

PKD Clinical Trials

The clinical trials part of the Foundation's website will see some major changes by the end of the summer. The new design will group the trials by drug being tested and show how far along in the testing and approval process each one is. Although approval can not come too soon for those with ADPKD, it is encouraging to see how far along in the process many of the studies are.

Here are some updates:

- Dr. Andreas Serra and colleagues recently published the preliminary safety and tolerability results of the first 6 months of treatment with sirolimus in 50 patients. They found that treatment of ADPKD patients with the drug at a low dose is safe and does not cause loss of protein in the urine or does not impair GFR. Efficacy results, or whether or not the drug slows or stops disease progression, will be published once the clinical trial is completed.
- A new clinical trial testing rapamycin in ADPKD has begun at Yale University. This study is designed to determine whether rapamycin is a safe and effective treatment for patients with ADPKD. Total kidney volume and cyst volume will be measured. Blood and urine samples will be collected to evaluate changes in biomarkers thought to be associated with the disease.
- Two recently-released scientific publications report on drugs that have been found to be effective in mouse models of advanced cystic disease. Both rapamycin and R568, a drug that affects calcium levels, were found to slow disease progression. Although it is still early in the process, it is hopeful to see research efforts directed to this segment of ADPKD patients.



9221 Ward Parkway, Suite 400
Kansas City, MO 64114

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



PKD Foundation

INDIANAPOLIS CHAPTER

SUMMER 2009



A Message From Your Chapter

Hello Indianapolis Chapter Members! I have now completed my first few months as your Chapter Coordinator. We are not alone in our quest to gain awareness and funding to help our cause. If you have never been to the National Convention I suggest you try to get to one soon. I learned so much in just a few short days and the speakers were top notch in their fields.

The time is now to get involved and volunteer. Our annual walk is scheduled for Sunday, Sept 13, at Ft Harrison Park. Since this is our signature fundraiser I hope everyone can participate. Please see article on the "Walk For PKD". If you need the walk posters or brochures to hand out please contact me. Something new for the walk this year is that a local radio station could possibly be there and will pass out free stuff and hopefully we can get a little airtime. In addition I am hoping to have a few other booths set up from Dialysis Centers and a booth selling hand made jewelry items showcasing PKD with 50% of the proceeds going to the walk.

If you haven't volunteered yet or would like to help out with The Chapter and/or The Walk, please come to a Chapter meeting or contact me directly. Check out the calendar for other events in the planning stages for this coming year.

Thank You,

Rosie Peterson, Chapter Coordinator

Volunteering Makes Your Chapter Stronger

The Indianapolis 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 IndianapolisChapter@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 costs of printing and postage, The Indianapolis Chapter now does most of its communication through email and the Chapter website: www.pkdcure.org/indianapolischapter. To be sure you don't miss out on the latest information, email indianapolisChapter@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:
Rose Peterson
317-985-2042
IndianapolisChapter@pkdcure.org
[www.pkdcure.org/
IndianapolisChapter](http://www.pkdcure.org/IndianapolisChapter)

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 Indianapolis we raised \$23,460 last year and are aiming for \$27,000 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 Indianapolis, 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/IndianapolisWalk 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!

We are so excited to be able to have a third annual walk held in Indianapolis. To be able to host it at the same location at Ft. Harrison is a big plus. This year we are holding the walk on Sunday, September 13th. Registration is at 11am and the walk is at 12. We even have a local radio station and a clown for face painting. In addition, we are hoping to have a few information booths along with some fundraising booths set up. Don't miss this great event and an opportunity to mingle with other PKD families. To volunteer contact us at IndianapolisWalk@pkdcure.org.

Indianapolis Chapter Calendar of Events

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

Our chapter meetings are held at 6:30 p.m. at the Glendale Library Branch Auditorium

October 8, 2009
Chapter Meeting

December 3, 2009
Chapter Meeting

September 13, 2009
Walk for PKD
Ft. Harrison State Park

Our chapter is also planning some other really great events for the future. We will be hosting a Euchre Tournament, Wine Tasting and Silent Auction, and a Chapter Education Seminar. If you would like to help plan any of these events contact us at indianapolischapter@pkdcure.org.

Exciting New ADPKD Clinical Database Project

The ADPKD Clinical Database is a collaboration which includes the major players involved in getting drugs approved to treat ADPKD: The Food & Drug Administration, the pharmaceutical industry, 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.

Plan Your Own Event

There are many people who support the PKD Foundation and want to get involved in their local chapter. However, it's not always possible to attend meetings or other chapter activities. Well, you can still participate by holding a fundraiser in your town and then donate 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?

Well, 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, PDK 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 execute the event
- Promote, Promote, Promote; PKD Foundation staff can help with this as long as you plan ahead.

Need Ideas?

Here are just some 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 fundraiser!

NEW Online PKD Learning Center

The PKD Foundation recently launched the PKD Learning Center online and you can access it from the www.pkdcure.org homepage.

The PKD Learning center is a compilation of many of the tools people use to help broaden their understanding of this disease. The information comes in the form of written material, webinars, and a *new addition* - video vignettes. As you will see we have tried to segment all these pieces to address the various ways people process information. Additionally, there is a "stages" module to help people pinpoint information pertinent to where they might be in their journey with PKD. Log on and check it out! Eventually, the PKD Foundation will look to provide the same full blown treatment for ARPKD.

