

## 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](mailto: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.

## 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.

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.



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## PKD Foundation

# KANSAS CITY CHAPTER

WINTER 2010



## A Message From Your Coordinator...

Happy New Year Kansas City! I hope everyone had a relaxing holiday season! As 2010 begins, our Chapter is planning fundraising events, an educational seminar and support meetings for the New Year. I encourage everyone to bookmark the Kansas City Chapter's website at [www.pkdcure.org/kansascitychapter](http://www.pkdcure.org/kansascitychapter) and to look us up on Facebook! You can even follow our chapter on twitter at [www.twitter.com/PKDKCChapter](http://www.twitter.com/PKDKCChapter). All are great ways to stay connected with our chapter. We have great opportunities in store for the Kansas City area coming up. My challenge to you in 2010.... get involved with our chapter. You will meet great friends, become more informed about the most up to date PKD research, receive legislative updates and I bet you will have some fun, too! See you soon.

## 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 Kansas City Chapter, continue to be organized and completely run by volunteers.

For as much as 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 Kansas City 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 Kansas City 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 and look for us on Facebook. Simply e-mail us at [KansasCityChapter@pkdcure.org](mailto:KansasCityChapter@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:  
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KansasCityChapter](http://www.pkdcure.org/KansasCityChapter)

## 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!

## 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."*



## The Walk for PKD...So Much To Celebrate!

Thank you to the 11,000+ participants who boldly stood up, stepped out and Walked for PKD this year in one of the 54 events that took place in 29 states. By sharing your stories and reaching out to friends, family, neighbors, co-workers and businesses, you have strengthened the PKD army in the fight for a treatment and a cure! Nationally we have raised over \$2.4 million – funds that will help fuel cutting-edge research (4 therapies in clinical trials and counting), extraordinary patient education (webinars you can engage in from the comfort of your home), life-changing advocacy efforts (lobbying the government to support the Immunosuppressive Drug Coverage for Kidney Transplant Patients) and more! Your passion is making progress possible... and this is why we walk.

### A word from your local Walk for PKD coordinator...

I'm thrilled to report that the Kansas City Walk had 400 participants come out to Theis Park on September 12th and helped raise more than \$67,000. A simple idea wrapped around our Vision for a Cure, asking 20 people for \$20, allowed walkers to scale new heights! I would like to give a special thanks to our top, individual fundraisers Breanna Farmer, Nicole Harr, and Mandy Riester and teams SageShine Strollers, Our Feet Are Your Foundation, and The ExorCYSTS@KU for their tremendous dedication to make a difference. I also want to thank top sponsor, Blue Cross Blue Shield, whose generous support helped underwrite our event expenses to allow more of the funds raised to directly support the PKD Foundation mission. Finally, I want to thank each of the volunteers who dedicated their time & talent on Walk Day and throughout the year to help make the Kansas City Walk for PKD such a success – you are truly appreciated!

Please feel free to contact me with any walk questions at [kansascitywalk@pkdcure.org](mailto:kansascitywalk@pkdcure.org). Also check out our walk web page at [pkdcure.org/kansascitywalk](http://pkdcure.org/kansascitywalk). We are looking forward to the **2010 Walk for PKD at Theis Park on Saturday, September 11.**

-Sue Full, Walk for PKD Coordinator



## Kansas City Chapter Calendar of Events

For additional information on our events and upcoming Chapter meetings, please visit our website at [www.pkdcure.org/KansasCityChapter](http://www.pkdcure.org/KansasCityChapter).

### February 9, 2010

Chapter Support Meeting

### March 2010

National Kidney Month

### March 6, 2010

Educational Seminar

11 am to 4 pm

Please check our website for more information and for online registration.

### April 14, 2010

Chapter Support Meeting

### April 22, 2010

Wine Tasting Fundraiser

6:00 pm to 8:00 pm

Wines by Jennifer - A Global Wine Boutique

### May 10, 2010

Driving Home a Cure for PKD Golf Tournament

11:00 am to 6:00 pm

The Deuce at The National

Please check our website for more information and for online registration.

### June 9, 2010

Chapter Support Meeting

### August 6-8, 2010

National Convention on PKD

San Diego, CA

All of our Chapter meetings are held at the Kansas City Public Library - Plaza Branch located at 4801 Main Street in Kansas City, MO 64112. For more information on our meetings and events, please visit our webpage at [www.pkdcure.org/KansasCityChapter](http://www.pkdcure.org/KansasCityChapter).

## Your Local Chapter - A Source of Information, Comfort, Friendship and More

### 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 Kansas City Chapter. Whether you are newly diagnosed or just want to connect with others, the Kansas City 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 Kansas City Chapter. You are not alone!

## Stay Informed Though Email and our Website!

With the rising costs of printing and postage, the Kansas City Chapter now does most of its communication through email and the Chapter website: [www.pkdcure.org/kansascitychapter](http://www.pkdcure.org/kansascitychapter).

To be sure you don't miss out on the latest information, email [KansasCityChapter@pkdcure.org](mailto:KansasCityChapter@pkdcure.org) and ask to be added to the email list. Don't forget to contact us when your email address changes. 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.