

Support Your Chapter

The Charlotte Chapter has a goal to increase its fundraising 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. Please continue to check our website to find out about our local fundraising opportunities.

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: Charlotte 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 Charlotte Chapter when
you make your contribution.



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Kansas City, MO 64114

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

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

PKD Foundation

CHARLOTTE CHAPTER

SPRING 2009



This is YOUR Chapter!

The Charlotte 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 and the PKD Foundation, 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.

We held our first Fall Seminar on November 1st, 2008. The seminar was a panel presentation at Presbyterian Hospital in Matthews and was sponsored by Southeast Renal and Metrolina Nephrology. Dr. Benjamin Hippen, a transplant nephrologist/internist, joined the panel along with a living kidney donor, transplant recipient, patient on the transplant list, representative from LifeShare of the Carolinas and a nurse practitioner from CMC Transplant Center. Luann Scruggs acted as a moderator for a question & answer session which led to great information being shared.

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 Charlotte Chapter holds meetings quarterly at different locations in and around the Charlotte area. Please see out calendar of events or visit our chapter webpage at www.pkdcure.org/CharlotteChapter for more information about our Chapter Meetings. We hope to see you there!

2008 by the Numbers

- 1 Educational Seminar
- 2 Chapter Meetings
- 1 Fundraiser
- Hundreds of hours worked by volunteers

More than \$1,300
Raised for Research and Education

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

CHAPTER INFORMATION

Chapter Coordinator:

LuAnn Scruggs

704-846-2551

CharlotteChapter@pkdcure.org

www.pkdcure.org/CharlotteChapter

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 Charlotte Chapter's email list. Then look for updates about meetings, events and volunteer opportunities, clinical trials, webinars and much more.

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, we are in the planning stages to host our first walk in Charlotte in 2009. Please check our website for more information on the walk in the upcoming months. 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.

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.

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 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:

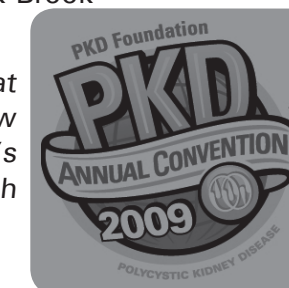
Chicago, IL • June 26 - 28, 2009 • Double Tree Hotel Chicago - Oak Brook

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.



Charlotte Chapter Calendar of Events

For more information, please visit us online at www.pkdcure.org/CharlotteChapter

March 2009
National Kidney Month

March 2009
Charlotte Focus Group Meeting
Check our webpage for updates
on a date and time.

March 2009
Mini Fundraiser
Encore restaurant in Blakeney

March 2-3, 2009
Champions on the Hill
Washington, D.C.

June 26 - 28, 2009
National Convention
Chicago, IL

July 31- August 2, 2009
National Convention
San Diego, CA

Fall 2009
Walk for PKD
Check our webpage for information on
our first Walk for PKD!

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 12, 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 LuAnn Scruggs at Charlottechapter@pkdcure.org or 704-846-2551 if you would like to receive PKD Foundation materials and for information on how you get involved in other ways.