



One Mission: End AHC!



YOUR ALTERNATING HEMIPLEGIA OF CHILDHOOD FOUNDATION NEWSLETTER

January/February 2016

2000 Town Center ■ Suite 1900 ■ Southfield, Michigan 48075

AHCF in Action

Message from President Lynn Egan

The AHC Foundation is supported by dedicated and generous people who believe a cure for AHC is within reach. The AHCF's mission is to end AHC and, in the meantime, support those affected with AHC and their families.

Through the amazing efforts of our supporters and those working on behalf of the foundation, the last four months have seen unprecedented success in the AHC community.

The struggles and day-to-day burdens of living with this life-changing disorder are overwhelming. The fact that so many of you step up to support the AHC community is inspiring and impressive. Please take a moment to recognize your contributions to our mission and accept the thanks of a grateful president and foundation. Your generosity is greatly appreciated.



DOUBLE the FUNdraising

Generous grant received by AHCF on International AHC Day



International AHC Day took place on January 18th with exciting information coming from the AHC Foundation!

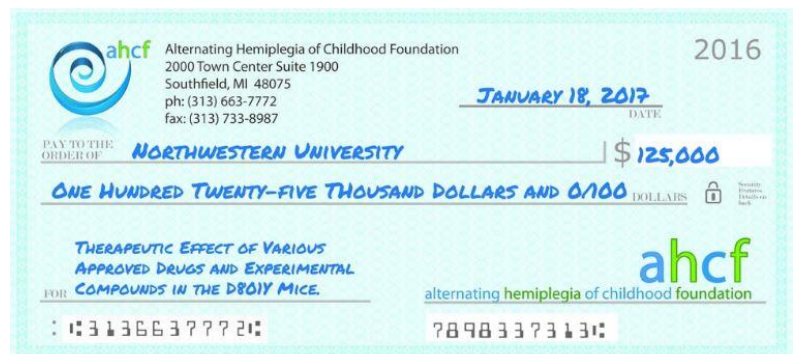
The **Jake and Nina Kamin Foundation** awarded the AHC Foundation another \$125,000.00 for critical research in helping us find a treatment for our children!

You may recall, the Jake and Nina Kamin Foundation awarded us \$125,000.00 back in March 2016, so **this marks the second grant awarded to the AHCF!**

These latest funds will be applied to the **ongoing research project** under the direction of Dr. Al George at Northwestern University Feinberg School of Medicine.

There are no words to **express our gratitude** to the Jake and Nina Kamin Foundation for their continued generosity in support of our children.

Please **continue to stay tuned**, as we will have even more exciting news to share in the coming months. This is just the beginning...cheers to 2017!



Your Dollars Matter Most. Our foundation is 100% donor-supported. Help improve the quality of life of children with AHC today...with your donation.

www.ahckids.org

PATH to a CURE **AHC campaign success**

Last month, 2017 started off on a high note with amazing news coming from our wonderful and engaged families, incredible doctors who are focused on finding a treatment, and of course, our generous donors who make it all possible.

We are thrilled to announce that through our Step Up Campaign, as well as two independent fundraisers, the AHC Foundation has received over \$125,000.00 to continue funding our pivotal research.

We are **so thankful to the families, and their friends**, who came together to make this happen for our AHC children. It truly is the greatest gift. With these funds, the AHCF will continue to fund the **2nd half of the research at Vanderbilt and Northwestern Universities**.

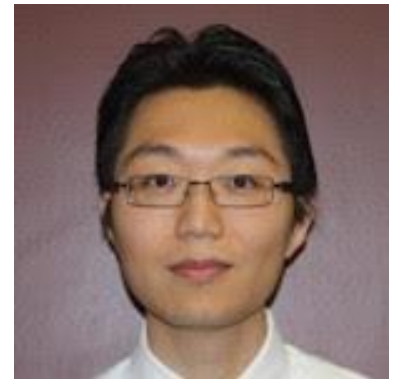
Be part of the movement in 2017 and plan on joining our 2017 Step Up to END AHC campaign!

All funds raised in this campaign will go directly to research that will not only benefit your child but the entire AHC community!

AHC Community News **AHC doctor receives educational honor**

AHCF Medical Advisory Board Member **Dr. Sho Yano** has been accepted into the **NIH Fellowship Program**, where he will study neuro genetics. The three year program focuses on clinical training for the first 18 months. After which he can pick a research project to concentrate on for the next 18 months.

During his fellowship he will remain engaged with the AHC community and continue on the **AHCF Medical Advisory Board. Congrats Dr. Yano!**



We hope that your Valentine's Day was filled with love, understanding, and contentment as you journey through life with those you hold dear.

The AHCF also extends our sincere thanks to Heather Gates for coordinating the Valentine's Day card exchange. It is a great way for our AHC friends to stay connected and celebrate our community.

Thanks Heather

AHC Community News

AHC family from Philly makes the news this month

On February 15th, a terrific story was covered by Fox News about **an amazing AHC family from Philadelphia: Emilia and Meredith Schalick.**

The story talks about how despite the fact that Emilia has AHC, **she triumphs** over the limitations of her condition in amazing ways.

“Emilia Schalick is a bubbly, fun loving, affectionate 5-year-old girl with so much personality she lights up any room. Spend a few minutes with her and she’ll melt your heart and you’re a fan forever.” **Thanks for sharing your story with everyone!**

To read the full story, simply go to:

<http://www.fox29.com/news/235999069-story>



AHC Community News

AHC fundraiser makes news in Indianapolis, Indiana



On February 1st, an article was published in the Connersville News Examiner. It **featured Kathryn Faith Marszalek**, daughter of Josh and Dr. Laura Marszalek. Josh is owner of Rural Valley Architecture and Design and Laura is a dentist at the Christie Family Dentistry.

In addition to **raising awareness about AHC**, the article also mentioned that the St. Gabriel Parish was hosting a fundraiser on Saturday, February 4th at Expo Hall.

Carrie Pfeiffer and Elizabeth Hauger organized the fundraiser to raise money for AHC research. The **effort at St. Gabriel grew from a simple fundraiser to a poker tournament and bingo.** It was a huge success. **Thank you to everyone who worked so hard on this wonderful event.**



Little Kathryn Marszalek suffers from the rare Alternating Hemiplegia of Childhood disease which at times causes her muscles to not work. The St. Gabriel Parish is hosting a fundraiser Saturday to fund research to find an answer to the disease. Contributed

AHC INFO EXCHANGE

Just in-German researchers find 2nd AHC gene mutation

In the February 2017 issue of *The Journal of Pediatrics*, German researchers conclude that mutations in the **adenylate cyclase 5 (ADCY5) gene** have been identified as an additional cause of AHC and expand the clinical spectrum of ADCY5 mutations to include Alternating Hemiplegia of Childhood.

This is indeed big news. Please watch for more news about this article as AHC experts help us understand what this means for our community.

DOUBLE the FUNdraising Support AHC research and have fun watching college hoops

To raise money, we are conducting a **HoopsMania fundraiser**. For \$10 you get music downloads at www.charitystudio.com and an exciting, complimentary HoopsMania sweepstakes game card! Follow the links below to make your contribution and enter the sweepstakes. *You have the chance to win up to \$1,000 in prize money!*

Read below for more information about the HoopsMania sweepstakes, and the CharityStudio music downloads.

HoopsMania is an exciting and engaging sweepstakes where participants can win prize money during the college national championship tournament. Your sweepstakes game card contains a set of **8 basketball teams, one of each seed from 1 to 8**.

Winning game cards are determined based on the total points scored by the teams assigned to it during the tournament. The 45 highest scoring game cards win prize money! The 4 lowest scoring game cards also win. Find more detailed information in the official rules. <https://www.charitymania.com/give/1707a>

Thank you to everyone supporting this event and having a bit of fun.



RARE DISEASE DAY 2017
28 FEBRUARY

February 28th marks the **10th Annual Rare Disease Day**. It is a day when the world comes together to bring awareness to the 7,000 Rare Diseases that are collectively impacting 350,000,000 people worldwide.

The main objective of Rare Disease Day is to raise awareness amongst the general public and decision-makers about rare diseases and their impact on patients' lives. The campaign targets primarily the general public and also seeks to **raise awareness amongst policy makers, public authorities, industry representatives, researchers, health professionals** and anyone who has a genuine interest in rare diseases.

On rarediseaseday.org you can find information about the thousands of events happening around the world on the last day of February to build awareness for people living with a rare disease and their families.

Share your photos, videos and your experiences! Be part of Rare Disease Day by informing others and raising awareness—sending a message of solidarity and community.

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

AHC INFO EXCHANGE

Parents - studies prove your stress is real

Two recently published studies confirm that parents with children diagnosed with neurodevelopmental disorders and disabilities are under higher levels of stress than other parents.

On February 3rd, the journal *Child: Care Health and Development*, published an article titled, "Time Use of Parents Raising Children with Severe or Profound Intellectual and Multiple Disabilities (PIMD)."



The aim of this study was to examine the total time use of mothers and fathers raising children with PIMD and compare it with the time use of parents of typically developing children.

This study showed that the parents of children with PIMD have to **spend a significant amount of time on care tasks and have on average 1.5 h less free time per day** than parents of typically developing children.

On February 8th, researchers published an article in *Community Mental Health Journal* titled, "Association between Parenting Stress and Functional Impairment among Children Diagnosed with Neurodevelopmental Disorders."

The study of 150 parents of children diagnosed with neurodevelopment disorders (NDD) found that **risk of stress to parents increased 5.5 times** with functionally impaired children with NDD. Further the risk of stress increased 4.6 times when these parents reported having their own disorder/disease.

The study concludes that health care providers should initiate early intervention strategies such as peer support and education that can prevent parenting stress and reduce the risk of potential incidence of depression.

This is a striking difference, because leisure time can substantially contribute to well-being. Therefore, it is important not only to consider a child with PIMD's support needs but also to **identify what parents need to continue their children's daily care and supervision.**

Child: care, health and development

Together, these studies **give credence to the challenges you face** every day caring for children with disabilities. They support the fact that **your life is more difficult** and that your free time is significantly more limited. While they may not tell you something you don't already know; they can help others understand your life a bit better than they did before.

**Thank
You**

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