



RENALIFE

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A Mother's Story... Worrier to Warrior

**Ray Harris: 1-2-3 Strikes
and Still Swinging at CKD**

**Meet Ted Lithgow, Ph.D. and
Jeffrey H. Lawson, M.D., Ph.D.
with Humacyte, Inc.**

**Get Connected: The Benefits of
Chronic Care Management Services**

National Kidney Month

A Publication of the American Association of Kidney Patients



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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.

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The Independent Voice of Kidney Patients Since 1969™

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MESSAGE FROM AAKP

Welcome to spring! I hope this issue of *aakpRENALIFE* finds you well and in good health.

Over the past several months, the AAKP professional staff, Board of Directors, Ambassadors and Medical Advisory Board have been intensely involved in a number of important AAKP national programs. As a full team, we have been involved in several groundbreaking initiatives involving government, non-profit organizations and the private sector that will have a profound impact on the future of kidney disease.

The work done on your behalf by our professional staff: Interim Director Diana Clynes, Director of Stakeholder Operations Erin Kahle, Director of Office Operations Valerie Gonzalez, Marketing & Communications Manager Deborah Pelaez and Administrative Services Tangi Falber, have been outstanding and you should be proud of the efforts these fine professionals are making every day to serve your interests and to expand the positive impact of AAKP across the country. When you call them, email or see them at a meeting – please thank them for

their service, they are among the best professionals our Board of Directors has ever had the honor to serve alongside.

At the national level, the individuals highlighted above have been managing the rescheduling of AAKP's National Patient Meeting after its postponement last fall due to Hurricane Irma. **The meeting will be June 8-10 in St. Petersburg, Florida at the Vinoy Renaissance – so please, register early!** Our agenda for this meeting will be nearly the same as originally planned – with one exception – we have **even more experts** coming who want to hear your stories, understand your experiences and use your voices to inform policy, legislation, regulation and new innovations. By attending – not only will you learn a great deal more about prevailing in the fight to overcome kidney disease – you will help future patients by educating key influencers working to create better treatments and save lives. Remember – the AAKP National Patient Meeting is the largest kidney patient meeting in America and the perfect place to learn, relax and share the humor and battle stories that only patients understand!

Our Ambassador Program continues to expand! It has been less than a year since Erin Kahle joined Team AAKP – and her efforts to engage more of you at the state and grassroots level has been very well received. AAKP

now has over 50 Ambassadors in 39 states – providing AAKP with greater reach into the communities we serve. Today, AAKP is far better positioned to engage kidney patients and loved ones in the educational programs and advocacy initiatives that equip you with important knowledge about nutrition, medications, modality choices and breakthroughs in treatment than we were less than a year ago. AAKP is also better able to fight for and protect your interests in Washington D.C., because we have one of the most sophisticated advocacy voices in the kidney space due to the combined tactics of social media, a national field organization and bipartisan relationships. To learn more on how you can become an Ambassador, please reach out to Erin at ekahle@aakp.org.

Below are a few key national initiatives to “watch” in the coming year – you will see them mentioned in AAKP social media feeds, Action Alerts from the AAKP Center for Patient Engagement and Advocacy, the pages of this magazine and by key leaders of each effort who will be at our National Patient Meeting. The leadership of the AAKP Board of Directors and members of our national Ambassadors are playing an important role in every one of these efforts. If you are interested in how you can become involved as a patient, contact our national office: 1-800-749-2257 or info@aakp.org

Kidney Health Initiative (KHI): AAKP is a founding member of KHI, a breakthrough collaboration between our allies at the American Society of Nephrology and our partners at the U.S. Food and Drug Administration. KHI brings together major influencers in the kidney space – including regulators, manufacturers and patients – to conduct and publish research to support innovation, clinical trials, devices, drugs and diagnostics. KHI has its own website and an established Patient and Family Partnership Council (PFPC) to include the patient voice and engagement in every aspect of KHI deliberation and research. Learn more here: www.asn-online.org/khi/

Kidney Precision Medicine Project (KPMP): This recently launched initiative is housed at the National Institutes of Health (NIH) within the National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK). The KPMP is designed as a collaborative effort of the Federal government, the non-profit sector and private industry aimed at providing the scientific basis to advance precision medicine for kidney patients. Learn more about the KPMP here: www.niddk.nih.gov/research-funding/research-programs/kidney-precision-medicine-project-kpmp

Clinical Trials Transformation Initiative (CTTI): CTTI just celebrated its 10th anniversary and is a tremendous collaboration between the Food and Drug Administration, Duke University and key stakeholder organizations, including private industry. CTTI develops and publishes research on issues related to clinical trial policy, design, and execution. CTTI is very committed to meaningful patient engagement and involvement and has made a number of positive impacts on the design of national clinical trials, including those in the renal space. Learn more about CTTI here: www.ctti-clinicaltrials.org

Center for Dialysis Innovation (CDI): Based at the University of Washington and involving key research partners including Northwest Kidney Centers, CDI is committed to addressing the lack of greater innovation in dialysis care and technology. With a world class team of experts, CDI has, in a very short time, gained national attention and sparked intense interest among patients. Learn more about CDI here: www.cdi.washington.edu

Kidney Innovation Accelerator: Launched by the U.S. Department of Health and Human Services (HHS) at the 2017 American Society of Nephrology annual Kidney Week meeting in New Orleans, the Kidney Innovation Accelerator is a Silicon Valley style initiative designed to inject critical funds, mostly from the private sector, into promising technologies being developed by startup or other companies that may rapidly advance solutions to kidney disease care. This effort will be of interest to every kidney patient in America – and AAKP will be a strong advocate as the effort builds: Learn more about it here: www.kidneynews.org/policy-advocacy/leading-edge/hhs-announcement-to-launch-kidney-innovation-accelerator-asn-kidney-week-2017-available

As an AAKP member, healthcare professional, caregiver or advocacy ally – thank you for continued support of AAKP and I hope you enjoy this issue of aakpRENALIFE. The future lives of patients like us depend upon the individual and combined efforts of everyone this magazine and AAKP impacts. Take care of your health - and if you want to join a noble cause that is far larger than yourself, contact us today so you can take your place alongside us in the honorable fight to save the lives of our fellow patients.



Paul T. Conway
President of AAKP

COVER STORY

KIDNEY KIDS ARTICLE

A Mother's Story... Worrier to Warrior

By Emily Payne

Last week we celebrated my daughters first year of life, one that we were told several times would not exist. Flashing back to the excitement of our first ultrasound and learning the sex of our baby quickly turned to disparity when I was only 20 weeks along. Her kidneys were bright and enlarged and at every appointment her amniotic fluid was slowly disappearing. Without amniotic fluid her little lungs couldn't develop and the doctors didn't even know if she would make it to delivery. My happiness of being pregnant for the first time diminished as I began dreading each day and each appointment. I lived in constant fear when I didn't feel her kick frequently.

We were advised to transfer our care to a larger hospital because they knew they were not equipped to keep our baby alive with such a severe case of autosomal recessive polycystic kidney disease (ARPKD).

My husband had just started a new job and couldn't risk asking for a day off this soon, so I travelled to



Zack Payne and Rilynn

The University of Michigan, two hours away without him for a second opinion. I was 35 weeks along and they quickly admitted me after finding a defect in her heart. The doctor said she was un-survivable. Three days later Rilynn was born via emergency C- Section after several attempts at inducing me. The first time I saw her was a picture my husband showed me. I heard no cries but only of my own.

The first two weeks were the hardest, we were told multiple times she wouldn't make it another night but Rilynn pushed through. She had both of her enlarged kidneys removed and began dialysis at a week old. The most important thing I learned in Rilynn's 95 day NICU stay is that you will become your baby's biggest advocate. Never lose hope because miracles like Rilynn happen every day!

When we were going through this diagnosis all I ever heard were discouraging stories and doctors stating facts that were terrifying. I wish I had someone to share with me the outcome of hope. Throughout this last year I have met so many

families who have gone through almost identical situations and have overcome this disease. Yes we have had many ups and downs in this journey, but maybe this is the moment we were created for. I cannot begin to explain the changes that have taken way in my heart and mind about life. You learn to appreciate life in a different way, you find what truly matters and who will stick it through with you. Most of all you find the most priceless love you can ever imagine. I remember feeling like Rilynn and I wouldn't have that great mother/daughter bond since I couldn't hold her daily, I couldn't be with her 24/7, and because I couldn't stop the pain she experienced. I now feel like we have a stronger bond than normal and have overcome many triumphs together.

What do parents of children with kidney disease want to hear? I'm not completely sure... all I know is when I was standing in your shoes, I was overwhelmed. I wanted to know all the information but yet I didn't know what to ask. There were

questions I wanted to ask, but was scared to hear the truth. I kept receiving the answers to my questions as "every case is different." I honestly hated that answer, I hated the uncertainty. We now chose to live our life one step at a time, once in awhile we get thrown a curve ball. But with prayer and faith I have finally come to a peace with this lifestyle. I know worrying won't change the outcome. I know that God knew Rilynn before she was formed in the womb. While going through this journey I read something that just clicked with me and I'll share it with you.

'Many times when God isn't changing our circumstances it's because he is mostly concerned with changing US within the circumstances. Our character, our inner strength, our integrity matters to him because they are everlasting qualities. The wisdom, the strength, and the maturity that grows within us are all the things we are going to need to sustain the calling God has on our life.' 🌱



43rd National Patient Meeting

Join us
June 8-10th
St. Petersburg, FL

Mark your calendars for the rescheduled AAKP National Patient Meeting – postponed last September due to Hurricane Irma. Plan to join us on June 8-10, 2018 at the Vinoy Renaissance Resort in St. Petersburg, Florida.

FOR MORE INFO. OR TO REGISTER:

<https://aakp.org/national-patient-meeting/>
or call (800) 749-2257.



Ray Harris

1-2-3 Strikes and Still Swinging at CKD

By Ray Harris

My story starts in early spring 1998 in Baltimore, Maryland to be exact, my hometown. My career was soaring as a recent graduate and police officer for the state of Maryland. My personal life was also fruitful as I was dating my lovely wife, Lauren. I knew I was winning at life and I could only see good getting better.

During my early career, as a rookie officer, I was required to work extended hours. I experienced swelling in my hands, legs and feet. I was not alarmed though, thinking back to my years of playing high school sports. I would say to myself “pain goes away, athletes get injured.” My symptoms increased with lower back pain, poor appetite and foamy urine. Within a few days, I was told my kidneys were failing and was referred to Johns Hopkins Hospital. A kidney biopsy was performed and the diagnosis was FSGS (Focal Segmental Glomerulosclerosis).

After diagnosis, all I could think about was life... death... dialysis... kidney disease. The severity of my situation was critical. I was not ready to acknowledge it myself, let alone tell anyone else about my diagnosis. Shortly thereafter, I began hemodialysis and my life was a new normal I never imagined. Dialysis is an invasive and impersonal process which preserves life. I then decided to call dialysis “the joint”. It was my way of dealing with CKD.

Nearly four years after starting dialysis, Lauren and I were married. Then, in mid-spring of the following year, I received a call from Johns Hopkins Hospital that they had a kidney for me. The kidney transplant

was successful. After my transplant, everything I experienced had an indescribable newness I’d never felt before.

In June 2005, I awoke with my head pounding and partial vision. I could not get out of bed. Still, I said to myself “pain goes away, athletes get injured.” I awoke in the hospital 10 days later and a nurse explained that I had a stroke and had been in a comma. Two months after my stroke, my transplanted kidney failed, and for the second time I needed dialysis.

During this time, I began my workup for a second kidney transplant. I regained a positive outlook by consuming myself with the brighter side of life. In the summer of 2007 I received my second kidney transplant. The kidney was sleepy after a few weeks, but then awoke. “Pinky” as I called her produced beautiful liquid gold. After the transplant, Lauren and I made good on visiting relatives, attending family reunions and vacations that were just not ideal before.

During the fall of 2013, before Thanksgiving, I was involved in a serious vehicle accident. There were multiple cars involved, and I was taken to the hospital. Officers later arrived at the hospital and told me I had an open arrest warrant in Virginia. The warrant was for failure to appear in court. (On the court date missed I was hospitalized in Maryland.) After being released by the hospital from the accident I remained in the custody of the Virginia police.

When in custody, some days I was provided my meds and other days not at all – this caused me to



Ray (left) serving as an AAKP Ambassador with fellow Ambassador Daronta Briggs



Ray and his wife, Lauren

become weak and sick. I began coughing up increasing amounts of blood; within hours, I was enroute to the hospital. After arriving, it was determined my transplanted kidney had officially failed, and I would again start dialysis. Hospital staff all expressed golden hearts of angels. They told me to fight like never before knowing this was my third bout with dialysis.

I returned to Baltimore and a familiar routine of the joint (dialysis). In fall of 2014 I decided to “control my controllables”. This meant to live despite dialysis. Lauren and I began attending kidney classes, symposiums and conferences. This increased our comfort level and knowledge of kidney disease; igniting us to promote kidney awareness everyday everywhere.

During my early experience battling kidney disease, it was very difficult to talk about my condition. Now in 2018, we cannot talk about it enough. As a kidney patient for 20 years it would be easy to be upset and bitter about life...death...dialysis...kidney disease, but I choose to focus forward on the future learning, teaching, speaking and helping all people to crush kidney disease in 2018. 🌸

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AAKP Innovator Series:

Meet Ted Lithgow, Ph.D. and
Jeffrey H. Lawson, M.D., Ph.D.
with Humacyte, Inc*Interview by Deborah Pelaez, AAKP Staff Writer*

Humacyte, Inc. is a privately held biotechnology company, based in Durham, North Carolina focused on developing bio-engineered tissue products. Humacyte develops novel human acellular vessels (HAV's or HUMACYL®) for important patient applications, including vascular surgery and vascular access for hemodialysis. Humacyte's proprietary process uses qualified cells from human donors to produce bio-engineered human tissues. These tissues are removed of all original donor identity, leaving behind a robust, bio-engineered, human vessel suitable for a surgeon to create an access for patients requiring dialysis. HAV's can be stored for up to 12 months on site in the hospital, allowing the product to be available on demand for hospital operating room needs. HAV's are not yet approved for marketing by the FDA, but are being investigated in a range of early and late-stage clinical settings, including as a vascular access for patients with kidney disease requiring dialysis.

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

Dr. Lawson:

I'm a physician, vascular surgeon, and serve as chief medical officer at Humacyte. I have been working with kidney patients for over 20 years. I have a long experience with how difficult dialysis is and how

many challenges kidney patients face. One thing that inspires me are the benefits of research and development to advance and improve care. With respect to the first patient we treated with the Humacyte blood vessel, that too was a very rewarding experience. It was one of my own patients that we enrolled in the first U.S. clinical trials. This was a patient that was inspirational because he was willing to try something new not just for himself, but in his own words, "if this might help other kidney patients, it was worth doing the research." Seeing patients willing to help us become pioneers is very inspirational. I think that we provided him with a vascular access free of complications for a long time – and this was a patient who had a number of prior vascular access failures.

Dr. Lithgow:

I have worked in a number of different therapeutic areas in the 30 years I have been in healthcare. I've conducted hundreds of patient interviews overtime, but the first time I worked with patients on dialysis was at the Kidney Health Initiative conference a few years ago. I found them to very passionate advocates who -- more so than any other area of treatment and patient care -- have a very strong and profound patient voice. They really would like to be heard and have an active voice in their treatment, and they are highly supportive of one another.



How would you explain or describe your investigational product (HUMACYL) to an individual with advanced kidney disease?

Dr. Lawson:

We are making a blood vessel that is compatible with your body that, when implanted, functions like your own natural blood vessel. We can put it in a location so that it is convenient for a dialysis unit. We are investigating whether we can eliminate some of the complications of synthetic vessels (such as a graft) or a catheter with respect to infection and failure related to foreign material because the Humacyte blood vessel that is engineered has the potential to become your own tissue.

In regard to vascular access health and care – what do you think are the most important things patients and their caregivers should know about this potential product?

Dr. Lithgow:

HUMACYL will potentially be relevant for a wide range of patients and it is “off-the-shelf”. Patients and physicians can benefit from a readily available biologic option. In general, our vessel is bioengineered from human smooth muscle cells and these are the same cells that make-up a patient’s own arteries. Our preliminary investigations suggest

that HUMACYL may have the best chance for long-term success for a dialysis patient, since the vessel comes from human cells, and is bioengineered potentially for all patients.

AAKP believes that every patient with kidney disease should be able to pursue their aspirations and that dialysis 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?

Dr. Lawson:

Having worked with thousands of dialysis patients as their active surgeon, those who have been able to maintain an active and fulfilling life with work and family appear to do much better. Those who can continue to have activities in their lives such as work or volunteering tend to do better physically, emotionally and mentally.

Dr. Lithgow:

Of course! Being able to pursue aspirations, such as a career and other personal goals, can be very fulfilling and rewarding, which

Information Article continued on next page

can contribute to self-esteem, sense of pride and accomplishment.

These are powerful motivators and may add to a patient's overall health.

As an entrepreneur in the renal industry, you know well that it is not easy to develop a novel approach to treatment.

What do you draw upon internally to keep your drive, optimism and focus on patients going at full speed during the tough days?

Dr. Lawson:

What keeps me motivated is not just the excitement of seeing this technology develop and grow over 20 years now, but also that this vessel may become a real solution for creating and proving a vascular access for kidney patients.

Dr. Lithgow:

I am a "new products" person at heart. "New products" people are very comfortable starting with a blank page and creating strategies that can be successful. During the tough days, I remind myself that there are literally hundreds of reasons to stop a project, and far fewer reasons to push your innovation ahead. New products like the one we are creating that are highly innovative -- and technically challenging -- require champions. The patients that started AAKP were champions -- and the Humacyte Founder is also one such champion! New product development is like a marathon. It takes stamina! It is so exciting that our life-sustaining product is close to being available in the market. -- that alone keeps us motivated.

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?

Dr. Lawson:

One thing I would like to see by 2020, and I think that our technology will help, is for kidney patients

to be more independent with treatments like home dialysis; where they can manage their own life by not being confined to the dialysis unit.

Dr. Lithgow:

Our innovation, by 2020, should be available to patients.

It is clear from speaking to regulatory groups and even independent organizations like AAKP and KHI, that these organizations are requiring greater patient involvement. Not long ago, the patient voice used to be really nice to have; now there is a greater demand to get the patient voice into the development cycle. Patients add a perspective that is real, important and complements the overall goal of research and development. 🌸



Theodore D. Lithgow, Ph.D. is currently the COO of Humacyte, Inc. an innovative regenerative medicine biotech company located in Durham, North Carolina. He was formerly President and Chief Science Officer of Meadwestvaco Healthcare, a

Group Vice-President for Schering Plough/Merck global businesses, and Group Vice-President and GM of the SP/Merck



Jeffrey H. Lawson, M.D., Ph.D. received his Medical Degree and a PhD in cell and molecular biology from the University of Vermont. He then completed his residency in General Surgery and a Fellowship in Vascular Surgery at Duke University.

He is currently Chief Medical Officer of Humacyte and Professor of Surgery and Pathology at Duke University. He is the co-author of over 120 journal articles on the topics of hemostasis, tissue engineering and vascular surgery and lectures internationally on these topics.

INFORMATIONAL ARTICLE

Get Connected: The Benefits of Chronic Care Management Services

By Beth Chalick-Kaplan, DNP,
CRNP, FNP-BC, RN, CCM



Managing your health while living with Chronic Kidney Disease (CKD) can be overwhelming. Taking multiple medications, following a special diet, and keeping appointments with different specialists while caring for your family and/or working can be difficult. Healthcare providers can also feel challenged in caring for patients with multiple chronic conditions. They must communicate with one or more specialists, review lab work and reports, create and update plans for care, consider medication and treatment changes, and coordinate patient transitions from one care site to another, or to home. Care coordination work takes significant time and effort. Most of this work is done outside of a face to face office visit. Patients may not be aware of the amount of time it takes to do this work, but it must be done to make sure patients can get high quality, safe, and effective care. Medicare pays providers for the important care management and coordination work they do outside of office visits.

Through the Connected Care campaign, the Centers for Medicare & Medicaid Services Office of Minority Health and the Federal Office of Rural Health Policy at the Health Resources and Services Administration are raising awareness of the importance of chronic care management (CCM) and coordinated care for patients with chronic conditions like CKD. CCM services help people with Medicare (and those with Medicare and Medicaid) who have two or more chronic conditions to stay on track with their treatment plans and improve their health.

Patients who receive CCM services partner with their participating Medicare provider to create a plan that supports their disease control and health goals. For patients with CKD, a treatment plan might work to lessen potential complications such as hypertension, anemia, mineral and bone disorders, electrolyte disturbances and fluid imbalances. The plan can also include a way to “check in” with your provider more often, without having to travel anywhere. Regular contact can help you and your provider stay on track with your treatments, appointments, and prescriptions. Some patients feel this lessens how often they visit the office in person, giving them more time to do things they enjoy. You can find out more about Connected Care and chronic care management services at <https://www.medicare.gov/coverage/chronic-care-management-services.html> or by calling **1-800-Medicare**. Ask your doctor about chronic care management services and get the connected care you need. If you are a community partner or health care provider, visit the Connected Care website at <http://go.cms.gov/ccm> for additional resources.

Beth Chalick-Kaplan, PhD is an Outreach Specialist for Region 3 at CMS. Dr. Chalick-Kaplan serves on the Regional External Affairs Team as CMS State Lead for Delaware and West Virginia and assists in the development and implementation of regional strategic plans to educate consumers regarding current CMS healthcare initiatives. 🌸

A Tribute to Darlene

Palliative Care as an Option

By the children of Darlene Heinrich

In Memory of Darlene...

Darlene passed away November 29, 2017 surrounded by her children. All were well-educated about the journey she had chosen. She was not a candidate for a transplant and opted not to go on dialysis.. Instead, she modified her lifestyle according to the vast information she was able to read; research; AND discussed with her healthcare team and her children. Most of this information came from American Association of Kidney Patients. She selected articles from their newsletters, was an avid reader of aakpRENALIFE magazine, and frequently requested materials from among the variety of brochures offered in the AAKP store.

Darlene's Journey...

As a young woman with a High School Diploma, Darlene started what would be a 30+ year career in banking with the largest bank in the State of Washington at that time. She spent years taking evening classes in order to expand her banking knowledge, allowing her to further her career. Eventually, she rose to one of the Vice President positions and the Head of the Regional Auditing Department.

In retirement, she maintained an ideal lifestyle that included her love of quilting and travel. Taking cruises and visiting her summer home in Arizona were always a given even though she



Two masterpieces – final quilt and final great-granddaughter



Vacation on the East Coast

had been diagnosed with chronic kidney failure 20+ years prior to her passing. Darlene was an avid reader and truly one of the smartest people you would ever meet. She was able to build a long life with chronic kidney failure by her research, partnership with her healthcare team, and perseverance. Of course, this also included the support of her family,



Summer with the children

When she hit stage 4 in the early 2000s, the extended family was included and totally involved with the research materials and her medical appointments. Darlene's commitment to learning everything about her condition and how to manage it, maintained her good health at Stage 4 for over 10 years. Remarkable! During this time many of her friends were diagnosed with kidney failure, eventually moved into dialysis, and passed. Still, she held strong. She constantly read the latest materials always from American Association of Kidney Patients. She watched her friends and their families become consumed by the rapid progression of their disease, still she held strong.

Finally, the inevitable Stage 5. At this time a decision had to be made. She got a lot of pressure from her nephrologist to start the fistula, finally she made the decision to simply leave her body alone and continue with the best health she could manage until it was her time to move on. There would be no dialysis. She informed the family and her healthcare team of her decision. The nephrologist told her not to come back. Her primary caregiver was appreciative of her depth of knowledge and her logical progress. The family did not all agree with the decision BUT we all agreed it was her decision to make. It was clear Darlene understood her condition, was attune to her health, and as always – did her research.



Hand Jive Family

And so, three years after stepping into Stage 5, she passed away at her home surrounded by her children. Her journey was fairly unremarkable, only one hospitalization during this time due to dehydration and some difficulty regulating her pills. The pill issue was solved by moving to monthly pharmacy prepack which her children strongly suggest for any one with multiple pills to be taken at multiple times. Otherwise, she lived at home and continued her hobbies of quilting for charity (estimated 50 quilts per year for 13 years is 650 quilts!), watching and armchair coaching for the Seattle Mariners, and keeping up with her career banking co-workers after being retired for nearly 30 years.

For Darlene “no” was her option, she would have the best possible life with palliative care. She held strong to that decision and never wavered. Her children agree, for her it was the right decision.

The AAKP would like to thank the family of Ms. Darlene for sharing her story in memoriam. In honor of National Kidney Month - we hope Darlene's story will inspire others to learn everything they can about their condition, be the leader of their healthcare team and understand their treatment options. Darlene made sure that her condition did not affect her quality of life... she lived every day to the fullest...and that is a wonderful legacy to leave behind... 🌸



MEDAL OF EXCELLENCE AWARD

The Medal of Excellence Program recognizes healthcare professionals who have made impactful contributions over the course of their career. This prestigious award is AAKP's highest honor for kidney healthcare professionals and is designed to elevate individuals who are strong patient advocates and shine a light on those whose actions, efforts and commitment to patients is an example of excellence in their field.

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Get to know the 2018 Honorees:

Physician Category: Rebecca Schmidt, DO, FACP, FASN



What have patients taught you and/or how have patients impacted your career?

"Patients have taught me much about medicine but even more about life...my patients have taught me...

...a deep admiration for willpower and inner strength;

...that life is relative – and a patient's

choice or decision may change with time and circumstance;

...that the teachings of my parents – humility, respect for the golden rule and the duty to place myself in others' shoes – are

central to the relationships I have with my patients; and

...that sometimes kindness is all I can give."

Rebecca Schmidt, DO, FACP, FASN, is Section Chief and Professor of Medicine with Tenure for West Virginia University School of Medicine, Department of Medicine – Section of Nephrology and affiliate of Fresenius Medical Care-NA in Morgantown, West Virginia.



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Excellence Program*

Nursing Category: Nancy K. Uhland, NP



What have patients taught you and/or how have patients impacted your career?

“In today’s world, access to information is plentiful, but what my patients have taught me is how to access wisdom from something less plentiful... the art of listening. Each patient is an individual and has invaluable information to communicate to the provider. The provider simply needs to listen!”

Nancy Uhland, NP, is a nurse practitioner in the Renal Division of the George Washington Medical Faculty Associates in Washington, D.C.

Social Work Category: Wanda Driggers, LMSW

What have patients taught you and/or how have patients impacted your career?



“That pride is a useless thing, everyone needs help sometimes. That indomitable patient spirit is something that I am always aware of in the clinics and watching their struggles...and triumphs...reminds me to be thankful for my own health and to be in the moment with patients with a smile,

conversation, a positive attitude and doing what I can to help them have a good day. Dialysis patients have reinforced my belief that giving just a little of yourself to others goes a long way. Working with dialysis patients, I have certainly learned to put aside the petty side of life and be thankful that I have the life I have. I am humbled at being a part of their experience.”

Wanda Driggers, LMSW, is a licensed social worker for Fresenius Kidney Care in the Myrtle Beach/Hilton Head, SC region.

Dietitian Category Award Winner: Stacey Adams, MPH, RD, CDN



What have patients taught you and/or how have patients impacted your career?

“Throughout my career, I have been fortunate to be able to work with some of the most wonderful patients. These patients have taught me the true meaning of “strength” because that is what it takes to live each day with a chronic illness. Being based in

The Renal Physicians Association Congratulates



Dr. Rebecca Schmidt

Recipient of the
2018 AAKP Medal of
Excellence Award

RPA

Renal Physicians Association

The RPA is a proud supporter of the
AAKP Medal of Excellence program.

The Medal of Excellence recipients will be recognized throughout the 2018 year. AAKP is proud to recognize such deserving individuals; whose career achievements set an example of the best in patient-centered care. The 2018 honorees represent every sector of the renal community and demonstrate the profound impact each member of the healthcare team has on patient outcomes, quality of life and helping those affected by chronic kidney disease achieve their aspirations. For more information on these individuals, visit www.aakp.org/medal-of-excellence.

New York, a true melting-pot, I have encountered patients from all over the world. My patients have taught me how to successfully work with people from many different walks of life. I have learned to be a much better listener. Every patient has their own unique story and sometimes, it isn't about teaching them about nutrition, but about listening to them, being compassionate and showing kindness. My patients are the reason that I come to work each day with a smile on my face. Knowing that I am making a difference in their lives has truly been one of the most rewarding experiences of my life."

Stacey Adams, MPH, RD, CDN, is a Senior Renal Dietitian at The Rogosin Institute in New York, New York. 🌱



CONGRATULATIONS!

In recognition of AAKP's **2018 Medal of Excellence Award**, we are proud to recognize all of the winners, especially two of our own:

Physician Category

Rebecca Schmidt, DO, FASN, FACP

Social Worker Category

Wanda Driggers, LMSW

Thank you for inspiring people with chronic kidney disease and end stage renal disease to lead fuller, more vibrant lives.

Successful people are always looking for opportunities to help others.
- Brian Tracy

Congratulations to the 2018 AAKP Medal of Excellence Recipients

Rebecca Schmidt, DO, FACP, FASN
Nancy Uhland, NP
Wanda Driggers, LMSW
Stacey Adams, MPH, RD, CDN



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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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