
LAW AND ORDER

A career that's spawned 50 years negotiating for some of the biggest names has been accompanied by a passion project for one of the biggest medical issues.

Though he is a top-rated entertainment lawyer who has worked in law for 56 years, Kenneth Kleinberg is also involved in the health sector. And not in a small way: He is the president of the University Kidney Research Organization, which is supporting and fundraising for the world's first synthetic kidney.

In an exclusive interview with *Lifestyles Magazine/Meaningful Influence*, Kleinberg shares his journey from being a kidney disease patient to raising awareness about the lack of funds and research in the area, working with experts in the field, and helping thousands of Americans struggling with the same illness. For more information, please visit ukrocharity.org.

AS TOLD TO
Luke Coulter



LIFESTYLES MAGAZINE: Why was kidney research an area that was so poorly funded back when you were diagnosed?

KENNETH KLEINBERG: In 1998, I was working as an entertainment lawyer when my body started filling up with fluid. My kidneys were both failing and I was directed to see Dr. Vito Campese, the department head for nephrology at Keck Medical Center of USC. I was hospitalized with 30 pounds of fluid threatening my body.

Dr. Campese diagnosed my condition as FSGS, a glomerular disease with unknown cause and cure. They got it under control with medication for a brief time, but, ultimately, I needed dialysis. Six years later, I was grateful to receive a successful kidney transplant.

Dr. Campese said that the prevalence of kidney disease at this time was not clearly understood. Research in kidney disease has never received the glamour other diseases have. A lot of government money was, and still is, allocated to paying for dialysis treatments for millions of Americans. Unlike AIDS, cancer, and diabetes, kidney disease was not getting attention from the private and public sector. The kidney is a very complex organ that comprises multiple cells with a complicated filtration system that cleans the blood, produces urine, and controls blood pressure—the medical community has long had trouble understanding how it functions.

In 2002, Dr. Campese and I decided to create a nonprofit organization called the University Kidney Research Organization (UKRO) to raise funds for kidney research. We created a board of directors and began to collaborate with USC and together, we opened the USC/UKRO Kidney Research Center.

LM: Did you have any interest in health-related endeavors before you established UKRO? What about before you were diagnosed?

PHOTO BY KEN WEINGART

KK: Yes. My wife Helen's mother contracted ocular melanoma, an aggressive and rare form of eye cancer. Her father established a nonprofit organization at USC called the Lucy and Berle Adams Foundation to fund research for ocular melanoma. We helped her parents set up the foundation and raise money—thus beginning what would become a long-term relationship with medical and science experts at USC. The research is still ongoing.

As a lawyer, one of our firm's clients was Paul Newman. His son, Scott, died of a drug overdose in 1978. After I suggested it to the family, I helped them create the Scott Newman Foundation at USC to educate the public, especially children and teens, about dangers associated with substance abuse. A prize was awarded annually to a student who produced or directed a film or television program that most effectively heightened awareness for drug abuse and addiction.

Both of these experiences exposed me to USC's health programs, medical experts, and the opportunity to understand how the collaboration of the private and public sector has the ability to make enormous strides in health advancement.

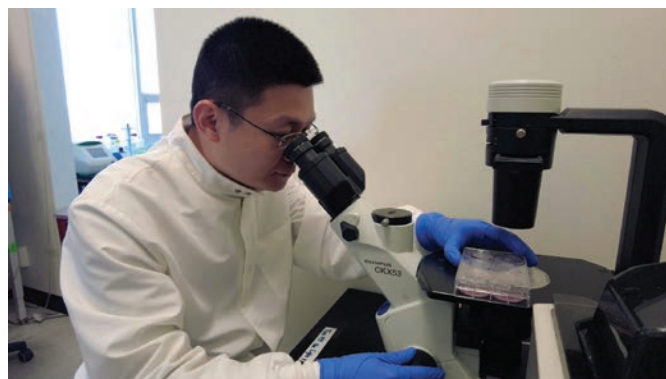
LM: How did you convince people to take your mission seriously when you wanted to advance kidney research? How has your experience as a lawyer aided you in your healthcare mission?

KK: Having some degree of familiarity with facts and problem solving is a skill set that has proven to be beneficial. Being presented with a problem and finding a solution was not a difficult leap. Kidney disease affects 37 million adult Americans and millions worldwide. There was limited money available for kidney research. I knew I had to do something to make research a priority in the medical community and figure out how to heighten the public's attention in a competitive and crowded marketplace consisting of many worthy causes.

As an entertainment attorney, I am accustomed to complex projects and overseeing their development. At times, this involved raising money to facilitate the project and often it involves collaboration, risk taking, and perseverance. The process is

dependent upon the ability to identify and engage multiple players with multiple skill sets.

The effort to achieve a synthetic kidney was only possible due to the involvement of USC, the expertise of Drs. Andy McMahon and Zhongwei Li, and all the medical talent at USC. UKRO has also benefited from the ongoing guidance and counsel of its co-founder Dr. Campese and the members of the UKRO board of directors, a number of whom are medical or business professionals and some of whom are personally impacted by kidney disease.



LM: What was the most challenging part of starting UKRO? What are some challenges you face today?

Dr. Zhongwei Li,
Keck School of
Medicine at USC

KK: Dr. Campese and I are both optimists. We saw few challenges because we were both determined. We have been fortunate to have compiled a strong board of directors for UKRO—many of them have been supporting this work with their time, their money, and their relationships for many years. Fundraising over a period of time is harder than we thought. Personal and professional relationships play an integral role, but raising money is an arduous endeavor. You can design a great campaign or event and have few

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Carol L. Folt, Dr. Vito
Campese, Kleinberg,
and Philip Palmer at the
UKRO 2022 Gala

people participate or attend. Maintaining relationships is a time-consuming process that requires dedication and perseverance. We're constantly working to identify the best people to approach for money and having a thoughtful strategy in place for how to cultivate and grow relationships with donors. There are so many organizations doing incredible work. We are always looking for innovative ways for people, including donors, to understand kidney disease and that it is a serious problem in our country.

There are a variety of ways in which kidneys can fail. Our early debate was whether to focus on a single form of kidney disease or to support a broad-based body of research. Now that the scientists are so close to perfecting a synthetic kidney, the UKRO board voted to put all of our energy and support into raising funds to support Dr. Zhongwei Li and his team. Today's challenge is to bring awareness to the need and to raise the necessary dollars to perfect the synthetic kidney and make it available to all whose lives can be improved or saved.

LM: What are some current projects UKRO is working on? What stage of testing is the Synthetic Kidney Project currently in?

KK: UKRO's mission is fundraising to support the synthetic kidney research. A massive medical breakthrough like the synthetic kidney requires both private and public dollars. We have the



unique opportunity to change the course of medical history and alleviate the terrible suffering of millions of adults and children. The methods and techniques used to create the synthetic kidney could also impact how we treat people with other life-threatening diseases, such as those in need of heart or liver transplants.

Dr. McMahon, the head of the Eli and Edythe Broad CIRM Center for Regenerative Medicine and Stem Cell Research at UCSF, believes that Dr. Li and his team are perfecting a synthetic kidney. The next step is to improve on it by incorporating more cell types into the current structure and to engineer those kidney-like structures. They have so far succeeded in producing urine in mice. This requires some additional approaches to the strategies being used. When these kidney-like structures are functioning, the short-term project would be to be able to transplant these synthetic kidneys into a patient to boost their failing kidneys and prevent the necessity of dialysis. The long-term goal is to have a fully functioning synthetic kidney that could replace failing kidneys and thus provide quality and a longer life for patients. The USC team is the only one that can produce high-quality kidney stem/progenitor cells in large scale quickly and cost-effectively, greatly accelerating their work toward rebuilding a kidney from these building blocks. Increased funding can greatly increase the timeline. The hope is to see this perfected within 10 years.

LM: How has kidney research gained more recognition since UKRO's founding?

KK: The success of transplantation, especially of kidneys, has generated more discussion and much more focus. In addition, there has been greater recognition of quality-of-life issues for patients on dialysis and the cost to the federal government of supporting dialysis.

Owing to recent scientific discoveries, some of which have received Nobel Prizes in medicine, there are new possibilities for further research. The problem remains that the high cost of research causes time to pass and delays possible breakthroughs. While the numbers of people affected by kidney disease, including those on dialysis, have increased substantially, our collaboration with USC has enabled us to make enormous strides in research and heightening awareness since establishing UKRO 21 years ago. There are currently only 20,000 kidneys available for transplant in the U.S., with at least 100,000 waiting on the transplant list annually. What's more staggering is that while 37 million Americans have some form of kidney disease, millions more have it and do not even know it. These numbers are challenging, but it motivates me and validates that the work we're doing matters.

I would encourage anyone affected by kidney disease to ask their nephrologists about the latest developments and treatments available to them, and to look out for updates on the creation of the synthetic kidney.

LM: What continues to drive your passion for this cause? What do you hope your legacy will be?

KK: I always wanted to know the cause of my illness. There are an increasing number of people worldwide suffering from kidney disease and our current treatments are inadequate and expensive. Dr. Campese says we need great improvement in quality of life and length of life for our patients. He and Dr. McMahon both believe that the kidney is not understood by the general population even though in America, one out

of seven adults has some form of the disease.

The prospect of having a transplantable synthetic kidney is a spectacular medical advancement. In the short run, I look forward to utilizing synthetic kidneys to replace dialysis for patients. There is also the likelihood that structures of the synthetic kidney can be used for the testing of new drugs. Ultimately, there is the hope that a fully functioning synthetic kidney could replace a native kidney and thereby replace the need for some transplants. To make this all possible, we need public and private institutions to join in providing financing and support that could bring this medical advancement equally to all the people who need it. We must not miss this great opportunity. This must be something we do now, not in the distant future.

LM: What are your goals for future collaborations with philanthropists in the health and science sector?

KK: We need to energize the public, philanthropists, venture capitalists, and pharmaceutical companies to help make this a reality for people around the world. I'd like to meet with Bill Gates and Melinda French Gates and the representatives of their foundation. The need to fund kidney disease aligns with their mission to support medical care to populations that are underserved. There are people in our country who are in need of access to proper health care. It would be an extraordinary achievement to have the Bill & Melinda Gates Foundation support our efforts. **LM**