

ADPKD Clinical Database Project Underway

The ADPKD Clinical Database is a collaboration which includes the major players involved in getting drugs approved to treat ADPKD: The Food & Drug Administration, pharmaceutical industry and clinicians with years of data collected from PKD patients and the PKD Foundation.

The years of accumulated clinical data gathered in observational studies at three major sites will provide the foundation of the database. New data from the CRISP & HALT studies, as well as other current clinical trials, will be added to the database in the future. This is a situation where more is better. Once it is all gathered in one spot, the data can be analyzed and will provide a natural history of the disease over time. Changes over time in various clinical measurements, such as blood pressure and total kidney volume, and more subjective factors, such as quality of life and pain, will be documented. This information will be used in the design of future clinical trials.

The first phase of the database project began July 1, 2009. This first year will focus on data elements in existing registries and those to be included in the new database. The first face-to-face meeting of major participants is scheduled for August 27-28 in Washington, D.C.

NEW Online PKD Learning Center

The PKD Foundation recently launched the PKD Learning Center online. It can be accessed from the www.pkdcure.org homepage. The PKD Learning Center is a compilation of many of the tools we use to help broaden understanding of this disease. This comes in the form of written material, webinars and a new addition - video vignettes. You will see we have tried to segment all these pieces to address the various ways people process information. Additionally, we have provided a "stages" module to help people pinpoint information pertinent to where they might be in their journey with PKD. Eventually, we'll also look to provide the same full blown treatment for ARPKD.



9221 Ward Parkway, Suite 400
Kansas City, MO 64114

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



PKD Foundation

DETROIT CHAPTER

SUMMER 2009



A Message From Your Coordinator

It has been a very busy summer already. I attended the National Convention on PKD in Oakbrook, IL in June. There I connected with Chapter Coordinators from all over the United States and Canada for two days of PKD Chapter training and then two days at the convention.

In July, members of our Detroit Chapter participated in taping an informational show for Ann Arbor Cable Television Network through a roundtable discussion format. The panel included, Dr. Benjamin Margolis, MD, University of Michigan Nephrology Department and member of the PKD Foundation Scientific Advisory Committee, Keith Reynolds, Rick Covault, and I. A huge "Thank You" to Rick Covault, Detroit Media Coordinator for developing the idea, writing and acting as commentator for the show, and to Keith Reynolds for sharing his story on how ADPKD affects his life. Thank you also to Carol Siedl for her assistance in getting us on air, and to Dr. Margolis for being a great resource and supporter to the Detroit Chapter. We hope to share this show with the other cable networks in the area. Just one more way, Detroit is spreading the word about PKD.

In August, we will tape a segment for Smooth Jazz Radio V98.7 to promote our upcoming Walk for PKD on 9/26/09 at Boulan Park, Troy, MI.

I would like to give a huge thank you to all our volunteers who give countless hours in their work for a cure!

Kathy Glynn, Detroit Chapter Coordinator

Volunteering Makes Your Chapter Stronger

The Detroit Chapter is bringing 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. Finding out about our Volunteer opportunities is easy and effortless. Simply contact us at DetroitChapter@pkdcure.org and ask to be placed on the volunteer email list. We will then e-mail you whenever volunteer opportunities come up, and you can decide if this is the right opportunity for you. It is that easy to start making a difference!

Stay Informed Though Email and our Website!

With the rising cost of printing and postage, the Detroit Chapter now does most of its communication through email and the Chapter website: www.pkdcure.org/DetroitChapter. To be sure you don't

miss out on the latest information, email DetroitChapter@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.

CHAPTER INFORMATION

Chapter Coordinator:

Kathy Glynn

248-761-9944

DetroitChapter@pkdcure.org

www.pkdcure.org/DetroitChapter

Walk For PKD: 20/20 Vision – A Clear View of a Cure!



In just eight short years, the Walk for PKD has become the signature event for funding programs of research, advocacy, education, support and awareness for polycystic kidney disease. Though the fundraising is truly impressive – more than \$12 million in eight years - we have just begun to scratch the surface. Here in Detroit we raised \$48,297 last year and are aiming for \$50,000 in 2009.

The PKD Foundation is focused on rallying everyone to get involved and make an even bigger impact in the fight against PKD. This year, we are asking all Walk participants to ask 20 friends for \$20, and join our 20/20 Vision. Can it really be that easy? Truthfully, It is. Keeping it simple and remembering that when we focus on fundraising, the results are clear – we will get one step closer to a cure for PKD.

Do you know 20 people whom you could ask for \$20 each to support your efforts? If all 14,000+ walkers last year had done just that we would have raised more than 5.6 million in 2008. Here in Detroit, if we had all walkers focused on 20/20 Vision we could achieve our highest walk yet – and that means doing the most yet for the fight against PKD.

Ready to find out just how simple it is for yourself? Visit us online at www.pkdcure.org/DetroitWalk and register to Walk; registration is free. Then start asking! Join us in 2009 as we set our sights on a cure with 20/20 Vision; though the biggest reward is knowing that you have made a difference, there are great prizes to say thanks. Raise \$100 and earn a T-shirt; raise \$200 or more and also receive a great prize!

The Detroit Walk for PKD will take place on Saturday, September 26, 2009, at Boulan Park, Troy, MI. Registration opens at 10:00 am and the walk starts at 11:00 am. Once again, the Troy Athens cheerleaders will lead us off the start. Bagels and fruit, as well as, lunch will be served along with many other surprises. Mark your calendar and join us for the Walk for PKD.



ARPKD Families...Connected

For years now, hundreds of walkers have come out on Walk for PKD day to honor the lives and memories of their loved ones with ARPKD. The 2009 Walk for PKD will be no different. Last year the ARPKD Chapter was able to arrange a feature during registration for the Walk for PKD that allowed ARPKD families to set up their teams in a "Division" – a way of connecting the ARPKD families across the world as one powerful group within the larger PKD community. Last year alone the PKD Foundation had 66 teams registered as "Walking for ARPKD" at over 34 walk events, raising more than \$202,000. Out of 32 teams recognized in the inaugural class of TeamFirst teams, seven were ARPKD-designated teams.

Joining in on a local level or hosting your own "Virtual Walk" under the "Walking for ARPKD" designation is a great way to connect locally and nationally with other families affected by PKD, including those with ARPKD. It's a great way to be a part of a larger community serving the same goal...that no one suffers the full effects of PKD. And if there is a walk in your area to attend, it's a fun and powerful way to do something positive to help support research, education and advocacy for PKD.

If you have questions about how your family can join or how you can get support year round, please contact Julia Roberts (404-731-8931) or Michele Karl (914-522-6193) or arpkdchapter@pkdcure.org.

Plan Your Own Event

There are many people who support the PKD Foundation and want to get involved in their local chapter. We understand it's not always possible to attend meetings or other chapter activities. However, you can still participate by holding a fundraiser in your town and then donating the proceeds through your chapter. Your fundraiser will play a major part in funding more PKD research, awareness, education and support!

Who should consider doing this?

Anyone who has a good fundraising idea, wants to devote some time to planning/promoting it and will work through the Chapter Coordinator. The fundraiser possibilities are endless. You name it and one of our chapters has probably done something similar.

What type of fund raiser do you hold?

Think about something you already know, like to do, would be fun and think others would attend. Examples: A person who is a regular golfer may want to hold a golf tournament. Someone who likes to throw parties, may have a dinner party/fundraiser. People who belong to clubs or other organizations may consider planning events that would appeal to members of those groups.

A few things that will make a fund raiser more successful include:

- Notify your Chapter Coordinator about your idea as soon as possible. Although you will take the lead on this event, working through the chapter will ensure that more people know about it, PKD Foundation procedures are followed and other chapter supporters possibly help you make it happen.
- Plan well ahead – it takes time to plan and promote any type of event; so plan at least a few months ahead for the best results.
- Keep expenses low – no more than 10-15% of your expected revenue; otherwise, you will spend more than it is worth to hold the event. Get as much donated as possible.
- Hold it in a safe, central location with ample parking or other transportation options.
- Get others involved in helping to plan and execute the event.
- Promote, Promote, Promote; PKD Foundation staff can help with this as long as you plan ahead.

Need Ideas?

Here are a few fundraisers that PKD Foundation Chapters have held: Golf Tournaments; Motorcycle Rides; Yard Sales, Bake Sales; Dinners/Cooking Demonstrations; Fashion Shows; Restaurant Fund Raiser (restaurants donate % of proceeds for that day); Silent Auctions; Parties – charge per person – promote through social networks; Holiday Book Wraps; Wine and Cheese Tastings; Local Sporting Team Events.

So, if you're ready – get in touch with your Chapter Coordinator. Discuss your idea. Then plan and hold your own fundraiser!

Detroit Chapter Calendar of Events

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

September 15, 2009
Chapter Meeting

November 17, 2009
Chapter Meeting

September 26, 2009
Walk for PKD
Boulan Park

December 15, 2009
Chapter Meeting

October 20, 2009
Chapter Meeting

The Detroit Chapter holds meetings on the third Tuesday of every month at the Beaumont Hospital Administration Building, Dining Rooms A & B, Royal Oak, MI from 6:30 p.m. to 8:30 p.m. We hope to see you there!

