serve the foundation in this added capacity.

*AHCF Contributes to AHC Documentary*

## Living with AHC documentary nearing completion

The foundation recently donated \$3,000 towards the making of a documentary on AHC. The mission of the project is to raise awareness and to locate the undiagnosed AHC patients so that they can receive best possible care. The mission is also to expedite research and find a cure for AHC.

AHCF has been a contributing partner from the beginning of the project and the executive board helped the documentary crew immensely this summer during the AHC family meeting in Minneapolis MN. Also many of the AHCF families have contributed to the film by being interviewed and sending videos of their children.

For more information on the AHC Documentary, go to <http://ahcdocumentary.com/>

*AHCF Celebrates Gene Discovery*

## 3<sup>rd</sup> Annual International AHC Day

On January 18<sup>th</sup> we celebrated International AHC Day by announcing the funding of our Northwestern and Vanderbilt University research grant.

On this day three years ago, the ATP1A3 gene mutations that are responsible for causing AHC in approximately 80% of patients were discovered.

Each year, we celebrate this major accomplishment and look forward to new projects that will help achieve our mission of Ending AHC!





*Tapping a New Source of Funds for AHC Research*

## Making your donations double

**Many companies support employee philanthropy by offering matching gift programs. By taking advantage of your corporate matching gift program, you can maximize the value of your gift to the foundation at no additional cost.**

Corporate matching, as it is known, was begun back in 1954 by General Electric Company. Through its Corporate Alumni Program, the GE Foundation began making matching gifts to colleges and universities, eventually expanding to other areas of charitable giving.

Today, countless companies such as Johnson & Johnson, Microsoft, and Union Pacific Railroad match employee contributions, sometimes at a ratio as high as 4:1. Naturally, some companies have overall and/or per-employee limits to their matching programs, but the leveraging power of these programs is nonetheless formidable. A 2012 survey by the Committee Encouraging Corporate Philanthropy found that 83 percent of surveyed companies offered at least one matching gift program.

Learning if your donation can be matched has been made even easier through the creation of several websites.

## Matching Gifts Made Easy

Raise More Money from Matching Gift Programs

### **STEP ONE: Check to see if your company matches charitable donations**

This can be easy to determine. You can always contact your human resources department and ask if a program exists. Or, you can use a web based tool. EasterSeals.com provides a list of companies with matching gift programs. Or, you can use a search tool created by Stanford University to see if your employer matches charitable contributions. Simply go to: <http://www.matchinggifts.com/stanford/> and type in your company name.

A yes or no answer pops up and you'll have an idea on how to proceed.

### **STEP TWO: Complete the paperwork**

If a company offers a matching program, paperwork will be involved. Usually, it involves filling out your general contact information and indicating which charitable organization is to receive the matching funds.

We're happy to assist everyone with completing the paperwork requirements and making the process as simple as possible. If you need assistance, please contact [Vicky@ahckids.org](mailto:Vicky@ahckids.org) or [Sharon@ahckids.org](mailto:Sharon@ahckids.org).

### **STEP THREE: Watch your donation double**

Once the foundation receives the corporate matching funds, we'll notify you that all of your hard work paid off and that you successfully doubled your donation to the foundation.

### **STEP FOUR: Receive our thanks**

We're fortunate to work for such generous companies and they are most deserving of our appreciation, gratitude and thanks. And, so too are you! Thank you for helping to find a way to End AHC!

*Five Part Series on Getting Diagnosed with AHC by Doug Morris*

## Part one: What is wrong with my child?

I clearly remember leaving the doctor's office in January 1994 when the doctor at the Chicago Children's Memorial Hospital told my wife, Chris, and me that our first child, Haley, just 2 ½ years old, had AHC. The doctor did not share much about what implications that held for Hayes' future. The comment came in the briefness and simplicity of "it's a cold, she'll get over it".

Then a few days later, Chris visited Loyola University Medical Center and slipped in the doctors' only library to research AHC. She summarized for me what she learned as her voice tapered off to a soft sob, "I don't like what I saw." I then realized why the doctor chose not to expand on his diagnosis to us a few days earlier.

Looking back now the diagnosis of AHC was accurate but back then; we did not embrace the diagnosis or even accept it. Twice actually as our second child, Caroline was born six weeks after Haley's evaluation and diagnosed within 18 months.

That was over twenty years ago. Back then, not much was really known, understood, or even documented about AHC; only in medical lingo and enough to scare us initially. The infrastructure of information and networking that AHCF provides today was not available for us to tap into to move forward if life with our family.

*This is the story of how one family went through various phases of learning about their children's AHC diagnosis to thriving in life.*

*Many of you may relate to their experience while others of you may see hope for all our AHC community.*

*By the end of the series we hope you all will see that our kids can lead a fulfilling life as we all work towards ultimately finding a cure.*

### PHASE 1 DENIAL

**Initially we went through denial.** As parents we searched for every piece of information we could find on AHC and talked to various doctors to understand the symptoms better. We wanted to be able to predict and provide a better future for Haley and Caroline.

Doing some comparing and contrasting with what we read to actual observations of the girls, we questioned whether they even had AHC. Classic denial tactics adopted by me. Because AHC was limited by the 'of Childhood' label, naively I thought they would grow out of the symptoms. You know, one day each would pop out of bed as a teenager, take their college entrance exams, and enroll in college like a fairy book story. We hoped for anything positive.

One of the cool things about the girls, they never went through denial. They never had to as both recognized they were different. They recognized their classmates, cousins, co-workers, teachers, parents, and everyone was different. And because they knew everyone was the same in being different, they fit in.

Be sure to join us next month as Doug talks about anger and how it played a role in dealing with the diagnosis of AHC for his family.



**DENIAL**

**ANGER**

**BARGAINING**

**DEPRESSION**

**ACCEPTANCE**

**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.

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