

Donations = Grants Funded and People Educated

This year we have many meritorious grants to be funded and thousands of people to educate about PKD! As you think about charitable giving, consider donating to the Nebraska Chapter of the PKD Foundation. Eighty cents of every dollar donated supports vital PKD research and patient education.

I would like to contribute under my name.

Name: _____

Address: _____

City/St/Zip: _____

Phone: _____

E-mail: _____

Please mail donations to:

PKD Foundation

Attn: Nebraska Chapter

9221 Ward Parkway, Suite 400

Kansas City, MO 64114

I would like to contribute in [Honor/Memory] of

Name: _____

Please send Acknowledgement to:

Name: _____

Address: _____

City/St/Zip: _____

Phone: _____

E-mail: _____

If you would like to contribute via credit card please call 1-800-PKDCURE and mention the Nebraska Chapter when you make your contribution.



9221 Ward Parkway, Suite 400
Kansas City, MO 64114

1-800-PKD-CURE
www.pkdcure.org

Learn more about
the PKD Foundation at
www.pkdcure.org

PKD Foundation

NEBRASKA CHAPTER

WINTER 2010



A Message From Your Coordinator

What a great first year we had as a new Chapter. We have an enthusiastic and willing group that is meeting and we are making progress with each meeting and have plans for 2010. We have a Walk coordinator and Jamie is doing a great job. We will be ready for our first Walk in several years. We also have Dr. Poole, an Omaha nephrologist, coming on March 14, 2010 to speak at our monthly meeting. I am excited to see what we accomplish this year and to watch us grow both in numbers and spirit. We would like to meet all of you receiving this letter and would be pleased if you would join us. This is a Chapter that is for all of us, including you. We are having monthly meetings the 2nd Sunday of each month from 2-4 pm. If this time does not work for you and you would like to involved or need someone to talk with, please email me at NebraskaChapter @pkdcure.org.

- Kim Beger

Now More Than Ever...

Since the Chapter movement began as a grass roots effort in the 1980s, we have had a tremendous impact on our mission to find a treatment and cure for PKD, and improve the lives of PKD patients and their families. Over the years, an army of people across the country have contributed ideas, skills, time, energy, and dollars to make the world a better place for themselves, their families, and the 12.5 million PKD patients worldwide.

Our dollars have fueled research, taking us from the identification of the PKD gene in 1994 to the first clinical trial in humans a mere ten years later. Today, only five years after 12 people participated in that first clinical trial, there are too many clinical trials taking place to refer to them by name. Instead, we now talk about the five different, potential treatments for PKD being tested worldwide.

While research may be the most important thing we have focused on, it is not the only place we have grown. Because of the knowledge we've gained and a desire to make sure each person has the latest information, PKD patient education is more important now than ever before in our history. The past few years have also shown incredible success in government advocacy, as evidenced in the passing of G.I.N.A. (The Genetic Information Non-discrimination Act) and raising federal PKD research dollars by the millions.

The driving force behind so much of this success has been the involvement of thousands of individuals across the country through local PKD Foundation Chapters. As well as the great strides made by all chapters, the reason so many of your dollars go directly to where they can do the most good is that all PKD Foundation Chapters, including the Nebraska Chapter, continue to be organized and completely run by volunteers.

For as much we have accomplished together, we cannot sit back now and let someone else finish the job. As we continue to move toward our goals, now, more than ever, it's time to make sure we are each committed to finding a treatment and cure for PKD. The perfect place to find opportunities and ideas to grow your commitment, and insure no one suffers the full effects of PKD, is your local Chapter. The Nebraska Chapter is where your PKD Community lives and breathes. It is where you can find meetings and events that educate, offer support, raise awareness and give you a voice in your future. The Chapter is where you and your family can connect with other members of the PKD Community, share information and work together toward a common goal. You can also learn how easy it is to be involved in government advocacy and make an impact on a national level.

Since the scope and success of PKD Foundation Chapters, including our chapter, is totally dependent on your involvement, the Nebraska Chapter also gives you the opportunity to use your ideas, skills, and talents to shape the chapter, or simply help on events big and small. Staying connected and involved with our chapter is easier than ever, through e-mail, NebraskaChapter@pkdcure.org, and now on Face Book at PKD Foundation Nebraska Chapter. Simply e-mail us at NebraskaChapter @pkdcure.org today, and say you want to make a difference. As we push harder and harder toward our goal, now, more than ever, you can help change the PKD world.

CHAPTER INFORMATION

Chapter Coordinator:

Kim Beger

402-274-4788

NebraskaChapter@pkdcure.org

www.pkdcure.org/NebraskaChapter

Stay Informed Though Email, our Website & Face Book!

With the rising costs of printing and postage, the Nebraska Chapter now does most of its communication through email, Face Book, at PKD Foundation Nebraska Chapter, and the Chapter website: www.pkdcure.org/NebraskaChapter.

To be sure you don't miss out on the latest information, email NebraskaChapter@pkdcure.org and ask to be added to the email list. Don't forget to contact us when your email addresses change. **If you thought you were on the list, but haven't received an email for some time, check your spam controls, or ask to be put on the list again. Be sure to include your complete name and address, or we will not be able to update your records, or add you to the database.**

The PKD Foundation Receives Highest Ratings

Charity Navigator, America's largest evaluator of non-profit organizations, recently gave the PKD Foundation its 4 Star (highest) rating for efficiency. They wrote... **"Only 12% of the charities we rate have received at least 3 consecutive 4-star evaluations, indicating that the PKD Foundation consistently executes its mission in a fiscally-responsible way, and outperforms most other charities in America. This "exceptional" designation from Charity Navigator differentiates the PKD Foundation from its peers and demonstrates to the public it is worthy of their trust."**

2010 National Convention on PKD



Please join us August 6-8, 2010 in Sunny San Diego for the 2010 National Convention on PKD! The Convention will be held at the Sheraton San Diego Hotel and Marina. Online registration will open on March first. Mark your calendars now for this unique educational and social opportunity!

Your Local PKD Foundation Chapter – A Source of Information, Comfort, Friendship and More

Gina's Story

"In November 2007, I was unexpectedly diagnosed with PKD. No one in my family has PKD and it was determined that I had a spontaneous mutation. I had many questions, was very frightened and truly felt isolated, with no where to turn. A dear friend found the telephone number for Judi Herr, the Pittsburgh Chapter Coordinator at the time. The initial call that I placed to Judi was such a comfort. Since that first conversation, I've attended several chapter meetings and have met uplifting and inspiring people who have helped me to see that I don't have to define myself as living with PKD - I can define myself as simply LIVING. I am enjoying my life, I lead a healthy lifestyle and I have a more positive outlook on my future than I have ever had before," Gina Berola Wilkes.

Gina is just one of many, many people who have received encouragement and a new outlook on life by connecting with their local PKD Foundation Chapters.

From Fear to Empowerment

Receiving a PKD diagnosis can be stressful and scary. While there is a lot of excellent information on the Internet, it's sometimes even more helpful to actually meet others who are dealing with PKD. If you are feeling alone in your PKD journey or just want to learn more effective ways to cope or live with PKD, consider getting in touch with the Nebraska Chapter. Whether you are newly diagnosed or just want to connect with others, the Nebraska Chapter is here for you. You may be worrying about something specific or simply wondering about dialysis, transplant, nutrition or some other aspect of your PKD situation. Connecting with others can open the door to new information, ideas and treatment options. You may choose to simply attend a meeting or to become an active chapter participant. That is up to each person to decide. Many chapters become like "families" where strong friendships are formed that last a long, long time. Chapters can make a huge difference for the individuals involved and in the larger, more global fight against PKD. Remember – there is strength in numbers, so contact the Nebraska Chapter. You are not alone!

Nebraska Chapter Calendar of Events

For additional information on our events and upcoming Chapter meetings, please visit our website at www.pkdcure.org/NebraskaChapter.

February 14, 2010

Chapter Meeting

March 2010

National Kidney Month

March 14, 2010

Chapter Meeting/Education Event

April 11, 2010

Chapter Meeting

May - TBD

Please check our webpage for updates!

June 13, 2010

Chapter Meeting

July 11, 2010

Chapter Meeting

August 6-8, 2010

National Convention on PKD
San Diego, CA

August 8, 2010

Chapter Meeting

September 12, 2010

Chapter Meeting

October 10, 2010

Chapter Meeting

November 14

Chapter Meeting

December 12, 2010

Chapter Meeting

All of our Chapter meetings are held at the Methodist Hospital, South Tower, in the Heritage Room located at 8303 Dodge Street in Omaha, NE 64114 from 2:00 pm to 4:00 pm. Don't forget to check us out on Face Book. Ask to join the group on our page at PKD Foundation Nebraska Chapter. We will be logged in on Facebook from during our Chapter Meetings, so please chat with us if you can't join us in person.

National Kidney Month

Your seldom-appreciated kidneys will get their time in the spotlight during National Kidney Month this March. The awareness campaign seeks to communicate the overall importance of keeping these vital organs healthy and functioning.

Increased attention on kidneys will offer many opportunities to get involved with your local PKD chapter program or attend various educational seminars. If you're interested in creating a local event to raise awareness or support research for the disease, the PKD Foundation encourages you to take advantage this special month. Some PKD patients, along with their families and friends, have organized charitable golf tournaments, fashion shows, barbeques and even wine tastings in the name of PKD support and awareness.

In addition to local opportunities, you can also get involved nationally. Consider taking part in United on the Hill, the PKD Foundation's annual legislative and public policy conference in Washington, D.C., which also takes place during National Kidney Month on March 1st and 2nd.

Other organizations, such as the National Kidney Foundation and the National Kidney Disease Education Program, will be promoting the importance of prevention and early detection of kidney disease, the ninth leading cause of death in the United States.

Growing Education

Our Education Department has been around for a little more than a year now. In that time, we've created the PKD Learning Center, added videos to explain various aspects of PKD, and started an ongoing series of PKD related webinars. Future plans include further expansion of information in the Learning Center, more videos and webinars on topics such as pain management, research/clinical trials, caregivers, and cystic kidney disease in children.

To make our education offerings the most effective, however, your input is key. We want to cover topics important to you and your family. What information and tools would you like the PKD Foundation to develop to help you better manage your journey or the journey of a loved one with PKD?

Please share your thoughts with Educational Programs Director, Dave Switzer, by emailing education@pkdcure.org. While we can't promise to cover everything, we'll do our best to provide more on what you want to know.