

NOVEMBER 2013



## Celebrating our 20th Year as a Foundation

### UPDATE FROM OUR PRESIDENT

I hope this newsletter finds you and your family happy and healthy. While we are often dealing with the ups and downs of AHC, may the start of the holiday season be a wonderful time for everyone.

As I continue to reflect on our 20th year as a foundation, I am incredibly thankful for the support and dedication of our foundation volunteers. It is through your generosity and devotion that the foundation continues to thrive after twenty years of service.

As we begin to celebrate the Thanksgiving holiday, we've put together a list of reasons to be thankful as a foundation. And, in honor of our twentieth anniversary year, our list will take the form of a, "Top Twenty Reasons to be Thankful."

I hope you enjoy the list and wish you a very Happy Thanksgiving!

**LYNN EGAN** [Lynn@ahckids.org](mailto:Lynn@ahckids.org)  
AHCF President

## TOP 20 REASONS TO BE THANKFUL THIS YEAR

### #1 OUR AHC PATIENTS

The AHCF is most thankful for all of the AHC patients who live with this disorder every day. Twenty years ago, the foundation was created by families who love an AHC patient. And, this continues to be the driving force behind the AHCF today.

Through the challenges and the crises, through the pain and the problems, through the love and the laughter; we are thankful to have each of you in our lives.

While we have lost some incredibly loved AHC patients during the last year, we continue to work hard on their behalf. You are and will forever be missed.

It is for all AHC patients that we are thankful and continue to exist after twenty years of dedicated service. Thank you for being you!

### #2 AHC FRIENDS & FAMILIES

It is because of the overwhelming support of our friends and families that we were able to do the work that we did this year!

Our support system participated in a record breaking variety of



fundraisers this year. Donations were made to Thred UP, raffle tickets were purchased from Charity Mania, walks were held, golf outings were played, races were run, tributes were purchased, garage sales were held, baseball outings were hosted, and auction items were collected.

Our volunteers knocked on doors, called on businesses, mailed letters, emailed colleagues, and so much more. The AHCF is thankful for the help we receive every day from our friends and family. Thank you, thank you, and thank you!

### #3 THE AHCF BOARD OF DIRECTORS

The AHCF is thankful to have thirteen dedicated and talented members currently serve on the Board of Directors.

Each member contributes to the success of the foundation by volunteering their time in service to AHC. This is a highly dedicated and well educated group of individuals for which we are grateful.

Thank you for your service!

Gene Andrasco  
Sharon Ciccodicola  
Cate Cohen  
Lynn Egan  
Mollie Erpenbeck  
Dr. Joe George  
Bill Gerber  
Josh Marszalek  
Doug Morris  
Vicky Platt  
Carol Presunka  
Mary Kay Riley  
Sue Roberts



### #4 OUR MEDICAL ADVISORY BOARD

The AHCF is thankful to have eight dedicated and talented doctors on our Medical Advisory Board, or MAB.

With many years of AHC-specific experience, the MAB is an incredibly valuable resource to the foundation and our families. Thank you for the many ways you help AHC patients all year long.



Thank you for your service!

Dr. Fred Andermann  
Dr. Suzanne DeBrosse  
Dr. Josh Magleby  
Dr. Terry Sanger  
Dr. Kenneth Silver  
Dr. Marcio Sotero de Menezes  
Dr. Matt Sweney  
Dr. Mary Zupanc

### #5 OUR FUNDRAISING FAMILIES

The AHCF is grateful for all of the time and effort our families put into raising money to support the mission of the foundation.

These families add to their already demanding schedules and accomplish amazing feats for the foundation. From the small to the big efforts; all contribute to bottom line. All are important. And, all are appreciated.

Thank you for finding the time to support the AHCF in 2013!

## #6 ACTIVE AHC RESEARCHERS

It is safe to say that all AHC families are very thankful to every single researcher working on projects to advance AHC research.

Not so long ago, the overwhelming majority of AHC research was being funded by a handful of family foundations in Europe and the United States. The financial burden fell on the back of our families and we struggled to bring more researchers to our cause.

Over the last two years, the interest in AHC research has exploded. International collaborations are taking place between a variety of universities and on numerous projects. With much work to be done, this is great news.

The work that these teams are doing is complicated and time consuming. We greatly appreciate every attempt being made to help our AHC patients.

We specifically wish to acknowledge the teams currently working on AHCF sponsored grants.



Thank you to Dr. Swoboda and her entire team at the University of Utah.

Thank you to Dr. George and Dr. Ess at Vanderbilt University.



Thank you to Dr. Jan Koenderink from Radboud University in The Netherlands.

## #7 MAJOR DONOR CONTRIBUTIONS

Over the summer, the AHCF received our first major private donation. A very generous anonymous donor contributed \$169,000 to fund a research grant at Vanderbilt University.

The overwhelming generosity of this single donation advances AHC research in a huge manner. We will continue to be thankful for this donation for years to come.



## #8 A TEST FOR AHC

For many years, AHC patients had a terrible time being diagnosed properly with AHC. Finding help was hard and a time consuming endeavor.

With the discovery of the ATP1A3 gene mutation in 2012, patients now have the opportunity to be tested for AHC through a simple blood draw.

Local doctors can order genetic testing to screen patients for the gene mutation in an attempt to properly diagnosis AHC. If the ATP1A3 mutation is identified, this screening provides for earlier diagnosis of AHC.

The AHCF is also thankful that we have the means to continue supporting the University of Utah in providing free testing for the mutation. In addition, the clinic provides free genetic consulting to any AHC family needing assistance.



We are thankful to Tara Newcomb, our Clinical Research Coordinator at the University of Utah, and the entire group, for helping diagnosis AHC at no cost to our families.

Additional information is available at  
<http://ahckids.org/atp1a3/>

## #9 THE 2013 MISSION VIDEO

Did you see it? Thousands of people saw it and liked it. It was the 2013 Mission Video and it was a huge hit.

Board Director, Cate Cohen, led our efforts in creating a dynamic and inspirational video that circled the globe. With the generous help of a marketing and advertising agency in Ohio, Engage, Inc., Cate helped spread the word about AHC in a new and professional way.

Thank you to the families who participated in making the video and the time you put into this effort. We especially thank Kelly & Kiley Andrasco for your speaking role and Marvin Feig for his comments in the corporate donor video.

We also thank Engage for donating your time to the video, Dr. Silver for helping explain AHC, and Cate for her hard work.



## #10 AHCF FINANCIAL TEAM

Did you ever notice that during the Academy Awards ceremony, the accounting firm gets recognized in the middle of the show? It is probably because little else would be possible without the contributions of the accounting and finance team.

Well, the AHCF is no different. The Finance Committee works hard to protect every dollar raised for the foundation and recommends ways to make it really count.



Thank you to the Finance Committee for taking on the task of ensuring the financial stability of the foundation.

## #11 ROME SYMPOSIUM PARTICIPANTS

In September, a symposium was held in Rome, Italy to discuss AHC and the ATP1A3 gene mutation. It brought together researchers and family foundation's representatives from around the world. It was a huge undertaking and an even greater success.

We wish to extend our thanks to Dr. Goldstein, Duke University, and Rosario Vavassori, AISEA, for your efforts in coordinating this wonderful event and helping advance the AHC cause. We also thank Lynn Egan for attending the meeting and representing the foundation.

Your efforts are greatly appreciated!

## #12 NEW AHCF VOLUNTEERS

This year the AHCF was fortunate to have two new volunteers join the foundation. We wish to welcome and thank Dr. Mary Zupanc for joining our MAB, and Josh Marszalek, for joining the Board of Directors. We're happy you have become part of the AHCF team.

## #13 SOCIAL MEDIA SUPPORTERS



Getting the word out regarding AHC and the AHCF can be challenging.

We thank all of you who follow us on Facebook and Yahoo. Sharing our postings with your friends and family is a huge benefit to the foundation and we are grateful for your help in this area. Keep it up!

## #14 MEMORIALS & HONORARIUMS

It is not a little thing to think about the AHCF throughout the year. We wish to express our thanks to those families that included the AHCF in their family events through memorials and honorariums during 2013.



While we wish we could recognize each family's participation individually, we must respect each donor's privacy. We offer you all our deepest appreciation and gratitude here today. Thank you.

## #15 FAMILY MEETING

Having the resources to host a Family Meeting is another reason to be thankful this year. The cost to the foundation is significant and we are proud to offer this opportunity to our families.

The Family Meeting Planning Committee is hard at work organizing the many components of the meeting. While June 2014 seems like a long time away, registration for the next family will begin soon. Thank you to everyone who makes this meeting possible.

## #16 FOUNDATION COORDINATOR

The foundation is grateful that we have the means to keep Sharon Ciccodicola as our foundation coordinator. Every year, the work of running our foundation increases. Without Sharon's efforts in the front office, we would not be able to do as much as we do. Thank you, Sharon, for your dedication and hard work.

## #17 OUR WEBSITE

We thank all of the people who help keep our website up to date. There is a lot of information on the website and we couldn't manage it without your help. Thank you for helping to inform people all around the world about AHC.



## #18 ADVOCACY PARTNERS

We are thankful to the organizations which help spread the word about AHC through a variety of platforms. It is an honor to participate with NORD, RareConnect, Global Genes, and Great Nonprofits. Each organization provides us with an excellent avenue to help achieve our mission of educating the public about AHC. For this, we are thankful.



## #19 INTERNATIONAL AHC COMMUNITY

We are thankful to the AHC International Alliance members for helping to increase awareness about AHC and raise funds for AHC related research around the world.

After two highly successful symposiums on the ATP1A3 mutation, it is a wonderful opportunity to continue working with our sister organizations in foreign countries.

Together we can accomplish great achievements and we are thankful for your support.



## #20 FAMILIES NEW TO AHC

For those families who were newly diagnosed with AHC this year, we are thankful that you found the AHCF. The early days of educating yourself about AHC can be frightening, overwhelming, and isolating. The AHCF is a place where you can receive help in numerous ways and from people with many years of experience. While no one ever wishes to have AHC, we are glad you found us this year. Welcome!

It must be said one more time, that we are incredibly grateful to all of the volunteers who have served the foundation over the last twenty years!

Many people have helped the foundation get to where it is today, and for your service, we are entirely grateful.

**We wish you all a very  
Happy Thanksgiving.**

### The 2013 AHCF Board of Directors

Gene Andrasco, Sharon Ciccodicola,  
Cate Cohen, Lynn Egan, Mollie Erpenbeck,  
Dr. Joe George, Bill Gerber, Josh Marszalek,  
Doug Morris, Vicky Platt, Carol Presunka,  
Mary Kay Riley, and Sue Roberts

