PKD Foundation Blog Samples

PKDConnection.org

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PKD Foundation (PKDConnection.org)

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PKD Community: Let's Get Connected!

https://pkdcure.org/blog/pkd-community-lets-get-connected/

Welcome to PKD Connection! I am Angela Connelly (pictured left with blog contributor Kelly Welsh). As Chief Marketing Officer for the PKD Foundation, one of the best parts of my job is getting to know people. And there are many amazing people connected to PKD. From patients to caregivers, to staff, researchers, and doctors – all play important roles and have something to share.

The PKD Connection is a hub to bring people affected by PKD together. It's a place for readers to find inspiration and hope, learn about the Foundation and the work of researchers, and get practical advice.

This blog is about, well, connections. I always get inspired when I visit Voices of PKD, pop by the discussion forums, or visit our Facebook page, where I can read stories of courage, strength, and dedication to ending this disease. Our goal is for the PKD Connection to be a similar place, as well as to educate and inform.

In addition to long-time favorites PKD Will Not Beat Me by Valen Keefer, and Health Notes by Renal Dietitian Kelly Welsh, we'll also have posts by:

- People in the PKD community about their experiences with PKD
- Researchers about their work and developments in PKD research
- Doctors and health professionals about managing PKD in your daily life
- Staff about the Foundation's services and programs
- Board of Trustees about the Foundation's work and vision

I'm excited to have this place for people affected by PKD to connect. I hope you find inspiration, and information that makes a difference in how you live your life. I also hope this leads to new friendships, lifts you up, and lets you know you're not alone. The PKD Connection will only be as good as you make it though, so please subscribe, share with friends, and post comments. We also welcome suggestions about what you want to hear about so let us know. I look forward to connecting with you!

Help spread the word on #PKDAwarenessDay

https://pkdcure.org/blog/help-spread-the-word-on-pkdawarenessday/

We have a few special times throughout the year, but ***the one*** I'm most passionate about is completely focused on spreading the word: #PKDAwarenessDay, which falls on Sept. 3.

Last year about this time I heard over and over, "Why can't we come up with our own ice bucket challenge?" Frankly, because

A) it's already been done and
B) it's not our challenge.

Our challenge is getting people to know about PKD, a largely hidden disease. We're going full tilt this year with a special call to action. We created a short video focused on asking people if they know PKD and to spread the word to help end it. Even though PKD is one of the most common genetic diseases – with an estimated 600,000 people in America who have it – very few people have heard of it. The thing is, people probably *do* know PKD, they just don't realize it. They probably have a neighbor, a friend or a co-worker who has 'kidney problems.' If they knew it was PKD to be exact, they would probably step up and help.

But I'm not done. Here's the other challenge:

We have about 80,000 loyal subscribers who receive our emails, along with 20,000 followers on Facebook. These are great numbers, however, if there are 600,000 people in America who have PKD, that's just a little over 16 percent of those who could be reached. **People impacted by PKD need to know about the Foundation. Because the Foundation is the only game in town.** The Foundation is the only organization in the United States solely focused on PKD, ***which means research toward treatment and a cure, and helping people live their best lives through education and information***. We need everyone with PKD, all in, to fight and bring an end to PKD.

So, please send this video on #PKDAwarenessDay to someone you think needs to know about PKD and the PKD Foundation. Please help widen our circle and make us stronger.

Learn more about this special day at pkdcure.org/aware.

Award-Winning Chef Michael Psilakis to compete on Chopped All-Stars for PKD Foundation

https://pkdcure.org/blog/award-winning-chef-michael-psilakis-to-compete-on-chopped-all-stars-for-pkd-foundation/

Tune in tomorrow night as Michael Psilakis competes against fellow celebrity chefs in the fourth season of the *Chopped All-Stars* tournament on Food Network. His episode airs Tuesday, May 12, at 9 p.m. Central Time. If he wins in the final competition round on May 26, Michael will donate $75,000 to the PKD Foundation, his charity of choice.

About Chef Michael

Michael Psilakis is the executive chef and owner of five New York restaurants, including Kefi, FISHTAG and three locations of MP Taverna (Roslyn, Irvington and Astoria). Michael will also be opening his fourth MP Taverna in Williamsburg this spring/summer, along with a restaurant and performance venue called The Hall at MP. Michael acquired many of the food world's highest honors in the short time he has been on the culinary scene. He will be competing against fellow celebrity chefs in the fourth season of the *Chopped All-Stars* tournament on Food Network. His episode airs Tuesday, May 12, 2015, at 10/9 central. If he wins in the final competition round on May 26, 2015, Michael will donate $75,000 to the PKD Foundation, his charity of choice.

"PKD ultimately caused my father's death," Michael said. "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."

Michael thought of the PKD Foundation when he was asked to participate in Chopped, and he viewed it as 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."

A tremendous cook, the chef's mother taught him everything about the flavors and techniques of classic Greek cooking and remains his greatest influence in the kitchen. He was named "Chef of the Year" by Esquire Magazine, as well as Food & Wine's Best New Chef, Bon Appetit's Chef of the Year distinctions; nominated for A-List Chef by Bravo TV; and had his upscale Greek restaurant, Anthos, nominated for a James Beard Award in the category of Best New Restaurant.

Michael has appeared on the "TODAY" show, "Good Morning America," and "Live with Kelly," as well as in numerous publications including The New York Times, Men's Health, and Food & Wine magazine. He was the Co-executive Producer and Co-star of BBC AMERICA's original adventure cooking competition series, No Kitchen required.

Tune in starting Tuesday, April 28, 2015, on Food Network for *Chopped All-Stars* to cheer on Michael! In each episode of the five-part series, four chefs go head to head in competition. The four winners then advance to the finale on May 26, 2015, where big bucks are at stake. One will walk away the All-Stars champion with $75,000 for his or her charity.

Award-winning chef brings national awareness to PKD by competing on Food Network's Guy's Grocery Games and Chopped All-Stars

https://pkdcure.org/voices-of-pkd/award-winning-chef-brings-national-awareness-to-pkd/

Chef Michael Psilakis competed for the PKD Foundation in Guy's Grocery Games and the Chopped All-Stars tournament on the 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."
On Sept. 13, 2015, Michael competed and was victorious in a cooking challenge on Food Network's *Guy's Grocery Games* to win cash for his charity of choice, the PKD Foundation.

On the *All-Stars in the Aisles*episode, host Guy Fieri sent Michael and three other talented chefs running through the grocery store aisles in a high-stakes, high-skills, grocery store cooking competition. Chefs made an upscale dinner using frozen and canned foods; prepared brunch in a multi grocery store cart swap game; and created a dish using one ingredient in two different ways.

This was Michael's second attempt to earn some serious dough and raise awareness for the PKD Foundation. In May he participated in the Food Network's *Chopped All-Stars* and was runner up in the competition.

Through his time on the shows, 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 both programs. "When I was asked to do participate and win money for a charity, it piqued my interest," he said.

Michael's inspiration is his father, who struggled with kidney disease. 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. "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."Many thanks to Michael for bringing attention to PKD and the PKD Foundation! To learn more about Michael, visit michaelpsilakis.com.

Researcher uses stem cells to grow kidney tissue and study PKD

https://pkdcure.org/blog/researcher-uses-stem-cells-grow-kidney-tissue-study-pkd/

Benjamin Freedman, Ph.D., is one of 15 scientists who have recently been awarded with a research grant from the PKD Foundation. He will receive a total of $160,000 over the next two years through the Foundation’s Research Grant Program.

Dr. Freedman’s project will study human pluripotent stem cells that can be used as personalized laboratory models for human kidney disease and as a potential source of on-demand, immunocompatible kidney replacement tissue. These stem cells allow for the generation of human mini-kidney “organoids” that are capable of recreating PKD in lab dishes. The goal is to understand how human PKD mutations cause cystic disease, to test drugs that intervene with this process and to generate patient-matched stem cell products for application in future clinical trials.

We asked Dr. Freedman to share more about his project and about his involvement with the PKD Foundation.

How did you become interested in PKD research?
I’ve always loved science and have been fascinated by the natural world. The scientific process, in a way, is a process of self-discovery, of understanding not just how we work as human beings but how the world works and our place in the scheme of life.

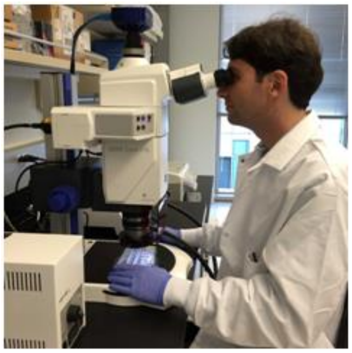
I went to graduate school and got a Ph.D. in molecular biology. This was important because it taught me at a mathematical level how life operates, how cells operate. Toward the end of my studies, I was becoming more aware of people who had medical problems. I was interested in the idea of using this abstract knowledge – about life and cells – to actually help people.

I was trying to decide what my next science project should be, and my mother reminded me that we had friends with PKD. So I started looking into it and that’s how my work in PKD got started.

It’s good to have that personal connection to what you’re doing. It puts a little pressure on me to see that my project results in something that’s going to help people.

What do you hope to achieve with this project?
We’re at the tip of the iceberg in terms of what we can do with these stem cells now. The grant from the Foundation will allow us to actually dig into the system and turn it into something that could really be used to find new therapies. Particularly for PKD, we’ve been able now to show that we can get cysts to form in a dish, but we don’t understand how PKD works in people or how the cysts are developing in a dish.

Now we have a very simple system we can test. It's a defined system, which means that we know everything that's in it. We can look at it under the microscope and watch cysts form over time and investigate how that's happening. In our preliminary work we've found that there are things you can add or take away from these little growing PKD cultures that can actually affect the growth of these cysts. We're excited about trying to see what components are most essential to cyst growth so we can translate that knowledge into therapeutic strategies for people with PKD.



How does your involvement with the PKD Foundation support your work?

The PKD Foundation is a source of connection to the PKD world, to the patients and other PKD researchers. In the kidney disease field, it's important to have a Foundation committed specifically to this very common disease, which has its own needs and will require its own strategies for therapies. As a young person relatively early in my career, I'm very thankful for the support and the opportunity to connect to the Foundation at a deeper level than I had before.

Learn about Dr. Freedman's study on a new gene-editing technology called CRISPR and how it could transform the future of PKD care.

Subscribe to the PKD Progress magazine to read more about Dr. Freedman in our upcoming spring issue.

Related articles:

Learn more about Dr. Freedman's research on mini-kidney organoids.

Read about the 2016 research grants awarded by the PKD Foundation.

Core research grants explained

https://pkdcure.org/research-medical-professionals/core-research-grants/

We provide grants to support facilities or service sused by PKD scientists at either no cost or a greatly discounted cost. **Core research grants** leverage our funding of research facilities, databases and services to benefit the entire PKD research community.

Why is it important?

We are the primary funder of each of the four labs. Without the support of the our donors, this critical work would be at risk.

PKD Electron Microscopy Core for PKD Research
Director: Robert Bacallao, M.D., Indiana School of Medicine, Electron Microscopy Center

Under the direction of an experienced electron microscopist, the lab is dedicated to facilitating research on PKD and other hepatorenal fibrocystic diseases.

- Lab performs electron microscopy (EM) evaluations for researchers around the globe at a 90 percent discount.
- In 2013, the lab handled seven projects from U.S. researchers.
- Four publications referenced the EM Core in 2013.

ADPKD Mutation Database (PKDB)
Director: Peter Harris, Ph.D., Mayo Clinic

The PKDB collects mutation information from ADPKD families and clinical testing results of pharmaceutical companies, which allows the database to provide greater clarity for PKD researchers about the significance of the many variants found in ADPKD genes.

- Most comprehensive listing of all published PKD1 and PKD2 mutations. Information is available to researchers around the world at no cost.
- In 2013, the PKDB had 6,421 visits from 1,845 unique visitors representing 56 countries and 39 states.
- Version 3.0 of the database launched in March 2014.

PKD Research Biomaterials and Cellular Models Core
Director: Darren Wallace, Ph.D., University of Kansas Medical Center

This core lab assists PKD research by providing human and animal PKD tissues, as well as high-quality biological materials, to researchers to assist in the development and use of PKD cell models to test specific hypotheses and evaluate drug effects. This includes fixed and frozen tissues, cyst fluids and primary cells isolated from human PKD kidneys retrieved during surgery (some of which come through our tissue donation program).

- Biomaterials provided to requesting research labs at no cost because of the support of the PKD Foundation.
- In 2013, 16 labs worldwide received biomaterials, including the
- National Institutes of Health and three biotech companies.

PKDOC Database
Director: Steve Broadbent, Critical Path Institute

The goal of the PKDOC Database is to use standardized clinical data from PKD patients to provide support for the use of total kidney volume (TKV) as a surrogate outcome measure in clinical trials. Glomerular filtration rate (GFR) is the current outcome measure, but it remains relatively steady in PKD patients until late in the disease, making it difficult to evaluate new therapies.

- Data for the PKDOC Database was compiled from three patient registries and the CRISP observational studies.

- Analysis of the aggregate data was performed to consider the relationship between clinical factors associated with PKD (hypertension, hematuria, end stage renal disease and TKV).
- Results of the analysis were submitted to the U.S. Food and Drug Administration and the European Medicines Agency in 2014 and we are currently awaiting response.

The PKD Research Experience

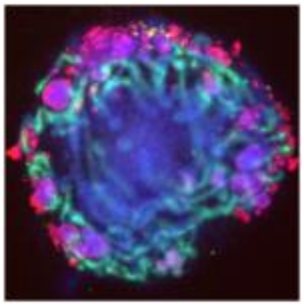
In response to recent findings of mini-kidney organoids, Dr. Benjamin Freedman recounts his research experience.

https://pkdcure.org/blog/the-pkd-research-experience/

I remember the moment clearly. I was staring through the microscope, as I had done countless of times before, expecting to see beating heart cells. Instead, I saw beautiful, convoluted tubules that somehow reminded me of a kidney. With just a small change in protocol, my stem cells had turned into kidney tissue instead of heart. And my own heart skipped a beat.

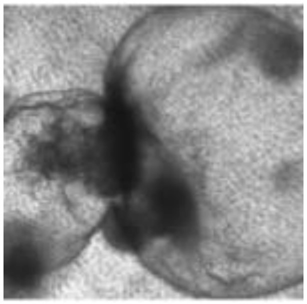
Only a few weeks later, the microscope surprised me yet again. I did the same experiment, but this time I started with cells carrying a genetic mutation that causes polycystic kidney disease (PKD). The idea that these cells would re-create PKD in a petri dish seemed like a long shot. But there I was, staring into the microscope, watching little cysts form off of the tubules. Our PKD mini-kidneys were acting just like the kidneys in PKD patients.

Eureka moments such as these are vanishingly rare for scientists like me. On most days, we are satisfied with much smaller victories. We make incremental progress, struggling to see the unseeable, deciphering like detectives the tiny shreds of evidence that cells leave behind. Every experiment is a new challenge, and most of the time they don't work. The work is hard, the hours are long, and there's a lot of delayed gratification. But that process of trial-and-error learning also opens the door to discovery. As Pasteur famously said, "Chance favors the prepared mind."



Mini-kidney from a patient's cells (1-mm diameter)

We live for those moments where all the years of work suddenly crystallize into something greater. I'd been telling family members and patients for years that we were trying to make kidney tissue from stem cells. Now, we have done just that. We don't know whether these mini-kidneys can produce urine, or when they will be safe for clinical use – getting there will take years of follow-up research. What we have done, though, is establish a starting point for regenerating new kidney tissues on-demand from our body's own cells, which would not require immunosuppression.



Cyst (1.5-mm diameter) from a mini-kidney with PKD mutations

What really takes this research to the next level is that these mini-kidneys can be genetically engineered to mimic PKD. PKD is a very mysterious disease, which is difficult to study. Now, we can study PKD in these tiny mini-kidneys. We can use fancy gene-editing techniques to correct PKD mutations, similar to the one we used to make PKD mini-kidneys. We can test thousands of drugs side-by-side to see which ones prevent cysts – perform PKD 'clinical trials in a dish' for a fraction of the cost of a real clinical trial.

I feel lucky to have had those moments at the microscope. They remind me of how much is still left to be discovered. It is fulfilling to give back to the community by sharing our findings with patients and supporters. Sometimes, nature surprises us, and in those surprises we can find hope for the future.

Dr. Benjamin Freedman is an Assistant Professor of Medicine at the University of Washington Division of Nephrology, Kidney Research Institute, and Institute for Stem Cell and Regenerative Medicine, in Seattle.