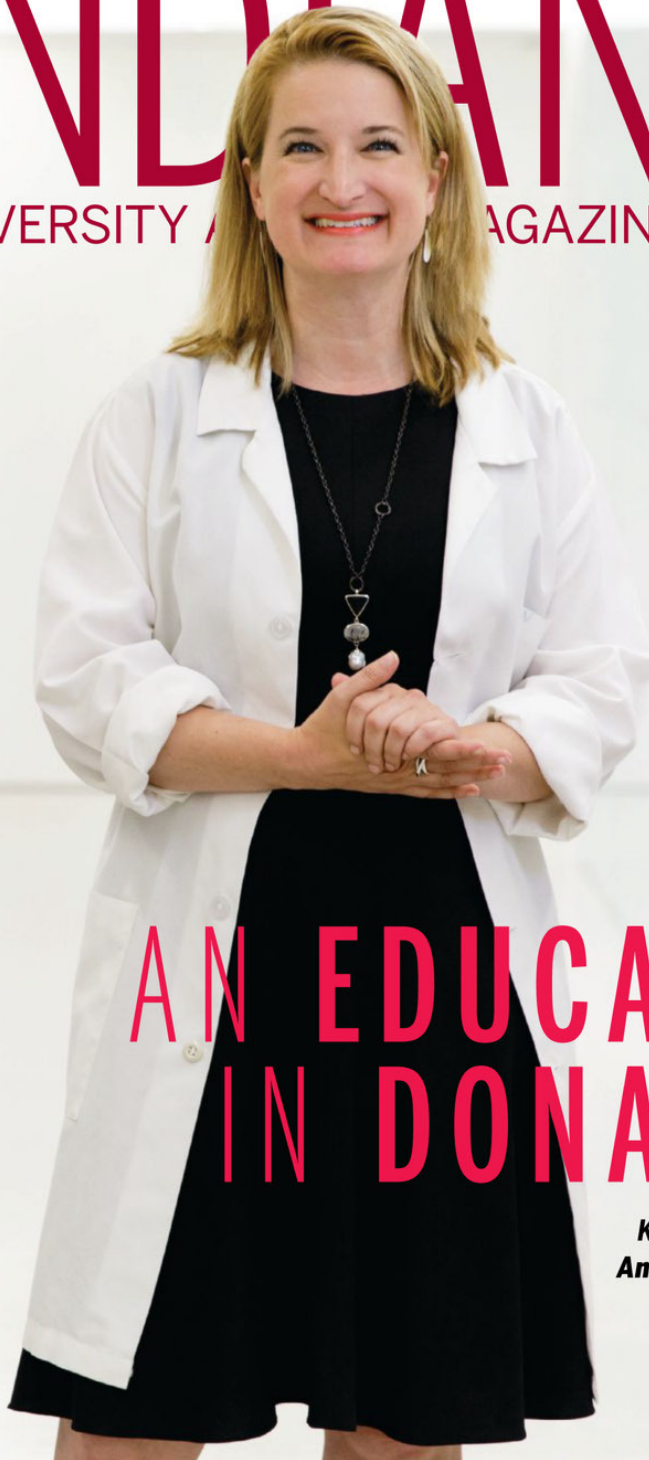




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AN EDUCATION IN DONATION

*Kidney Donor Advocate
Amy Waterman's Path to
National Prominence*

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Amy Waterman at the Terasaki Research Institute, where she oversees the Transplant Research and Education Center.



THE RISK AND REWARD OF THE UNKNOWN

Today, Amy Waterman is thriving as a national player in the kidney-donation world. But six years ago, that outcome was anything but certain. She had taken a chance that quickly dropped a huge hurdle in her path. She struggled, thinking she had ruined her life. Ultimately, though, Waterman found a mindset that pointed her in the right direction.

BY **DAWN REISS**

PHOTOS BY **CORAL VON ZUMWALT**

Amy Doggette Waterman, BA'92, knows what it is like to be consumed by uncertainty.

"It was a sad and lonely time," she says. It came suddenly, about six years ago, soon after Waterman—who has since become nationally known for her work to support living kidney donation—arrived in California.

Prior to the move, she was on faculty at Washington University in St. Louis, where she had established herself as someone on the rise in the field. Her accomplishments up to then included creating and leading Explore Transplant, a not-for-profit consortium of transplant and health experts that educates patients and living donors about kidney transplant options.

Her work caught the attention of UCLA, and the university offered her an opportunity to help start and direct its Transplant Research and Education Center. The move would give her a chance to secure more funding and conduct more research, though her professorship would be without tenure. Another benefit was on the personal side: Her fiancé at the time lived in California.

"It was a chance for a fresh start and to take a big chance," Waterman says.

But soon after her arrival on the West Coast, the relationship ended and a million dollars in promised grant funding for her research lab wasn't delivered.

"I came expecting marriage and for my financial situation to be solid," she says. "None of it worked out."

Alone in a new state, without a partner or a network of friends and family—and with a tenuous professional situation—Waterman says she went into a tailspin.

"I thought I had ruined my life," she says.

Unsure of what her future held—feeling like she was "at the beginning again"—she struggled for about a year. Outside of work, she stayed at home in her apartment, too overwhelmed to drive around the unfamiliar city.

Then something happened: Waterman told herself that it was OK to feel the way she did, recognizing that she was facing a sudden major change and failure. She acknowledged her fear and how she honestly felt.

Waterman likens it to being in a Los Angeles traffic jam, where you're tired and can't stop driving, and you



wish you were home. Acknowledging and honoring how you feel, she says, even when you can't change the situation, helps to release your emotions.

"A lot of times, we resist fear because it feels so uncomfortable," she says. "It's not about the fear going away. It's about making friends with it."

Accepting the Challenge

That change in mindset helped Waterman shift her perspective. She reminded herself that she moved to California because she wanted more of a challenge, to grow as a person and leader. She just "needed to keep growing toward that," she says.



Describing her mindset, Waterman says: "I'm just a Curious George kind of person. I will always [choose] the unknown because I'm always like, 'What else can life show us? What other kinds of adventures are out there?'"

She grieved the end of her relationship and worked through the financial pressures of starting a new interdisciplinary research lab and education center.

To bolster her self-care, Waterman got massages and found a light-filled, two-bedroom apartment that became her sanctuary. Recognizing that she needed to thrive on her own as well as build a social network, she started doing meet-ups at art museums, which connected her to a variety of quirky people from L.A. She recalls an 83-year-old woman who, Waterman says, was "up for anything." Waterman started dating again.

"It was wonderful to be out engaging and living," Waterman says. "It's all part of living a life of adventure. That's the gift of getting through failure."

She adds: "In those moments of uncertainty or loss, you grieve and freak out. But then you've got to go fight the good fight."

Solving the Shortage

In 2016, during a speech at the White House Organ Summit, Amy Waterman addressed the organ shortage plaguing the national health care system. She emphasized the need for effective and accessible donor education.

"Research shows that patients who receive better transplant education and living donor education are more likely to become wait-listed and receive transplants," she said, adding that knowledge saves lives when the clock is ticking.

BY THE NUMBERS

1-2 — Approximate number of days a living donor spends in the hospital after surgery.

Fact: The average total recovery time for a kidney donor is four weeks.

15 — The percentage of Americans living with some form of kidney disease.

18 — The age you must be to donate a kidney.

Fact: Donors do not have to be the same race, age, blood type, or sex as the recipient of the kidney.

1954 — The year a medical team performed the first successful living donor kidney transplant.

5,000 — Number of people who donated kidneys in 2018 through deceased donation.

6,000 — The approximate number of annual living kidney organ donors. *Fact: Over time, the donor's remaining kidney grows bigger to do the work of both kidneys.*

100,000 — Number of patients on the kidney transplant waitlist.

25,000,000 — Number of Americans with a chronic kidney disease who are at risk for kidney failure.

Source: *Explore Living Donation*

Waterman, on this page and the next, interacts with colleagues at the Terasaki Research Institute.





Finding Her Calling

Waterman's trajectory toward finding her life's passion—a career focused on patients' decision-making and behavioral change—came into focus while at graduate school at Washington University. She began working with a hospital psychologist who was studying whether living kidney donors regretted their decisions.

"I was just trying to get enough money to live," says Waterman, who was attempting to make ends meet with a \$10,000 annual stipend.

The job earned her the needed money, but, more importantly, it set her on a path that would give her career a particular purpose.

As part of the job, Waterman called kidney donors. To her surprise, she heard stories about how donating a kidney transformed the donors as much as the recipients. Many, she says, talked about how inspired and joyful they felt when they saw their recipients returning to health.

"One woman said she became a poet because she now got what life was about," Waterman says. "And, I was like, 'Who are you? What do you know? What did this teach you?'"

Waterman became curious about what prompted people to donate a kidney, and she also investigated how the donation process could be improved.

What she repeatedly heard was that, although many kidney donors donated for altruistic reasons, there was a lack of information about the process and a need for better education. Many living

donors were afraid to discuss their medical questions and concerns because they didn't want their doctors to think they would change their minds about wanting to donate, Waterman says.

With the demand for kidney donors far outweighing the supply—more than 100,000 people are currently on the kidney transplant waitlist, and only approximately 6,000 people become living donors annually—Waterman wanted to do something.

Better education, Waterman hypothesized, would increase the number of living kidney donors. And that increase, among other benefits, would help patients on dialysis live longer.

Waterman, still in graduate school, created an educational brochure that addressed common questions for living kidney donors, and she studied how to improve the educational system for patients, donors, and health care professionals. She began researching and testing ideas that aimed to make education more effective and to inspire patients and donors to pursue living kidney donation.

It has become her life's work.

Breaking Away

Waterman spent her very early years in Bloomington, Ind., where she was born while her father, John Doggette, EdD'73, was working on a doctoral degree. She grew up in Knoxville, Tenn., but when it came time for college, she headed back to Bloomington.

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“I like to say the South taught me to be really kind and have [a sense of] community, the Midwest taught me to be humble and work hard, and the West Coast taught me to be really visionary and entrepreneurial. And I’ve been able to put them together.”

...



“Going to Indiana launched me into traveling and living in lots of different places,” Waterman says.

During her time on campus, Waterman enjoyed going to soccer games—a sport she played in her youth—taking art classes, seeing free movies at the Indiana Memorial Union, and working at an educational center to help pay for school.

Every Saturday during her sophomore year, she recalls, she would go to the Herman B Wells Library from 9 a.m. to 4 p.m. Part of her routine was eating pizza from the food court in the basement.

“And I’d then go up three floors and sit in the beautifully lit rooms of the library, and I’d do one area of my homework at a time,” she says. “It was one of the semesters I made straight A’s. I credit the pepperoni pizza plus the library for doing that.”

Waterman, who was in the Hutton Honors College, earned her degree in three years. She spent her first two in Bloomington before attending the University of Kent at Canterbury, through IU’s study-abroad program.

“I was actually sad to leave Bloomington,” she says. “I made friends at IU and wanted to stay. But everyone told me, if you

have a chance to study abroad for a year, do it, because your life won’t always allow you to.”

Hopping on the train to experience a new country and culture quickly expanded Waterman’s perspective. Sigmund Freud’s home in Vienna, she says, inspired her future studies.

“[That year] helped me see my passion for social psychology,” says Waterman, who visited Paris and Santorini, Greece, among other places. “Every weekend, the people who came from IU and other [universities] would just get backpacks and go somewhere.”

High-Profile Moments

Two decades after IU and six years after her move to California, Waterman is now a professor of nephrology at UCLA, the director of the Transplant Research and Education Center at UCLA, and deputy director of the Terasaki Research Institute. Her research has been supported by more than \$28 million in federal grants, and she continues to direct the Explore Transplant consortium.



She credits time spent living in different parts of the country —Knoxville, Bloomington, St. Louis, LA—for an approach that is tailor-made for her work.

Waterman likes to say, “The South taught me to be really kind and have [a sense of] community, the Midwest taught me to be humble and work hard, and the West Coast taught me to be really visionary and entrepreneurial. And I’ve been able to put them together.”

One of her current projects is to recruit people—donors, recipients, those on the transplant waitlist—to share their stories via cell-phone videos for the Living Donation Storytelling Project. The library (housed at explorelivingdonation.org) aims to help people better understand the experience of living donor kidney transplant.

“You can go and listen, or [you can] add your own story,” Waterman says. “It will be an ever-evolving library. My hope is, regardless of whether you donate or not, these stories inspire you in some way.”

Efforts like these have led to at least a couple of high-profile moments.

In 2018, *The M Dash* (a digital magazine produced by fashion startup M.M.LaFleur) asked Waterman to talk about her career path and accomplishments and to model designer clothing.

“A woman in her 40s does not do a photo shoot for a New York magazine,” she says. “Not a researcher. I’m an intelligent and lovely person, but I’m not a supermodel.”

“They did my hair and makeup and put me in these clothes that are fun,” she says. “They made me walk back and forth at the light with everyone just walking around Times Square with the busyness of the city. I’m grinning like a crazy person, because I’m so alive and vibrant. I did Carrie Bradshaw [of *Sex and the City*] proud.”

And back in 2016, the administration of President Barack Obama reached out to her for its White House Organ Summit. The administration was looking for health causes to highlight before the end of Obama’s second term. The summit included discussions as far ranging as 3D-printed kidneys and whether donated pig kidneys might work in humans.

Initially, Waterman just hoped to get an invitation to attend. “I got a call from an ‘unknown caller,’” she says. “You get those all the time with someone trying to sell insurance, and then I hear, ‘It’s so-and-so from the White House,’ asking me if I wanted to go to the summit.”

A second call asked her if she wanted to speak for two minutes at the event. The topic would be the launch of the Kidney Transplant Learning Center, an online resource developed by the United Network of Organ Sharing, a health-information provider.

A subsequent call informed Waterman that her role was expanding once again. She was asked to write a five-minute speech and record it into her phone so it could be vetted by the White House.

“I’m sitting in my pajamas in my bedroom, writing out my speech about how every American deserves the right to have equal access to the best quality health care,” she says. “I’m sure writers who have worked at the White House do this all the time, but it feels surreal.”

In less than 24 hours, she recorded her speech and sent it in.

“They say you’re in, show up here, and buy a dress,” she says. “So, I run to a clothing place I know and say, ‘What would Michelle Obama wear? I have to go to the White House.’ Everyone starts pulling dresses for me.”

Ultimately, Waterman was one of just a few experts to address the audience on that day at the White House. She connects that success with her early struggles in California.

“Getting broken up with and losing [research] money was a training ground, so when I was asked to go to the White House, I could be a ‘Yes’ about it,” she says.

So, all things considered, would she make the same decision to leave the familiar and take a chance like she did six years ago? She compares these types of decisions to being on a television game show. You’re offered two doors: One is open, with a prize you can see; the other is closed, a mystery.

“I would always pick the closed one,” Waterman says. “I’m just a Curious George kind of person. I will always take the unknown because I’m always like, ‘What else can life show us? What other kinds of adventures are out there?’” ■

Dawn Reiss, BA’00, is a Chicago-based journalist who has written for The New York Times, The Atlantic, and Time.com, among others.