Transplant Times

Organ Transplant Awareness Program
August 1, 2021
Promoting Organ Donor Awareness; Supporting the Transplant Community

The support group will meet, Friday, August 6, 2021, from 1:00 pm to 3:00 pm at Evelyn's home please email me for directions - rioreal@earthlink.net

Hello!

It is Sunday the first day of August and we finally had a cool morning in Albuquerque. This newsletter includes an article about a study on the effects of a fasting diet for those afflicted with Polycystic Kidney Disease and a synopsis of a book written by transplant surgeion, Thomas Starzel,"*The Puzzle People*", who conducted the first liver transplant at the University of Colorado. My surgeon was one of his students. The photo below was taken at an impromptu meeting of fellow recipients. It was fun to be with reunited with other recipients!

-Evelyn

From left to right: Robert Golding (liver), Lynn Davis (liver), Patricia Pistorio, (liver), Evelyn Rivera (liver), Dana Nighswonger (heart), and Rebecca Golding (Robert's wife/caregiver)

Transplant Recipient Anniversaries

Bert Clemens	***Kidney***	***August 10, 2000***
Philip Hargis	***Heart***	***August 12, 2012***
Nancy Dodge	***1st Kidney***	***August 1984***

The Puzzle People: Memoirs Of A Transplant Surgeon

Given the tensions and demands of medicine, highly successful physicians and surgeons rarely achieve equal success as prose writers. It is truly extraordinary that a major, international pioneer in the controversial field of transplant surgery should have written a spellbinding, and heart-wrenching, autobiography.

Thomas Starzl grew up in LeMars, Iowa, the son of a newspaper publisher and a nurse. His father also wrote science fiction and was acquainted with the writer Ray Bradbury. Starzl left the family business to enter Northwestern University Medical School where he earned both and M.D. and a PhD. While he was a student, and later during his surgical internship at the Johns Hopkins Hospital, he began the series of animal experiments that led eventually to the world's first transplantation of the human liver in 1963.

Throughout his career, first at the University of Colorado and then at the University of Pittsburgh, he has aroused both worldwide admiration and controversy. His technical innovations and medical genius have revolutionized the field, but Starzl has not hesitated to address the moral and ethical issues raised by transplantation. In this book he clearly states his position on many hotly debated issues including brain death, randomized trials for experimental drugs, the costs of transplant operations, and the system for selecting organ recipients from among scores of desperately ill patients.

There are many heroes in the story of transplantation, and many "puzzle people," the patients who, as one journalist suggested, might one day be made entirely of various transplanted parts. They are old and young, obscure and world famous. Some have been taken into the hearts of America, like Stormie Jones, the brave and beautiful child from Texas. Every patient who receives someone else's organ - and Starzl remembers each one - is a puzzle. "It was not just the acquisition of a new part," he writes. "The rest of the body had to change in many ways before the gift could be accepted. It was necessary for the mind to see the world in a different way." The surgeons and physicians who pioneered transplantation were also changed: they too became puzzle people. "Some were corroded or destroyed by the experience, some were sublimated, and none remained the same."

Can fasting slow the progression of the genetic form of kidney disease, ADPKD?

The University of Colorado – Anschutz Medical Campus trial considers the feasibility of using a time-restricted diet as a possible way better manage autosomal dominant polycystic kidney disease, which causes silent and often serious damage to many.

By: Tyler Smith

June 11, 2021

About a decade ago, Debbie Kaschik checked into the hospital for an appendectomy. Not a pleasant experience, but she got rid of the problem and recovered without incident. Kaschik discovered, however, that she had another health issue – one that she and millions of others face.

A CT scan prior to the appendectomy revealed cysts in her kidneys. Her family physician immediately referred her to a nephrologist (kidney specialist) for tests. The diagnosis: autosomal dominant polycystic kidney disease (ADPKD). It's a genetic condition, passed on by just one parent, that produces fluid-filled sacs in the kidney. Over time, the sacs, or cysts, occupy more space in the kidneys, enlarging and weakening them. The stress can lead to a host of health problems, including kidney failure.

Trial participant Debbie Kaschik discovered her ADPKD after a routine appendectomy and entered into trials to help find ways to slow ADPKD progression. Photo courtesy of Debbie Kaschik.

This was all a surprise to Kaschik, now 56, who owns a group of suburban Houston preschools and a clinic for children with autism. She had not felt any symptoms but immediately contacted her family to alert them to the need for genetic testing. It turned out her mother and brother have ADPKD. All three are managing their disease successfully, although her mother, now 80, needed a kidney transplant seven years ago.

That bad appendix turned out to be a good friend.

"We were all asymptomatic," she said. "None of us would have known had I not had the appendectomy."

A "fast" track study to slow ADPKD progression

Since her diagnosis, Kaschik has participated in several clinical trials centered on ADPKD, all of them at the University of Colorado – Anschutz Medical Campus. The latest is a small, randomized one-year study of using time-restricted feeding – cutting down the number of hours that people eat each day – as a possible way to slow the progression of ADPKD in overweight and obese individuals.

It's led by Dr. Kristen Nowak, associate professor of Medicine in the Division of Renal Diseases and Hypertension at the University of Colorado School of Medicine. Nowak's research focuses on how the body's own metabolism may help to slow or promote the progression of ADPKD.

All study participants receive information and advice on healthy eating habits, including group sessions led by registered dietitians with the Anschutz Health and Wellness Center. The study group, in which Kaschik is enrolled, also follows a fasting regimen that restricts their eating to one eight-hour window each day.

Participants can eat whatever they want in that window, but they document all their intake during seven-day periods with time-stamped photos of their meal items, said Cortney Steele, a postdoctoral fellow who is working on the project under Nowak's mentorship.

Diet as possible cyst growth deterrence

The study's primary outcome measure is simply whether enrollees stick to the eight-hour eating window regimen, Nowak said. But beyond that, the study is part of a growing body of research examining the role of overweight, obesity and abdominal fat in the progression of ADPKD – and conversely whether modifications in diet and lifestyle might slow it.

Dr. Kristen Nowak leads a new study of using time-restricted feeding to possibly slow the progression of ADPKD. Photo by UCHealth.

"Big picture, we are looking at whether time-restricted feeding is a feasible dietary approach," Nowak said. If it is, the pilot study could lead to a much larger trial that probes the biology of ADPKD.

The work began several years ago with rodent studies that suggested cell-signaling in normal-weight animals is linked to the growth of kidney cysts – and that diet restrictions, such as fasting or calorie restriction, could put the brakes on it by changing the signals the body receives.

Nowak co-authored a 2018 article that analyzed data from some 400 patients enrolled in the HALT Progression of Polycystic Kidney Disease study. That trial examined ways of controlling blood pressure in patients with ADPKD; Nowak and her colleagues concluded from their analysis that "overweight and, particularly, obesity are strongly and independently associated with the rate of progression in early-stage ADPKD." She added that MRIs analyzed thus far from a small number of the HALT trial enrollees suggest that abdominal fat is another strong predictor of cyst growth. The suspected metabolic link: cyst-growth signaling from the cells (adipocytes) that store the fat.

Combatting ADPKD's financial and human cost

Beyond her own scientific curiosity, many factors spur Nowak's work with ADPKD. It affects some 10 million people worldwide and is a lifelong disease with only one FDA-approved treatment available only to those whose condition is rapidly deteriorating, Nowak said. It is a leading cause of kidney failure, leaving dialysis or transplant as the only treatment options. By one estimate, ADPKD imposes direct and indirect costs of $7.3 billion a year in the United States alone.

Given all that, it's not surprising that many ADPKD patients and their caregivers are interested in a "dietary approach" to managing the disease, Nowak said. That's clearly reflected on the website of the PKD Foundation – the funder of Nowak's current trial – which features dozens of entries on diet and nutrition.

For Debbie Kaschik, the decision to enroll in Nowak's current trial wasn't difficult. She was also an enrollee in the HALT study and several others, including Nowak's previous trial, which looked at daily caloric restriction and intermittent fasting to slow cyst growth in ADPKD patients. That one has finished, with results to be published soon, Nowak said.

Kaschik's most important reasons for getting involved in the studies are close to home: her 19-year-old son, who has a 50-50 chance of getting ADPKD, and her brother's three children. None of them has had genetic testing yet, but Kaschik wants to improve their chances of good health if they have the disease.

"I want [researchers] to find out anything and all they can in the event that as these kids get older, maybe they could find a cure," she said. "If they learn anything from me volunteering, that's awesome."

Plenty of support for trial participants

As for the logistics of the trial, Kaschik acknowledged that she was concerned at first about the long hours of fasting, but found that she quickly adjusted to the study routine.

Participants must eat their first meal of the day within three hours of getting up. Kaschik said she eats as late as possible within that three-hour window. That's typically around 11 a.m. She's free to eat what she wants for eight hours, then shuts things down until the next day, aside from water and no-calorie drinks. (She said she drinks a lot of tea, but a nice recent find was a calorie-free creamer for her coffee.)

Kaschik said she's also found it easy to comply with other study requirements. She carries her cellphone to the table to take before-and-after photos of her food plates and drink containers, along with notecards she sets

beside them for size comparisons. She also regularly sends the study team her weight with a wireless scale, and provides her blood pressure readings, along with blood samples drawn at local providers.

For the first month, Kaschik met weekly with her registered dietitian, Kristen Bing, and two other study enrollees via Zoom. The meetings are now monthly. The discussions follow a curriculum focused on topics like managing food portions, identifying "triggers" for food cravings and finding ways to eat a healthy diet. Kaschik said she also values trading experiences and ideas with her fellow study participants, both at the meetings and through period email exchanges. She recently sent the group a photo of her calorie-free creamer discovery.

"That's been helpful because we're all in the same boat," she said. "You have a team."

Taking control over ADPKD progression

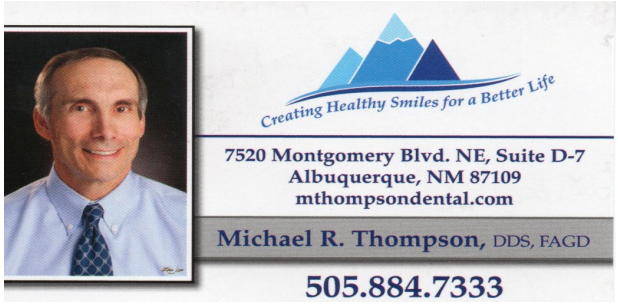
The study regimen could help her lose weight, but Kaschik said her main concern – beyond helping to advance knowledge about ADPKD and protect her family – is to find ways to keep her kidneys as healthy as possible. The study bolsters what she already does, including managing her blood pressure and seeing her nephrologist every six months to monitor her kidney function.

"I don't do anything without his permission," she added. "He is always aware of what I am taking and putting in my body."

Nowak said she hopes her research helps to highlight "the importance of examining diet and ADPKD and the strain it puts on the health care system and society." Regardless of the outcomes, people with ADPKD can use diet to take a stronger role in their own care.

"It is attractive for many patients to look at lifestyle and meals as a way to slow the time to dialysis," Nowak said. "At the very least there is a general health benefit."

For more information about the study, contact Diana George, 303-724-1684.



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OTAP Mission Statement

The mission of Organ Transplant Awareness Program is to promote organ donation and support transplant community members including transplant candidates, donor families, living organ donors, transplant recipients, and transplant families. We promote organ donation by participating in a variety of community events. Our support group meets once a month for those who need support or are seeking information about the transplant process.