



AAKP RENALIFE

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AAKP's 43rd National Patient Meeting, June 8-10, St. Petersburg, FL

**The Happiest Place on
Earth turned out to
be just that for
Robert Leibowitz**

**6 Tips for Traveling
While on Dialysis**

**Things I Wish I Had
Known Before Traveling**

**Innovator Series:
CareDx, Inc. President
and CEO, Peter Maag**

Welcome to the Fight

A Publication of the American Association of Kidney Patients

AAKP **RENALIFE**

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Understanding kidney disease is a critical first step to improving your health. The American Association of Kidney Patients is the leader in kidney patient centered education. For nearly 50 years, AAKP has provided patients and families the educational tools they need to understand kidney disease and take a more active and informed role in their health care.

Our efforts across the country to speak on behalf of patients and their families have improved their lives and well-being - benefiting all of America's kidney patients. Building communities among kidney patients and their families, health care professionals, and other support groups is an important goal of AAKP.

Education • Engagement • Community • Advocacy

AAKP promotes education and encourages conversations that help improve patients' everyday lives.

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MESSAGE FROM AAKP

Happy spring to our AAKP Members and Allies!

We are well on our way to our National Patient Meeting in St. Petersburg, FL. By the time many of you read this message, some of you will be reading it at the annual conference! As the nation's oldest and largest fully-independent and patient-lead organization, it is only natural that AAKP hosts the largest kidney patient meeting in America! AAKP is entering into our 50th Anniversary Year – and the kickoff of that celebration begins at the 2018 Annual Meeting!

For those who miss this year's Meeting, or who are not able to watch the livestream, your absence will be felt by your fellow patients. However – due to the tremendous efforts of our staff and very generous meeting sponsors – you will be able to watch recorded video of selected sessions in the weeks ahead. Look-out for notices online, on our social media pages and in upcoming issues of *aakpRENALIFE*.

AAKP has been building our strength, influence, Ambassador teams and communication capacities over the past several years. As a part of our ongoing national engagement and

advocacy strategy, we work hard to bring your concerns and experiences to decision-makers who benefit from your **independent** voice. When your fellow AAKP patients meet with professionals at The White House, on Capitol Hill and even at the United Nations (we have been to all of these in the past 30 days!), decision-makers immediately recognize the AAKP viewpoint as unique and **independent**. Since 1969, this has been our heritage and our legacy – and we will hold true to our values and purpose.

Because we are united as patients, with a patient-majority national Board of Directors and leadership team, AAKP is never mistaken as a special interest group run by detached paid professionals with no link to your patient experience. Your AAKP Board and leadership team have experienced the frustration and pain of coping with a chronic illness, have had the surgeries and the scars to prove it, have lived on dialysis, have experienced transplants – and have seen both the cloudy days of kidney disease and the blessed sunny days. AAKP stays true to our roots – meaning real grassroots education and advocacy. We are never confused for an “astroturf” organization founded by special interests. We choose our allies wisely – and our allies are among the finest U.S. civil servants, like-minded association policy and Congressional legislative experts and experienced medical professionals in America.

So what is it we are trying to accomplish through our education,

advocacy efforts and alliances? What is the vision the AAKP mission has been placed in service to? We have listened carefully over the years to your voices at our Annual Meetings, in patient surveys, to your most recent comments on social media and to your calls to our AAKP national headquarters. In a very succinct way – this is the vision we share and work toward together:

For Kidney Patients: A care system built upon the simple truth that humans have an inherent desire to live, to aspire and to prevail.

For Kidney Disease: A true, patient-centered treatment system defined by: early disease detection and intervention to slow progression; early education on ALL choices of treatment and work-compatible options to include pre-emptive transplantation, home hemo and peritoneal dialysis; and full access to high quality in-center dialysis care with teams that encourage transplantation among those eligible.

For America: The fundamental rejection of the decades-old, passive and costly dialysis care status quo – and a commitment to support research and innovation aimed at reducing kidney disease occurrence while increasing the availability of safe, new treatments that allow greater freedom, are less burdensome and produce better health outcomes.

As AAKP works on education and policy issues that support this vision, we want you to know the principles upon which the AAKP Board of Directors and



Dr. Robert Star, Director of the NIH/Kidney Precision Medicine Project (KPMP) with AAKP patients are shaping innovation at NIH.



HHS Secretary Alex Azar discusses kidney disease, high drug prices and KidneyX with AAKP Pres. Paul Conway and VP Richard Knight

professional staff operate to achieve our national advocacy and policy agenda. They are honest and straight-forward:

1. AAKP elevates the patient voice in national issues and across drug, diagnostic and device development.
2. AAKP protects the *unique* relationship between patients and their doctors.
3. AAKP educates patients and preserves their access to choices as informed consumers of healthcare.
4. AAKP maintains our full independence in *all* national policy and decisions.
5. AAKP honors the principle of “*no surprises*” among trusted allies and Federal and state government officials.

By sticking to our principles, we stay true to our mission and make measurable progress in achieving the vision. We avoid making short-term decisions that risk AAKP’s ability to shape care choices and future innovations for years to come. As the leadership of AAKP, we understand that on our watch, we must maintain the reach and credibility of this organization for generations to come.

In just the past year, AAKP has assumed national leadership roles on the leading-edge of kidney

treatment – this includes the groundbreaking ***Kidney Precision Medicine Program (KPMP)*** at the National Institutes of Health (NIH) under the leadership of Dr. Robert Star as well as ***KidneyX*** – a special joint initiative of the U.S. Department of Health and Human Services (HHS) and the American Society of Nephrology (ASN), ***KidneyX*** will jump-start new kidney treatments and devices using both private sector funding and Federal taxpayer funds. We have also greatly increased our focus on Veterans health outcomes through the ***AAKP Veterans Health Initiative*** under the leadership of fellow Board Member and U.S. Marine Veteran Edward V. Hickey, III.

And, we have taken a firm stand against the well-intentioned yet highly controversial Patient Demonstration Act. This poorly written legislation, presently before the U.S. Congress, was originally sold as a bill that reflected a consensus among nearly all kidney experts and patients. In reality, the bill has no consensus. It is written in a way that limits patient access to transplantation while simultaneously giving patients only 75 days to “opt-out” of a proposed demonstration program or be automatically enrolled! This program, in many cases,

would disrupt patient access to the nephrologists and experts they have already come to trust for care. AAKP and our allies had proposed edits to this bill in an effort to avoid these negative consequences. Regrettably, the voices of patients like you and our allied healthcare allies were ignored. Today, we are united against the controversial Patient Demonstration Act along with our highly-credible allies at the American Society of Nephrology (ASN), the American Society of Transplant Surgeons (ASTS), the American Society of Transplantation (AST), Dialysis Clinic, Inc. (DCI), the Rogosin Institute, Northwest Kidney Centers, the Washington State Medical Society, nearly all other non-profit dialysis providers in America – and leaders at nearly every level. The Patient Demonstration Act bill has become incredibly divisive. Sadly, the bill has split what is normally a united kidney community. In addition to the many groups and patients opposed to the bill, other national kidney organizations such as the American Kidney Fund (AKF), the Renal Support Network (RSN), and Kidney Care Partners (KCP) chose to avoid the by citing their need to focus

President’s Message continued on next page

resources on other issues.

As AAKP members, you have done a superb job contacting your representatives and fellow patients by phone and online to fight The Patient Demonstration Act and we appreciate it. We too prefer to focus our time and energy on positive efforts aimed at improving your care and impacting the future; however – when your care is threatened – we will inform you and use every relationship and tool at our disposal to make your opinion known among key decision-makers.

Please continue to follow us on social media and visit www.aakp.org for the latest information. Stay tuned for more announcements on how **YOU** can get involved with AAKP at the national, state and local level as we expand our Ambassador Program and our grassroots impact online and in your community! Have a safe spring – and enjoy each day.



Paul T. Conway
President of AAKP

AAKP's 43rd National Patient Meeting

June 8 -10, 2018

The Vinoy Renaissance Resort & Golf Club,
501 5th Ave NE, St. Petersburg, Florida 33701

****Accepting on-site registration! ****

Full registration

\$150 for patient/family member;

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\$75 for patient/family member;

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Hear from the top influencers in kidney care from the Federal government, medical professionals, private industry and non-profit professional organizations in the kidney community!

- **6 General Sessions**
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- **Souvenir Attendee Bag & Items**
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- **Much More!**



General Session Highlight

Innovations in Kidney Disease Care

AAKP's Medal of Excellence Award winner, Rebecca Schmidt, DO, FACP, FASN will lead this exciting General Session on the latest innovations in

the kidney community and what the future holds for patient care and treatment options for those with kidney disease. Hear from some of the nation's top innovators who work every day to improve the future for those with and affected by kidney disease.

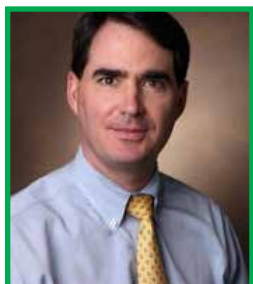
Panelists for Innovations in Kidney Care:



Ekemini Riley, PhD, Milken Institute (Leader in philanthropic work to advance solutions in patient care)



Peter Maag, CEO, CareDx (AlloSure for organ transplant health)



William Fissell, MD, Vanderbilt University (The Kidney Project - artificial implantable kidney)



Akhtar Ashfaq, MD, Senior VP of Clinical Development and Research (Rayaldee for Vitamin D and Phosphate management)



Rob Chioini, CEO, Rockwell (Triferic, iron therapy for the treatment of anemia caused by iron deficiency)

See the **FULL meeting agenda and register at**
www.aakp.org/national-patient-meeting

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The **Happiest Place on Earth** turned out to be just that for **Robert Leibowitz**

By Deborah Pelaez, AAKP Staff Writer



Robert in his t-shirt at Disney

Robert's first sign of kidney problems started at age 12. His parents took him to the hospital with a 107 degree fever and found out that he had kidney reflux, which is the backward flow of urine from the bladder into the kidneys. He would need surgery to correct the issue. After the surgery, everything returned to normal. There were no follow-up visits required; he had perfect health and was no longer concerned about his kidney function.

Robert worked in the corporate world for a number of years. The company he worked for required an annual health check. It was during these health checks that he first learned that he had an elevated creatinine level, a direct indication of poor kidney function. He was then referred to a nephrologist and learned that he would eventually need dialysis or a new kidney. His doctor explained to him that kidney disease can at times be a hidden, silent disease.

After hearing this shocking news, and before he had to start dialysis, Robert did lots of research. He talked to his nephrologist thoroughly. He learned that as an O+ blood type, he could only have an O blood type kidney donor. He learned that the waiting time for a deceased donor is seven to ten years. He also learned that if a kidney from a deceased donor became available, he would need to get to the hospital within three to four hours. He proactively started getting on

transplant lists at all the hospitals within a four hour drive of his home in New Jersey.

As end stage renal disease approached, Robert's nephrologist suggested to him that he start sharing his need for a kidney publicly. Robert tried posting on Facebook but he got a low response.

A few months later, Robert started in-center hemodialysis. As a single dad of five kids and a full-time employee, dialysis required him to get up at 2:30 a.m. on his treatment days. He would walk his dogs, take a quick shower and get on the train to Manhattan to do four hours of dialysis in the city before his work day even started. He would arrive home from work after 5 p.m., eat and go to bed.

Robert tried peritoneal dialysis so he would not have to go in center, but it wasn't for him. He eventually changed jobs, finding a work-from-home position that allowed him to be able to go to dialysis just 10 minutes from his house. During his time on dialysis, Robert says he never gave up hope. There were days when he did start to feel depressed but he would just call one of his kids and that always gave him the hope and motivation he needed to keep going.

Robert had always dreamed of a family vacation to Disney World in Orlando, FL, and he wanted to take all of his kids ages 15, 17, 26, 29 and 32. As he started to make plans to travel and



Robert and Richie with family right before surgery

knowing that he would be in front of thousands of people, he came up with the idea to make a shirt to wear while he was at Disney to let others know that he needed a kidney. He told himself if just one person noticed the shirt – it would be worth his \$35 investment.

While at Disney on the three day trip, the shirt was noticed by an Orlando couple who shared it on their Facebook page. That one post went viral and was seen and shared by thousands of people, many who called the number on the shirt.

Robert had several people go online and complete the application process to donate a kidney to him. The application for donating a kidney first looks at family health history, then requires a blood test and a series of other tests including a psychological exam. The first three people in line to donate to Robert did not pass the battery of tests. Robert said that the hospital and doctors want a 100% success rate – they look at everything and would eliminate anyone who does not measure up as a perfect match.

The fourth person in line was Robert's donor, Richie Sully. Richie saw the Facebook post while with a friend, giving blood at the Red Cross in Indiana. The friend he was with happened to be a nurse and suggested to him that he was the right blood type and should consider donating. Robert said that Richie was



Robert and Living Donor, Richie in New York

a proactive donor. He kept Robert in the loop and sent him photos of completing each step of the application process; with each successful pass, Robert was getting hopeful. Finally in December 2018, Richie took a Greyhound bus from Indiana to New York to get tested to be the donor and was determined to be a match.

The transplant surgery took place in January of 2018 at New York Presbyterian Weill Cornell. They were both released just a few days after the surgery. Robert and Richie appeared together one week after surgery on The Today Show with Megan Kelly. Both men are doing great. Robert shared that he was very tired for the first few weeks, but now he has all his energy back and he feels extremely lucky. He says that it's a miracle.

Robert's goal now is to continue to tell his story and encourage living donations.

If you are on dialysis and on a transplant list, Robert shares this advice with AAKP readers:

- Call your local radio and TV stations – they are always looking for human interest stories.
- Put a sign up in your car.
- Post on social media.
- Get on as many transplant lists as possible with as many hospitals as possible.
- Never give up hope – your time will come! 🌱

A UNIQUE OPPORTUNITY FOR PEOPLE WITH DIABETIC KIDNEY DISEASE



A NEW WAY TO TREAT YOUR DIABETIC KIDNEY DISEASE MAY ALREADY BE INSIDE YOU

Right now, a medical research study is evaluating the safety and effectiveness of a therapy that aims to restore your kidney function and delay or avoid dialysis or a kidney transplant. Made from your own healthy kidney cells, the therapy intends to harness your kidney's natural ability to heal itself. **To find out if you may qualify to participate, visit reactstudyakp.com today.**



6 Tips for Traveling While on Dialysis

By Laura Richardson, MFN, RD, LDN

Goodbye snow, hello warmer weather! Spring and summer are the seasons for traveling, but many dialysis patients may be wondering if they'll be able to go on vacation while not missing a treatment. The good news is yes! People on dialysis can absolutely travel, but do need to make a few more arrangements prior to leaving. Here are six tips to help you make your trip as smooth as possible.

1. Plan ahead.

When possible, plan your trip as far in advance as possible. The staff at your dialysis unit will help you find a center close to where you'll be going so that you can receive treatment while you're away, but this can take time. Where you're going and what time of year you'll be there can affect the availability at nearby centers, so the more time the staff has to look for available spots, the better off you'll be.

2. Verify your insurance coverage.

Double check with your insurance company to find out what your coverage will be at your visiting dialysis center, especially if you're traveling out of state. You don't want to get back home, only to receive a bill you weren't expecting.

3. Make sure you have your meds.

Fill any prescriptions you need to make sure you have plenty to take with you on your trip. You'll want to make sure you have enough for every day of your trip, plus extra in case of delays coming back, or in case you can't get a refill right when you get home.

4. Don't take a vacation from your diet.

It may be tempting to let loose while on vacation,



but at a bare minimum, make sure you're keeping your fluids and potassium in check. Cocktails on the beach can cause fluid overload just as easily as plain water at home.

5. Protect your access.

Keep in mind weight restrictions if you have a fistula or graft, and don't lift anything too heavy, such as a stuffed suitcase. If you have a catheter, be careful not to get it wet if you wind up at a beach or pool.

6. Ship your supplies.

If you do peritoneal or hemodialysis at home, consider shipping your supplies to your destination ahead of time, especially if you'll be flying. These can take up a lot of space in a car or airplane, not to mention be a hassle for you. Call your supplier or your nurse to set up a delivery to your hotel and you won't have to worry about it.

7. Bon voyage! 🌸



Laura Richardson, MFN, RD, LDN Laura is a dialysis dietitian working in St Petersburg, Florida. She is originally from Indiana and completed grad school in Ohio. She also teaches CKD classes in the community and will be presenting at the AAKP

National Patient Meeting in June.

Things I Wish I Had Known Before Traveling

By Maile Robb, AAKP Ambassador

Hi. My name is Maile. I have been a dialysis patient for more than twenty years and serve on a number of related associations as a patient advocate and subject matter expert. Often in these roles, travel is required to attend face-to-face meetings, take part in medical studies, and to even meet with state and national legislators.

These events have been a wonderful opportunity to learn and educate others about renal failure. They also have given me the chance to meet and share my experiences with fellow dialysis patients, but travel and receiving dialysis away from your home center can have its challenges.

Below, I have gathered a collection of tips I have learned in my travels over the years.
(Sometimes the hard way!)

Plan before you go...

- As most dialysis related meetings take place in business hotels, they may not be ready to accommodate the needs unique to dialysis patients. Some basic Internet searching can yield a great deal of information about the location you are about to visit.
- Is the hotel in a downtown or urban area? Is the dialysis clinic on a second or third floor of a building? Do you use a walker or a wheelchair? Taking the stairs before and after a treatment can be time consuming, not to mention exhausting!

Getting from here to there...

- Airports can be difficult enough for the seasoned traveler, not to mention folks like us. One of the most important things is the most obvious, give yourself a lot of extra time. Let the airline know before you arrive if a wheelchair may be needed to the gate. This way, it only takes a few minutes to arrive and you are not waiting for a long time. Often, when I travel alone, my husband can get a companion gate

- pass to help me to the gate/plane. This is a huge help, especially when getting through security.

... and around the town:

- What forms of transportation does the area have? I ask the staff at my hotel for a recommendation. Most likely, they use a specific company for their guests. Uber and Lift may be less expensive but may not be as reliable or may not be able to accommodate wheelchairs or motorized scooters. Some places do not offer Uber or Lift, yet.
- Keep enough cash on hand for the rides going both directions.
- Keep hotel information and the chosen ride's phone number not only with you, but easy to get to. Remember, at the end of treatment, our brain may not be working as well! It makes things a lot less stressful if we do this ahead of time. I also like to investigate what the cost will be to and from my hotel and treatment.

Getting dialysis...

I have rarely had any problems when getting dialysis when I travel, but have learned that every center is different.

ACCESS-

As a travel patient, the chair times are often later in the shifts. Know if getting into and out of the clinic is functional for your situation. Late hours may require you to wait for a cab/Uber outside of the clinic.

FOOD AND DRINKS-

- Do they allow food or drinks on the clinic floor?
- Are you Diabetic? If you are used to eating a meal while in your chair, you will need this information.

IV MEDICATION- LIDOCAINE

- Not all clinics have or use IV Lidocaine.

- You may want to bring a lidocaine cream (like Emla) with you. It needs to be prescribed by a doctor.
- You should call the clinic and ask if they have the medication. It can cause unneeded anxiety to walk into a unit and be told they have no Lidocaine.

EPO, HECTORAL, IRON-

- Do they give these medications to visiting patients?

Missing one dose may not be a big deal, but a week without these drugs could be CRITICAL.

SODIUM-

- Do the machines have the ability to infuse sodium during your treatment?

I have low blood pressure. I can run without it, but I feel better with it! When choosing a clinic, this is something that I consider. Remember, there are many CHOICES available to us. If the facility cannot meet our needs, simply look at a different clinic. As a consumer, we shop around for the perfect pair of sunglasses. I want you to look at your travel the same way. Shop around!

BENADRYL-

- Allergies. This is VERY IMPORTANT. I am allergic to bleach fumes. The dialysis machines and the chairs get wiped down with a bleach and water solution. I keep a mask at my fingertips at all times. For a patient with allergies, we MUST go to a clinic that uses Benadryl.

These tips help prevent anxiety and allow me to truly enjoy my travel. I hope that they help you too.

Travel can be overwhelming. There are a lot of details to remember. It takes time, planning, and some patience, but in the end, it is worth it.

So, come on, do some investigating! Where do YOU want to go? The more information we can get, the less scary it will be.

KNOWLEDGE IS POWER. 🌸



Maile Robb is an AAKP Ambassador for the state of Nevada. She has been on hemodialysis since 1995. As a dialysis patient, Maile takes a very active role in her care, including keeping up with new treatment alternatives, communicating with her health care professionals, taking part in medical awareness events, and being Self Care Certified through her local dialysis center. As a long term ESRD patient, Maile has an impassioned investment to improving the lives of fellow dialysis patients through knowledge, education, projects and programs. She is a subject matter expert (SME) for the ESRD Quality Measure Development, Maintenance, and Support Project, the Kidney Patient Advocacy Counsel (KPAC), and the Kidney Community Emergency Response (KCER) among other roles in the kidney community.

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AAKP Innovator Series:

CareDx, Inc.

President and CEO, Peter Maag

CareDx, Inc., headquartered in Brisbane, California, is a molecular diagnostics company focused on the discovery, development and commercialization of clinically differentiated, high-value diagnostic solutions for transplant recipients. CareDx offers products across the transplant testing continuum. AlloMap and AlloSure are used in post-transplant surveillance by leading transplant centers today. With its Olerup products, CareDx support leading transplant laboratories in pre-transplant HLA testing. The company has 180 dedicated employees with the focus to improve long-term outcomes in transplant patients worldwide.

Tell us about your first experience with kidney patients and what impressions that left on you as a person and as a professional.

We have a transplant patient visit CareDx and meet our Brisbane associates during our monthly Town Hall meetings. This gives us a better perspective on understanding the kidney transplant patients' journey and the many challenges they are facing and how it affects their lives. The stories we hear about multiple years of ordeal with ESRD and dialysis, combined with the realities of the transplant waiting list are leaving a deep impression on me and the team at CareDx. Being part of "the village" – the support system – can be tremendously gratifying, when we see patients and family members smile even though they've gone through so much.

How would you explain or describe AlloSure to kidney patients?

AlloSure helps to monitor the health of the transplanted organ through the latest technology. We are your lifelong partner to track the health of your transplanted kidney. More than 45 transplant centers across the U.S. have started using AlloSure, which holds great promise to impact long-term outcomes.

In regards to kidney transplantation as a treatment option – what do you think are the most important things patients and their caregivers should know about CareDx's innovation?

We support the long-term care of kidney transplant patients. The test reveals it's better than serum creatinine in detecting rejections and, as a blood test, is so much easier for patients than a biopsy. We believe in a regular checkup after transplant that lasts years after transplantation.

AAKP believes that every patient with kidney disease should be able to pursue their aspirations and that treatment and modality should be prescribed based on those aspirations, including the desire to work either part-time or full-time. Do you think that work, for those who are able to, plays a role in a patient's ability to stay fully engaged in life?

I couldn't agree more. We support the desire to lead a productive life by providing a novel surveillance

tool, which monitors the health of the transplanted organ. AlloSure, together with better tools for adherence and compliance to medications, promises to make a big difference. I believe caregivers sometimes underestimate the impact of getting a “green light” – everything is okay – and the effect that has for a recipient pursuing their personal happiness.

As an entrepreneur in the renal industry, you know well that it is not easy to develop a novel approach to treatment or enhanced care. What do you draw upon internally to keep your drive, optimism and focus on patients going at full speed during the tough days?

There is not a week that passes where I don’t directly interact with a transplant patient. I recently received an innovation award from a patient organization; And I am speaking at the upcoming AAKP meeting in June. My life is dedicated to making a difference in transplant patient lives right now. You can ask me any day, how many patients has CareDx cared for yesterday and I will have the answer readily available.

By the year 2020 – what do you expect to see in terms of how care is provided to kidney patients, what immediate changes do you think can occur?

I see a lot of variability in care for transplant patients and I think we, as a community, can do a better job in personalizing the approaches to post-transplant care which will lead to better organ survival long-term. With our presence in the organ matching space, I think there is a lot we can do to improve the organ matching process, which will increase the number of available organs and reduce the waiting lists. Hopefully.

AAKP is doing a great job in putting kidney disease on the agenda of healthcare issues in Washington. It will take an even bigger village (Capitol Hill, CMS, etc.) to make changes in the way we incentivize innovation and reimburse long-term patient care and immunosuppression beyond 3 years. I am hopeful that all of us working together can make a difference.

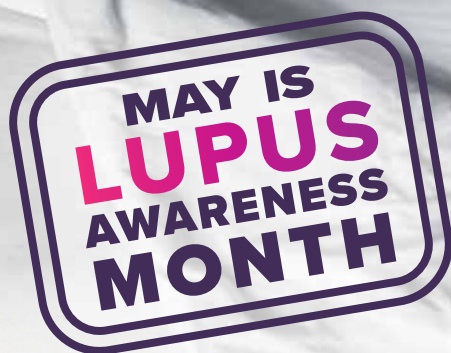
AAKP believes this can reveal a lot about a person – who is one of your heroes and why?

I spent a couple of days earlier this year with Angelica Hale, a 10 year old kidney transplant patient that has become famous as a runner up of “America’s Got Talent 2017 season”. She has a dream of becoming the next Whitney Houston. When she shared with me her dream, it reminded me about having big dreams and living up to them. As a father of 2 teenage kids, I hope that all kids have the chance to live their dreams with or without chronic medical conditions. Angelica is my hero. 🌸



Peter Maag has over 25 years of executive management experience in the pharmaceutical and diagnostic industry. Prior to joining CareDx, Peter worked for Novartis in various positions with rapidly increasing responsibilities. Starting out at headquarters in Switzerland as the Head of Strategy, he then launched the Infectious Diseases franchise. Leading Novartis Korea and Germany through rapid growth was followed by a global responsibility as the President of Novartis Diagnostics based in California. He headed the unit through worldwide growth in its blood screening business and established new ventures in molecular diagnostics. Prior to joining Novartis, Peter worked at McKinsey & Company in New Jersey and Germany, focusing on pharmaceuticals and globalization strategies. Today, he also supports various healthcare and high tech companies in their growth efforts, he holds board positions at Phoenix, MolecularMD, and Personalized Medicine Coalition (PMC). Peter studied pharmaceutical sciences in Heidelberg and London, and received his PhD from the University of Berlin, Germany.

unpredictable seizures confusion photosensitivity
mouth sores muscle aches chest pains
fatigue anemia **WHICH LUPUS DID YOU** headaches
isolating **WAKE UP WITH TODAY?** debilitating
dry eyes hair loss swelling tingling extremities rash
unpredictable memory loss arthritis shortness of breath



With all the questions about your condition, consider participating in a **research study** that may help researchers find answers.

The Paisley Study is a research study that is evaluating an oral investigational drug for people with moderate to severe systemic lupus erythematosus (SLE).

You may be able to participate if you:

- Are 18–75 years old
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- Are currently taking medication for lupus

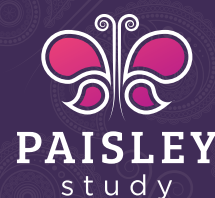
During the study:

- The study drug, study visits, and any medical tests specifically needed for this study may be provided at no cost to you.
- You may be responsible for other costs (for example, tests you would receive as the usual care for your disease), some of which may be covered by your insurance.

You may be able to continue taking your current lupus medication(s) during the study.

To learn more, or to see if you may qualify, please
visit AAKP.PaisleyStudy.com

Requesting information does not obligate you to take part in this research study.



Welcome to the Fight

By Genevieve (G.A.) Morgan, AAKP Ambassador

I've never thought of myself as a warrior. In fact, I've never considered myself to be all that competitive. I was pretty good at tennis for a while and got drafted into a league where I competed in weekly matches against other, similarly ranked women. At first I enjoyed it, but as I progressed through the year and up the ladder, I found that as the competition got stiffer, so did the lousy attitudes. My opponents were angry when they lost and gloating when they won, and all I could think of was, "this is amateur tennis, why do they care so much?" To me, the playing was the point. Then, a decade later, I wrote a trilogy about a small band of people who fight a great evil that threatens their entire way of life. I had no idea that these two life events were setting the stage, metaphorically speaking, for my own eventual battle with Polycystic Kidney Disease (PKD).

I was diagnosed with kidney disease 7 1/2 years ago, at 43, after a standard blood pressure screening revealed an unexpected high blood pressure reading. My PCP ordered a sonogram of my kidneys and the die was cast. Stage 3 PKD. Before that day, I had no inkling this genetically inherited disease existed. In fact, before this diagnosis, I went to the doctor only when I was violently ill or pregnant. My worst vice was a cup of coffee or two in the mornings. I exercised regularly and ate well. Heck, I hydrated. Looking back through my family tree, my genes held no clues either. My ancestors were outrageously long-lived. If they happened to die young, it was due to an accident, childbirth, or war. No lethal kidney disease except for a great-great-great uncle who died of nephritis before penicillin was invented.

At my first nephrologist visit, I was told to expect a ten-year window before I would need dialysis or transplant. I hardly heard the doctor. I felt fine. I was used to managing my health and the appearance of these random letters in my medical charts meant little to me, except that I would now have a pre-existing condition that might scuttle my ability

to buy affordable health insurance, and I had to worry that I had passed this damaged gene onto my children. Children of a parent who have expressed the PKD genes have a 50/50 chance of inheriting the disease. A coin-flip. I have two children, so two coin-flips. Because of my sons, and because I'm a writer and used to reading a lot, I chose to walk crab-like into my personal battleground via research.



ADPKD is the most common of inherited cystic kidney diseases, in which large fluid-filled cysts bubble up in the kidneys, engorging them and damaging function. It impacts 1 in 1,000 people worldwide. Cysts can also occur in other organs, and those with PKD also have a higher risk of aneurysm, mitral valve prolapse, hernias, and diverticulitis. Approximately 50% of PKD patient do not progress into full-blown kidney failure before age 70. I think I fixated on that statistic often in the first few years, despite my nephrologist's window warning, because I saw no reason why I would not be in that club.

I did what I could. I changed my diet—reducing protein, caffeine, and processed foods and trying to drink 64 ounces of water a day—and, for the first time in my life, began to take a regular prescription of blood pressure medicine. I took Epsom salt baths and downed turmeric to help me detoxify. I learned a lot about how other cultures value the kidneys—and in particular, the role the kidneys play in Traditional

Ambassador Profile continued on next page

Chinese Medicine, where they are considered critical for maintaining the body's homeostasis and processing toxic emotions, like fear. I studied the connection between inflammation and cyst growth and how emotions and diet can influence the speed at which PKD advances, but nothing can stop it outright.

I heard this, but the brutal reality of it only truly dawned on me a couple of years ago, when I began to notice some changes in my levels of fatigue and my GFR continued to spiral. For the first time since my diagnosis, I truly understood that I was facing an opponent I couldn't beat or escape. It was laying siege, slowly—relentlessly—on this most vital of organs and all the systems that rely on healthy kidney function. My only options were to put up as many road blocks as I could by taking care of what I ate and drank, dealing with my anxiety, and trying to keep my life as steady and stress-free as possible (something I still find amusing in the face of a life-threatening illness).

It strikes me now as ironic that it was at this moment, as the odds stacked against me, and, as my friend has joked, I “discovered that no ashram would save me” that I truly decided to fight. It was like going back to those tennis matches—where playing the game felt more important to me than winning—only this time the game was my life and playing well meant feeling as well as possible in the face of the inevitable. I realized that what I needed most—more than any green smoothies or Epsom salt baths—was other people who understood what I was up against. I needed a team to stand with me, to talk to me, to hug me, to share their experience with me, to help me wage war against this silent killer in the hopes of changing the future for all kidney patients. I joined the AAKP and became a regional ambassador—and just like that, I found my own real-life band of brave and inspirational warriors, just as I had imagined them in my books.

As I write this, my GFR has slipped below 20 and I was recently listed at UNOS for kidney

transplantation. My two phenomenal brothers have signed up to be evaluated as live donors, along with a handful of other angels. I've made arrangements to be prepped for peritoneal dialysis if I fall off a cliff while I'm waiting for transplant. And even though I'm on the slippery part of the slide, every day, my AAKP community stands with me, advising me, encouraging me, and together we plan the next phase of what will be required to eventually ace this disease. These days, I look at my children with hope not fear, because I know that, thanks to the AAKP and other like-minded organizations, the future will indeed be different for them. 🌸



*Genevieve (G.A.) Morgan is a writer and editor in Portland, Maine. Her most recent book, *The Kinfolk*, is the third and final volume of her award-winning MG/YA adventure-fantasy, *The FiveStones Trilogy*. She is also the author of *The Fog of Forgetting* and *Chantarelle*, volumes one and two in the series, and the non-fiction book for high schools students called, *Undecided: Navigating Life and Learning after High School*. Her fiction has won the Silver Moonbeam award for pre-teen fantasy and has been a finalist for the Maine Literary Awards. She was recently the host of the regional interview TV show “The Writer’s Zone” and has worked in communications and marketing for the past 20 years. As a volunteer, she is the state administrator for the Women’s March on Washington-Maine, and has worked to protect health coverage for the individual market and for those with pre-existing conditions. She was diagnosed with Polycystic Kidney Disease in 2010, the first in her family, and is currently in Stage 4 with the expectation of undergoing a pre-emptive transplant. She has two children, to whom she is dedicating her advocacy for funding for research into a cure for PKD, better choice for kidney patients, and continued focus on quality of life and protections for all kidney patients.*



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About AAKP

The American Association of Kidney Patients (AAKP) is a national non-profit organization founded by kidney patients for kidney patients. We are dedicated to improving the quality of life of kidney patients through education, advocacy and through fostering patient communities.

STAY *Connected*

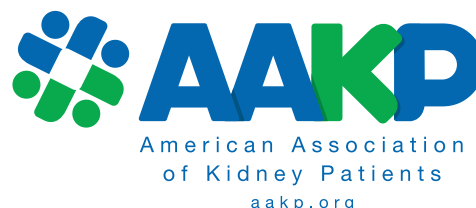
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