



*International Collaboration Brings AHC Experts Together*

## AHC community is thankful for new study



To present the results of a genetic and clinical study of the largest AHC cohort ever reported requires the collaboration of a dedicated and hardworking group.

This study included 187 AHC patients enrolled since 1997 in the US AHC Foundation (AHCF) registry and biobank at the University of Utah. We wish to recognize everyone who helped on this project and acknowledge their dedication to our AHC community

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Eva Andermann  
Mary E. Brunkow  
Suzanne D. DeBrosse  
Chad Huff  
Richard J. Leventer  
Louis J. Ptáček  
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Francis Renault  
Peter Uldall  
Kenneth Silver

**We wish to thank all of the clinicians, researchers, scientists, and doctors for their work on this study. We look forward to learning more about your current projects and wish you well on your future endeavors.**



*AHC Community Clinician and Researcher Changes Institutions*

### Dr. Kathryn Swoboda on the move

Kathryn J. Swoboda is the new Katherine B. Sims M.D. Endowed Chair in Neurogenetics and Director of the Neurogenetics Program at Massachusetts General Hospital and Harvard Medical School.

Dr. Swoboda's research and clinical activities are dedicated to the diagnosis and treatment of neurogenetic disorders, especially neuromuscular diseases and movement disorders with childhood-onset.

Dr. Swoboda has been a long-standing advocate for AHC patients and their families. For over two decades, she has helped the AHC community by attending AHCF Family Meetings, conducting AHC research, holding clinics with AHC patients, speaking at conferences, and meeting with members of the F.D.A.

Dr. Swoboda looks forward to continuing her work with the AHC community in her new position in Boston.

**We wish Dr. Swoboda much success in her new position at Harvard Medical School!**

*AHC Community is Expanding*

## Leaders in AHC research circle the globe

Not so long ago, finding researchers familiar with AHC was extremely challenging. With the recent advancements in technology, it is now clear that AHC work is being done at highly prestigious and reputable institutions around the world.



**Below is a list of institutions where the authors of the PLOS ONE article are currently affiliated.**

- University of Utah, Salt Lake City, **Utah, USA**
- Institute for Systems Biology, Seattle, **Washington, USA**
- Montreal Neurologic Institute and Hospital, McGill University, **Montreal Quebec, Canada**
- Connecticut Children's Medical Center and University of Connecticut School of Medicine, Hartford, **Connecticut, USA**
- University of Rochester School of Medicine, Rochester, **New York, USA**
- Diablo Valley Child Neurology, an affiliate of Stanford Health Alliance, Pleasant Hill, **California, USA**
- Children's Hospital of Michigan, Wayne State University, Detroit, **Michigan, USA**
- Palo Alto Medical Foundation Redwood City Clinic, Redwood City, California, USA
- Children's Hospital Colorado, University of Colorado Hospital, Aurora, **Colorado, USA**
- Case Western Reserve University and University Hospitals Case Medical Center, Cleveland, **Ohio, USA**
- Pacific Northwest Diabetes Research Institute, Seattle, Washington, USA
- University of California San Diego, San Diego, California, USA
- The University of Texas M.D. Anderson Cancer Center, Houston, **Texas, USA**
- University College Dublin School of Medicine and Medical Science, **Dublin, Ireland**
- Murdoch Children's Research Institute, University of **Melbourne**
- The Royal Children's Hospital Melbourne, **Parkville Victoria, Australia**
- College of Medicine Jacksonville, University of Florida, Jacksonville, **Florida, USA**
- University of Pittsburgh School of Medicine, Pittsburgh, **Pennsylvania, USA**
- Stevens Henager College, Salt Lake City, Utah, USA
- University of California San Francisco, San Francisco, California, USA
- University Of Virginia UVA health system, Charlottesville, **Virginia, USA**
- Hopital Armand Trousseau APHP, **Paris, France**
- University of Southern California, Los Angeles, California, USA
- Swedish Neuroscience Institute, Swedish Medical Center, Seattle, Washington, USA
- Juliane Marie Centre, Rigshospitalet, University of Copenhagen, **Copenhagen, Denmark**
- Children's Hospital Orange County, University of California, Orange, California, USA
- Massachusetts General Hospital, Boston, **Massachusetts, USA**
- University of Chicago and Comer Children's Hospital, Chicago, **Illinois, USA**

**Thank you to all of the institutions from around the world which support AHC research and the entire AHC community!**



**Words of  
Wisdom**

**"Love is a positive, symbiotic, reciprocal flow between two or more entities."  
Inga Muscio**



*Simple Idea Helps Increase Fundraising Response Rate Significantly*

## When people receive something first, they are more likely to give.

**Leading fundraising experts, Richard Perry and Jeff Schreifels, recently shared a great idea on how to increase the response rate to your requests for donations. Here is a simple idea everyone can use from their May 27<sup>th</sup> blog post, “Six Principles of Influence for Fundraising: #1 – Reciprocation.”**

Building on the writings of **Dr. Robert Cialdini**, who has written extensively about the ethical use of influence, Perry and Schreifels adapted one of his principles on reciprocation and applied it fundraising.

The reciprocation principle says that when a person does something first, others are more inclined to do something in return. Dr. Cialdini states that *you have to go first*. “Give something: give information, give free samples, give a positive experience...” In his application of this principle, Brady says “when people receive something first, they are more likely to give.”

Social scientist Randy Garner published a 2005 experiment that tested whether sticky notes could persuade people to respond to a marketing survey. He sent a third of the surveys with a handwritten sticky note requesting completion, a third with a blank sticky note, and the final third without a sticky note.

The results? Handwritten note: 69% response rate. Blank sticky note: 43% response rate. No sticky note: 34% response rate. So how is a sticky note giving something? It is giving a personal request. It is saying “you matter” to the recipient. **Yes, it is a small thing – but still very powerful.**

You can see how this experiment would apply to communication with your donors. A handwritten personalized note goes such a long way to validate that the donor means something to you – that he is not just a “donor” but a real person. It is a gift.

Next time you are seeking donations, try adding a short personal comment on a sticky note and see what happens.

The full text of Perry and Schreifels’ post can be found at:

<http://veritusgroup.com/six-principles-of-influence-for-fundraising-1-reciprocation/>



**Thank you to everyone who has been hosting events to raise money and awareness for AHC this year!**

**The parents and family members who love someone with AHC are doing an outstanding job helping our community!**

**It is through the dedication and hard work of our volunteers that is making the difference for our loved ones!**

**Thank You!**

## **Golf Outing to Benefit Alternating Hemiplegia of Childhood Foundation**

**Sponsored by Terry Sharo**

**For his granddaughter, Kiley Andrasco**

Terry's granddaughter, Kiley, is afflicted with a rare neurological disorder called AHC (Alternating Hemiplegia of Childhood). It has affected her since birth and makes every day a challenge for both her and her family. Almost every week, she has to deal with bouts of temporary paralysis, which impairs her ability to speak, walk, and perform other functions we take for granted. There is no known cure for AHC.



### **Golf Outing Details**

#### **Register by June 3, 2015**

The 4<sup>th</sup> annual golf outing will be held at beautiful Deer Creek Golf Course, located in University Park, Illinois. The course is rated 3 ½ stars by Golf Digest Magazine and continually voted one of Chicago's best places to play. The day includes 18 holes of golf and a buffet dinner for all participants.

- Date: Friday, July 31, 2015
- Time: golf at 10 am, dinner at 3 pm
- Cost for golf and dinner: \$75
- Cost for dinner only: \$25
- Sponsor a hole: \$100
- General donation

Deer Creek Golf Course  
25055 Western Avenue  
University Park, IL 60484  
<http://deercreekgolfcourse.com>

### **The AHC Foundation**

The Alternating Hemiplegia of Childhood Foundation raises funds to find the causes of AHC and effective treatments or cures. The foundation is funded entirely by family fundraising efforts and activities, like this golf outing.

Learn more at  
<http://www.ahckids.org>.

As you can imagine, the fundraising to find treatment and a cure is incredibly important to the entire Sharo and Andrasco families. We appreciate your support in whatever way works best for you, including donations.

AHCF Foundation Classification - 501 (c) (3) 509 (a) (1)  
I.D. No.. 38-3225425, DLN:(case no.) 315203063

**To register, please fill out and mail the attached registration form by June 3, 2015. For more information, contact Terry Sharo at 708-478-3011 or [tsharob@att.net](mailto:tsharob@att.net).**

# Golf Fore a Cure 2015

for Alternating Hemiplegia of Childhood

Saturday, June 13, 2015 at Plum Creek Golf Course, Winchester, IL

2 flights; 7:30A and 1:00P; call 742-9018 for a Tee Time

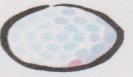
\$55 a person; 4-person teams; 1st place \$300; 2nd \$150;

10th Place \$50; Poker Run

\*\*prizes adjusted according to the number of teams\*\*

\*\*Each team will receive 5 cards throughout the day; \*\*

Up to 3 Extra poker hands at \$5 each may be purchased at the time of entry; 1 Mulligan for \$5, 1 team can only win one prize, the larger dollar amount



## Prizes and Betting Hole

Deadline for Free T-shirt with Entry Fee is May 31, 2015

## A Chance for Hope Raffle

You could win \$100; or

\$100 Gift Certificate to Jones Meat Locker, Jacksonville, IL

4 Cardinal vs. Padres Tickets for Sunday, July 5 @ 1:15 PM

4 Cardinal vs. Reds Tickets for Monday, September 21 @ 7:15 PM

Homemade Patio Set including 2 chairs and a Table

\$5 per chance or 3 for \$12

Prizes to be given away at the conclusion of the golf tournament

"need not be present to win"

Music by Tim Hart, Hull, IL

Memorial Wine Glasses and Tastings Available

### Silent Auction

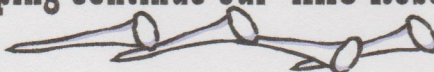
Come join us starting at 5P, for live entertainment, pork loin sandwiches and beverages will be available and all donations are greatly appreciated!

Good Cooking All Day!!!

Thanks for making a difference in Michael's life

and helping continue our AHC Research!

Come out and grab a bite



and join in the fun!!!

