



RENALIFE

Volume 50 • Number 2 *The Independent Voice of Kidney Patients Since 1969™*

March 2017



Kidney Disease Awareness Month

**This issue is dedicated to the
individuals and families
affected by kidney disease.**

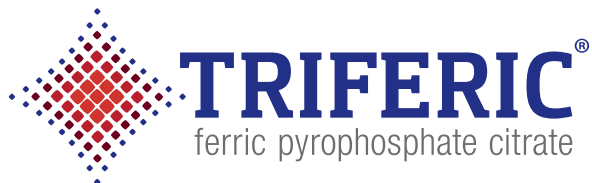


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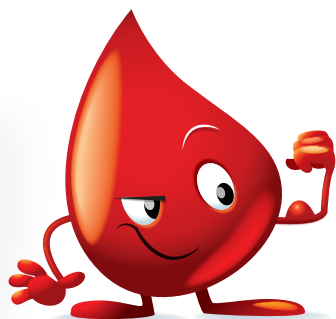
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Design and Production-DebraRobertsDesign, LLC

aakpRENALIFE is published six times a year by the American Association of Kidney Patients (AAKP). It provides articles, news items and information of interest to kidney disease patients and their families, as well as individuals and organizations in the renal health care field.

aakpRENALIFE is distributed in January, March, May, July, September and November and is a membership benefit.

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Non-profit postage paid at Tampa, Fla., and additional mailing offices.

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

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The Independent Voice of Kidney Patients Since 1969™

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Meet Ashley, from the time she was seven years old, she was attending AAKP's Annual Patient Meetings and was training to be her mother's caretaker. However, the red tape to become her caretaker has proven to be a long and stressful process on both Ashley and her mother. Luckily, Ashley never backed down and now many years later, Ashley has become one of the youngest trained in-home dialysis caretakers and is studying to become a pediatric transplant surgeon.

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MESSAGE FROM AAKP

March is Kidney Awareness Month and together we celebrate all of the patients, donors, families and professionals that have helped preserve and protect the lives of kidney patients.

We dedicate this Renalife to each of you who have refused to bow to hardship and who model, every day, how faith, optimism and rugged determination help you and others keep fighting the good fight. I have battled this disease for over 36 years know the battle you and your family fight. As AAKP President, know that you have a combined team of over 100,000 AAKP members at your side and together we will PREVAIL. We are united in our belief that we serve a cause larger than ourselves and mere self-interest – our fight is for the yet to be diagnosed and for the lives of future generations.

During Kidney Awareness Month, you are our best advocate in spreading the message of kidney disease awareness and treatment. You can make an impact through our new Center for Patient Engagement and Advocacy by doing 3 simple things:

- Become an AAKP fan and promote AAKP's website within your circle of friends on social media
- Tell your friends, fellow patients, caregivers and family members to sign-up for a FREE AAKP membership! FREE membership includes aakpRENALIFE magazine subscription, three monthly electronic newsletters and access to all AAKP educational materials!
- Use our website for details on upcoming Capitol Hill Days, Healthline webinars, and other AAKP events.

Remember – every person that joins and learns about AAKP and our work contributes to our mission. And every contribution to our mission helps improve the life of a fellow kidney disease patient.

In this issue, we honor our 2017 Medal of Excellence Honorees. The Medal of Excellence program honors and thanks representatives of the entire health care team for their commitment to patient-centered care and quality care as defined by patients.

We are excited to announce our 43rd Annual Patient Meeting will be held September 8-10, 2017 in St. Petersburg, Florida in the landmark Vinoy Renaissance resort. We have secured a \$139/night room rate, so be sure to book your room at this great price. This meeting is the largest patient meeting in America and the most spectacular venue in AAKP's history.

Please contact AAKP at 800-749-AAKP for information on Kidney Month events or questions on kidney disease. Stay positive, keep fighting and we will see you soon!



Paul T. Conway
President of AAKP

UPCOMING CALENDAR OF EVENTS

MARCH 17 Medal of Excellence Dinner at Renal Physicians Association Meeting

MARCH 29 Capitol Hill Day – Visit to Washington D.C.

JUNE 25 - JULY 2 World Transplant Games in Malaga, Spain

SEPTEMBER 8-10 AAKP National Patient Meeting, Florida

For more information, please visit <https://aakp.org/events/>

PATIENT PROFILE:

Alex Reed



The Ultimate Alumni Gift ... The Gift of Life

By Shari Routch (Previously published by the Penn State Alumni Association)

The setting: State College, PA, 7:00 a.m., September 12, 2015. Pre-game tailgate for Penn State vs. Buffalo game.

John Hyde '84, was hosting his regular tailgate at Beaver Stadium for his son's Penn State Altoona baseball teammates and friends. Alex Reed '13, was in attendance as usual. But this was no usual day.

Hyde was manning the grill and asked Alex what he needed. There was only one thing on the griddle, so Alex had no choice but to ask for a breakfast sandwich. Or maybe not. "I asked him over and over if there was anything else he needed," recalls Hyde. "Finally I said, 'How about my kidney.'"

Alex was diagnosed with end-stage renal disease just two weeks after his graduation from Penn State Altoona in spring 2013. For the next two years, rather than embarking on the future for which he had planned, Alex spent a large portion of his time receiving kidney dialysis. His continuing hope, and that of his mom Bobbie Reed, was to find a kidney donor.

When Penn State Altoona, via its alumni e-newsletter *Ivy Link*, featured Alex's struggle, Bobbie shared the article on Facebook. Hyde, who kept tabs on the tailgate attendees through Facebook, saw the post. "I didn't know Alex very well, but the others spoke so highly of him," states Hyde. "The article said he was on dialysis four hours a day, four days a week, and in between was

wiped out. That's no way for any 24-year-old to live. That's what hit me."

Hyde knew of Alex's illness for about a year before he took any action to help. "I wasn't in the position to do anything about it. I wasn't healthy. There were a number of girls in the tailgating group who gave so much of themselves for things like THON and volunteering at camps for children with special needs. I looked at what they did and I felt small. It was time to give more of myself, something more significant than hosting tailgates," states Hyde.

"So I lost the weight and got back in shape. After another Facebook post by his mom, I thought I could do it," says Hyde. "I asked my wife if it was okay to do something that I really wanted to do, but was dangerous." He first joked that it was skydiving, but then revealed that it was kidney donation. "She was hesitant, but always supportive."

Alex recalls the life-changing tailgate. "I am a quiet, private kind of guy. I shocked, happy, excited, and probably a lot more. Emotions ran deep. I didn't know what to say." So he called his mom.

"When Alex called me, I was in a state of shock and disbelief," Bobbie says. "He said, 'Mr. Hyde is giving me his kidney. Do you want to talk to him?' I started to cry; it was a very emotional moment."

Alex and Hyde agreed on November 9, 2015, for the surgery. From Hyde's perspective the surgery was "a piece of cake. I was out of the hospital the

next day and walking three miles the day after. It's like getting your appendix removed." One year post-surgery, Hyde still feels good, working on staying in shape and keeping his blood pressure in check.

Recovery for Alex was "a lot of adjusting. There was an immediate relief of not having to do dialysis to stay alive. I have more energy and more freedom to do the things I took for granted in the past, like spending time with friends and traveling. There were a lot of adjustments initially with the new medications to keep my kidney healthy, which I'll have to take for the rest of my life. But one year later, I feel great and I am enjoying life."

Both mother and son are very thankful to the Penn State Altoona alumni network. "The power of being a Penn State Altoona alum is far-reaching," notes Bobbie. "I really believe that Penn Staters take care of their own. This asset develops not from the learning in a book, but from the bonds that grow and flourish within the Penn State Altoona campus community. It's very easy to understand why so many students elect to remain at the Penn State Altoona campus for four years. Friendships form early on, and remain." Notes Alex, "The Penn State Altoona alumni network affords all alums the vehicle to give back. It anchors the words we hear often: WE ARE ... PENN STATE ... THANK YOU!"

And of course, they are forever thankful to Hyde. "Saying thanks doesn't even scratch the surface," says Bobbie. "John is an amazing human being. He loves his family and he cares deeply about others. He wanted to give back and lead by example. As a Penn Stater, I am sure his actions will have a lasting

impact on others through inspiring them to help others."

Alex still has a hard time expressing his thoughts and feelings about this part of his life. "It's as personal as it gets. John will always be a part of me, in a very real life-saving way." Although kidney disease will always be a part of his life, because transplantation is a treatment not a cure, Alex really wants to put this behind him and look forward. "My goal is to focus on building a better future. I need to remain healthy and move forward both professionally and personally."

Now transitioning into his new role with his family's insurance agency, Alex is also looking forward to traveling and spending time with his Penn State Altoona baseball teammates and classmates. But the importance of organ donation is at the forefront of his thoughts. "My life has been forever changed. I strongly encourage everyone to register to be an organ donor. You can and will make a difference in someone else's life, like John did for me."

Through navigating her son's illness with kidney disease, dialysis, finding a donor, and transplant, Bobbie has become quite an advocate for this topic, having been named as the Pennsylvania Liaison by the National Kidney Foundation's Kidney Advocacy Committee, as well as being active with the American Association of Kidney Patients. "As I sit here today, there are well over 100,000 people here in the United States waiting for a lifesaving kidney donor. Last year at this time, my son was one of them. He was fortunate to find a living donor to save his life," states Bobbie. "But a person doesn't have to be a living donor to save a life. It is so simple to register to be an organ donor these days. Simply checking a box on your driver's license renewal or going online and registering as a donor can take just a few minutes. Science and technology is advancing but not there just yet. Perhaps someday there won't be a need for organ donors to sustain life, but for now, perhaps registering to be an organ donor can be your way of giving back."

Patient Profile continued on next page



Bobbie Reed:

A Mother's Love for a Son and His Donor



I cried when I found out that John was giving Alex his kidney, so when people ask, do I maintain a relationship/stay in touch with John? Absolutely! I keep in touch with John and his wonderful family through Facebook. We have also become staples at his now famous PSU Tailgate parties.

As a mom, what can you say about John and what he did for us? Reflecting on what I experienced as a mother, who was in the fight of her life to find someone to save the life of her son—I ask you “what would you do?” Then it happens—just when I thought nothing was working, I told myself to remain positive and keep trying to help Alex. This man gave my son, Alex, his life back. Saying thanks doesn’t even scratch the surface and I have told him and his family that many times.

What would I say to others considering organ donation? As I sit here today there are well over 100,000 people here in the United States waiting for a lifesaving kidney donor. My son was one of them, he was fortunate to find a living donor to save his life. A person doesn’t have to be a living donor to save a life. It is so very simple to register to be an organ donor these days. Simply checking a box on your driver’s license renewal or going online and registering as a donor can take just a few minutes.

Other thoughts I would like to share? When Alex graduated Penn State Altoona in May 2013, kidney disease, dialysis, finding a donor, and transplant were not on my list. I am sure they weren’t on Alex’s list either. The plan was to graduate and come to work in our family insurance agency, George A. Reed Agency, Inc.

The “finding a donor” portion of the journey was where Penn State Altoona Alumni Association proved to be the key that opened the door to “transplant”.

After the Penn State Ivy Link article appeared in 2015, I was running out of people and organizations and ideas of what to do next in searching for a kidney donor for Alex. Two very important things happened at that point and yes—Penn State alum played a crucial role.

First, I contacted my niece, Gina Villiani Richardson, who graduated Penn State and became employed with a national public relations firm. I asked Gina to put the word out over her firms intercompany information system on Alex’s need to find a donor. Gina told me she could not do that, but offered to organize her team of public relations professionals to brainstorm a plan and ideas to further explore and promote Alex’s need. I provided her all the contacts and communications which I had previously taken on. She then pulled her team together and came up with a comprehensive list of ideas and a plan of execution of which I had not previously considered.

Within that plan the first thing they suggested was to reach out to our church. Go and talk to the priest—ask to have something published into the church paper. The second thing I did was to have that meeting with the priest. A week later the article was published in the church paper. The following week, Saturday, September 12, 2015, John identified himself and offered his kidney

to Alex. On November 9, 2015 Alex got his life saving kidney transplant from John. I truly believe the power of Penn State Alumni and the power of God intervened and saved Alex.

Advocating For the Kidney Community

You see, through my navigating my son's illness with kidney disease, dialysis, finding a donor, and transplant, I have become quite an advocate in helping others. I have been named by the National Kidney Foundation's Kidney Advocacy Committee, the Pennsylvania Liaison. In addition to this, I am also very active with the American Association of Kidney Patients.

There are two bills now before congress that have a tie into the donation of kidneys and the other on medications necessary following transplant to prevent rejection. Both of these pieces of legislation impacted Alex finding his donor and going forward insuring he gets the medication to sustain his transplanted kidney.

The first piece of legislation is: The Living Donor Protection Act (H.R. 4616/S. 2584)

This legislation would afford individuals who want to be an organ donor legal rights and protections not currently available. It would protect donors from losing their jobs or suffering consequences/loss of pay by extending them the same FMLA rights available to others. Language would be written into this existing law specifically guaranteeing an organ donor the same protection given to others who for example, take leave for pregnancy etc. It would also prohibit insurance carriers from discriminating or charging higher premiums to organ donors for life insurance coverage.

In Alex's case, this legislation would have had a tremendous impact. Many young people expressed an interest in helping Alex, however when they began the process of being tested to donate, they learned that financially it would not be possible to continue. Think about it, a young person, just graduating college and starting a new job. They

could not afford to jeopardize their financial future--nor could they take the risk of being deemed uninsurable for life insurance. John, Alex's donor, was older, financially established, and had insurance coverage in place.

The second piece of legislation is: The Comprehensive Immunosuppressive Drug Coverage for Kidney Transplant Patients Act (H.R. 6139) For Alex and many others this legislation is really important. Alex, like everyone else who has gotten a kidney transplant is covered under Medicare. Unfortunately, as it is written today, Medicare ceases exactly 36 months following transplant if you are not 65 or older. That means Alex will lose all benefits, including coverage for his medication that prevents his new kidney from rejecting. These drugs are expensive--thousands of dollars per month. If he can find insurance coverage after the 36 months when Medicare expires, the medication costs are often placed on the highest tier level and the out of pocket payments would also be financially straining.

The Comprehensive Immunosuppressive Drug Coverage for Kidney Transplant Patients Act would extend coverage and guarantee him access to the transplant sustaining medication for the life of the transplanted organ.

What can you do to help? The answer is simply take a couple minutes of your time:

1. Register to be an organ donor, if you haven't already done so. Check the block on your driver's license or go online to: <https://www.unos.org/donation/register-to-be-an-organ-donor/>
2. Contact your congressman and senators and ask them to support the legislation on the bills now before Congress.

For more information on these two pieces of legislation, please contact AAKP at info@aakp.org. 🌸



PATIENT PROFILE:

Shawn Booker

Dialysis Doesn't Stop Patient from Working Full-Time as a Firefighter

Shawn Booker knew he wanted to be a firefighter ever since he was a kid. Upon returning home from serving in Operation Desert Storm, there was no question what Shawn's next adventure would be; however, while studying to become a firefighter and paramedic, Shawn received some unexpected news. At 21 years old, Shawn learned that his kidneys were failing as a result of inhaling burning oil during his overseas deployment. He was diagnosed with Goodpasture syndrome, a rare autoimmune disease that affects the lungs and kidneys. Shawn's doctors tried to slow the progression of his kidney failure, but by age 23 he needed to start dialysis. He received a transplant 4 ½ years later and joined the fire department. Shawn knew at the start that his transplant wouldn't last forever; Shawn's lasted for 16 years. Back on dialysis for the past four years, Shawn refuses to let in-center dialysis slow him down, especially in his line of work.

From his family history of service in the military and his own experience in the Army, Shawn has always had the desire to help and protect others. In

the line of duty as a firefighter, he's not only saved people from fires, but also numerous car wrecks and even helped deliver a baby. Shawn loves his job and wants to keep doing it as long as he physically can. Dialysis makes that possible.

A typical firefighter's schedule is 24 hours of work followed by 48 hours off, and as many know, it is a very physically demanding job. To make both his work and dialysis schedules fit, Shawn often goes to work at the fire house, where he serves as Lieutenant, after his treatments, but for the sake of his health won't go into any burning flames on dialysis days. Instead, on these days he leads his teams in their rescue missions, oversees his fire engine and ambulance and uses his skills as a paramedic when needed. This flexibility allows Shawn to focus on monitoring his fluids and energy levels, which is important while on dialysis. Working with his dialysis care team, Shawn has learned to recognize his limits and to rest where he can so that he can be at his best when called upon to help others.

Shawn's fellow firefighters are his second family. When they learned he had to go on dialysis a second time, the fire house held a benefit for Shawn and raised approximately \$12,000 to help cover his medical bills. At home, Shawn's wife has things covered making sure he's comfortable in between the physical demands of both his job and his treatments. And at Fresenius Medical Care Greenfield, which he chose because it worked well with his irregular schedule, Shawn has yet another home away from home, where he always shares a laugh with his care team.

When he's not fighting fires, Shawn keeps fit by lifting weights and running. Currently he is training for a half marathon. He lives the advice he shares with others living with kidney disease - stay as active as you can.

"I don't always have a lot of energy after dialysis, but encourage those on dialysis to always do a little physical activity each day, even if it's just walking around the block," Shawn says. "If you take care of yourself through physical fitness, your body will thank you and you will feel better. As for me, I'm



just trying to keep up with my younger coworkers at the firehouse."

When it comes down to it, it's a love of life that keeps Shawn going. He makes sure he appreciates the daily joys of life – riding his motorcycle with his wife, scuba diving while on vacation with his family, playing with his dog, volunteering at a horse therapy center. He recognizes that he needs to be healthy to enjoy these experiences and to pursue his other dreams. 🌸



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MEDAL OF EXCELLENCE A W A R D

The Medal of Excellence recipients are healthcare professionals and individuals who have contributed to the advancement and evolution of direct patient care, encouraged the expansion of the patient engagement model within the renal community and enhanced the quality of life for kidney patients and their families.

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Get to know the 2017 Honorees:



How have patients impacted your life and career?

Celeste was convinced of the transformative power of collaborations between patients, families, staff, faculty and community stakeholders to drive research forward.

Celeste Lee, Celeste was interviewed for this issue last year and told she had been awarded the AAKP Medal of Life Special Recognition for her lifetime work on patient-centered care. Celeste passed away in January 2017 and AAKP honors her memory and her family.

How have patients impacted your life and career?

A patient's commitment to preserve and thrive while coping with a chronic illness has been a catalyst that continually drives me to research and uncover methods for slowing the



progression of kidney failure. Both as a physician and an investigator, I work to improve the treatment of patients with chronic kidney failure. If they don't give up, then neither will I.

William E. Mitch, MD, Director of the Division of Nephrology at Baylor College of Medicine (Houston, Texas) and a Professor of Medicine at the Selzman Institute for Kidney Health



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

Having chronic kidney disease poses a major challenge to individuals as they strive to make adjustments in their lifestyle to slow the progression of their disease I'm impressed by how these individuals to manage their kidney disease by attempting to follow the worst diet ever, taking a cupful of pills every day and dialyzing when needed with a smile on their face and offering a thank you to me for my small contribution to all of that.

Janelle Gonyea, RDN, LD, FNKF, Clinical Dietitian at Mayo Clinic Dialysis Services and Assistant Professor of Nutrition, College of Medicine



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

Resilience. Patience. Strength through adversity. I often admire the dignity with which these patients greet each member of the medical team when they

likely feel so poorly. What a privilege to be with someone during those important moments in life and provide a touch, a ray of hope, insight, or comfort at the end of life. As many patients greet me when I ask them how they are doing, I would say that I have been “blessed and highly favored” to have been given the opportunity to be a small part of the journey for many people with kidney disease.

Mary Beth Callahan, ACSW, LCSW, Senior Social Worker at Dallas Transplant Institute and a former Chair of the National Kidney Foundation’s Council of Nephrology Social Workers



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

Patients have inspired me to be an advocate for improving clinical outcomes through best

practices in patient-clinician partnerships and scientific inquiry. This is the heart of caring.

Helen Currier, BSN, RN, CNN, CENP, Director of Renal and Pheresis Services at Texas Children’s Hospital and former President of the National Renal Administrators Association (NRAA)



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

The resilience and zeal of the human spirit is something I have witnessed through the eyes of my patients. By extending their longevity through life-saving

dialysis, we are giving patients an opportunity to live their life- to reach milestones and to see their future generations. The spirit of the dialysis patient to live and to thrive, has taught me most about humanity, patience, and the importance of having the will to live life to its best and utmost potential.

Philip M. Varughese, BS, CHT, Facility Administrator at DaVita, Inc. 🌸

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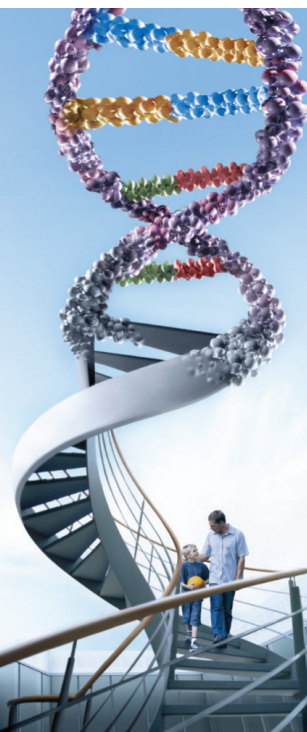
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PATIENT PROFILE:

Christopher Melz

FROM DJ TO DONOR TO RN

By: Christopher H. Melz, RN



In 1993, I began my career as a Hip-Hop DJ. My brother was my partner and we started off by performing at college campuses and touring the country. In 1998, we began broadcasting our own pirate radio show from the living room of a one bedroom apartment in Queens, New York. After 4 years we advanced to the big time and became part of the starting line-up of on-air personalities for Sirius satellite radio. If somebody had told me back then that I would become a registered nurse someday, I would have not believed them.

In August 2008, I learned that a childhood friend of mine was suffering from end-stage renal failure. After hearing the news, I decided to get tested to see if I would be a qualifying candidate for kidney donation. I spoke with the donor coordinator and learned about the steps that were involved. Becoming a donor is not as simple as just deciding to do it; there are qualifications that must be met. The first step was to see if our blood and tissue types were a match, and they were! Once that

was determined, it was time to prepare for the next step: the surgery. After months of testing and preparation, our surgery was scheduled for April 21st, 2009.

At 4 a.m. that morning, I arrived at Stony Brook University Hospital prepared to give away my kidney. Up until that moment, my time inside a hospital was very limited. This was the first time that I was going to be admitted as an in-patient. I was not nervous at all. Instead, I was very anxious and excited about being able to help my friend live a better life. Within the hour, I began to receive some attention from the transplant team involved with my surgery. Every member of the team greeted me in a warm and friendly manner. The team began to prepare me for the surgery. Shortly after the warm greetings concluded, I was introduced to the epidural needle. After the anesthesia was administered, my pre-surgery memories faded rapidly. Roughly 6 hours later, I awoke from the surgery, lying in my hospital bed. My brother was there to film that moment. There is still always a good laugh to be had by watching that video and trying to figure out what I was saying. The medication had my speech extremely slow and difficult to comprehend.

The following morning, I woke up with a feeling of great accomplishment along with some pain. The biggest obstacle that I faced was the extreme gas pain caused by the carbon dioxide that was administered during surgery. The gas pain was truly unbearable at times. The nurses were very sympathetic to my pain, yet they explained that

ambulation was the best method to get rid of the pain caused by the carbon dioxide. However, convincing somebody who is in pain that walking around is more beneficial to them than lying in their bed, is not as easy as it sounds. After I decided to listen to their advice, the pain started to subside due to the amount of walking I conducted in the hallway.

My time in the hospital allowed me to see the role of the nurse in a new way. I was amazed by the display of strength, courage and compassion! It was that experience that inspired me to return to school to become a registered nurse. After a few years of contemplating on whether or not I was too old or too busy to go back to school, I enrolled at Suffolk County Community College in October 2012. Becoming a college student again at the age of thirty nine was exciting! While I attended school I became involved with various clubs and student affairs and I was elected president of the nursing club. I also earned two scholarships for academic achievement. My campus was a great venue for

spreading awareness of kidney disease and the importance of organ donation. I organized several on-campus workshops about Kidney Transplant, including a live presentation from a renal surgeon, as well as a guest speaker from the National Kidney Foundation.

I graduated from my nursing program in May 2016 and received an A.A.S. degree. As a nursing school graduate I was now qualified to take the board exam. In September 2016 I passed the exam and received my license as a registered nurse. I am now enrolled in an online RN-to-BSN program at SUNY Delhi.

Life is a wonderful journey filled with many twists and turns. Often the biggest obstacles we face are the ones that we personally put in front of ourselves. It is hard to believe that it has almost been eight years since my surgery. I am very pleased to announce that my recipient is still healthy and living his life without dialysis! Knowing that he is able to do that is my reward. 🌸

CONGRATULATIONS

AAKP Medal of Excellence Award Social Work Honoree

**Mary Beth Callahan, ACSW, LCSW,
Senior Social Worker at Dallas Transplant Institute**

- ◆ Society for Transplant Social Workers Board Member
- ◆ Past Chair of the Council of Nephrology Social Workers
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- ◆ 2015 NKF Council of Nephrology Social Workers Robert W. Whitlock Lifetime Achievement Award Recipient

*Best Wishes from the Physicians and Staff of
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PATIENT PROFILE:

Ashley Martin

My Life and Journey as a Caretaker

By Ashley Martin

My journey started way before I was born, as it started with my mom. At the rightful age of 18 she was diagnosed with kidney disease and was told she had less than 50% function in both kidneys. This was called reflux nephropathy, it started at childhood but was never caught. Fast forward to 15 years later; I was a seven year old attending my first AAKP convention.

By this time my mom was doing peritoneal dialysis and growing sicker. My mom started bringing me to the conventions so I could be educated about her disease and better understand just what was happening to her. She turned them into vacations. Her philosophy was if this disease is going to impact her daughter's life, it shouldn't affect her childhood. Much to her surprise, I enjoyed the seminars and actually loved the convention itself.

I kept asking her just as it ended, when the next one would start. Unfortunately, as I grew older, she got sicker. Many doctors advocated that I was too young to be her caregiver and requested she start hiring outside services. During those early years, she did have people help, but it never stopped my passion for medicine and want to be a part of her care.

At age 9, I learned how to hook up her IVs at home. Through one of the AAKP conventions, we learned about NxStage home dialysis. During this time it wasn't available in the Cincinnati area, so unfortunately we didn't



have access to it. My mom eventually went to in-center hemodialysis, while being on a transplant list. She eventually received her first transplant in 2006 from a deceased donor.

I was in fifth grade at the time and it honestly couldn't have come at a better time. After the transplant my mom did a lot better and it gave me my childhood back. While my mom never pressured me to grow up and tried to take most of the burden off my shoulders, I had always felt the need to act maturely and help her as much as possible. The feeling when your family receives a kidney transplant is beyond imaginable. It's such a blessing.

Words can't describe it that well. It's a feeling that if I could I would want every patient and family to feel. During that time my mom was able to actually play with me, go on field trips and not have to be connected to a machine all the time. The transplant lasted five years, but unfortunately it fractured. This is when the organ had the consistency of ground beef and occurred due to the numerous rejection episodes my mother had gone through. The news came that she would have to go back to dialysis and the transplant would have to be removed.

We then asked to do home hemodialysis and

was told I still wasn't old enough to be her care taker. Also, we were informed that children weren't usually caretakers, instead, it was typically a husband and wife duo. I got so frustrated. I had felt that being young was always used against me and didn't understand. We weren't allowed to do home hemodialysis until I was 18 and graduated high school.

Even then, we still fought. I wanted to donate a kidney to my mom as soon as I turned 18 but AGAIN, they felt I was too young despite the fact that I was a perfect match. At this point I felt that no matter what it took I had to make home hemodialysis happen for her. I felt that if she had to hook up to a machine to survive, it shouldn't be all day for hours at a time. They were very reluctant to train me even at the age of 18.

I honestly don't think we would've ever gotten to do it if we both hadn't fought so hard and kept challenging the staff and doctors about it.

The summer before I started college we started doing home hemodialysis with a NxStage machine. I am proud to say I was the very first 18-year old trained and we were one of the very first non-husband and wife duo. I chose to live at home and go to The University of Cincinnati nearby so I can help my mom complete dialysis. We have been doing home hemodialysis ever since.



We actually have used this as an opportunity to advocate for patients who can't do so for themselves. To say this disease has impacted my life would be an understatement. While it may be easy to say it has affected me negatively, that is the complete opposite of how I truly feel. If anything, it has made me who I am today. It has shown me such a passion I have for ESRD patients. As a result, I have decided to become a Pediatric Transplant Surgeon.

I don't think I will ever stop advocating. I feel like whenever we find ourselves in an unusual circumstance it must be for a reason. I believe I grew up in such a different lifestyle so I can help others. Life may be challenging but if you can turn your struggles into something positive, you can really change the world. 🌸

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PATIENT PROFILE:

JANINE DIEBEL

My Battle with Alport Syndrome

By Janine Diebel



Alport Syndrome is a rare disease named in 1961 for A. C. Alport M.D. who observed nephritis and hearing loss in a multigenerational British family in 1927. Of the 650,000 people in the United States who have end stage renal failure, only .2% or about

1,300 of those have Alport Syndrome. It is a Type IV collagen mutation that affects the structure and function of kidneys, cochlea, and eyes. Patients present with chronic persistent hematuria and proteinuria, high frequency sensorineural hearing loss, possibly tinnitus, and they may have anterior lenticonus and dot and fleck retinopathy. There are three forms of Alport Syndrome, x-linked affecting 80% of those with Alport Syndrome, autosomal recessive and autosomal dominant, each with a somewhat different inheritance pattern. Clinical Practice Recommendations describe best practice treatment with angiotensin-converting enzyme ACE or angiotensin receptor blocker ARB to delay the progression of declining kidney function by decreasing the patient's proteinuria.

Alport Syndrome manifests differently within family groups depending on variants in the Type IV collagen mutation. Some families experience early childhood symptoms including hematuria and significant hearing loss. My experience was different. I grew up aware that my mother had chronic hematuria which had been explained by a urologist as being caused by a leaking capillary hemangioma in her bladder. I also knew that both of her brothers had died in their late 40's of renal failure before dialysis was available, one uncle supposedly as a result of childhood scarlet fever causing renal scarring and the other uncle from long term kidney trauma due to driving heavy equipment. As I went through nursing school, these explanations did not seem plausible. I graduated from nursing school in 1974 and was found to have hematuria and proteinuria at the time of my post school physical and again a month later at my pre employment physical. I was referred to a nephrologist who diagnosed me with Alport Syndrome based on my symptoms and family history. He identified, as was the understanding at the time, that I was a carrier and my disease would not progress. My kidney function and hearing was monitored from time to time over the years showing only slow progression even with four successful pregnancies although I had preeclampsia with the last two and an increase in proteinuria that did not return to pre-pregnancy levels.

As a Registered Nurse, I initially worked in critical care but within a few years was recruited to work as a dialysis nurse. Being closer to the field of nephrology practice and literature, I began reading more current research about Alport Syndrome and had the opportunity to hear a nephrologist from University of Michigan speak on the issue of genetic counseling for those with inherited kidney disease. I was struck by the fact that my own medical pedigree was stronger than any he had presented. In 1989, my daughter was identified with chronic hematuria. Even in the 1980's, women were still considered carriers so there was no proposed treatment plan for either one of us. In 2012, I began seeing a nephrologist who recommended that I have a skin

biopsy to confirm the Alport diagnosis which it did. Two years later, I began participating in the Athena Study sponsored by Regulus which is a 2½ year observational study of those with Alport Syndrome. The study included genotyping which again confirmed X-Linked Alport Syndrome.

Our family is fortunate as Alport Syndrome for us has a later onset than for many. Today, I am in Stage 3 CKD, my hearing loss requires hearing aids and my optometrist monitors my dot and fleck retinopathy. I maintain a very low protein and sodium restricted diet, I take an ACE and never use NSAIDS. I worry about my family members who are also affected. As a nurse who has kidney disease,

I use this as a springboard to continue my involvement in political advocacy at a national level and to participate as a co-administrator in our Alport Syndrome Foundation Support Group on Facebook.

Other members of my family have not had the benefit of today's science but during a simple moment of genealogy research we identified another generation of likely Alport Syndrome. Bright's disease refers to a disorder of the kidneys caused by protein in the urine. It was named for Richard Bright, a pioneer in kidney disease research who first published his findings in 1827. It was listed as the cause of death for poet Emily Dickinson, author H.P. Lovecraft, and former U.S. president Chester A. Arthur. The term "Bright's disease" is most often found today by people researching their genealogy. My great uncle died in 1915 at the age of 47 from a gunshot wound. In his obituary, we read that he was "also known to have suffered from Bright's Disease." 🌸



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