# KIDNEY CARE

A newsletter from the Glomerular Disease Collaborative Network: Health care professionals and patients working together to learn more about diseases that affect the filters (glomeruli) in the kidney.

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## PATIENT PERSPECTIVE: CHANCE ENCOUNTER PAYS BIG DIVIDEND

*By: Nancy Kaylor and Kathy Olevsky*

A chance meeting 12 years ago sparked a valuable bond between two women with vasculitis. Kathy Olevsky, from North Carolina, and Nancy Kaylor, then a resident of Virginia, were attending the May 2011 Vasculitis Foundation symposium for patients, families and medical professionals held at the University of North Carolina-Chapel Hill. Until that day they were strangers.

An athlete, Kathy, is owner of three martial arts studios and has a black belt in Karate. She is also active in the Vasculitis Foundation serving as webinar moderator. Nancy retired from a career as an award winning journalist and corporate communications executive and is an active community volunteer.

At the conference lunch break, attendees were asked to sit at tables with signage that matched their type of vasculitis. Nancy made her way to the remaining empty seat at the "Microscopic Polyangiitis" table and introduced herself to Kathy and her husband, Rob. The two women started sharing their experiences with MPA since being diagnosed in 2009. "We kept interrupting each other with 'Me, too. That's what happened to me!'" Kathy recalls.

It quickly became clear that they shared a diagnosis, eerily similar hospitalizations and treatment timelines AND a UNC physician, Dr. Ronald J. Falk, who had encouraged them to attend the symposium at recent clinic appointments. After lunch they attended the same sessions and used every break to continue their whirlwind conversation. "At the end of the day, we exchanged contact information and promised to stay in touch," Nancy said. "And for more than a decade we have."

Both women recall that attending the vasculitis symposium was a game changer. "Because I was so newly diagnosed, I didn't know what to expect," Nancy recalls. "I came away with so much knowledge and more importantly, hope." At one session, the women recalled, experts traced the history of vasculitis and current treatments, as well as historical mortality rates. Clearly, thanks to research, vasculitis is no longer the death sentence it was decades ago.

Now best friends, Kathy and Nancy describe themselves as a small but crucial support group for one another. Kathy even coined the term "ANCA Buddies" and they often sign texts and emails "AB." "We touch base frequently to compare notes," Kathy said. "We're each other's biggest cheerleader. It's good to know, whether it's a triumph or a setback, Nancy understands what I'm going through." Because MPA patients may not display outward signs of a rare illness, the reaction of some friends or acquaintances can be frustrating and disheartening. It's not uncommon to hear "You don't look sick to me."

*Continued on next page…..*

## Join Our New GDCN Patient Panel!

The UNC Kidney Center has always been dedicated to our patients. We would love to support and educate patients and their families about different types of glomerular diseases, laboratory tests, and treatment. The UNC Kidney Center will be hosting a panel of patients with glomerular diseases alongside our team of glomerular experts. Please join us virtually for this event. We will be advertising the event once the date is finalized. Please reach out to us at gdcn@unc.edu if you are interested in participating on the panel.

## Patient Perspective Continued from page 1..

The symptoms, fears and flares are much easier to share with someone who knows first hand the impact of vasculitis. "We know we can always reach out and there is no question too small," Nancy said. "If Kathy texts she's stopping for a milkshake on her way home from an appointment with Dr. Falk, it's a signal that all is well."

The women agree that an important lesson from the vasculitis conference is the importance of being an informed and engaged patient. "It's not enough to just show up at medical appointments," Kathy said. Learn about vasculitis, monitor your health and keep up with new research and treatment options, she advises.

Both Kathy's husband Rob, and Nancy's late husband Steve, were quick to grasp the importance of the key role families play in living with vasculitis. Accompanying their wives to their vasculitis checkups helped them learn first hand about the disease, and how best to support their spouse. After her husband's death, Nancy now travels from her home in Florida for her vasculitis checkups. Kathy stepped forward and offered to pick Nancy up from the Raleigh airport and Nancy stays with Kathy at her home in Wake Forest. Now the women schedule their appointments on the same day.

The following morning they hop in the Kathy's convertible and head for Nancy's Virginia home in the mountains near the Blue Ridge Parkway for a few days to catch up with one another. Dr. Falk has dubbed them "Thelma and Louise." During one of those trips, Nancy and Kathy got into a discussion of blood work results which typically post to the UNC patient portal while they are still together. "As usual, we were comparing our numbers," Nancy said. "I think we were both under the impression that the other had a better grasp on what those numbers mean.."

The upshot of that conversation? A Vasculitis Foundation online webinar moderated by Kathy in which Dr. Falk did a line-by-line review of Nancy's recent lab results, answered Nancy and Kathy's questions and explained the significance of particular results. Dr. Falk emphasized that rather than focusing on a snapshot of a lab reports, it's important to look at trends that may emerge over time.

Their webinar collaboration is an example of the important teamwork between the medical community and patients as research continues to unravel the mysteries of vasculitis in its many forms. That's why both women gladly participate in research efforts with both the UNC Multidisciplinary Vasculitis and Connective Tissue Diseases Clinic and the Vasculitis Foundation. "Nancy and I have been given the gift of better lives because of the many patients who have participated in research studies over the years," Kathy said. "The best way to show our appreciation is to do our part."

# PATIENT PERSPECTIVE: HURRICANE ANCA

*By: Tonya Francis*

Hello my name is Tonya M. Francis and I am a 55-year-old Black female. This is my story. In 2016, I had my own Hurricane Matthew called ANCA Vasculitis. This is the technical name for it: Anti-Neutrophil Cytoplasmic Antibody.

ANCA is a type of autoimmune disease. It is a rare disease that affects the small blood vessels in the body. Autoimmune disease is what happens when the body's immune system attacks the body itself. ANCA Vasculitis is rare. It is mostly diagnosed in late middle age people (50 – 60s). It is equally common in men and women. It is uncommon in the African-American population.

Years prior to ANCA Vasculitis, when I gave birth to my son in 1988, I had to stay in the hospital for 5 days because I had some sort of infection in my kidneys. So, when ANCA Vasculitis came into my life it hit the weakest organ in my body which was my kidneys.

Fast forward to October 2016; for the first two weeks I experienced stiff joints and pain in my legs and arms, blood in my urine and stool, foamy urine, fatigue, weight loss, coughing up blood, shortness of breath after walking upstairs, a painful sore throat, nose bleeds and crusting around my nose.

When I finally could not take the pain in my body anymore on the morning of October 9, 2016, I asked my husband to take me to the hospital and he took me to a local hospital in Siler City, NC. The doctor took all kinds of tests. In my blood work there was cause for concern, so the doctor came into my room and said, "your kidneys are angry! We need to transport you to UNC Chapel Hill by ambulance because we cannot treat you here." Once I got to Chapel Hill, they told my husband it was good I was there because I was losing my kidneys and was in danger of losing my life. My kidneys were failing and were at 20% use. In my hospital room I was surrounded by doctors and nurses. My main doctor told me that they were going to do a number of tests to confirm what they thought was going on with me.

I was given prednisone, went through x-rays, scans, and ultrasounds, had a kidney biopsy, had a blood transfusion, and received plasma exchange (Plasmapheresis), blood thinners, and Rituximab, which is a type of chemotherapy. I was in the hospital for 6 days and then had to go back because of blood clots in both legs and they kept me for another 5 days.

With all of this going on in my life I had to make a change, so in 2017 I did some research and found a documentary called "What the Health." This got my attention because it showed me that I could help myself by living a healthy life style. That is exactly what I did. I cut meat totally out of my diet. And began to eat fruit, vegetables, grains, nuts plant-based butter and milk. I also started to exercise.

I have a Pastor (Bishop Ann Dockery) that believes in the power of food and it being your medicine. She already was teaching me about eating better for my health. My blood count got better and my kidneys are at 61% now. I do see my kidney doctor every 3 to 6 months and have good reports. They say that I am in remission, I say that I am healed by my God. For the past 6 years, I have become a plant-based eater and I feel very good. I am not on any medication. I take B12 vitamin and E, C & D vitamins. I drink turmeric, pineapple and ginger juice. I am inspired and live my life by the following words: Beloved, I wish above all things that thou mayest prosper and be in health, even as thy soul prospereth.

## KEEPING UP WITH THE KEOP

As times and the landscape of healthcare continue to change, the Kidney Education and Outreach Program (KEOP) remains committed to spreading the word about kidney health and disease prevention. In April 2023, we participated in the annual Women's Health Awareness Conference in Durham through the NIEHS (National Institute of Environmental Health Sciences). There, KEOP spoke with women about ways to keep their kidneys healthy, and we screened approximately 50 women and provided screening results and consultation. In addition to the screening component, Drs. Emily Chang and Keisha Gibson gave a talk titled, "Karing for Your Kidneys – What Every Woman Should Know About Kidney Health." It was a great day, full of providing women with helpful information regarding their kidney health. We look forward to more community events this Fall.

Over the past year, we have continued to strengthen our partnership with the NKF of North Carolina to complement each other's screening and education efforts throughout the state. In late October, we look forward to joining the National Kidney Foundation (NKF) of NC on their walk in Charlotte, hoping to raise significant money as the UNC Kidney Center team to help support the NKF in their efforts. We have also continued to strengthen our community partnerships with organizations in Nash and Edgecombe counties and look forward to additional community activities.

KidneyTalk®
24/7 Podcast Radio Show
Informative. Inspirational. Entertaining.

RSN's KidneyTalk® is an informative, inspirational, and entertaining, half-hour online radio talk show that launched in 2006. RSN Founder & President Lori Hartwell, who has been a renal disease survivor since 1968, serves as host. KidneyTalk™ provides the audience with practical advice on how to live a full and productive life despite CKD. The show features healthcare professionals and people living successfully with kidney disease who share personal experiences and wisdom. Visit www.rsnhope.org for a full list of podcasts or find them on Apple Podcasts, Google Play and on iHeart Radio. Popular episodes include "Surviving & Thriving: A life-long Kidney Journey", "Tips to Help the Search for a Living Kidney Donor", and "Cooking for your Kidneys."

# Enrolling at UNC: Kidney Precision Medicine Project

## What is KPMP?

The Kidney Precision Medicine Project (KPMP) studies each participant's unique kidney disease to revolutionize the way we diagnose and treat kidney disease. KPMP is a national program bringing patients and researchers together. It is paid for by the National Institutes of Health (NIH) and the National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK).

**Goals of KPMP:**

1. Identify new treatments for kidney disease
2. Ethically collect kidney biopsies from participants with acute kidney injury or chronic kidney disease
3. Create a Kidney Tissue Atlas
4. Define disease subgroups

**What is a Kidney Tissue Atlas?**

The Kidney Tissue Atlas is a set of maps that will give researchers, patients, and caregivers important information about the inner workings of the kidney. The Atlas will help us understand different types of kidney disease.

**What is a Subgroup?**

Not all kidney diseases or injuries should be treated the same. Right now, we only have a few diagnoses for kidney diseases and injuries, but we believe there could be hundreds more. That would mean hundreds of treatment options. Before we can figure out what those treatments are, we have to discover all the different kinds of the disease and group them together for more study.

## Who Can Join?

If you have either a chronic kidney disease or an acute kidney injury, you can join the KPMP research study. We need people from all walks of life, races, and age groups to give us the most accurate and complete kidney information.

By joining, you will help transform the future of kidney health.

**Who Cannot Join?**

If you have had a kidney transplant or are on dialysis, you cannot join the KPMP study. If you have friends or family members with a chronic kidney disease or an acute kidney injury, please encourage them to enroll.

## What Do I Do Once I've Enrolled?

KPMP is a study that can last up to 10 years. In order to participate, you must do the following:

- Have a kidney biopsy
- Collect samples like blood and urine
- Talk to the study team two to three times a year. Sometimes this will be in-person and other times over the phone.

**What is a Kidney Biopsy?**

A kidney biopsy is when a doctor takes out a small piece of the kidney to look at under a microscope. The tissue is studied to understand how the kidney has been damaged, and what could have caused that damage. All KPMP biopsies are performed by highly trained, experienced doctors.

**What Will It Cost?**

Study visits and procedures will be paid for by KPMP. Additionally, participants will receive a stipend for their time.

## What Happens to My Kidney Samples?

The kidney samples will go to the KPMP research sites where scientists will study them. Any extra tissue will be stored in a central location, to be shared only with other researchers. Important biopsy results that could affect your treatment will be returned to you.

## How Does KPMP Protect my Data?

KPMP takes data security and privacy very seriously. We take many steps to keep your medical data safe at every stage of the study. Your personal information will never be shared. Only approved research teams can see your data and samples. Data that is shared will be anonymized.

For more information:
email kidneytrials@unc.edu or call 1-866-462-9371

KIDNEY PRECISION MEDICINE PROJECT

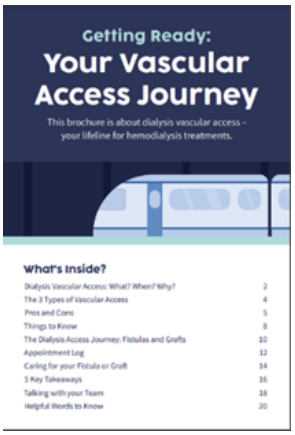
www.kpmp.org

## Inroducing the THRiVE Trial

Starting Fall 2023, in collaboration with the University of Pennsylvania and Johns Hopkins University, the University of North Carolina Flythe Research Team will begin enrolling people with advanced kidney disease preparing for hemodialysis in the Transforming Hemodialysis-Related Vascular Access Education (THRiVE) Trial. The THRiVE Trial was inspired by the need to better educate and support people as they consider getting a vascular access for hemodialysis. Research shows that starting hemodialysis with a fistula or graft rather than a catheter is better for most patients. However, only 20% of U.S. patients start dialysis with a fistula or graft. Additionally, there are racial disparities in vascular access. Black patients are 20% less likely than White patients to start hemodialysis with a fistula (1-2). Many patients are hesitant to get a vascular access because of lack of understanding about vascular access, fear of vascular access creation, and/or worries about what a vascular access will look like on their body. The THRiVE Trial will help us understand if education and emotional support can aid patients in making decisions about vascular access.

The THRiVE Trial will compare three different methods of education: usual care, education, and education plus. "Education"-randomized participants will receive the "Getting Ready" education materials (video and brochure) shown below. "Education-Plus"-randomized participants will receive the "Getting Ready" education materials and will have sessions with a motivational interviewing coach to provide additional support. "Usual Care"-randomized participants will have the usual education provided by their care teams just like they would if not in the trial. The trial will determine the effectiveness of the three educational methods for increasing patient understanding of vascular access and increasing the number of patients who get a fistula or graft before starting hemodialysis. The trial will also evaluate if these methods of education can decrease racial disparities in vascular access creation.

Recruitment for the THRiVE Trial will happen at UNC Kidney Specialty and Transplant Clinic—Eastowne, UNC Nephrology—Sanford, UNC Nephrology—Panther Creek, and UNC Nephrology—Burlington. If you are a patient at one of these clinics and are preparing for hemodialysis, you may be eligible to participate. If interested in learning more, please contact Veronica Joseph at 919-966-4615 or Veronica_Joseph@med.unc.edu.


**THRiVE Educational Materials: "Getting Ready" Vascular Access Video and "Getting Ready" Vascular Access Brochure**

References: (1) Ravani P, Palmer SC, Oliver MJ, et al. Associations between hemodialysis access type and clinical outcomes: a systematic review. J Am Soc Nephrol. 2013;24(3):465-473. (2) United States Renal Data System. 2013 USRDS Annual Data Report: Epidemiology of Kidney Disease in the United States. National Institutes of Health, National Institute of Diabetes and Digestive and Kidney Diseases, Bethesda, MD, 2022

# 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.

**What can kidney biopsies tell us about diabetes and glomerular disease?**

This study included patients with diabetes, enrolled in the Glomerular Disease Collaborative Network, with biopsies from 2008 to 2015, diagnosed with diabetes and any of the following diagnoses: Focal Segmental Glomerulosclerosis (FSGS), IgA Nephropathy (IgAN), Minimal Change Disease (MCD), Membranous Nephropathy (MN) or Anti-Neutrophil Cytoplasmic Autoantibody Glomerulonephritis (ANCA GN). Data from health records and kidney biopsy tissue was reviewed. Some diabetic patients have damage from diabetes (called "lesions") in their kidneys but others do not. The investigators wanted to see if there were differences between patients with diabetic lesions in their kidneys compared to diabetic patients without lesions in their kidneys.

Data from 134 patients were available for analysis (78 with diabetes + lesions and 56 without lesions). The length of time a person had diabetes and how well their diabetes was controlled was similar between the two groups. Use of immunosuppression (like cyclophosphamide and prednisone) was not different between the two groups ($p=0.3$). In this study, among people with diabetes and glomerular disease, mild diabetic lesions on biopsy did not impact a person's risk of reaching end stage kidney disease or death but moderate-severe lesions increase the risk for ESKD and death. A future study will look at whether or not the use of immunosuppression is more or less successful in helping people with moderate-severe diabetic lesions go into remission.

Kim YH, Saha MK, Hu Y, Kumar S, Poulton CJ, Hogan SL, Nachman P, Jennette JC, Nast CC, Mottl AK. Impact of Diabetic Lesions on Pathology, Treatment and Outcomes of Glomerular Diseases. Kidney360. 2023 Aug 29.

Link: https://pubmed.ncbi.nlm.nih.gov/37642555/

**Does the genetic marker APOL-1 have an effect on black patients with membranous nephropathy?**

Black individuals with high risk variants in the apolipoprotein L1 (APOL1) gene may have a higher risk for developing kidney problems. Studies looking at lupus nephritis and focal segmental glomerulosclerosis have shown that individuals with high-risk APOL1 markers have more severe kidney damage. This study investigated kidney outcomes in black individuals with membranous nephropathy and high risk APOL1 genes compared to low risk APOL1 genes or non-black individuals.

Samples from 165 participants diagnosed with membranous nephropathy and enrolled in the GDCN were analyzed, along with samples from 525 CureGN participants. Data was compared between Black and non-Black participants and between Black participants with and without the high risk APOL1 alleles. Black participants with high risk APOL1 alleles and membranous nephropathy had a faster decline in kidney function and had a higher risk of kidney failure. This study highlights the continued need to study new medications targeting the APOL1-related diseases, and to include patients with membranous nephropathy in those studies.

If you are interested in finding out if you could be eligible for an APOL1 study, check out https://kidneycareandjustice.com/ and https://amplitudestudy.com/ (also on page 11 of this newsletter).

Chen, Dhruti P.; Henderson, Candace D.; Anguiano, Jaeline; Aiello, Claudia P.; Collie, Mary M.; Moreno, Vanessa; Hu, Yichun; Hogan, Susan L.; Falk, Ronald J.; on behalf of CureGN. Kidney Disease Progression in Membranous Nephropathy among Black Participants with High-Risk APOL1 Genotype. CJASN. March 2023. Link: https://pubmed.ncbi.nlm.nih.gov/36763808/

# Manicure Dream

***By:*** *Anne Froment, Clinical Research Manager*

After admiring beautifully adorned nails on other hands than mine, I was ready to get a manicure. The same day, my husband sent me a news release from the National Institutes of Health (NIH) about a group of chemicals known as phthalates and their effect on pregnancy: "Pregnant women who were exposed to multiple phthalates during pregnancy had an increased risk of preterm (early) birth, according to new research by the National Institutes of Health. Phthalates are chemicals used in personal care products, such as cosmetics, as well as in solvents, detergents, and food packaging" (1).

As I dug deeper I found that phthalates are often a main ingredient in nail polish. Instead of going to the nail salon, I read what the US Food and Drug Administration (FDA) had on these chemicals in nail polishes. In summary, they were safe if used as intended in a well-ventilated place. I was glad to read that the use of phthalates in cosmetics "decreased considerably from 2004 to 2010" (2). The FDA requires a list of ingredients on most cosmetics, including nail polish. One of the phthalates, diethylphtalate (DEP), is used as a solvent and a fixative for fragrance. You would think that you could avoid phthalates by reading the label. Wrong. The regulations do not require the manufacturer to give the ingredients in a fragrance or flavor. To be certain to buy a product without phthalates, you need to avoid products with "Fragrance" or "Flavor" in the list of ingredients.

Since the FDA data dated back to 2010, I looked at what the Campaign for Safe Cosmetics had to say about nail products. There were many other chemicals with unwelcome effects in those products (3). For instance, artificial nails and nail polishes can contain acrylates, which are toxic to many organs, including the kidneys (the most important organ in the body, as everyone at the UNC Kidney Center can attest). Incredibly, the Methacrylate Producers Association, Inc., has stated that these chemicals are not appropriate for nail products (4), but they are still used for that purpose.

Additionally, nail polish - and lip balm - can contain benzophenone to protect the products from UV light. It's toxic and it's best to read the labels and avoid products with benzophenone, ingredients containing the word benzophenone (e.g., benzophenone-2), BP# (e.g., BP2), oxybenzone, sulisobenzone, or sulisobenzone sodium. The color in nail polish can come from heavy metals like lead, arsenic, mercury, etc. It's especially unsafe for pregnant women, young children, and adolescents.

Formaldehyde, a cancer-causing preservative, is found in nail polish and nail glue. To avoid it, you almost need a chemistry degree along with very good eyesight to read small labels and avoid products containing: formaldehyde, quaternium-15, dimethylol-dimethyl (DMDM) hydantoin, imidazolidinyl urea, diazolidinyl urea, sodium hydroxymethylglycinate, 2-bromo-2-nitropropane-1,3-diol (bronopol), etc.


You can make it a bit easier on yourself and find nail products that are labeled "formaldehyde-free" or "three-free" (formaldehyde, toluene, and Dibutyl phthalate (DBP)). Some "eight-free" nail polishes exist; those are free of formaldehyde, toluene, DBP, formaldehyde resin, camphor, xylene, ethyl tosylamide, and triphenyl phosphate (5). For those of you with beautifully done nails, I'm glad there are safer options out there and I hope this helps you avoid polish with toxic chemicals.

Sources :

(1) https://www.ncbi.nlm.nih.gov/pmc/articles/PMC8157593/. (2) https://www.fda.gov/cosmetics/cosmetic-products/nail-care-products. (3) https://www.safecosmetics.org/products (4) http://static1.1.sqspcdn.com/static/f/1405676/22020353/1361810987690/artificial_nails2.pdf?

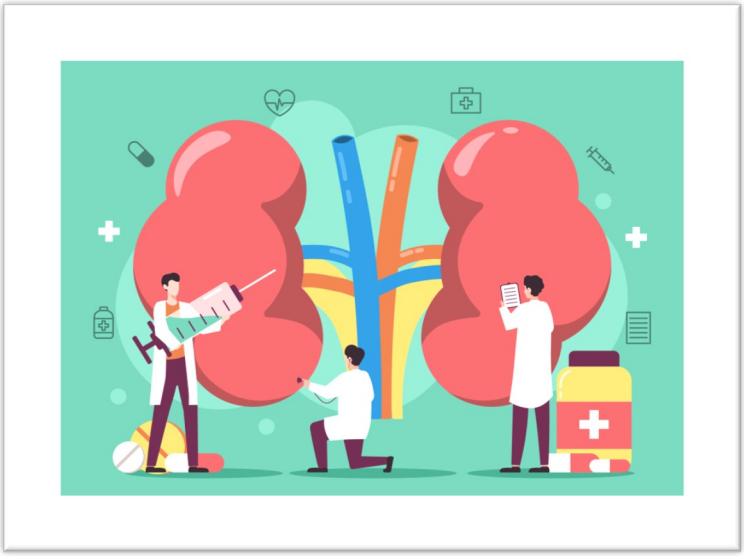
token=shomjmAvP3NDphvtSYBL3nz4vl8%3D (5) https://www.bigelowchemists.com/blog/ask-a-beauty-expert/best-nontoxic-nail-polishes/

# INSHORE : A CLINICAL STUDY FOR IDIOPATHIC NEPHROTIC SYNDROME

**What is idiopathic nephrotic syndrome?**
Childhood-onset idiopathic nephrotic syndrome is a kidney disorder that starts in childhood and causes the body to pass too much protein in the urine. The condition causes swelling (also known as edema) especially in the face, legs, and feet, and changes in the person's urine. In most cases the cause is not known; this is called 'idiopathic'.

Current standard of care for childhood-onset idiopathic nephrotic syndrome is a combination of steroids and immunosuppressive drugs (such as a drug called mycophenolate mofetil [MMF]). However, in many people who receive these treatments, the protein in the urine keeps coming back. This is called 'relapsing'. Treatment with steroids is also linked to the risk of certain side effects. Researchers are looking for new treatments which are more effective and have better long-term health outcomes.

**What is the INShore study?**
INShore is a clinical trial that compares an investigational drug obinutuzumab with mycophenolate mofetil (MMF) in children and young adults with a kidney disorder called idiopathic nephrotic syndrome.



The INShore study wants to assess how safe and effective obinutuzumab is when compared to MMF in people aged 2 to 25 years old with childhood onset idiopathic nephrotic syndrome.

This study is for patients who are in remission (no protein in the urine, and no swelling in the face or body) to see if the investigational drug helps people to stay in remission.

After screening to make sure the study is a right fit, there is a 52 weeks treatment period with 4 infusions of obinutuzumab or a twice-daily dose of MMF taken orally. Participants will know what drug they are receiving. If the treatment does not work, the doctor can change the treatment or add a treatment. There is a possibility to stay longer on the study for up to 2 years, if desired and recommended by the study doctor.

Potential participants will be told about any potential risks and benefits of taking part in the clinical study, as well as any additional procedures, tests, or assessments they will be asked to undergo. These will all be described in an informed consent document (a document that provides people with the information they need to make a decision to volunteer for a clinical study). A potential participant should also discuss these with members of the research team and with their usual healthcare provider. Anyone interested in taking part in a clinical study should know as much as possible about the study and feel comfortable asking the research team any questions about the study

If you would like to see if you are eligible for this study, please contact Jasmine Durham at: jrdurham@email.unc.edu or by phone at 919-962-5450.

You can also learn more at https://www.clinicaltrials.gov/study/NCT05627557.

## 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 coordinators listed at the bottom of page 11 or email kidneytrials@unc.edu if you are interested in learning more.

**ANCA VASCULITIS**

| *Study name and sponsor* | *Study Doctor* | *Study coordinator* | *More about the study* |
|---|---|---|---|
| GOOD-IDES-02 (Hansa Biopharma AB) | Vimal Derebail | Anne Froment | Hospitalized patients with severe anti-GBM antibody disease (Goodpasture disease) with kidney and/or lung involvement will be treated with standard of care and the study drug imlifidase or standard of care alone. |

**FOCAL SEGMENTAL GLOMERULOSCLEROSIS**

| *Study name and sponsor* | *Study Doctor* | *Study coordinator* | *More about the study* |
|---|---|---|---|
| BI 764198 (Boehringer Ingelheim) | Vimal Derebail | Anne Froment | Adult patients with FSGS or with a known TRCP6 gene abnormality will receive the study drug being tested BI 764198 or a placebo. BI 764198 is a capsule |
| LIPOSORBER (Kaneka) | Koyal Jain | Anne Froment | Patients with primary FSGS that did not respond to standard treatment will use a blood processing device called LIPOSORBER®LA-15. |

**LUPUS NEPHRITIS**

| *Study name and sponsor* | *Study Doctor* | *Study coordinator* | *More about the study* |
|---|---|---|---|
| SANCTUARY (Alexion) | Amy Mottl | Anne Froment | Adult patients with Lupus Nephritis with 1 gram of proteinuria or more will receive Ravulizumab (a longacting anti-C5 monoclonal antibody) or placebo. |
| VOCAL (Aurinia) | Keisha Gibson | Jasmine Durham | Patients between 12 y.o. and 18 y.o. with Lupus Nephritis will be treated with Voclosporin or placebo to assess its efficacy when added to two drugs commonly used to treat this disease; Mycophenolate mofetil (MMF) and corticosteroids. |

**IGA NEPHROPATHY**

| *Study name and sponsor* | *Study Doctor* | *Study coordinator* | *More about the study* |
|---|---|---|---|
| ASSIST (Chinook Therapeutics) | Amy Mottl | Anne Froment | This study wants to find out if taking the study drug atrasentan along with a drug called an SGLT2 inhibitor is safe and helps people with IgA nephropathy. An SGLT2 inhibitor is a drug that has been approved to treat chronic kidney disease. |

**MEMBRANOUS NEPHRITIS**

| *Study name and sponsor* | *Study Doctor* | *Study coordinator* | *More about the study* |
|---|---|---|---|
| REBOOT (NIH) | Vimal Derebail | Anne Froment | Adult patients with Membranous Nephritis who need treatment with Rituximab will be treated with Rituximab. In addition they will have intramuscular injection of belimumab or placebo. |

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

| *Study name and sponsor* | *Study Doctor* | *Study coordinator* | *More about the study* |
|---|---|---|---|
| CureGN (NIH/NIDDK) | Ronald Falk/ Amy Mottl | Tashas Cameron-Wheeler | Observational study of children and adults with MN, FSGS, IgA, or Minimal Change Disease biopsied in the last 5 years. |
| EPPIK (Travere Therapeutics) | Keisha Gibson | Jasmine Durham | Children with FSGS, Minimal change disease (MCD), IgAN, Immunoglobulin IgAV, or Alport syndrome (AS) will be treated with Sparsentan to test for safety, efficacy, and tolerability. |
| AMPLITUDE (Vertex) | Vimal Derebail | Sara Kelley | Adult patients with APOL1-mediated proteinuric kidney disease will be treated with a APOL1 inhibitor or placebo. |
| Inshore (F. Hoffman-LaRoche Ltd.) | Keisha Gibson | Jasmine Durham | Children and adults who were diagnosed in childhood up to 25 years old will be treated with study drug Obinutuzumab—given as an infusion - or mycophenolate mofetil – a tablet. Participants will know which drug they receive. There is an extension period after 52 weeks when more Obinutuzumab can be given, if needed, to any participant. |

**DIABETIC KIDNEY DISEASE AND CHRONIC KIDNEY DISEASE**

| *Study name and sponsor* | *Study Doctor* | *Study coordinator* | *More about the study* |
|---|---|---|---|
| CureGN Diabetes (NIH) | Any Mottl | Sara Kelley | Observational study of adults with a diagnosis of diabetes MN, FSGS, IgA, or Minimal Change Disease biopsied since 1/1/2009. |
| Confidence (Bayer) | Amy Mottl | Sara Kelley | Adult patients with chronic kidney disease and type 2 diabetes will be treated with finerenone or empagliflozin or both drugs to compare efficacy and safety. |
| Kidney Precision Medicine Project (KPMP) (NIH) | Amy Mottl | Sora Lee | KPMP is an NIH initiated study to better understand and find new treatments for chronic kidney disease (CKD) in people with diabetes and/ or hypertension as well as acute kidney injury (AKI). Volunteers donate kidney tissue obtained via kidney biopsy and blood and urine samples. Participants are asked to come for an annual visit for up to ten years. |

**ALPORT SYNDROME**

| *Study name and sponsor* | *Study Doctor* | *Study coordinator* | *More about the study* |
|---|---|---|---|
| NEPTUNE for Alport Syndrome (NIH) | Vimal Derebail | Sara Kelley | Men, women, and children less than 80 years of age, with Alport Syndrome, are eligible to participate. This study will collect health information and laboratory samples, with a goal to learn more about Alport Syndrome and find better ways to prevent and treat this condition. |

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