

Support Your Chapter

The Raleigh Durham Chapter has a fundraising goal of \$50,000 this year. Please help us kick-start the year with your donation. Every dollar makes a difference in the lives of 12.5 million people with PKD.

I would like to contribute under my name. I would like to contribute in [Honor/Memory] of

Name: _____ Name: _____

Address: _____ Please send Acknowledgement to:

City/St/Zip: _____ Name: _____

Phone: _____ Address: _____

E-mail: _____ City/St/Zip: _____

Phone: _____
E-mail: _____

Please mail donations to:
PKD Foundation
Attn: Raleigh-Durham Chapter
9221 Ward Parkway, Suite 400
Kansas City, MO 64114

If you would like to contribute via credit card please call
1-800-PKD-CURE and mention the Raleigh-Durham Chapter
when you make your contribution.

PKD Foundation

RALEIGH-DURHAM CHAPTER

SPRING 2009



This is YOUR Chapter!

The Raleigh Durham Chapter is taking great strides in 2009. We want to bring a variety of exciting events, meetings, and educational opportunities to the area. But to do this we need your help! We have a wide assortment of volunteer positions in our Chapter. From helping to lead our education and support efforts, to something as simple as providing refreshments at our meetings – there is something for everyone. Being involved in the Chapter is a great way to support your community, as well as a way to play a big part in the fight against PKD! This is YOUR Chapter and we want everyone to be a part of it.

Contact Le Anne Creech at raleighdurham@pkdcure.org or 919-696-2956 to find out how you can start making a difference in your Chapter today!

2008 by the Numbers

- 1 Walk for PKD
- Hundreds of hours worked by volunteers

**\$67,580 Raised
for Research and Education**

Visit us online at www.pkdcure.org/RaleighDurhamChapter to see what we plan to do in 2009!



9221 Ward Parkway, Suite 400
Kansas City, MO 64114

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



Connect With Others at a Chapter Meeting

While PKD effects whole families, sometimes it can leave you feeling all alone – but you are NOT alone. Let us prove that to you at our upcoming Chapter Meetings. Chapter Meetings are a great time to connect with other PKD patients and families, learn about the latest PKD research from a variety of speakers and find out how you can make a difference in the lives of 12.5 million people – and your own family.

The Raleigh Durham Chapter is in the process of planning quarterly meetings with the location dates and times to be determined. Please visit our chapter webpage in the upcoming weeks at www.pkdcure.org/raleighdurham for more information about our other Chapter Meetings that are in the works.

Our first meeting of the new year will be on March 18th. Our special guest speaker will be Dr. Michael Casey from Wake Nephrology Associates, P.A. We are finalizing the details of this meeting so please check our webpage for further details on the time and location. We hope to see you there!

CHAPTER INFORMATION

Chapter Coordinator:
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919-696-2956

RaleighDurhamChapter@pkdcure.org
[www.pkdcure.org/
RaleighDurhamChapter](http://www.pkdcure.org/RaleighDurhamChapter)

The 2008 Walk for PKD...Much To Be Thankful For



Between September 13th and November 9th, fifty-nine different Walk for PKD events took place in 32 different states. Nationally, the Walk for PKD put nearly \$3 million into the pipeline for critical research funding and for patient education and support. Locally, the Raleigh-Durham Walk for PKD raised \$24,697. There is much to celebrate and be thankful for.

The positive effects of the Walk for PKD go well beyond walk day. Because of the funds raised through the walk, someone newly diagnosed will be able to find the PKD Foundation on the web and lessen their fears by arming themselves with information. Because of funds raised through the Walk for PKD, we will continue to lobby on Capitol Hill for issue important to the PKD population. Because of funds raised, in part through the Walk for PKD, clinical trials are taking place and may someday soon lead to a treatment. Because people with PKD need a voice, we walk. A cure for polycystic kidney disease is our finish line, so until there is a treatment and ultimately a cure, we walk.



Be a part of a team and increase your fun and fund raising for the 2009 Walk for PKD



It's all about family and friends!

National Convention on PKD - More Opportunities For You

In 2009 the PKD Foundation will hold TWO National Conventions on PKD to serve you better. Both conventions will offer the same topics and caliber of speakers so the location choice is up to you. Join us in:

Chicago, IL • June 26 - 28, 2009 • Double Tree Hotel Chicago - Oak Brook

San Diego, CA • July 31st – August 2, 2009 • Sheraton San Diego Hotel & Marina

"I quickly realized that these strangers all understood and cared about the disease that has harmed my family for generations. That realization led to the joy of making new friends and realizing that my fate is not sealed. Please come and join me at this year's National Convention on PKD, and see that you are also not alone in your battle with PKD."

- 2008 National Convention on PKD Attendee



For more information about this great opportunity for PKD patients and families visit www.pkdcure.org.

Your Advocacy Can Help End PKD

By getting involved, your efforts can make a vital difference in the lives of 600,000 Americans suffering from PKD and millions more in future generations of their families. Need proof? The work of our PKD Champions helped lead to a remarkable victory in 2008—the passage and signing into law of the Genetic Information Non-Discrimination Act (GINA), which Senator Edward Kennedy (D-MA) called “the first major civil rights legislation of the 21st century.”

That's amazing progress in a short period of time. Our work, however, is far from over. A lack of adequate federal funding of PKD research threatens the momentum in this field. PKD patients and families still face challenges to a better quality of life, such as inadequate Medicare coverage to pay for expensive anti-rejection drugs after a kidney transplant. PKD costs Americans more than \$2 billion a year in Medicare costs related to dialysis, transplantation and related therapies.

What's the next step? Simple: Get involved. Your advocacy can make all the difference in our mission to find a treatment and cure for PKD. Visit www.pkdadvocacy.org to start making a difference!

National Kidney Month March 2009

Every March, PKD families from around the world come together to celebrate National Kidney Month and World Kidney Day (March 12th, 2009). Now, you and your family can take part in this exciting opportunity to raise awareness of PKD and the need for additional research funding!

Here are four quick ways to promote National Kidney Month and the PKD Foundation:

- 1) Distribute PKD Foundation posters and/or brochures throughout your community.
- 2) Tell 5 people about PKD and why the PKD Foundation is important to you and your family.
- 3) Sign-up for Action Alerts at www.pkdadvocacy.org and call or send a letter to lawmakers.
- 4) Put a link in your email tagline directing people to the PKD Foundation (www.pkdcure.org).

There are many more ways to make a difference in March and every month. Contact Le Anne Creech at Raleighdurham@pkdcure.org or 919-696-2956 if you would like to receive PKD Foundation materials and for information on how you get involved in other ways.

Email Reminders

Would you like to receive updates directly to your in-box on the latest Chapter and PKD information? Send your name, mailing address and email address to volunteers@pkdcure.org and we will add you to the PKD Foundation and the RaleighDurham Chapter's email list. Then look for updates about meetings, events and volunteer opportunities, clinical trials, webinars and much more.

PKD Webinars

The PKD Foundation is taking education to the next level! In October of 2008 the PKD Foundation unveiled its quarterly webinar program to rave reviews. The program offers everyone the chance to hear from top PKD experts on topics important to you from the comfort of your own home. Two webinars have already been presented and can be viewed anytime by visiting www.pkdcure.org. While you are there, take a moment and sign-up for the next live webinar which will take place in March.