

KIDNEY CARE

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Health care professionals and patients working together to learn more about diseases that affect the filters (glomeruli) in the kidney.

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PATIENTS CAN PLAY AN IMPORTANT ROLE IN IMPROVING RESEARCH

By Julia Narendra, MPH, UNC Kidney Center Dialysis Research Program Manager

Why is it important for patients to be involved in research?

Patients play a key role in making research more relevant. As research participants and as partners in research development and design, patients can provide valuable perspectives and insights to research teams. Involving patients in research development helps make sure that patient opinions and experiences are counted, and that research focuses on topics important to them. Patient engagement in research allows patients to have a big say in what is studied and how research is done and communicated to patients. Patients who get involved in research have the opportunity for their unique voices to be heard and affect research that may improve the lives of future patients.

What is "research", anyway?

Research is a process that helps discover new knowledge. Research studies gather new information and/or test an idea. Dr. Jenny Flythe and her research team at the University of North Carolina, Chapel Hill asked how dialysis research experiences for both dialysis patients and clinic staff might be improved. The Patient-Centered Outcomes Research Institute (PCORI) funded the project. They invited a group of dialysis stakeholders (patients, clinic staff, dialysis organization representatives, researchers, medical providers, and patient organization representatives) to share their ideas and experiences during the project. The group helped the research team understand the perspectives of people involved in or receiving dialysis care. While the project focused on dialysis research, the lessons learned and engagement model developed could be applied to other types of medical research, including other types of kidney disease research.

How can dialysis research be more useful for patients and clinic staff?

Dr. Flythe and her research team studied dialysis stakeholders' (patients, care partners, clinic managers, nurses, patient care technicians, dietitians, social workers, and medical providers) perceptions of research and asked participants to identify useful ways to learn about research. The research team found that most stakeholders were interested in research but some had concerns due to mistrust and frustration with past research experiences. Openness to research was influenced by things like research topic interest, understanding of research, desire to help future patients, and convenience of study procedures. Participants thought researchers could build trust with patients and clinic staff by more clearly communicating expectations and study progress. While large gaps in research knowledge existed, project results suggested that research education delivered in short multi-format communications may boost engagement in and knowledge of research .

Continued on Page 3...

SUGAR AND CHRONIC KIDNEY DISEASE

By Judy Lester, MS, RDN, CSG, LDN

Have you been listening to the news media about the latest studies about sugar? As a result of these news reports, patients often ask me if they can eat sugar. Do you need sugar or carbohydrates in your daily diet? Carbohydrates are a fancy word for sugar because carbohydrates are broken down in our bodies to form sugar or the energy we need to fuel our body. Examples of carbohydrate containing foods are potatoes, corn, beans, breads, pasta, rice, refined sugar, cookies, cakes, pies, vegetables, fruits, and milk.

Recently the news media publicized a study which appeared in the British journal Lancet. Sara Seidelmann and her team from Brigham and Women's Hospital in Boston examined past data from several studies and the amount of carbohydrate intake in people who participate in research studies. From the data, the researchers discovered that people who eat about 50-55% of their calories from carbohydrates tend to live longer. They found that people tend to shorten their life span when following a lower or higher carbohydrate diet. This caused a media frenzy since the paleo and ketogenic diets are so popular for weight loss. A paleo diet is a low carbohydrate diet with more protein and fats. A ketogenic diet requires about 50% of calories from fats, 30 % of calories from proteins and less than 20 % of calories from carbohydrates. Keep in mind since this research was not a clinical trial that would show cause and effect, it can only show an association of carbohydrate intake level and life span.

How does this study relate to people with chronic kidney disease? One of the leading causes of chronic kidney disease is diabetes. People who have diabetes have difficulty processing sugar in their bodies. Can patients with diabetes eat sugar containing foods like cakes, cookies and ice cream? Of course, you count the carbohydrates or sugar towards your servings of carbohydrates you should eat for each meal or snack. Counting your carbohydrates to include the serving of dessert allows you to have a small treat. It may not be the large portion you desire, but it is allowed if the portion is counted towards your carbohydrate amount for that meal. For example, if you are allowed 60 grams of carbohydrate for each meal, and if you choose a cookie which may be 20 grams (from reading the label or recipes), you subtract the 20 grams from 60 grams which leaves 40 grams of carbohydrates for the remainder of your meal. Instead of a cookie you may want to focus eating complex carbohydrates like brown rice, whole grain bread, dried beans, etc. rather than cookies so you will feel fuller longer and have more nutrient dense foods choices. Often we encourage pairing carbohydrate with small amounts of protein to assist with feeling fuller longer and providing more nutrition. Your doctor or dietitian can help you determine the right amount of carbohydrate to eat during the day to help manage your blood sugar which can slow the progression of your kidney disease.

Are sugar or carbohydrates good for people with chronic kidney disease? We need sugar or carbohydrates in our daily diet to fuel our bodies especially our brains, heart, lungs and kidneys, but we need to eat the right amount. When we eat too much carbohydrates, it is stored in our bodies as fat. This creates stress and inflammation in your body which could harm your kidneys. Eating too little sugar may cause hypoglycemia and other issues as well. Consume sugar or carbohydrates in moderate amounts spread throughout the day to assist with blood sugar control, provide energy, and assist with other important body functions.



LISTEN NOW! AUTOIMMUNE DISEASE PODCAST: PIECES OF THE PICTURE

We can't see our immune system, but we know it's there to defend the body against disease and infection. What happens when our defense changes? When autoimmune disease develops, the immune system attacks healthy cells by mistake.

Produced in early January, 2017, Pieces of the Picture reflects the rise in autoimmune disease and the invisible conditions that often require patients to make multiple trips to the doctor before ever receiving a diagnosis. Chair's Corner creator/producer Kristen Hendrickson had experienced this in her own life. Podcast host and GDCN co-director Dr. Ron Falk had long studied autoimmune kidney disease and ANCA vasculitis. They planned a 12 week series that could help people understand autoimmune diseases more broadly by drawing attention to experts across the UNC Department of Medicine. Topics include the science behind autoimmune disease, getting diagnosed, coping strategies, and episodes for specific diseases including lupus, Sjogren's syndrome, and rheumatoid arthritis.

Listen online here: <https://www.med.unc.edu/medicine/news/chairs-corner/autoimmune-disease-series> or do an internet search for "UNC Pieces of the Picture"

Patients Can Play an Important Role in Improving ResearchContinued from page 1

How can educational materials engage patients and clinic staff in dialysis research?

The research team used what they learned from stakeholders to develop research educational materials to increase dialysis patients' and clinic staff's knowledge of and interest in research. They created a dialysis research educational video (<http://go.unc.edu/DialysisResearchVideo>), a brochure, a "lunch and learn" discussion guide for clinic staff, and a tip sheet for researchers. The video features animation and a real dialysis patient and dialysis nurse. It is an engaging way to learn about basic research concepts and receive an introduction to research before participating in or facilitating research. The brochure provides additional information about dialysis research in a colorful, easy-to-read format. Dialysis patients and other stakeholders gave valuable feedback on the materials, shaping their look, wording, tone, and content. Richard Fissel, a patient and project stakeholder from Newark, DE noted, "Most patients don't seem interested [in research]. Hopefully this video can help spark interest and spur more people to get involved."

What would it mean to get involved in research?

Ultimately, researchers and patients want the same thing: they want patients to feel their best and live the lives they want to live. Patients of all types can help future patients by getting involved in research. In fact, dialysis patient involvement in this research project helped Dr. Flythe and her team create educational materials that connected with patients and clinic staff. Researchers and patients often speak very different languages. The materials break barriers down so they can understand each other better. It is our hope that these materials will increase patients' knowledge of research, make them more comfortable asking questions of researchers, and inspire them to get involved in research. To learn more, go to <https://unckidneycenter.org/research/>. If this article has piqued your interest, ask your medical team if there is a way YOU can get more involved in research!



RECENT PUBLICATIONS USING GDCN REGISTRY DATA

Thanks to your generous participation in our patient registry, we are able to conduct a wide range of studies to help further our understanding of glomerular (kidney) diseases. See below for some of our most recent publications. To read more, you can look up these articles on www.pubmed.com.



How does where you live effect your ANCA disease? Data from 170 participants in our registry was combined with data from several other large registries to investigate the relationship between ANCA type (MPO/PR3), latitude, and ultraviolet radiation levels. A total of 1,408 patients were included and all patients included had a kidney biopsy.

Latitude is the distance of a place north or south of the earth's equator. Ultraviolet radiation is a type of electromagnetic radiation that comes from the sun that is most commonly associated with suntans and sunburns. Other registries included in addition to ours were from Norway, Sweden, the United Kingdom, the Czech Republic, Croatia, and Italy. These countries have a broad range of latitudes, meaning different amounts of ultraviolet radiation (daylight and sun).

The results of this study suggest that in more northern latitudes, where there is less sun and less ultraviolet light, PR3 positive ANCA is more common than MPO positive ANCA disease. However, the geographic difference was small and the authors recommend that genetics may play a larger part than geography. The cause of ANCA disease is not well understood, but both environmental exposures and genetics are thought to play a role.

This research helps us to understand that sunlight may play a small role in the development of ANCA with kidney involvement. However, there are a few limitations of the work. It is not known if the results apply to those with the disease who do not have kidney involvement. Also, latitude and ultraviolet exposure were known only by city and not specifically for an individual over their lifetime or when they were diagnosed. Also, this study did not consider other environmental exposures besides latitude and ultraviolet radiation.

It is not known how ultraviolet radiation may contribute to developing ANCA disease or different types of ANCA. Scientists suggest, but have not confirmed, that it might be related to vitamin D levels, which play a part in a person's autoimmune system. Vitamin D levels are influenced by exposure to the sun. There are other influences on vitamin D including diet and skin color. Vitamin D levels were not measured in this study. Other research studies show that both latitude and ultraviolet rays may influence development of other autoimmune diseases including multiple sclerosis and type 1 diabetes.

Overall, this study suggests that more research on the influence of latitude and ultraviolet rays on ANCA disease are important, but there is a need to explore the contribution of genetic differences in along with these and any other environmental exposures.

Publication details: Weiner M, Bjørneklett R, Hrušková Z, Mackinnon B, Poulton CJ, Sindelar L, Mohammad AJ, Eriksson P, Gesualdo L, Geetha D, Crnogorac M, Jayne D, Hogan SL, Geddes C, Tesar V, Aasarød K, Segelmark M. **Proteinase-3 and myeloperoxidase serotype in relation to demographic factors and geographic distribution in anti-neutrophil cytoplasmic antibody-associated glomerulonephritis.** *Nephrol Dial Transplant.* 2018 Apr 30.

RECENT PUBLICATIONS USING GDCN REGISTRY DATA CONT...

What are the pregnancy risks for women with glomerular disease? Investigators reviewed the charts of 43 women with IgA Nephropathy, focal segmental glomerulosclerosis (FSGS), membranous nephropathy, and minimal change disease) who received pregnancy care at UNC. There were 48 pregnancies altogether; 13% of pregnancies resulted in perinatal death and 48% of babies were born before their due date. A third of pregnancies were complicated by pre-eclampsia (a condition that causes high blood pressure, swelling, and protein in the urine). Outcomes did not seem to change by disease group, but women with FSGS had an increased risk of a decline in kidney function as a result of pregnancy. A larger study with more women is needed to better understand how glomerular disease type may effect pregnancy.

Publication details: O'Shaughnessy MM, Jobson MA, Sims K, Liberty AL, Nachman PH, Pendergraft WF. **Pregnancy Outcomes in Patients with Glomerular Disease Attending a Single Academic Center in North Carolina.** Am J Nephrol. 2017;45(5):442-451

What are the long term outcomes for people diagnosed with anti-glomerular basement membrane (anti-GBM) disease? Data from 34 patients diagnosed with anti-GBM disease at UNC were combined with data from 5 other centers to investigate the clinical course of the disease. A total of 123 individuals were studied to better understand what happens to people diagnosed with this rare and aggressive disease. People diagnosed after 2007 did not reach end-stage kidney disease as much as those diagnosed before 2007, probably because in recent years early detection has increased and patients have been treated with more medicine. If patients were already on dialysis when they had their biopsy they did not recover kidney function, so this population will not benefit from the use of immunosuppressive medicine to treat anti-GBM. This was one of largest studies to date of patients with this disease.

Publication details: van Daalen EE, Jennette JC, McAdoo SP, Pusey CD, Alba MA, Poulton CJ, Wolterbeek R, Nguyen TQ, Goldschmeding R, Alchi B, Griffiths M, de Zoysa JR, Vincent B, Bruijn JA, Bajema IM. **Predicting Outcome in Patients with Anti-GBM Glomerulonephritis.** Clin J Am Soc Nephrol. 2018 Jan 6;13(1):63-72.



KIDNEYTalk[®]
24/7 Podcast Radio Show

Informative. Inspirational. Entertaining.

KidneyTalk™ is an informative online talk show hosted by Renal Support Network's Founder & President Lori Hartwell. Each half-hour show features a special guest who has first-hand knowledge, an inspirational story or decades of wisdom to share with listeners on how to survive and thrive with kidney disease. Hundreds of shows available 24/7 at RSNhope.org and on iTunes.

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Breakthroughs in Antibody Desensitization Therapy Web ID 1107 · **Living the Fullest Life Possible with Kidney Disease** Web ID 3012 · **To Be Young and Dating with Kidney Disease** Web ID : 943
Renal Warrior: The Power is Within You Web ID 3005 · **KidneyGrub** Web ID 3002

FINDING ACCEPTANCE: PSYCHOLOGICAL STAGES OF CHRONIC ILLNESS

Swiss psychiatrist Elisabeth Kubler-Ross explains the psychological process one goes through when they experience loss as the five stages of grief.

When you or someone close to you has been diagnosed with kidney disease, it's important to understand the emotions you are feeling. It will help you identify where you are within the five stages as you navigate your new normal. There is a light at the end of the process. The five stages are a natural, healthy process that one needs to experience in order to mentally come to terms with their diagnosis. As one goes through the stages they gain insight and develop skills to cope with chronic illness

The 5 Stages of Grief	Strategies to Help You Cope with Grief
<p>1. DENIAL: Once the shock diminishes, the defense mechanism of denial kicks in. Thoughts turn to "this is not happening to me" or "I can't be sick, my doctor must be wrong."</p>	<p>Do everything you can to learn about your disease. Research treatment options to discuss with your doctor. Ask your healthcare professionals to show you how to read and understand your labs. Explore the internet for some information, but don't rely entirely on the internet. Seek out others who have gone before you and can offer their advice and support.</p>
<p>2. ANGER: One will question why they are chronically ill. They may look for someone to blame. Anger and frustration can be directed inward or toward other people.</p>	<p>Find a creative outlet. Creative activities can help take your mind off your worries and your pain. Dabble in creative writing, painting, and crafting hobbies. If you don't already have a favorite creative activity, search the internet and YouTube for a tutorial on something that interests you.</p>
<p>3. BARGAINING: During this stage, people look for ways to circumvent their illness by bargaining with themselves or a higher power, thinking it will go away. They might also start questioning choices or actions they believe may have led to their illness.</p>	<p>Filter out internal negativity by surrounding yourself with positive people. Ask good friends to visit for an afternoon if you don't feel like going out. Sharing a laugh and just having a good time can lift your spirits.</p>
<p>4. DEPRESSION: Feelings of isolation, sadness and hopelessness may start to take over your thoughts. This can lead to potentially damaging behavior like skipping medication or not keeping doctor appointments.</p>	<p>Entertain yourself when you are alone by watching a favorite movie or listening to your favorite music. Start a Facebook group based on something you love like art, movies or books. Invite and ask people to post their favorites and share their memories with the group.</p>
<p>5. ACCEPTANCE: At last a sense of knowing that although there is no cure for your illness, you can adapt. Feelings of loss or anxiety will not completely go away. But one can learn coping strategies to overcome those emotions one day at a time.</p>	<p>You don't have to go it alone. You and the people closest to you are in this together. Look for a local support group for people with kidney disease and their families that you can attend together. If there isn't one near you, consider organizing one yourself. Chances are good that there are people in your community who would gladly participate if you get things going. Don't give up hope!</p>

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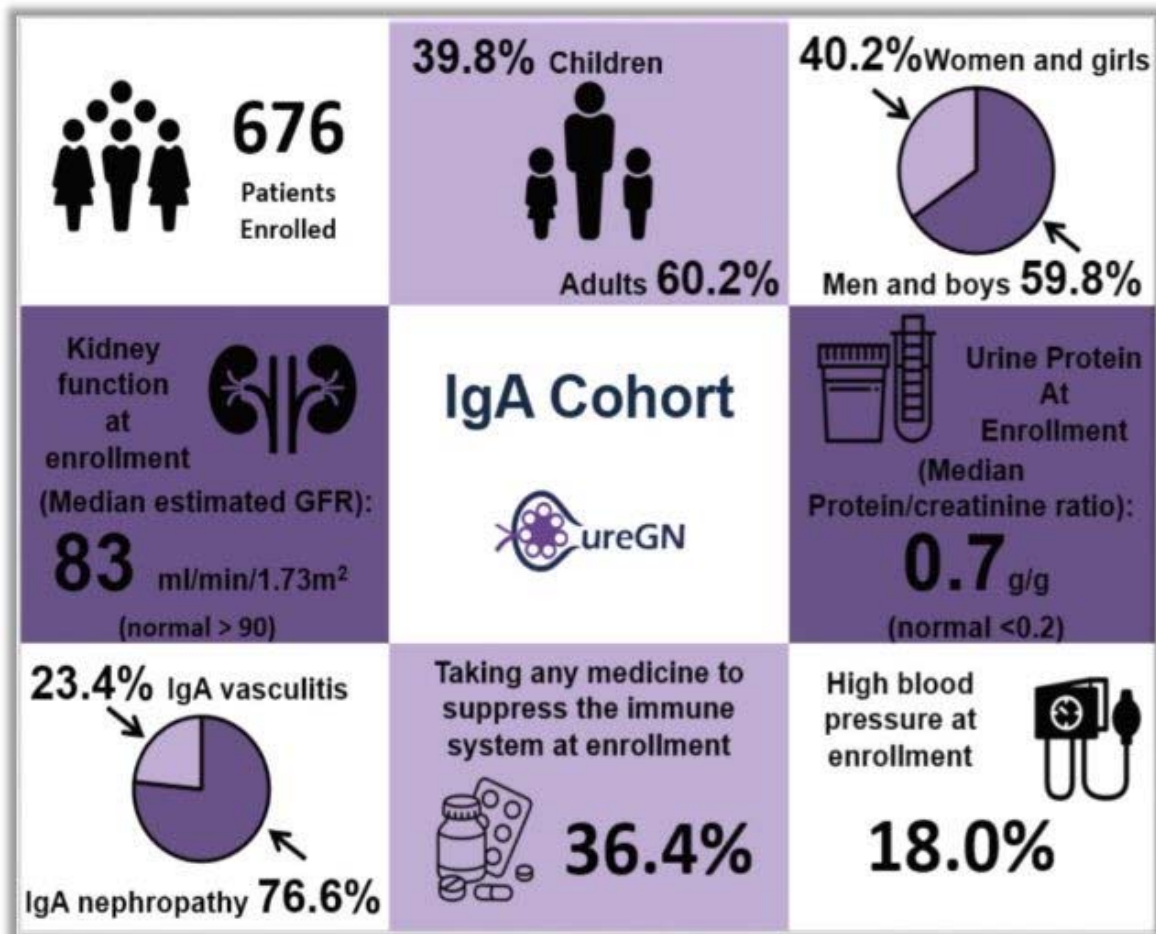
CURE GLOMERULONEPHROPATHY (CUREGN) NETWORK

The Cure Glomerulonephropathy Network (CureGN) is a study of 2,400 children and adults with glomerular disease. The glomerular diseases this study focuses on are minimal change disease (MCD), focal segmental glomerulosclerosis (FSGS), membranous nephropathy (MN), and IgA nephropathy (IgAN). You may be eligible for this study if you have been diagnosed with one of these four diseases and had your first kidney biopsy in the past 5 years. Enrollment is now closed for IgAN.

Participants in CureGN are included in a registry of patients who provide data via blood and urine samples as well as clinical information, pathology reports and health histories, similar to the way the GDCN registry is organized. De-identified data collected from patients is stored in two central locations (National Institutes of Health and Arbor Research Collaborative for Health) and researchers will be able to look at the information obtained in different ways in order to be able to learn more about glomerular disease, hopefully leading to better care for patients affected by these conditions. For more information, please contact Maggie D'Angelo at 919-445-2682 or maggie_dangelo@med.unc.edu.

You can also visit www.curegn.org, or follow CureGN on Twitter (@CureGN) and Facebook (facebook.com/CureGN).

Below is a snapshot of our IgAN patient cohort:



STUDIES CURRENTLY RECRUITING GDCN PATIENTS

The GDCN and the UNC Kidney Center are actively recruiting patients into the studies listed below and on the next page. Please contact the study coordinator listed at the bottom of page 9 if you are interested in learning more.

NEPHROTIC SYNDROME (FSGS, MEMBRANOUS, MINIMAL CHANGE DISEASE, IGAN)

<i>Study name and sponsor</i>	<i>Study Doctor</i>	<i>Study coordinator</i>	<i>More about the study</i>
C-NEPTUNE (NIH)	Keisha Gibson	Sandy Grubbs	Observational study of children newly diagnosed with Nephrotic Syndrome. Before renal biopsy and < 30 days of treatment.
CureGN (NIH/NIDDK)	Ronald Falk	Maggie D'Angelo	Observational study of children and adults with MN, FSGS, IgA, or Minimal Change Disease biopsied in the last 5 years.
APIXABAN	Vimal Derebail	Anne Froment	Study to understand how Apixaban (a blood thinner) works in patients with nephrotic syndrome. Blood and urine are tested before, 0.5, 1,3,4,6,8, and 24 hours after taking one dose of Apixaban.
ECHO Study for CureGN/NEPTUNE participants	Keisha Gibson	Sandy Grubbs	Observational study: evaluating cardiovascular health in children already enrolled in NEPTUNE and CureGN study. Will have echocardiogram and 24 hour BP monitoring.

FSGS

<i>Study name and sponsor</i>	<i>Study Doctor</i>	<i>Study coordinator</i>	<i>More about the study</i>
DUPLEX (Retrophin, Inc)	Vimal Derebail	Anne Froment	FSGS: Patients with FSGS will be treated either with sparsentan, a dual endothelin receptor and angiotensin receptor blocker or with irbesartan.
AUR-VCS-2017-03 (Aurinia)	Amy Mottl Vimal Derebail	Brenda Meier	Patients with FSGS who have > 3 grams of proteinuria will be treated with Voclosporin

STUDIES CURRENTLY RECRUITING GDCN PATIENTS

LUPUS

<i>Study name and sponsor</i>	<i>Study Doctor</i>	<i>Study coordinator</i>	<i>More about the study</i>
AURORA (Aurinia)	Keisha Gibson Vimal Derebail	Brenda Meier	Patients with active lupus nephritis will be treated with standard of care (MMF/Cellcept) plus oral study drug (Orelvo/Voclosporin) or placebo.
MSCs in SLE Trial	Sarah Sheikh Keisha Gibson Manish Saha	Brenda Meier	Patients with moderate to severely active treatment refractory lupus (renal and non-renal) will receive an infusion of mesenchymal stromal cells (stem cells known to possess significant immunosuppressive properties) or placebo.
GS-US-437-4093 (Gilead)	Vimal Derebail	Brenda Meier	Patients with active lupus nephritis (pure class V) will be treated with oral Filgotinib and/or GS-9876
DIVINE (RILITE Foundation)	Manish Saha Vimal Derebail	Brenda Meier	Patients with lupus who are scheduled to have a kidney biopsy will have an MRI of the kidney 1-3 days prior to the biopsy and repeated 6 months later. MRI findings will be compared to kidney biopsy findings to determine whether MRI may provide a set of non-invasive tools to assess renal function and pathology in Lupus Nephritis.

DIABETES

<i>Study name and sponsor</i>	<i>Study Doctor</i>	<i>Study coordinator</i>	<i>More about the study</i>
TRIDENT (Boehringer Ingelheim, GSK, Regeneron)	Amy Mottl	Emmie Cole	Observational study of patients with Type 1 or Type 2 diabetes who are about to have a kidney biopsy. A piece of the kidney biopsy will be collected along with clinical information.
NeoKidney Augment Study (inRegen)	Amy Mottl	Paula Steele	Patients with moderate to severely active treatment refractory lupus (renal and non-renal) will receive an infusion of mesenchymal stromal cells (stem cells known to possess significant immunosuppressive properties) or placebo.

STUDY COORDINATOR CONTACT INFORMATION:

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KEEPING UP WITH THE KEOP (KIDNEY EDUCATION OUTREACH PROGRAM)

The KEOP has been busy this past year making connections throughout North Carolina and planning for future events. We have conducted several community events, bringing awareness to community members about kidney health, and screening community members for indicators of kidney disease. We also attended a UNC basketball game, greeting fans as they entered the arena and providing education about kidney disease and the UNC Kidney Center.

The KEOP is also working closely with Edgecombe and Nash Counties to brainstorm ways to reduce the burden of kidney disease in their communities. Members of our team met with community stakeholders in May and we are all eager to start working together on specific, community based programs related to keeping kidneys healthy.



Drs. Barb Gillespie, Patrick Nachman, and Vimal Derebail at a screening in Kinston, NC

Mark your calendars! The 2018 Triangle Kidney Walk, put on by the National Kidney Foundation, will be in Durham, NC on Saturday – November 4, 2018! Come walk and join our UNC Kidney Center team!

And make sure to check our website for upcoming events: <https://unckidneycenter.org/outreach/>

For more kidney disease information, internet links, podcasts, and printable copies of this newsletter, check out our website: www.unckidneycenter.org

HOPEline
Peer Support Hotline

SUPPORT FROM SOMEONE WHO HAS BEEN THERE.

IF YOU HAVE QUESTIONS RELATING TO CHRONIC KIDNEY DISEASE
CALL (800)579-1970
CALL TOLL-FREE 10:00AM TO 6:00PM (PACIFIC TIME)

RENAL SUPPORT NETWORK RSNhope.org

RECIPE BOX: TACO PASTA SALAD

Diet type: CKD non-dialysis Dialysis Diabetes

Recipe submitted by DaVita dietitian Arlene from Virginia.

Portion: 4

Serving Size: 1 cup pasta salad, 1 cup lettuce



Ingredients:

- 12 ounces penne pasta, uncooked
- 1 large garlic clove
- 2 green onions
- 1/2 cup red bell pepper
- 8 cups iceberg lettuce
- 1/2 cup sour cream
- 1/2 cup salsa
- 2 tablespoons hot taco sauce
- 1/2 cup canned diced green chiles
- 2 tablespoons sliced black olives
- 1/2 cup shredded Mexican cheese

Preparation

1. Cook the pasta according to package directions, omitting salt. Drain and rinse until cooled.
2. Mince the garlic; slice the green onions; chop the bell pepper; shred the lettuce
3. In a small bowl, combine the sour cream and salsa. Mix into the pasta.
4. Add hot taco sauce, garlic, chiles and olives to pasta and stir.
5. Sprinkle green onions and bell pepper over top of pasta mixture. Cover and refrigerate to chill.
6. Before serving, sprinkle cheese on top of pasta salad (optional). For each serving place one cup of shredded lettuce on a salad plate. Top lettuce with one cup of Taco Pasta Salad.

Nutrients per serving

Calories 230
 Protein 8 g
 Carbohydrates 36 g
 Fat 6 g
 Cholesterol 14 mg
 Sodium 205 mg
 Potassium 261 mg
 Phosphorus 128 mg
 Calcium 97 mg
 Fiber 2.8 g

Renal and renal diabetic food choices: 2 starch, 1 medium-potassium vegetable, 1 fat

Carbohydrate choices: 2-1/2

Helpful hints

- Look for canned or bottled hot taco sauce.
- Compare labels and choose the brands of salsa, green chilies, olives and taco sauce lowest in sodium.
- Look for queso anejo, a Mexican cheese that easily crumbles. If unavailable, buy the shredded cheese labeled "Mexican."
- Make a wrap with flat bread or flour tortilla and Taco Pasta Salad with lettuce inside.

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