One Mission: End AHC!

YOUR ALTERNATING HEMIPLEGIA OF CHILDHOOD FOUNDATION NEWSLETTER February/March 2016

2000 Town Center ■ Suite 1900 ■ Southfield, Michigan 48075

The AHC Foundation Receives a Donation from the Jake and Nina Kamin Foundation for

$125,000

On Rare Disease Day, February 29, 2016, the Alternating Hemiplegia of Childhood Foundation received a donation from the Jake and Nina Kamin Foundation in the amount of $125,000.

The Jake and Nina Kamin Foundation is a tax exempt organization located in Sugar Land, Texas. This organization has been in operation for 29 years. In commenting on the donation, foundation president, **Susan Smith, said, "I am glad to help in this endeavor and I am very optimistic** that the research will find better drugs that will help the AHC kids."

The AHCF hopes to raise $550,000 to fund the next round of research projects and this amazing donation will get the foundation closer to that goal.

Tobe Cohen, father of AHC Hero Asher, commented, **"It is so rewarding to see the caring and generosity** that I saw in my Uncle and Aunt in their lifetime, continue on through the Jake and Nina Kamin Foundation. The foundation's gift will enable critical research to continue in the search for a treatment and cure for Asher and all the kids who battle AHC every day."

The entire AHC Community is incredibly thankful to the Jake and Nina Kamin Foundation for their support, kindness, and generosity!!! With their help, we are closer to fulfilling our **One Mission: End AHC!!!**

Let's Continue to Make Our Good Luck through Hard Work
Check out These Golden Fundraising Ideas

Do-it-yourself fundraising ideas come in a variety of sizes and shapes. There are even ideas for those of us with the busiest of schedules.

Some contain detailed instructions while others are just brief summaries of past fundraising activities of other organizations. Hopefully you can adapt some of them to have some fun and raise funds for AHC research.

Check out this site and maybe... just maybe, you'll find one that works for your entire family.
http://www.fundraising-ideas.org/DIY/

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

Carissa Cascio, Ph.D.

PATH TO A CURE

Vanderbilt University Study Links Sensory Difficulties to Serotonin System

In December 2014, an article was published in *Molecular Brain* which discussed a relationship between sensory dysfunction and mutations in the ATP1A2 and ATP1A3 genes. AHC was one of the neuromuscular conditions covered in the article along with rapid-onset Dystonia Parkinsonism and familial hemiplegic migraine. http://molecularbrain.biomedcentral.com/articles/10.1186/s13041-014-0089-

Fast forward one year to a new study published in *Research in Autism Spectrum Disorders*. Researchers at Vanderbilt University sought to **shed light upon sensory dysfunction and certain behaviors** of some children with autism spectrum disorder (ASD).

Carissa Cascio, Ph.D., assistant professor of psychiatry and autism researcher at the Vanderbilt Kennedy Center said, “This study provides a first hint that there is a relationship between sensory difficulties, specifically tactile defensiveness, and the serotonin system in children with ASD.”

“While the distinct mechanisms underlying hyper- and hypo responsiveness in ASD are currently unclear, serotonin is a potential modulator of hyper responsiveness, and that provides a potentially fertile ground for future research, Cascio said.”

Sensory dysfunction is broadly classified as either hyper- or hypo responsiveness — that is, unusually strong reactions to touch, sound or visual stimuli, or diminished or absent reactions to stimuli.

For more information on this research, go to:
http://news.vanderbilt.edu/2016/01/autism-study-links-sensory-difficulties-serotonin-system/

PATH TO A CURE

CRISPR-Cas9 and the Value of Cutting-Edge Gene-Editing Technology

On February 12, 2016, an article appeared in *Scientific American* titled, “Patients Unsure about the Value of Cutting-Edge Gene-Editing Technology.” **The discussion focused on a gathering of patient advocacy organizations and their opinions on gene editing.**

“Patients and their families are wrestling with these questions because new, powerful gene-editing techniques such as CRISPR–Cas9 allow researchers to make targeted changes in DNA much more easily than ever before. Yet any tinkering with the germ line remains particularly controversial because such alterations would be passed down to future generations so any mistakes could inadvertently be introduced into a family’s gene pool.”

To learn more about CRISPR-Cas9 and read the entire article go to:
http://www.scientificamerican.com/article/patients-unsure-about-the-value-of-cutting-edge-gene-editing-technology/

AHCF in ACTION

February Rare Disease Month Celebration

AHCF Funds $250,000 Grant to Vanderbilt University

On February 9th, we hope you saw our press release in PR Newswire. In honor of Rare Disease Month, we were pleased to announce the funding of the second half of our $250,000 grant. Final payment was made for the research project, "Molecular Physiology and Pharmacology of ATP1A3 Mutations in AHC."

AHCF Funds $250,000 Grant to Vanderbilt University

This project is being conducted at Vanderbilt University School of Medicine under the direction of Dr. Kevin Ess and at Northwestern University Feinberg School of Medicine, Chicago, under the direction of Dr. Alfred George.

The second portion of the project was funded with the support of the Alternating Hemiplegia of Childhood Foundation (AHCF) in the amount of $120,000 and the **Alternating Hemiplegia of Childhood Ireland (AHCI)** in the amount of $5,000.

Dr. Ess stated, "The very generous donation by the AHCF and AHCI will enable us to determine mechanisms used by specific ATP1A3 mutations that cause AHC. Our experiential approach was designed to most quickly identify disease pathways as well as potential therapeutics that can help those afflicted with AHC."

Fully funding a project of this size is only possible through the incredible efforts of our AHC community. Thank you to AHCI and everyone around the world working with us to END AHC!!!

Registration for the family meeting is now open.

We are also interested in sponsors and possibly vendors that would help pay for the conference and in return be able to demonstrate their product like special needs strollers, educational toys etc... Do you have any suggestions for who might be interested in doing this? Would you be willing to check them out?

Lastly, we would really like to celebrate the kids and for this we need your help. We want to highlight things they love to do, their successes, and what makes them happy. If you would like to share any of your videos or photos which tell a little bit about them, please let us know by the end of April.

Please don't hesitate to register, comment, or share you memories.
Contact Lynn at lynn@ahckids.org or 650-796-1910 or Sharon at sharon@ahckids.org or 313-663-7772.

DOUBLE the FUNdraising
Hee-Hawing for Hope
19 Years and Going Strong

Cindy and Dave Ryan have put on a fundraiser for AHC research for around 19 years. Their son, Michael, has AHC and, though the events wear him, he still loves to visit with the people he knows are helping him out each year.

This was the 6th year for the Hee-Haw variety show, and the 19th year for the fundraiser overall that had featured golf outings and get-togethers of all varieties. Throughout its tenure, Cindy said, "the group has raised over $200,000 for the disease." This year the group hopes to raise over $10,000.

We thank Cindy and Dave for their unwavering support for close to two decades. Their dedication to the cause in honor of their son, Michael, is inspiring and greatly appreciated.

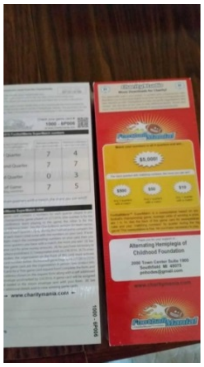
Checkout an article about their work at: http://myjournalcourier.com/news/92158/hee-hawing-for-hope

DOUBLE the FUNdraising
IMCU Gives Back
Program Update

The Indiana Members Credit Union (IMCU) Gives Back program was created to celebrate their 60th anniversary by giving back to the communities they serve. The AHCF entered the contest and was fortunate to lead in online voting because of the amazing support of our AHC community.

Unfortunately, we were notified during voting that we were removed from the contest because we did not meet one of the requirements for inclusion in the contest. Since the oversight was noticed during the voting period, IMCU graciously recognized the great works of our community and made a contribution to the 2016 AHCF Family Meeting.

While we weren't able to finish the contents, we certainly appreciate the family that thought to nominate us. We also appreciate the level of support we received through voting, sharing, and beating the bushes during the contest. **Finally, we are grateful to the IMCU for supporting our community and making a donation that will help our tremendous kids at the family meeting! Thank you all!!!**



DOUBLE the FUNdraising
Charity Mania – Another Super Success

Thanks to everyone who helped sell Charity Mania Super Bowl tickets this year, we raised over $1,900 this year. Not only was it fun to watch the scores for each quarter of the Super Bowl, but it was great to help the AHC Community at the same time!

Special thanks go to **Paul Hodes** for coordinating the event!

ADVOCATES FOR AHC

Supporting the AHC Community in Different Ways

A big **THANK YOU** goes out to **Heather Gates** for organizing the **Valentine's Day** card exchange this year. Heather gathered the names and address of kids who then mailed a Valentine's Day message to their AHC friends. It's a great way to connect with our community. **Thanks again Heather!**

ADVOCATES FOR AHC

Thank you AHC Ireland

We wish to thank the families with the **AHC Ireland (AHCI)** family foundation for their generous $5,000 donation to the grant currently underway at Vanderbilt and Northwestern Universities.

Together, the AHC Community will find a way to make our one goal a reality: End AHC!

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ADVOCATES FOR AHC

International AHC Research Consortium Issues Public Communication N. 03-2016 Activity Plan JANUARY –JUNE 2016

In October 2014, the IAHCRC International Consortium was created as a coordinated network of clinical centers and basic research labs, to carry out large-scale studies based on common collaboration rules and on common elements, formats and methods for the data and information sharing.

The Consortium has planned many activities to carry out in this first semester of 2016 with the support of the main patient associations for AHC. Among such initiatives:

- The development of the IAHCRC-Cloud Service, for the on-line data collection and sharing for the collaborative studies of the Consortium. The service is developed by the IEMEST Research Institute, an IAHCRC member Center.
- We are also creating the on-line IAHCRC Forum, to facilitate the participation to the discussions about the main topics identified by the Standardization Workgroups and the contribution to the related activities. The Forum will be accessible by all the IAHCRC members and, upon invitation, also by external researchers, patients and any other stakeholders.
- Finally, we have scheduled the annual General Assembly in June, as the highest expression of participation and of collaboration, for the harmonic and positive contribution of all the IAHCRC members to the development of the research on AHC and all the ATP1A3 diseases.

You can read the full text of the notice on IAHCRC's Facebook post from March 10th.

You can find more information about the IAHCRC at their website: **http://www.iahcrc.net**

INFO EXCHANGE

Tax Strategies for Parents of Kids with Special Needs

Check out the website from TACA: Talk about Curing Autism.

They have a great article on tax strategies for parents of kids with special needs.

Make sure you check out this article if you traveled to the symposium last year or are planning to attend the upcoming family meeting. There are special provisions for deducting expenses incurred to attend medical and scientific meetings.

The information in this article is educational in nature and is not to be considered tax advice. Please contact a qualified tax professional to discuss how these concepts may or may not apply to your personal situation.

You can find the article at this link:

http://www.tacanow.org/family-resources/tax-strategies-for-parents-of-kids-with-special-needs/

INFO EXCHANGE

Certain Medicaid Waiver Payments May Be Excludable From Income

On January 3, 2014, the Internal Revenue Service issued Notice 2014-7, which provides guidance on the federal income tax treatment of certain payments to individual care providers for **the care of eligible individuals under a state Medicaid Home and Community-Based Services waiver** program described in section 1915(c) of the Social Security Act (Medicaid Waiver payments).

Section 1915(c) enables individuals who otherwise would require care in a hospital, nursing facility, or intermediate care facility to receive care in the individual care provider's home.

The notice provides that the Service will treat these Medicaid waiver payments as difficulty of care payments excludable from gross income under § 131 of the Internal Revenue Code.

Individual care providers who receive Medicaid waiver payments for the care of eligible individuals in their homes and payers of Medicaid waiver payments have raised several questions not addressed in Notice 2014-7.

Questions and answers that clarify the notice and provide guidance on the information reporting requirements, and the employment tax requirements for Medicaid waiver payments are available on the IRS website.

Remember to contact a qualified tax professional to discuss how these concepts may or may not apply to your personal situation.

Follow this link to read the article:
https://www.irs.gov/Individuals/Certain-Medicaid-Waiver-Payments-May-Be-Excludable-From-Income