

PKD

A magazine to inform and educate PKD patients and families,
Foundation supporters, health professionals and researchers.

Progress

Summer 2015

PKD IN THE SPOTLIGHT: Celebrities Raise National Awareness

Pages 3, 8, 9

INSIDE:

3

Celebrity chef competes
for PKD on Food Network

4

Under the microscope: A closer
look at year-one progress from
PKD research grants

8

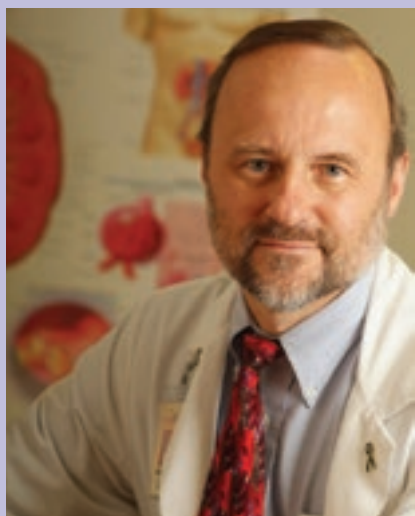
New Orleans Saintsations
cheerleader fulfills dream
and helps raise awareness

10

NEW: Education programs



PKD FOUNDATION
Polycystic Kidney Disease



Benjamin D. Cowley, Jr. M.D., is the incoming PKD Foundation Board Chair.

“My interaction with PKD patients and their families fuel my determination to help the Foundation be successful.”

New Board of Trustees Chair leads the journey to end PKD

Early in my career as a physician and researcher, I had the good fortune to train with Jared Grantham, M.D., co-founder of the PKD Foundation. That experience lit a passion for me to focus my life's work on PKD. I've published papers and presented at conferences. I've rubbed elbows with the biggest names in PKD and kidney research. Now, as the new Chair of the PKD Foundation Board of Trustees, I have an opportunity to have an even bigger impact. Through my early experiences with Dr. Grantham, I've been a part of the Foundation since its very beginning. For the past 32 years, the Foundation has put immense effort and resources into finding treatments and a cure for PKD, and we're just getting started.

I'm particularly encouraged by initial reports from the 15 research grants that the Foundation awarded last year. In just 12 months we're already seeing progress. *Read pages 4-7 about what we've learned, including a closer look at two of the grant recipients, and visit pkdcure.org/research/grants.*

As a physician, I see firsthand how PKD impacts people. My interaction with PKD patients and their families fuel my determination to help the Foundation be successful. In addition to research, this includes providing education and information so people can better manage their lives with PKD, and elevating awareness.

There are big things ahead for PKD and I'm proud to be a part of that. Dr. Grantham has put his faith in the leaders of the Foundation, and as the Board Chair, it is now my job to help steer us on the journey to find effective treatments and ultimately a cure for PKD. I hope you stay with us on our path to changing the future of PKD.

Sincerely,

Dr. Cowley lives in Oklahoma City Okla. He is the Chief of Nephrology & Hypertension and John Gammill Professor in Polycystic Kidney Disease at the Oklahoma University Health Sciences Center, and has been involved in PKD research for nearly 30 years. He has been named one of Oklahoma's "Top Doctors" by Castle Connolly Medical Ltd. for the past five years. Read his full bio at pkdcure.org/board-of-trustees.

Meet Dr. Cowley and other top PKD experts at the PKD National Convention 2016.

Orlando / June 24 to 26, 2016

Learn more and hear what people had to say about Convention 2014 at pkdcure.org/convention

Dr. Cowley served on a panel at the PKD National Convention 2014 discussing progress and the future of PKD research with Scientific Advisory Committee Chair and Board Member Terry Watnick, M.D., and Arlene Chapman, M.D., former SAC Chair and Board Member.



Award-winning chef brings national awareness to PKD by competing on Food Network's *Chopped All-Stars*

Chef Michael Psilakis competed against fellow celebrity chefs in the fourth season of the *Chopped All-Stars* tournament on the Food Network in May. Michael was the runner up in the competition, coming very close to winning \$75,000 for the PKD Foundation, his charity of choice. Through his time on the show, the PKD community came together to cheer him on, and he helped raise awareness of PKD on a national level.

Michael thought of the PKD Foundation when he was asked to participate in *Chopped*, and he hoped it would be a great way to raise awareness. "When I was asked to do *Chopped All-Stars* and win money for a charity, it piqued my interest," he said. "If I can raise awareness and tell the story of PKD on television, I will do it. I want to engage the viewers and reach those affected by PKD."

PKD ultimately caused his father's death. He was on dialysis for 10 years and came close to a match for a transplant several times. After a thyroid procedure, he passed away from complications from his PKD. "My father was a very strong and powerful man. He was the head of our family, but PKD took his strength away from him, which hit us the hardest. He wasn't the same person."

Michael is the executive chef and owner of seven New York restaurants and has acquired many of the food world's highest honors in the short time he has been on the culinary scene.

Many thanks to Michael for bringing attention to PKD and the PKD Foundation! To learn more about Michael, visit michaelpsilakis.com. ■



Chef Michael Psilakis on *Chopped All-Stars*.
Photo Courtesy of Food Network

"If I can raise awareness and tell the story of PKD on television, I will do it. I want to engage the viewers and reach those affected by PKD."

AWARDS

Esquire Magazine "Chef of the Year"

Food & Wine's "Best New Chef"

Bon Appetit's "Chef of the Year" distinctions

Nominated for A-List Chef by Bravo TV

Restaurant Anthos (upscale Greek) nominated for a James Beard Award/Best New Restaurant.

RESTAURANTS

Executive chef and owner of seven New York restaurants: Kefi, FISHTAG, MP Taverna (Roslyn, Irvington, Astoria, Williamsburg), The Hall Brooklyn (a performance venue and restaurant).

NATIONAL SPOTLIGHT

Appeared on the TODAY show, Good Morning America, and Live with Kelly and Michael.

In numerous publications including *The New York Times*, *Men's Health*, and *Food & Wine* magazine.



During the competition, the Foundation followed along on social media. Comments included:

"You are a PKD champion to those of us who suffer every day."

"Thank you for making America aware of what this disease is all about."

"You should have won it, but ultimately you heightened awareness of PKD and that is a victory in itself."

"Thank you for shining a light on PKD."





Promising directions and diverse research shine in PKD Foundation funded research grants

There are many different biochemical and molecular pathways that are altered by PKD in renal cystic cells. Therefore, a “one size fits all” treatment may not be found in the near term. To help meet this demand, the PKD Foundation is funding 15 research projects selected for their promise in developing diverse new strategies to treat ADPKD and ARPKD. The PKD Foundation is spending nearly **\$2.4 million over two years** on these grants.

After the first year of funding, we ask for updates on the progress of this research. The results reported represent one year of work and are subject to change as the research progresses toward its stated goals. We are excited the results to date highlight the diversity of this research and the promising directions it has already taken.

Interim research results 2015

The use of 2-deoxy glucose (2-DG) in PKD is being explored. These studies have shown that the treatment of rodents with 2-DG can slow the growth of cysts through metabolic alteration, without affecting the overall body weight of these animals, a simple measure of potential toxicity. Therefore, these results are encouraging because the effect of 2-DG seems to affect the abnormal kidney more than other tissues.

The growth of cysts in PKD has also been shown in part to be due to two chloride transporters in the cells lining the cysts. An experimental reagent, which may be a lead for a new drug, has been shown to reduce cyst growth by affecting the function of these transporters. Yet another approach to slowing cyst growth is 11- β -dichloro, an experimental anti-tumor agent. It has been shown to slow cyst growth in rodents missing polycystin-1 (PC1), one product of one of the mutated genes that cause PKD, in their kidneys. Curiously, the cells lacking PC1 underwent programmed cell death (apoptosis). Importantly, the overall body weight of these animals was not significantly affected, nor was kidney function.

Showing that there is no shortage of potential targets, heat shock proteins (HSP) are expressed in ADPKD

caused by mutations in either PC1 or polycystin-2 (PC2). Inhibitors of HSP90 have been shown to decrease growth of cysts due to either mutation. Importantly the use of 2-DG appeared to work in concert with the HSP90 inhibitor to slow cyst growth. It may be that a combination approach to these pathways will be the most effective.

MicroRNA, a hot topic in a variety of biomedical research areas, has been shown to play a role in ADPKD pathogenesis. Deleting a specific microRNA cluster, miR-17, has been shown to limit cyst growth in a relevant model of ADPKD. This research highlights how much is yet to be discovered about the cellular effects of PKD.

A new model of a recessive form of PKD involving a new gene mutation, TULP3, has been developed: the Tulp3GS mouse. This mouse will serve as an important genetic tool to determine how defects in the single cilium of kidney cells are translated into increased proliferation and secretion by these cells. Other genetic models of mice are being developed, which can be induced to re-express the normal form of PC2 during the lifetime of the animal. These experiments will be extended to the more common form of ADPKD involving PC1. These forward-looking experiments will test the

Read full summaries at pkdcure.org/research/grants



hypothesis that mutant forms of these proteins might eventually be replaced with their normal forms to determine whether this switch promotes the long-term survival of these mice.

New research is focused on both ADPKD and ARPKD, and what they share in common with the intracellular transport of proteins to the cilium and elsewhere. This research will identify additional targets for correcting the defects in renal tubular cells prone to forming cysts.

Yet another target of PKD research is a group of enzymes called histone deacetylases (HDAC). Inhibition of these enzymes act on chromosomal proteins called histones which affect the way genes are expressed or silenced. Inhibitors of HDACs have now been shown to decrease the severity of ADPKD in mouse models. More specific inhibitors of HDACs are being explored whose effects might be more specific for the kidney.

Cyclic AMP (cAMP) is known to increase the growth and proliferation of cysts in PKD. Phosphodiesterases are enzymes that can break down cAMP. The use of phosphodiesterases to control cyst growth is being explored in zebra fish, in part because these animals have the same relevant phosphodiesterases as do humans.

One of the many abnormalities in PKD involves the potassium channel KCNN4. Genetic animal models of PKD that lack this channel do better than those that have the channel. Therefore, it is reasonable to assume that inhibition of this channel may be effective in reducing the severity of PKD. An inhibitor of KCNN4 known to be safe in humans is being tested to determine if it will limit the growth of cysts in animal models, and because it is safe, its testing in humans as a repurposed drug could be expedited.

The mutations responsible for PKD are expressed in the cilium that renal tubule cells have. This research looks at the fundamental physiology of the cilium in renal physiology and how normal function becomes pathophysiological in PKD. This type of research is critical to our understanding of PKD as a type of ciliopathy (pathology of the cilium) due to the mutations in polycystin-1 or polycystin-2. Like the zebra fish, much of the critical research on the cilium has utilized microscopic multicellular or even unicellular organisms. ■

Using fish might seem strange at first, but many of the most significant breakthroughs in biomedical science have occurred in small and sometimes strange organisms.



A Closer Look

The Mrs. Pamela Whitcomb Larsen Award

The Role of Beta-catenin as Signal Integrator in PKD

Jordan Kreidberg, M.D., Ph.D.

Boston Children's Hospital



Jordan Kreidberg, M.D., Ph.D.

Jordan Kreidberg, M.D., Ph.D., received advanced degrees from the Johns Hopkins University School of Medicine when molecular biology was growing exponentially. Following his residency in pediatrics at Boston Children's Hospital, he did his post-doctorate fellowship at the Whitehead Institute for Biomedical Research in the early to mid-90s. The two genes Dr. Kreidberg worked on during that time are both crucial for normal kidney development.

"During my time as a post-doc, researchers were just beginning to use mouse knockouts (putting specific mutations into mice)," Dr. Kreidberg said. "This was a brand new technology at the time, and helped with understanding the function of these genes in mammals, as now. Mouse knockouts allowed researchers to create mouse models of human genetic disease, placing mutations in the same genes that cause the human disease."

The two genes he studied were the Wilm's tumor-1 gene, in which a mutation causes mice to be born without kidneys, and a member of a family of proteins called integrins, in which a mutation causes the kidney not to develop normally. **After 10 years studying the role of these genes in developmental biology Dr. Kreidberg has spent the last 10 years applying the knowledge gained to see how it fit into the understanding of kidney disease.** Specifically, his lab defined signaling pathways regulated by Alpha3Beta1 Integrin that are involved in the growth and differentiation of kidney cells during kidney development. He wanted to see if the pathways he found

were relevant to PKD and particularly if they were exaggerated in cells with a PKD mutation.

The research project funded by the PKD Foundation is focused on the Wnt pathway, thought to be exaggerated in cells that form cysts. Research has not been definitive to this point, so Dr. Kreidberg is aiming to prove that the Wnt pathway is involved in cyst formation.

"If research proves it is involved, pharmaceutical companies are looking for ways to develop inhibitors of the Wnt pathway and this could elevate their interest in using these inhibitors to target PKD," Dr. Kreidberg said. "Since the pathway is also involved in aspects of normal physiology, inhibitors can't blindly block the pathway or it would damage normal organs. So, the challenge is to find the specific Wnt-related pathway forming cysts and block that without affecting the normal physiology."

Dr. Kreidberg appreciates the funding the PKD Foundation provides for his work. "The National Institutes of Health (NIH)'s downturn in funding has affected the kidney research field disproportionately," he said. "Compared to other fields, there is less philanthropy and few private foundations or other sources of funding. The PKD Foundation is one of the very few supporting research in kidney disease, so the funding from the PKD Foundation is extremely important for our field. For us, it specifically has made a huge difference as the NIH funding is much less than it was 10 years ago. The PKD Foundation funding fills in that gap." ■

"The PKD Foundation is one of the very few organizations supporting research in kidney disease, so the funding from the PKD Foundation is extremely important for our field."

Dr. Vincent H. Gattone Research Award for the Top-Rated Grant Proposal Funded by The Carlo and Micol Schejola Foundation

Advancing HSP90 Inhibitors Towards Clinical Trials for ADPKD

Erica Golemis, Ph.D.

The Research Institute of Fox Chase Cancer Center

Erica Golemis, Ph.D., and other researchers at Fox Chase Cancer Center are reviewing the pathological features of ADPKD, and they found many similarities between ADPKD and cancer's signaling pathways and inhibitors. This discovery highlights potential avenues for the use of existing cancer therapeutics in the treatment of ADPKD.

"As we learn more about molecular defects of disease and build really detailed 'maps' describing what goes wrong in cancer or chronic kidney disease or stroke, the more we realize that some specific cell signaling pathways are similarly affected, even though the gross manifestation of the disease at the organ level looks very different," said Dr. Golemis.

"By identifying common signaling defects, we may have the opportunity to take drugs developed for conditions affecting lots of patients, where there has been a huge investment in therapeutics, and use them to benefit patients suffering from conditions that are serious but affect fewer people—and hence have not attracted the same level of investment," Dr. Golemis said.

In their review, Dr. Golemis and colleagues systematically compared ADPKD with the hallmarks of cancer— such as inducing angiogenesis or the presence of inflammation—and identified a surprising number of common signaling features between the two disease types.

According to Dr. Golemis, **researchers have already begun mining available sets of drugs developed for heart disease and cancer to develop clinical trial concepts for ADPKD.**

One example is the use of angiotensin

inhibitors such as lisinopril, developed to control high blood pressure.

"Conversely, by systematic comparison of ADPKD and cancer, and pinpointing areas where the two diseases differ, we can potentially gain insight into important mechanisms that are essential for the presentation of the disease," Dr. Golemis said. "Despite many signaling similarities, ADPKD cells form cysts and 'stay in place'; tumors invade and metastasize, contributing to the much greater lethality of cancer."

In their review, the researchers also evaluated features of ADPKD and determined whether these same features exist in cancer cells.

One element of cell signaling function that researchers find particularly interesting is the role of ciliary function. The cilium is a small organelle (a structural and functional unit in a cell) that stick outs of the cell surface and displays a receptor for certain types of cell signals. Cilia play an important role in the maintenance of normal kidney function.

There is growing evidence in ADPKD that the cilia are absent or function abnormally, whereas with cancers, the role of cilia seems to be split, with certain tumor types depending on the cilia for signaling whereas other types do not.

"These data show that it pays to look more broadly across disease types and not work in research silos," Dr. Golemis said. "We have found that a similar set of genes is being used in different diseases in slightly different contexts, and we have reached a point where comparing signaling defects from one disease to another might allow us to develop ideas for new therapeutics." ■



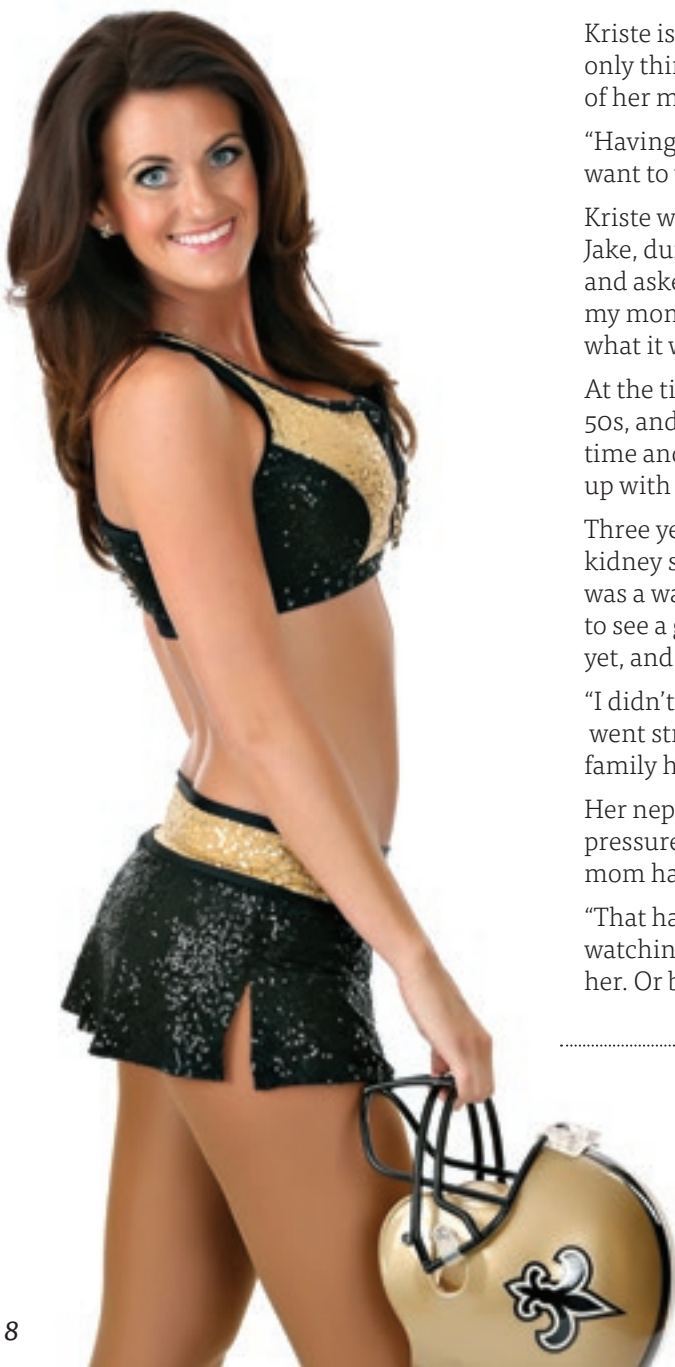
Erica Golemis, Ph.D.

"This discovery highlights potential avenues for the use of existing cancer therapeutics in the treatment of ADPKD."



Kriste Lewis fulfills her dreams and lives her best life with PKD

It was always on Kriste Lewis's bucket list to try out to be an NFL cheerleader. As she approached her 40th birthday, she decided to give herself a gift and fulfill a lifetime dream by trying out to be a New Orleans Saintsation. Kriste made the team in 2014, competing against women mostly ages 18 to 28. And in April of this year, Kriste made the team for the second year in a row!



Kriste is one of only two NFL cheerleaders in her 40s. Her age isn't the only thing that sets her apart. Kriste has PKD. And it has been a big part of her motivation.

"Having PKD had a lot to do with me auditioning," Kriste said. "I didn't want to waste a day. I don't want to let any time go."

Kriste was diagnosed 15 years ago while pregnant with her first son, Jake, during a routine ultrasound. The ultrasound tech got really quiet and asked if she had kidney problems in her family. "At this time, I knew my mom and twin uncles had PKD," Kriste said. "I knew immediately what it was. I had PKD too."

At the time, she didn't worry, thinking it wouldn't affect her until her 50s, and she was only 26. "I tried not to worry about it. I thought I had time and was more focused on having a baby," she said. "I didn't follow up with a doctor about it at all."

Three years later, after having her second son, Rob, she had issues with kidney stones that put her in the ER. Her interaction with the ER doctor was a wake-up call and he said she needed to see a nephrologist. Kriste went to see a general practitioner, who told her that her kidneys weren't an issue yet, and with no treatment or a cure, there was nothing he could do.

"I didn't stop there," she said. "My mom was on dialysis at the time, so I went straight to a nephrologist. I knew that was the right move with my family history."

Her nephrologist visit was successful, and Kriste has been taking blood-pressure medication for the last 10 years. Around the same time, Kriste's mom had a transplant.

"That had a huge impact on me," Kriste said. "I was holding my two babies watching my mom lay in a hospital bed, and thinking about how I could lose her. Or be next. Or that my children could have it as well."

"At this time, I knew my mom and twin uncles had PKD. I knew immediately what it was. I had PKD too."

“Being a member of the Saintsations has taught me that everything we do, no matter how big or small WE think it may be, can potentially have an impact on others. So we should always give our best.”

This was a turning point for Kriste. “I knew I wanted to be strong. So if it was my turn to receive a transplant, I wanted my body to be the best shape it could be. My body already fights my kidneys every day, it shouldn’t have to fight me too. I wanted to give my body the tools it needs to be as healthy as possible.”

Having trouble getting the weight off after her second child, Kriste started slow with a Yoga DVD while her children napped. As they got older, she joined exercise classes and made more of a commitment to physical fitness, working as a fitness instructor the past few years.

“I had been a teacher, then a stay-at-home mom and was now a fitness instructor,” Kriste said. Kriste strongly encourages PKD patients to take the best care of themselves they can.

“Even though I am 10 years older than when I first visited a nephrologist, my blood pressure and creatinine numbers have improved,” Kriste said. “My lifestyle and commitment to health matter. I encourage everyone, make a change and live your healthiest life. Exercise doesn’t have to be torture. Don’t give kidney disease a leg up!”

Kriste uses the spotlight to raise awareness for PKD

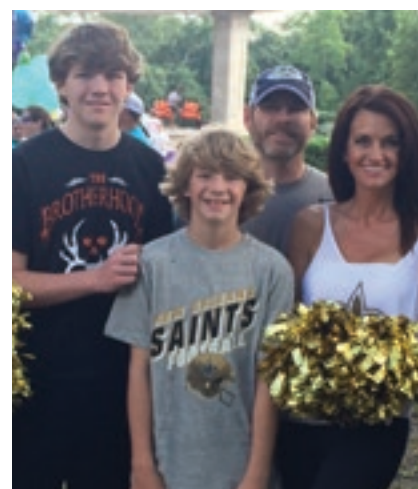
“I never thought I would be a fitness instructor, but I also never thought I would be an NFL cheerleader either!”

Once Kriste made the team, she immediately garnered national recognition. With appearances on Good Morning America, ESPN, The Doctors, and The Steve Harvey Show, Kriste has helped to raise national awareness of PKD. Kriste also attends local events to support the Foundation

“I honestly had no idea that anyone would be interested in my story, but just being able to share about PKD with people, I think has really been a blessing for me,” Kriste said. “I encourage others to take what they are given and give back. People come up to me at games and tell me they are a kidney donor or their mom is on dialysis, and being able to relate and connect with them is magical. **Find your blessing in an unusual place and give back!**” ■



Kriste with former Board of Trustees member, Mike Haggard, who organized Kidney Casino for a Cure with his wife, Bekki, and sister Becky McCarron. This was a DIY event for the PKD Foundation ([visit pkdcure.org/diyforpkd](http://pkdcure.org/diyforpkd)).

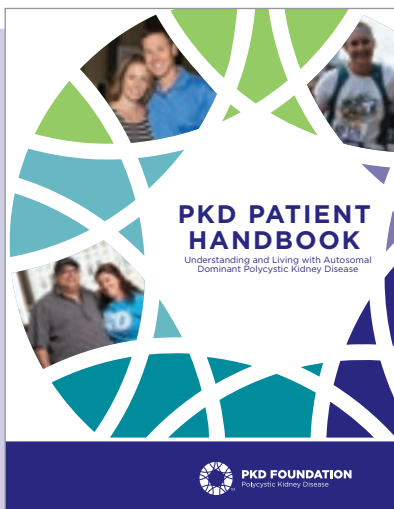


Kriste and her family at the New Orleans Walk for PKD.

SHARE KRISTE’S VIDEO ON #PKDAWARENESSDAY

Kriste is featured in a short video to help widen the circle of people who know about PKD. “You may not have heard of PKD, but you probably know someone who has it.” We are asking people to share this on #PKDAwarenessDay Sept. 3. Stay tuned to emails, social media and the website for more about this. pkdcure.org/aware





PKD Patient Handbook Available

The PKD Patient Handbook is an education resource for PKD patients and anyone impacted by PKD. It is available to download for free, or you can request a free print copy by visiting pkdcure.org/learn/resources.

New Education Programs

Introducing Webinar Wednesdays with CSO

Webinar Wednesdays, with PKD Foundation Chief Scientific Officer (CSO) David Baron, Ph.D., is a new ongoing virtual series held the third Wednesday of each month at Noon Central Time.

Dr. Baron will speak about the science of PKD with time for questions at the end.

Upcoming topics are:

August – How do cysts form?

September – The ABC's of drug development.

Register at pkdcure.org/webinar-wednesdays.

Upcoming national webinars

Kidney stones

Aug. 18
7 p.m. Central Time

Emotional toll of PKD

October (date TBD)
7 p.m. Central Time

The sequence of drug development

Speaker: PKD Foundation CSO David Baron
Dec. 2
7 p.m. Central Time

For more information, visit pkdcure.org/webinars.

Research News

Treatment for ADPKD approved in Europe

JINARC® (tolvaptan) is the first approved treatment in Europe for autosomal dominant polycystic kidney disease (ADPKD). JINARC® was discovered in Japan by Otsuka Pharmaceutical and was first approved there for ADPKD in 2014. Canada approved JINARC® in February 2015.

For patients in the United States, we are hopeful a treatment is within reach as well. Learn how you can play a key role by participating in clinical studies, visit pkdcure.org/clinicalstudies.

FDA Letter of Support issued for TKV as ADPKD biomarker

The U.S. Food and Drug Administration (FDA) issued a Letter of Support to the Critical Path Institute's (C-Path) Polycystic Kidney Disease Outcomes Consortium (PKDOC) for the use of total kidney volume (TKV) as a prognostic biomarker for clinical trials of new therapies for ADPKD.

The Foundation's Chief Scientific Officer David Baron explains, "This is important because it shows that the FDA acknowledges variances in the disease progression of ADPKD patients. It means we are increasing the possibility to be able to treat PKD earlier, at a time when treatments can be more effective, rather than after major damage to the kidneys has already occurred."

TKV is a measurement of the impact of ADPKD on the size of the kidneys and is believed to be an indicator of future kidney function decline. There is no current accepted measure of kidney function that is an accurate marker of disease progression in ADPKD.

PKDOC is a collaboration between the PKD Foundation (the primary funder), C-Path, members of the pharmaceutical industry, PKD researchers and clinicians, and the FDA.

Join the Walk for 2015 and be the difference

Every year, people like you rally around the tens of thousands affected by PKD and take part in the Walk for PKD, our signature fundraising and awareness event taking place in more than 50 cities nationwide. A Virtual Walk is also available for those without a Walk in their area or who are unable to attend their local Walk.

In 2014, the Walk for PKD raised \$1.8 million to fund research, provide education and support to those living with the disease and their families, raise awareness and energize our advocacy work. Since 2000, walkers like you have raised nearly \$24 million.



Registration is now open for the 2015 Walk for PKD.

This year, walk, donate and be the difference for all of those impacted by PKD. Visit walkforpkd.org to register, start a team and learn more.

Watch and share the new **Walk for PKD video** with friends, colleagues and family. Available as a PSA for local media.



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for better health worldwide

The name "Otsuka" translates to
"major milestone."

And indeed, for over 85 years,

Otsuka's people have achieved major milestones in their quest to create new products for better health. Otsuka is hard at work investigating potential new treatments, with numerous compounds in various stages of development to treat disorders of the cardiovascular, gastrointestinal, respiratory, renal, and central nervous systems, and to treat cancer and ophthalmic disorders. We've funded new research, supported new clinical trials, and pursued the development of new medications – an unfaltering commitment of energy and resources with one goal in mind – to create new products for better health worldwide.

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Polycystic Kidney Disease

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GET READY FOR PKD AWARENESS DAY, SEPT. 3

This year we're asking you to share the "Do You Know PKD?" video featuring Kriste Lewis. We'll have other challenges as well, and new PKD gear so stay tuned to email, social media, and the website.

Help us spread the word so that someday, *everyone will know PKD!*

#PKDAwarenessDay
pkdcure.org/aware



PKD FOUNDATION
Polycystic Kidney Disease

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The mission of the PKD Foundation is to promote programs of research, advocacy, education, support and awareness in order to discover treatments and a cure for polycystic kidney disease and improve the lives of all it affects.



ORLANDO | JUNE 24 TO 26, 2016

Join us in Orlando to:

- Discover the latest in research
- Connect with others in the PKD community
- Learn ways to manage your health or a loved one's
- Meet an all-star assembly of doctors, researchers, and PKD experts
- Have fun with friends and family

Learn more and hear what people had to say about
Convention 2014 at **pkdcure.org/convention**.

Held at Disney's Coronado Springs Resort



**Better
Together**
Orlando 2016
#PKDCONVENTION