

## 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.



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



## PKD Foundation

# ST. LOUIS CHAPTER

SUMMER 2009



## A Message From Your Chapter

We met many inspired and dedicated people from around the United States and Canada at the National Convention in Chicago which may help rejuvenate the batteries for our chapter in St. Louis.

We are very fortunate in the St. Louis area to have many resources in the medical facilities and staffs and the local area businesses. We are even more fortunate to have a group of volunteers who regularly step up to the plate when they are needed. We are all volunteers working together to raise awareness of PKD to support our mission, that no person should have to suffer the full affects of Polycystic Kidney Disease.

## ARPKD Families...Connected

For years now there are hundreds of walkers that 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 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, 7 were ARPKD- designated teams.

Joining 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](mailto:arpkdchapter@pkdcure.org).

## Stay Informed Though Email and our Website!

With the rising costs of printing and postage, The St. Louis Chapter now does most of its communication through email and the Chapter website: [www.pkdcure.org/StLouisChapter](http://www.pkdcure.org/StLouisChapter). To be sure you don't miss out on the latest information, email [StLouisChapter@pkdcure.org](mailto:StLouisChapter@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.

## Volunteering Makes Your Chapter Stronger

The St. Louis Chapter is bringing a variety of exciting events, meetings, and educational opportunities to the area. But to do this we need your help!

### CHAPTER INFORMATION

Chapter Coordinator:

Reed Shafer

314-517-1161

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

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

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 [StLouisChapter@pkdcure.org](mailto:StLouisChapter@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.

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



"We would like to give a special 'Thank You' to SCOTTRADE for being our general sponsor for the 2009 PKD Walk in St. Louis"

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 St. Louis we raised more than \$72,000 last year and are aiming for \$60,000 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 St. Louis, 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/StLouis](http://www.pkdcure.org/StLouis) 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!

## 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.

## 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](http://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.

## St. Louis Chapter Calendar of Events

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

**September 14, 2009**  
Chapter Meeting

**September 20, 2009**  
Walk for PKD  
Tower Grove Park

**October 12, 2009**  
Chapter Meeting

**November 9, 2009**  
Chapter Meeting

**November 13, 2009**  
Trivia Night

**December 3, 2009**  
Wine and Cheese Tasting  
The Wine and Cheese Place

Our Chapter meetings are generally held the second Monday of each month from 7:00 p.m. to 9:00 p.m. at the World Trade Center, in room 1012, located at 121 Meramec in Clayton, MO 63105.

## 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?

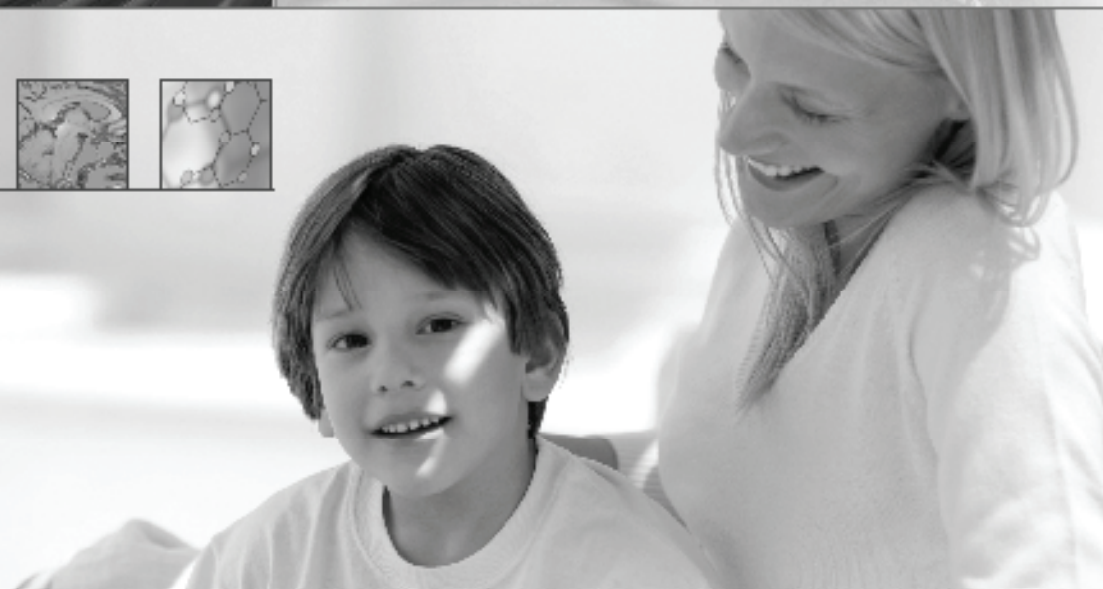
Well, think about something you already know, like to do, would be fun and think others would attend. Examples: A person who is a regular golfer may want to hold a golf tournament. Someone who likes to throw parties, may have a dinner party/fundraiser. People who belong to clubs or other organizations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

## 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.

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# Benefit Trivia Night

Please Join Us

In Helping Nelson Capita Fight PKD

Proceeds will benefit the Nelson Family and the  
PKD Foundation.

**Friday, November 13, 2009**

**6:00 p.m. to Midnight**

**Open Bar 7:00 p.m. to Midnight**

St. Charles Elks Lodge  
560 St. Peters Howell Road  
St. Peters, MO 63376

**Cost: \$240/Table of 8**  
**\$30/person**

Open Bar

Silent Auction

50/50 Raffle

Door Prize Raffles

For More Information and to reserve your spot, please contact  
Katie Capita at 636-448-7851 or by email at [kcapita@charter.net](mailto:kcapita@charter.net)  
or Linda Zellweger at 636-261-7427.