AAKP

RENALIFE

Volume 50 • Number 1 *The Independent Voice of Kidney Patients Since 1969™* January 2017

Committed To Keeping Patients Safe

Dialysis Leads to PhD

The Award that Promotes and Advances Patient Safety

Tips on Oral Health for Kidney Patients

A Publication of the American Association of Kidney Patients

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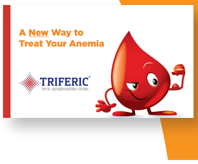

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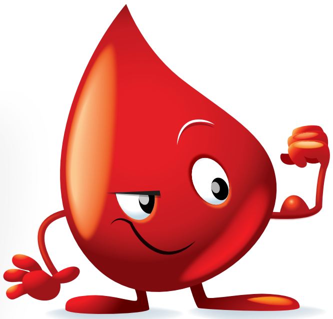

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Understanding kidney disease is a critical first step to improving your health. The American Association of Kidney Patients is the leader in kidney patient centered education. For more than 45 years, AAKP has provided patients and families the educational 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.

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The Independent Voice of Kidney Patients Since 1969™

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MESSAGE FROM AAKP

It is no mistake that our first 2017 issue of AAKP's RenaLife magazine has *Patient Safety* as its theme. Safety should be a New Year's resolution for all patients - and especially among their caregivers.

As patients, we need to be the owners and drivers of our health management. Being an active participant means that we must have a firm voice and never be passive in the decisions that impact our health outcomes. When our health care team proposes their best plan to manage our condition we need to have the confidence and to ask questions about any aspect of our care.

For almost 50 years, AAKP has worked hard to provide patients with the practical tools necessary to lead an "empowered" life. Our recent collaboration with the Centers for Disease Control and Prevention as a partner for the new "Making Dialysis Safer Coalition" described in the article *Committed To Keeping Patients Safe* (in this issue) is a tremendous example of the leadership that AAKP is providing to the kidney community. Please learn more about this initiative, download the conversation starter from the CDC website, and ask any questions of your healthcare providers regarding this vital and important safety initiative which will save patient lives.

As a patient, you have the experience and skills to make a difference – both in your own care and for the care of others. We invite you to join us in Washington D.C. for one of our upcoming visits with members of the U.S. House and Senate and Federal agency leaders. AAKP needs volunteers who are willing to visit their Congressional leaders to discuss their concerns about kidney disease and the need for new treatments, devices and medications. If you would like to join AAKP in Washington, please contact Sarah McConnell at smconnell@aakp.org or call us at 800-749-2257.

Paul Conway
President of AAKP

UPCOMING CALENDAR OF EVENTS

MARCH 6-7	Capitol Hill Days – Visit to Washington D.C.
MARCH 17	Medal of Excellence Dinner at Renal Physicians Association Meeting
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/

COVER STORY:

Committed To Keeping Patients Safe

In 2015, when Dr. Priti Patel approached AAKP about partnering with the Centers for Disease Control and Prevention (CDC) to develop a program to reduce infections in dialysis patients, she was hoping to make the process of dialysis safer for the thousands of Americans who rely on dialysis to replace the function of their kidneys. Little did she realize that her work would lead her to win the 2016 AAKP Patient Engagement and Advocacy Award. But one year later, that is exactly what happened—her dedication to this effort has contributed to the respect of her peers and among patients.

"I've received several awards related to my work at the CDC and as an officer in the United States Public Health Service, but the AAKP award is by far the most meaningful honor in my public health career," said Dr. Patel. "The award has motivated and energized us as a team to work even harder to keep patients safe and serves as a reminder to put patients at the center of our efforts. It has helped to draw attention to the issue of infection prevention as one that is important to patients, and it also tells us we're on the right path with what we're doing to improve patient safety."

Beginning this journey in 2009, Dr. Patel and her team at the CDC saw a chance to make a significant impact on the kidney community. Approximately 37,000 bloodstream infections occur each year among dialysis patients with central lines. These infections often cause hospitalization for patients and can be deadly. To address this critical public health issue, the CDC launched a collaborative project to prevent bloodstream infections among dialysis patients and invited outpatient dialysis centers to participate.

"*We have worked closely in a partnership with select dialysis facilities to develop tools that can help dialysis providers follow CDC recommendations. During a testing period, facilities that used these guidelines and tools were able to reduce their rates of infection by half and kept their rates lowered for four years after the project started. We estimated more than 280 bloodstream infections were avoided in these centers that worked to improve their practices and lower their rate,*" *said Patel.*

"This means a real difference, and lives saved, for the patients treated in those facilities."

"*Because bloodstream infections are such a big problem for dialysis patients, we at the CDC have always been interested in trying to do something about it. When we learned that facilities could actually take steps to drive down infections, we wanted to get the word out to all facilities that there are things they can do to protect their patients,*" said Patel. This interest in spreading the successes to other dialysis facilities led to creation of the *Making Dialysis Safer for Patients Coalition*.

The CDC's Making Dialysis Safer for Patients Coalition is a partnership of healthcare-related organizations, patient advocacy organizations, industry partners, and other public health partners that span the dialysis spectrum. The Coalition aims to prevent bloodstream infections (BSIs) in hemodialysis patients, and increase the use and visibility of CDC evidence based practices. AAKP was honored to be a launch partner with the CDC to create education materials for patients and caregivers that will help start conversations in dialysis facilities to ensure necessary safety precautions are taken before and during the hemodialysis treatment.

Responsibility does not lie solely with the dialysis centers and healthcare providers. Patients and caregivers must get involved to help win this fight in prevention.

"*We have learned from our experiences talking to patient advocates that patients want to feel engaged in their own care, and find this can result in better outcomes,*" *said Patel.*

Taking an Active Role in Preventing Bloodstream Infections

Being an empowered patient means getting involved in your healthcare, knowing what you can do and taking an active role as a patient.

"*Patients should know they are a key member of the infection prevention team. Patients are their own best advocates and should understand the steps in their care that are taken to avoid infections. By learning about infection prevention, keeping those*

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around them accountable and actively engaging in their own care, patients can help to make a safer dialysis care environment for themselves and others," said Patel. "The first step to feeling empowered is educating oneself. For this reason, the CDC wants patients to become familiar with their treatment, learn about the risks, and understand what steps can be taken by patients or staff to keep them safe from infections. The Coalition has patient-centered information that can be found on the CDC website."

As a patient, it is important to take an active role in preventing infections. AAKP encourages you to review the following steps to help reduce the possibility of bloodstream infections:

1. Check your vascular access daily for signs of infection such as redness, pus and swelling. Notify your healthcare professional if you notice these signs.
2. If you have a catheter, keep your catheter bandage clean and dry. If your bandage gets wet, notify your healthcare professional.
3. If you have a central line catheter, ask your healthcare professional why it is needed, how long it will be in place, and if you can use a fistula or graft for your dialysis treatments.
4. Make sure that all healthcare providers clean their hands with soap and water or alcohol-based hand sanitizer before and after caring for you or your vascular access site.
5. Download the Conversation Starter at *http://aakp.org/education/brochures/* and begin asking questions of your healthcare provider and nursing staff to start a discussion about safety protocols that are being taken at your dialysis facility.

Continuing To Put Patients First

Dr. Patel and the CDC are committed to putting dialysis patients first in every possible way. They have taken a multi-faceted approach to preventing bloodstream infections and have made great strides to get to zero infections.

And Dr. Patel is not stopping her crusade to end infections. "*We are working with doctors, nurses, technicians, dialysis provider companies, advocates, and patients to ensure that everyone is dedicated to the same goal of reducing infections,*" *said Patel. "Our goal is to eliminate preventable bloodstream infections among hemodialysis patients.*"

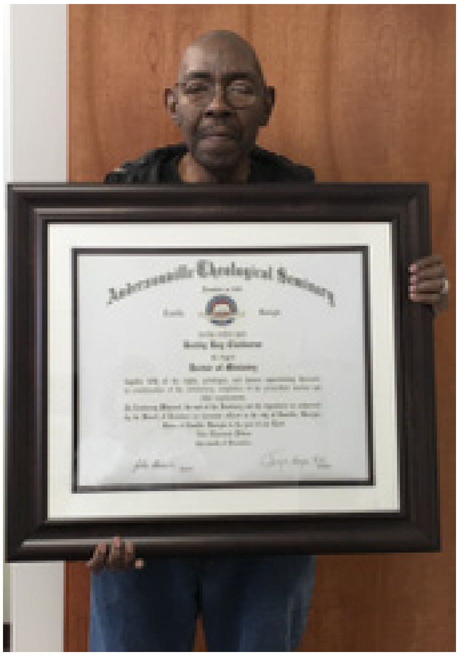
To learn more about Making Dialysis Safer for Patients Coalition, please visit: *http://www.cdc.gov/dialysis/coalition*

Priti Patel, MD, MPH
Dr. Priti Patel is the Medical Director of the Making Dialysis Safer for Patients Coalition. Most of her 14 years at the CDC have been dedicated to preventing dialysis-related infections and promoting safe healthcare for dialysis patients. She was an author of the National Action Plan to Eliminate Healthcare-Associated Infections in ESRD Facilities, co-led CDC's Dialysis Bloodstream Infection Prevention Collaborative, and has partnered with the Centers for Medicare and Medicaid Services and others in the dialysis community for many years to measure and reduce preventable infections.

PATIENT PROFILE:

Dialysis Patient's Simple Request Leads to Ph.D.

By Charlie Rice Minoso



When Bobby Claiborne, 56, asked the staff at Fresenius Medical Care Coushatta, for a table to use during his four-plus hour dialysis treatments that he receives three times a week, they happily fulfilled his request without hesitation. It wasn't until Bobby walked into the center eight months later with his diploma that his care team learned he needed the table to study as he pursued his mother's dying wish for him to earn his Ph.D. in theology.

Bobby, a U.S. Army Honor Guard veteran and pastor, began dialysis in September 2012. At his wife's suggestion, Bobby started using his treatment time to pursue his Ph.D. He then asked Clinic Manager Shawn Pleasant, RN, if she could provide a small table for him to rest his laptop and other studying materials. His care team then made sure to assign him an available treatment chair so he could easily use the table to study. Every time Bobby came to dialyze, a table was always ready and waiting for him.

When he concluded the self-paced, online course, Bobby exceeded his own expectations by receiving a 4.0 grade point average. It was then that he shared with his care team how their special attention to his request helped him earn his degree and keep a promise he made to his mother. Bobby graduated sum cum laude from Andersonville Theological Seminary and Bible College Online in Camilla, Georgia. To remain close to home and his center for dialysis treatments, Bobby participated in the graduation ceremony at United Baptist Theological Seminary and Bible College in Shreveport, Louisiana in May.

As pastor at St. John's Baptist Church, a modest-sized, but engaged and committed congregation, Bobby's advanced theology degree helps him provide understanding, knowledge and guidance to his parishioners. Since completing his coursework, Bobby noticed an immediate change in the level of insight and type of advice he is able to provide to his congregants and those enduring crisis and traumatic experiences.

In addition to helping him in his ministry, the degree strengthens Bobby's counseling work at Dallas-based Marketplace Ministries, where he has been working for the past 16 years. In his role, Bobby primarily works with young adults living with alcohol and substance abuse problems, as well as those with critical illnesses.

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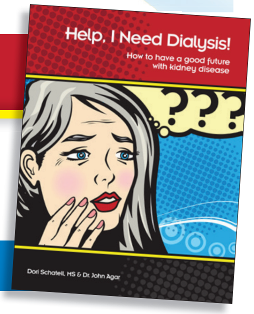
Many of the youth Bobby works with are from disadvantaged backgrounds and need everyday role models within their community who contribute to society. Bobby's newly acquired degree has allowed him to further the lives of those who look to him for guidance.

Having accomplished a personal goal, Bobby remembers his early days of his renal failure diagnosis. He had to "dig deep" and rely on the training he learned during his time in the Army. By physically and emotionally preparing himself, Bobby knew that it would make treatments less draining. Bobby's care philosophy is to give it his all – adhering to his medication regimen, recommended nutritional plan and fluid intake. He also believes success comes as a result of a positive attitude. Through proper self-care – physically, emotionally and spiritually – Bobby believes patients can overcome any obstacle that may arise as a result of their kidney disease; they just need to surround themselves with a supportive care team and ask for assistance when needed.

By providing a patient with a simple table, not only did a care team help a man reach his goals, but they also helped him have a positive impact on his local community. Bobby Claiborne is living proof that no matter the obstacle before him, he will continue to thrive on.



FEATURE ARTICLE:

The Award that Promotes and Advances Patient Safety

The delivery of dialysis treatments is a complex highly technical process that takes place in outpatient dialysis clinics on a daily basis to about 500,000 individuals on hemodialysis. In a survey conducted in 2006 and again in 2013, close to half of the patients responded that they were at times worried about their safety. The major risks and errors associated with dialysis have been documented. They are medication errors, infections, patient falls, vascular access events and dialysis equipment factors. Regulatory requirements for safety monitoring, multidisciplinary staff training and required policies have been established yet there are still medical mistakes and the risk of medical errors. Multiple governmental agencies and medical institutions are collaborating to seek better training tools, improved process of care, methods to establish a culture of safety and stronger patient participation to seek safety solutions.

Patients who undergo dialysis treatment have an increased risk for getting a health care-associated infection (HAI). Hemodialysis patients have weakened immune systems, which increase their risk for infection, and they sometimes require frequent hospitalizations and surgery where they might acquire an infection. Jenny Kitsen, AAKP Treasurer and a longtime Network Executive Director has been an advocate for patient safety standard and devoted much of her career ensuring this issues remain at the forefront of the kidney community.

"*During my 45 years of working in the ESRD field, I have observed errors, evaluated patient complaints about mistakes and participated in studies to obtain data on causes related to medical errors,*" said *Kitsen*. "*No one wants to make a mistake that can cause harm to a patient. We must all strive to work together to find better solutions to protect patients and reduce medical risk.*"

AAKP Jenny Kitsen Patient Safety Award

In 2014, AAKP accepted an endowment from the Network of New England Board of Directors to establish the Jenny Kitsen Patient Safety Award and continue the patient safety work of the nonprofit organization led by Jenny Kitsen. The $150,000 endowment supports an annual lecture or presentation that advances patient safety. Eligible applicants include 501(c)(3) and 501(c)(6) organizations, public and government agencies, organizations and institutions.

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"*AAKP has been committed to the education of patient safety, and discussing the gaps between the healthcare management systems for the kidney community. This award is about ensuring patient safety is a top priority for all healthcare professionals who care for those living with kidney disease and empowering patients to take an active role in their healthcare journey," said Diana Clynes, the Programs Director for AKKP. "Every year, AAKP's Award Selection Committee chooses one or more organizations that are dedicated to promoting patient safety and have created a unique opportunity or platform to deliver their message. The 2017 Jenny Kitsen Patient Safety Award recipients are vastly different in their presentation model, however their intent and passion for patient safety is commendable just the same*," said Clynes.

2017 Award Winners

A.T. Still University of Oral Health, Dr. Maureen Munnelly Perry – Oral Health Safety Protocols

Dr. Maureen Munnelly Perry, Associate Dean for Post-Doctoral Education Director at Arizona School of Dentistry & Oral Health- A.T. Still University of Oral Health, found a lack of consistent, established protocols for patients with end stage renal and oral health care. "*There is no consensus in the medical and dental community regarding what a protocol should contain, when it should be implemented and the type of antibiotic prophylaxis that should be prescribed for patients with renal disease*," said Dr. Perry. To help bridge this gap, Dr. Perry submitted her grant application to AAKP for the Jenny Kitsen Patient Safety Award to present her findings to the kidney community and bring awareness to the importance of oral healthcare to those with end stage renal disease.

"*The goal of this lecture will be to offer a strong voice for patients with kidney disease to advocate for better care coordination between dentists and other healthcare professionals*," said Perry. To hear more about this topic, read her article in this issue of aakpRenalife and be sure to attend the 2017 AAKP Annual Convention where Dr. Perry will be a featured speaker.

All Kidney Patients Support Group (AKPSG) – Patient Safety and Empowerment

The All Kidney Patients Support Group Corporation (AKPSG) is a non-profit organization, designed to support kidney patients in the Tampa Bay Area at various stages of dialysis and transplantation. Founded and managed by dialysis patient/transplant recipient, Janice Starling-Williams, the AKPSG is dedicated to educating kidney patients, families, caregivers and healthcare professionals about the importance of reducing infections in dialysis centers, fistula safety, infection/disease control and more. This small yet mighty non-profit uses online webinars, live meetings, seminars, banquets, and presentations to educate hundreds of people in the manner in which they are accustomed to learning. "*We are committed to enhancing the health of this community through education and shared experiences," said Starling-Williams. "AKPSG strives to help patients develop their voice to better involve their doctors, dialysis centers, and caregivers with the information and education they need to improve personal coping skills and health outcomes*."

The 2017 Award recipients join an elite group who are dedicated to promoting safety throughout the kidney community:

2016 Award Winners

- National Renal Administrators Association
- Renal Physicians Association

2015 Award Winners

- American Nephrology Nurses Association
- Forum of ESRD Networks

AAKP is committed to educating patients, caregivers, and healthcare professionals on the importance of patient safety within the kidney community. By partnering with the Jenny Kitsen Award recipients, AAKP can spread the patient safety messages that will hopefully avoid costly medical mistakes. By combining patient empowerment, hard work, and an open dialogue, a safer environment for hemodialysis patients is possible and AAKP is determined to make this happen for the patient community.

Jenny Kitsen

Ms. Kitsen has over 45 years of experience in the field of end stage renal disease. She began her career as a renal social worker at Yale New Haven Hospital for 10 years. For 35 years, she served as executive director for the End Stage Renal Disease Network of New England. She has participated in several advisory task forces and HHS funded projects. She has specific interest in and has published articles on topics related to quality improvement, patient safety, end of life management and ESRD public policy. Currently, she is Treasurer of AAKP and is doing consultant work for nonprofit organizations. She has worked many years to promote patient empowerment and believes in the Mission of AAKP.

CHRONIC KIDNEY DISEASE CAN LEAD TO ANEMIA LEAVING YOU FEELING TIRED AND WEAK

There are some things that you should know if you've been diagnosed with chronic kidney disease. In certain people, chronic kidney disease can lead to a serious condition called anemia. Anemia occurs when your body doesn't have enough red blood cells. Red blood cells carry oxygen to the rest of your body, giving you energy to do your daily activities.

If anemia due to chronic kidney disease is left untreated, you are at risk for serious health consequences, including a higher risk of heart complications or needing a blood transfusion. If you are unsure if you have anemia, or it's been a while since you've checked, a doctor can diagnose it through a simple blood test.

› QUIZ ‹

COULD YOU HAVE ANEMIA DUE TO CHRONIC KIDNEY DISEASE?

	YES	NO
Do you have chronic kidney disease?	☐	☐
Do you have any of the following symptoms:		
› Feel tired often	☐	☐
› Shortness of breath	☐	☐
› Dizziness	☐	☐
› Racing heartbeat	☐	☐

If you have chronic kidney disease and checked off at least one of the above symptoms, you may have a condition called anemia.

PROTECT STUDY

ANEMIA SYMPTOMS ARE EASILY MISSED

Symptoms of anemia are very common to many other conditions and can therefore be easily missed. Common anemia symptoms include:

- Feeling tired often
- Shortness of breath
- Dizziness
- Racing heartbeat

ANEMIA DUE TO CHRONIC KIDNEY DISEASE CAN BE TREATED

Anemia due to chronic kidney disease is primarily treated with an injection of a medication that helps your body produce red blood cells. Because your body needs iron to make red blood cells, your doctor may also give you iron, either in pill form or as an IV.

A RESEARCH STUDY MAY BE AN OPTION

The PROTECT Study is a new research study evaluating an investigational oral medication for people with anemia due to chronic kidney disease. The study compares the effectiveness of the investigational oral medication to an approved anemia medication given by injection. During the study, qualified participants will either receive the investigational oral study medication or the approved injection.

Treating your anemia may give you more energy and reduce your risk of serious health consequences.

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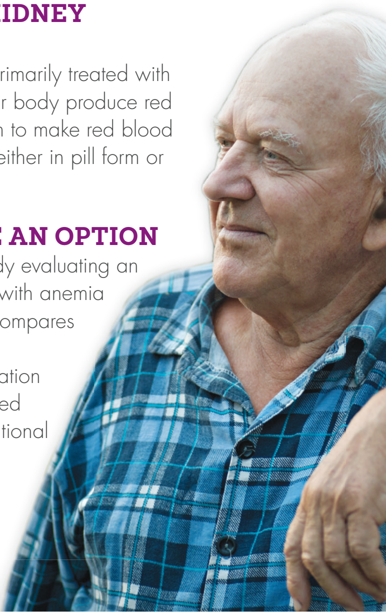

EDUCATION ARTICLE:

Tips On Oral Health for Kidney Patients

By Dr. Maureen Perry

Your oral hygiene plays a major role in the well-being of your overall medical health. Maintaining good oral habits can help ward off and prevent serious medical issues such as a heart attack, stroke, uncontrolled diabetes and/or preterm labor. It is important as a kidney patient to make schedule regular visits to your dentist. However, before you go, make sure that you have consulted your nephrologist. Once your nephrologist has talked to you, bring a list of all medications to the dentist and be ready to explain the details and history of your condition.

The dentist will ask for additional information such as the stage of your disease, medications you are taking, the underlying cause of the disease, and lab work results. During your dental visit, you should ask the dentist to put you in a comfortable position. Do not be shy to request breaks to stand up and move around.

If you are undergoing hemodialysis, it is very important that you visit the dentist on a day after your dialysis treatment. This is because the anticoagulants you are given during dialysis will increase your chance of bleeding during dental procedures. Therefore, you do not want to see the dentist on the same day you are having hemodialysis. Several studies have shown that patients with kidney disease have higher rates of gingivitis, periodontal disease and higher decayed, missing and filled teeth (DMFT). If you are a kidney patient, it is critically important that you take care of your oral health well. The bacterial condition in your mouth must be well-managed, especially if you have been diagnosed with any type of periodontal disease, even gingivitis. You will need more frequent visits to the dentist to ensure that there is a reduction in oral bacteria. Your dentist will work hard to aggressively eliminate all potential sources of infection, so as to avoid bacteremia (bacteria in the bloodstream) which may lead to serious health issues.

Patients on hemodialysis have more periodontal disease than other kidney patients. According to a study by Atassi (2002), their teeth form more calculus than healthy individuals. This is because their salivary urea and phosphate levels are high. The calculus is always covered by a non-mineralized plaque layer and is dangerous. Studies have shown that the longer a person is on hemodialysis, it will have a more negative impact on their oral health. Patients undergoing hemodialysis also have dry mouth and while there are some remedies to relieve symptoms, there are no long-term, effective cures. In addition, such patients should be aware of metabolic syndrome. This includes a group of risk factors that raise your risk for heart disease, diabetes and stroke. Metabolic risk factors include high blood pressure, increased cholesterol levels and obesity. The association of kidney disease, metabolic syndrome and periodontal disease is dangerous to your health. This is due to increased levels of inflammation in the blood stream. While there are no concrete studies that link better oral health to a reduction in metabolic syndrome in hemodialysis patients, a study by Chen (2011) has shown that almost 65% of hemodialysis patients with metabolic syndrome showed moderate to severe periodontitis. Thus, it is critically important for such patients to have more frequent periodontal recall visits to reduce the risk for oral infection and transient bacteremia.

So, what keeps dentists awake at night when they think of treating kidney patients? For the most part, it is dental provider anxiety that stems from the risk of systemic infection and managing a patient who is medically complex. There is also a growing population of patients with kidney disease and many dentists may not have been taught to care for such patients.

A more serious issue is the absence of a uniform treatment protocol among dental providers, nephrologists and other allied health professionals in treating patients with kidney disease. Should patients take antibiotics before dental treatment? The absence of a uniform protocol poses a huge risk as medications may be prescribed to those who do not need them and they may not be prescribed to those who really need them.

Thus, it is critically important that all providers caring for a patient with kidney disease talk to each other. This will reduce errors and result in improved patient safety. If you are a family member or a caregiver of a kidney patient, please make sure that you help by providing all relevant information to the dentist so that she or he can provide the correct and safest treatment in the most comfortable environment possible.

Maureen Perry, DDS, MPA, MA

Dr. Maureen Perry is an Associate Professor and Director of the Center for Advanced Oral Health at A.T. Still University, Arizona School of Dentistry & Oral Health (ASDOH). She received her BS from Adelphi University and her DDS from New York University College of Dentistry. Following a general practice residency at Staten Island University Hospital, Dr. Perry completed a two-year New York State Consortium of Medical Education in Developmental Disabilities Fellowship in Special Care Dentistry. She received her master's in Public Administration with a concentration in healthcare administration from Long Island University. Dr. Perry is a fellow of the Academy of Dentistry for Persons with Disabilities and is a diplomate of the American Board of Special Care Dentistry. She is a past president of the Special Care Dental Association and serves as the United State council member for the International Association for Disability & Oral Health. Dr. Perry has presented at many national and international meetings and has published on such areas of special care dentistry as autism, restraint and consent, rare syndromes, pre-doctoral education and self-injurious behavior. She recently completed a Master's in Dental Education from the University of the Pacific.

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INFORMATIONAL ARTICLE

Transitioning from Pediatric to Adult Care

By Robert Miller, MD

As a parent, when you first learned of your child's renal condition, you suffered from a great deal of anxiety. Numerous questions arose in your mind including "what kind of treatments are there for my child", "what about dialysis", and finally "what is this kidney transplant that they are talking about". As your child progressed through the treatments, you reached a point where each of these questions have been answered and you have come to some sense of "normalcy". As your child matured, however, new questions may arise including transitioning from pediatric care to adult care. The transition from pediatric to adult medicine can be as anxiety provoking as finding out about your child's underlying renal condition.

The transition from pediatric to adult medicine raises a great deal of concern amongst families, as well as amongst medical professionals who have been caring for your child. It has been reported that renal transplant patients between 14-16 years of age have the greatest risk of losing their kidney (JAMA 2013, Sep 9; 173: 1524-32). Each of us, families and medical staff, have a great deal of concern about the transition from pediatric care to adult care. Comprehensive programs are needed for pediatric renal transplant patients as they mature into adulthood.

As you are working with your family member's care provider, there are numerous items that need to be discussed. First, when do we start the process of transition? Second, how do we start the process? Third, when is the transition process completed? When do we start transition – typically during the teenage years, long before the actual transition will occur. The initiation of the transition process requires close collaboration between the family and the medical team. When the discussion starts to occur about transition, this will typically be concerning to the family. This is the time when providers recognize the concern expressed by the family.

The process of starting the transition typically starts when the patient has reached a level of maturity to begin the discussion about transitioning. Many different tools have been developed to assess the level of maturity of the patient. It is the responsibility of your child's physician to determine the level of maturity of the patient. Starting the process involves a discussion about why the patient had lost their kidney. There are times when families cannot recall why the kidneys were lost. The potential for recurrence of the underlying renal process needs to be understood. Following the understanding of the underlying renal process,

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the next step is the medications and treatments (if needed). Each of the medications is discussed regarding why the medication is administered, and the potential side effects that may occur with each medication. The need for adherence to the medication treatments is essential for the patient and their family. Many times the worsening of renal function is directly related to not taking medications as prescribed. The development and support of the patient with self-management skills is important to ensure the patient has the confidence to adhere to their medical plan. Some patients have specific treatments that may be required for their transplant. With approximately 40% of renal transplants in children being performed for congenital issues with the genitourinary tract (kidneys and/or bladder) many require specific treatments to be done. Some of these treatments include intermittent catheterization or other treatments. Each of these treatments needs to be discussed as to why each one is important for their long term health.

The process of transition also includes issues that are many times not realized. The need for discussion and education regarding employment and insurance also needs to occur. What types of jobs are appropriate for a child with chronic renal disease and/or a renal transplant? While the goal for our patients is a “full and healthy life”, some employment options may not be possible. The discussion about those options should occur long before children turn 18. Additionally, a discussion about reproduction needs to occur. Some medications need to be discussed because of the risk of birth defects to the children of the transplant patients. When the patient decides to become pregnant, the medications need to be adjusted to minimize/prevent the risk of birth defects. Additionally issues surrounding birth control need to be discussed. What types of birth control are possibilities and how are those options accessed.

As children grow into adults the financial pressures of their condition will start to become more concerning. Issues related to payment for medical visits, payment for medications and other therapies, and insurance are important. Under the Affordable Care Act, children under 26 can be covered on their family’s private insurance. If the patient, however, is under a state/federal aided program, typically the patient needs to secure their own insurance by age 19. The potential need for dual insurance (private and state/federal aided) is an option that may need to be accessed. It is essential that the patient and their family work closely with a social worker on insurance coverage options to ensure ongoing insurance coverage.

The final step of transition takes place well after the transfer to adult care. As our pediatric patients grow, they will reach the age of majority (18 years of age) when they will become responsible for their own care. Taking medication, attending clinic visits, doing personal treatments are again very stressful. Because of HIPPA (Health Information Portability Privacy Act) the pediatric patient needs to complete and sign paperwork to allow the family to be part of the clinical visits and to receive information. Even though the parents may wish to receive information regarding the clinic visits and laboratory evaluations, they cannot receive the information unless the appropriate paperwork is completed when the patient reaches this age. Some practices do not allow other adults to be part of a patient's clinic visit. Work with your provider to allow for the family/care givers to be part of the visit, whether to receive laboratory results and/or full participation in the visit. Be mindful that the provider is very concerned about the patient, but also that the provider has specific legal responsibilities under HIPPA to protect the patient's medical information.

Each practice has their specific transition methods. The University of North Carolina has created the STARx program in an effort to help transition their patients. They have developed numerous tools that have been employed to help with the transition. Some of these tools include the "TRxANSITION" Scale, "STARx" programs, and the "Nephrology Medical Passport". The "Trxansition Scale" is a measure of how and when to start the transition process. The "STARx" program is the actual program utilized to work specifically with the family regarding each of the steps of transition. Finally, the "Nephrology Medical Passport" is a document carried by the patient with simple basic information regarding the diagnosis, medications, and contact individuals.

Do not imagine that the process of transition will be completed "quickly". The process of transition takes time to accomplish. The assessment of when to start the transition process typically starts in the teenage years, and the process likely will take an extended period of time to be accomplished. ❖

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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.

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