

DECEMBER 2013

## GREAT EXPECTATIONS



From the above referenced title, you might be wondering if the AHCF is providing a book review on Charles Dickens' great novel, or a holiday message to their families. Rest assured it is the latter of the two.

Last month, we expressed gratitude to our friends and families for their generosity and dedication to the AHCF. This month, as we come to the end of 2013, let us look at great places we shall go in 2014.

My participation in the foundation began with a plea from Richard George. He simply asked for people to help with fundraising for the AHCF. After hosting a couple of walks, my involvement increased to volunteering on the Board of Directors. Nine years later, I am proud to have raised over \$237,000 for the foundation.

While I have learned a lot about operating a foundation and the complexities of AHC, one of the greatest lessons I have learned comes from balancing the complex personalities of passionate people.



It is from combining the hopes, dreams, desires, and expectations of many people that make up our great foundation.

## AHCF'S CHARACTERS

Over the last 20 years, the foundation has been privileged to have incredible characters join in the telling of the AHC story. There are patients, researchers, volunteers and the Board of Directors, to name a few.

Each brings an important voice and perspective to our community. Without one, the other is somehow weaker. Sharing the stories of each character is what makes the narrative of our foundation so great.

## BOARD OF DIRECTORS

Each director brings a variety of skills and experiences to the board. It is a diverse group of men and women. Some have children with AHC; some do not. Some are parents of toddlers or tweens, while others have young adults at home. Together, the board becomes an accurate representation of the AHC community.

As the working body of the foundation, there are many expectations on the board. Each board member shares a dedication to ensuring the funds entrusted to the foundation are used wisely. In 2014, you can expect every dollar you donate or raise for the foundation will only be used, or invested, after great thought and deliberation.



## RESEARCHERS

Looking forward to the research projects of 2014, everyone's expectations are high. More researchers than at any time during our twenty year history are working to advance the science behind AHC.

Researchers are connecting with other researchers not only in the United States, but in France, Germany, Japan, Spain, and The Netherlands; to name a few. An international alliance of AHC family foundations is working together to fund as many projects as possible. The research into the complexities of AHC has truly gone global.



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Every AHC parent wants to have a treatment found, questions answered, life made better, and for AHC to be a disease of the past. A lot of demands are placed on the researchers and foundations to have these expectations met quickly.

The best way to help researchers achieve these goals is to increase our financial support of their efforts in 2014. Their time is precious and the more funding we can provide them, the more time they can spend on solving the many mysteries of AHC.

## PATIENTS

Every day of their life, the AHC patient must deal with many expectations. Therapists expect cooperation during therapy, teachers expect compliance in school, doctors expect appointments to run smoothly, siblings expect equality and fairness, and parents expect that tomorrow will be better. There are many demands on the AHC patient and parents continually struggle to find the right balance. But, what do they expect of us?

Some AHC patients expect researchers to find answers and bring help now. Some patients expect to go to the mall and shop with their friends. Some patients expect to be surrounded by family at all times. And, some expectations remain internal to the AHC patient, as they are unable to communicate them to us.

In every case, their expectations exist and are incredibly important. Parents often become the storyteller of the AHC patient's expectations. Hopefully, we get it right most of the time and accurately share their hopes and dreams.

Indeed, there are many AHC messages to be shared. In 2014, the AHCF is planning to bring our community more opportunities to do so. Be sure to stay tuned for details in the New Year.



## VOLUNTEERS

In writing *Great Expectations*, Charles Dickens' Victorian masterpiece wasn't created as one massive book. The work was originally published, over the course of a year, as a serial in a small weekly publication.

Dickens dedicated his time to public speaking events in order to increase awareness about his work. Eventually, this great literary achievement became most widely known for the growth and personal development of the story's characters.

The path of creating *Great Expectations* reminds me of the journey the AHCF took to becoming a great foundation. Starting out small, coming together over time, and increasing awareness about AHC helped create the large and successful foundation we have today.



Over the next year, we hope that you will participate in a variety of AHCF activities.

Some may choose to share our mission with their Facebook friends. Some may host a fundraising event for the first time. Others may

join a committee or volunteer to help fill a short-term need. And hopefully, many will be able to join us in Minnesota next June for the AHCF Family Meeting.

## CONCLUSION

We hope that in any way you choose to participate with the AHCF, you will feel a sense of accomplishment in helping achieve great success for every AHC patient worldwide.

AHC is an incredibly demanding and challenging disorder. In our version of *Great Expectations*, our characters are all busy people: researchers, patients, volunteers, and the AHCF Board of Directors. We all want our loved one with AHC to have a life filled with joy, love, and good health.

The work required to make this happen is great. However, if enough people come together and combine their efforts, we will achieve great things in 2014. With great expectations comes the possibility of great achievements. We look forward to making this a reality with you next year.

Vicky Platt, AHCF Secretary

As our foundation's 20<sup>th</sup> year anniversary comes to an end, we are thankful to the families who helped develop the foundation and create an organization of which we can be proud.

**Wishing you and your family a  
Happy and Healthy New Year!**

## 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