

## 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](mailto:volunteers@pkdcure.org) and we will add you to the PKD Foundation and the Memphis Chapter's email list. Then look for updates about meetings, events and volunteer opportunities, clinical trials, webinars and much more.

## Support Your Chapter

The Memphis Chapter has a fundraising goal of \$120,000 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: \_\_\_\_\_

Please mail donations to:  
PKD Foundation  
Attn: Memphis 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 Memphis Chapter when  
you make your contribution.



9221 Ward Parkway, Suite 400  
Kansas City, MO 64114

1-800-PKD-CURE  
[www.pkdcure.org](http://www.pkdcure.org)

Learn more about  
the PKD Foundation at  
[www.pkdcure.org](http://www.pkdcure.org)

## PKD Foundation

# MEMPHIS CHAPTER

SPRING 2009



## This is YOUR Chapter!

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 Memphis 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.

The Memphis chapter is seeking volunteer leaders to assist with planning chapter meetings and activities. We have many opportunities to fit your interests from media awareness, to community health fairs to fundraisers to advocacy. Our chapters are 100% volunteer run and your participation is vital to helping us find a cure!

Please contact Karyn Waxman at [memphischapter@pkdcure.org](mailto:memphischapter@pkdcure.org) or 901-491-4799 to find out how you can start making a difference in your Chapter today!

## Annual Memphis PKD Educational Seminar

Please join us for annual Spring Education Seminar, Saturday, April 4th at Baptist Memorial Hospital Memphis, from 10:30 am until 3:00 pm. We are thrilled to once again host PKD Foundation Scientific Advisory Committee Vice-Chair, Ben Cowley, M.D., as our special guest speaker. Dr. Cowley is a Professor of Medicine, a John Gammill Professor in Polycystic Kidney Disease, and the Chief of Nephrology Hypertension at Oklahoma University Health Science Center.

### CHAPTER INFORMATION

Chapter Coordinator:

Karyn Waxman

901-491-4799

[MemphisChapter@pkdcure.org](mailto:MemphisChapter@pkdcure.org)

[www.pkdcure.org/MemphisChapter](http://www.pkdcure.org/MemphisChapter)

A modest registration fee of \$15 per person includes information packets as well as a kidney friendly lunch featuring recipes from the new PKD Foundation endorsed Brilliant Eats cookbook. For updated information regarding guest speakers, discussion topics, and pre-registration, please visit our web site at [www.pkdcure.org/MemphisChapter](http://www.pkdcure.org/MemphisChapter) or call Karyn Waxman 901-491-4799. We hope to see you there!

## 2008 by the Numbers

- 1 Educational Seminar
- 3 Chapter Meetings
- 4 Fundraisers
- 1 Walk for PKD
- 3 Booths at Health Fairs
- 1,500 hours worked by volunteers

\$115,000 Raised

for Research and Education

Visit us online at [www.pkdcure.org/MemphisChapter](http://www.pkdcure.org/MemphisChapter) to see what we plan to do in 2009!

## 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 Memphis Walk for PKD raised over \$28,000! 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.



Chapter Coordinator Karyn Waxman thanks walk registration volunteers Anne and Beth at the Memphis Walk for PKD.



Memphis volunteers Jennifer and Elaine Krueger enjoyed the beautiful weather and selling the pin wheels at the 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 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](http://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](http://www.pkdcure.org)).

There are many more ways to make a difference in March and every month. Contact Karyn Waxman at [MemphisChapter@pkdcure.org](mailto:MemphisChapter@pkdcure.org) or 901-491-4799 if you would like to receive PKD Foundation materials and for information on how you get involved in other ways.

## 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](http://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.”

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. Your advocacy can make all the difference in our mission to find a treatment and cure for PKD. Visit [www.pkdadvocacy.org](http://www.pkdadvocacy.org) to start making a difference!

## Memphis Chapter Calendar of Events

For more information, please visit us online at [www.pkdcure.org/MemphisChapter](http://www.pkdcure.org/MemphisChapter)

**March 2009**  
**National Kidney Month**  
**March 2-3, 2009**  
**Champions on the Hill**  
**Washington, D.C.**  
**April 4, 2009**  
**Educational Seminar**  
**Baptist Memorial Hospital**  
**located on Walnut Grove in Memphis**  
**May 16, 2009**  
**Above Par Classic:**  
**Wine, Dine and Auction Event**  
**Windyke Country Club**

**May 19, 2009**  
**Driving Home A Cure For PKD**  
**Golf Tournament**  
**Windyke Country Club**  
**June 26th - 28th, 2009**  
**National Convention**  
**Chicago, IL**  
**July 31- August 2, 2009**  
**National Convention**  
**San Diego, CA**  
**October 11, 2009**  
**Walk for PKD**  
**Shelby Farms Park**  
**Registration at 12:00 noon**  
**Event at 1:00 p.m.**

# Athena Diagnostics

## Comprehensive Molecular Testing for Polycystic Kidney Disease



BETTER TOOLS FOR BETTER INSIGHT

- Autosomal dominant PKD (ADPKD) is an inherited disorder.
- Each child of an ADPKD parent has a 50% chance of inheriting the disease.
- Family testing is important in tracking and managing ADPKD.
- Athena Diagnostics is the only laboratory to offer direct sequencing of PKD1 and PKD2.

### Why genetic testing?

- PKDx molecular testing from Athena Diagnostics permits specific patient management and can be useful in the assessment of living related donors.
- PKDx is private and accurate.
- PKDx testing is an efficient and cost effective approach to the diagnosis of autosomal dominant polycystic kidney disease.
- Prenatal Diagnosis.



Testing You Can Count On.

800-394-4493

377 Plantation Street • Worcester, MA 01605 • [www.AthenaDiagnostics.com](http://www.AthenaDiagnostics.com)

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## Third Annual Above Par Classic May 16, 2009

Please join us for the third annual Above Par Classic: A Unique Dining & Auction Event, Saturday evening, May 16th, at the Windyke Country Club in Memphis. This entertaining fundraiser features wine and beer tastings, culinary delights from area restaurants and caterers, an extensive live and silent auction, music, and a unique \$10,000 Putting Challenge geared for golfers and non-golfers alike. Admission is \$50 per person in advance and \$65 per person at the door. Reserved table sponsorships are available in advance for parties of 8 for \$500.

For more information, including online registration, visit [www.pkdcure.org/memphischapter](http://www.pkdcure.org/memphischapter)

In order to make this year's event our best one ever, help is needed securing quality auction items. If you, or anyone you know, can assist with this effort, please contact Karyn Waxman 901-491-4799 or email [memphischapter@pkdcure.org](mailto:memphischapter@pkdcure.org).



Don't miss your chance to bid on the great items we will have at this year's Above Par Classic!

## Driving Home a Cure for PKD May 19, 2009



Now in its eighth year, the Memphis Driving Home A Cure For PKD Golf Tournament has raised in excess of \$300,000 to help promote programs of research and education benefiting those affected by PKD. This year's all day golf event will take place Tuesday, May 19th, at the Windyke Country Club in Memphis. Golfers may participate in our morning Triple Play Pairs Event for \$250 per player/\$500 per team, our afternoon Strategic Tee Box: Four Person Scramble Event for \$200 per player/\$800 per team, or golf all day as VIP Sponsors. All players enjoy welcome gifts, a free golf clinic, boxed lunch, mulligans, putting & driving contests, closest to the pin competitions, beverages, snacks, and a dinner Awards Banquet. Prizes are given to first and second place team finishers in the morning, and the winners of four random flights, "CURE", "P", "K", and "D" in the afternoon event.

For information about golf sponsorship opportunities and team pairings please contact golf Chair Jerry Waxman (901) 755-7831 or email [jwaxman@mississippipolymers.com](mailto:jwaxman@mississippipolymers.com). Online registration is available at [www.pkdcure.org/memphischapter](http://www.pkdcure.org/memphischapter).

## Celebrate The Spirit of the Flame

To help thank our participants and celebrate our success, we invite our non-golfing friends and family members to join us for the annual Driving Home A Cure For PKD Dinner Awards Banquet, beginning at approximately 5:45 p.m. Tuesday evening, May 19th. It is here where we will pass the torch of The Spirit of the Flame Award--honoring the memory of beloved volunteer Margaret Anne Underwood—onto an outstanding Memphis Chapter volunteer. Dinner only guests may join us for an \$18 per person donation. Reservations are requested by Friday, May 15th.

Register online at [www.pkdcure.org/memphischapter](http://www.pkdcure.org/memphischapter). For more information contact Karyn Waxman (901) 491-4799 or email [memphischapter@pkdcure.org](mailto:memphischapter@pkdcure.org).