

Leading by Example: How a Health Care Provider's Actions Can Impact the Public's Perspectives

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The man from Clintonville, Wisconsin, and the man from Tehran, Iran, were like brothers.”¹

The story of Arjang “Aji” Djamali, MD, caught the attention of multiple national media outlets, from *People* magazine to *ABC News*. Dr Djamali became a “brother” to John—one of his patients suffering from kidney disease—when he donated one of his own kidneys to John at the University of Wisconsin in July 2022. As rates of living donor donations steadily decline, Dr Djamali—a transplant nephrologist—led by example, showing that a healthy and fulfilling life is not lost after donating an organ. What’s more, he extended the gift of life to another individual. For many suffering from chronic kidney disease (CKD) waiting for a transplant, Dr Djamali’s story offers hope.

More than 800 million people globally (approximately 10%) are living with CKD.² It has become a leading cause of mortality worldwide—especially given the rising prevalence of associated risk factors, such as dia-

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betes and hypertension.² Patients with CKD eventually develop end-stage kidney disease (ESKD) and require dialysis. Although lifesaving, dialysis has many consequences on quality of life. Patients often spend 9 to 15 hours a week in dialysis centers, leaving many feeling drained or depressed afterward.³ Further, dialysis is very costly, being the major con-

worldwide to change the attitudes and perceptions of organ donation. Donors can opt to undergo living donation or donate after death. Although both types of donations are valuable, recipients of live-kidney donors tend to have better outcomes, such as higher graft survival and lower risk of delayed graft function.^{6,7} Unsurprisingly, there are fewer living

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tributor to the cost of ESKD management, which accounted for roughly 5% (\$37.3 billion) of total Medicare expenditures in 2019.⁴ A kidney transplant remains the best treatment modality for patients with ESKD. It is associated with increased lifespan, higher quality of life, and decreased expenditures compared to dialysis.³ However, a transplant is not an option for many, as the demand for kidneys far exceeds the supply. For instance, in 2021, at least 90,000 people in the United States were on the waitlist for a kidney transplant, but only about 24,000 kidney transplants were performed.⁵ And while 24,000 represents a new milestone in the number of kidney transplants performed each year, many patients are still left without a new kidney.

To increase the number of registered organ donors, there have been myriad efforts

donor kidney transplants performed versus the deceased donor. What’s more striking, however, is that since 2004, the number of live donations has decreased steadily compared to increasing rates of deceased donor transplants—at least within the U.S.^{8,9} This begs the question as to why. Plenty of research has been conducted to examine and understand the attitudes and behaviors of individuals toward organ donation.

In Canada, it was demonstrated that physicians are more likely to support organ donation than the general public.¹⁰ Among health care workers specifically, physicians and nurses were the most likely to support and be registered as organ donors.¹¹ However, the percentage of registered organ donors is much lower than the percentage of those who support donation, among both health care

workers and the public.^{10,12,13} Multiple studies correlate negative beliefs or lack of education on the safety of organ donation—specifically, that a donor’s body may be disfigured during donation or fear of organs being sold on the black market^{13,14}—with lower rates of being willing to register as a donor.¹³⁻¹⁵ Some worry about the health risks associated with the donation as a barrier to the willingness to donate.¹⁶ Many cite fixed religious and/or cultural beliefs for unwillingness to register for organ donation.^{13,14} It also has been demonstrated that relationships between donor and recipient play a role in willingness to donate. For instance, nephrologists surveyed in the US were much less likely to support a living donation from themselves or close relatives if the recipient was a stranger versus a relative.¹⁷ The common threads among these studies include an incongruence between support of organ donation versus registering to donate, health care workers having higher support of organ donation than the general public, and beliefs/education on donation affecting willingness to donate.

Of the factors serving as barriers to a living donation, it would be most feasible to target the lack of education and negative attitudes against organ donation. One way to target both lies within storytelling. Again, Dr Djamali’s story highlights the possibility of being able to live a healthy life after donating, in addition to having exponentially improved the quality of life of another human being. This is important because, as described before, many individuals cite worries around health risks, regulations, and practices as barriers to their willingness to donate organs. With the existence of a considerable level of distrust towards physicians from the general public,¹⁸ examples of physicians undergoing procedures they promote may allow a shift in public attitudes—a shift that can hopefully stop the downward trend in the amount of living organ donor transplants performed each year. With physicians being more likely to register for organ donation than the general population,¹⁰ there are possibly additional powerful stories of altruism like Dr Djamali’s.

Another consideration regarding Dr Djamali’s story is that he was a “great match” for his recipient. However, being a great match for a recipient is not a necessity. There are now

increasingly popular exchange/swap programs that serve as a workaround for the scenario of a donor-recipient mismatch. The donor donates a kidney and their desired recipient receives the kidney of another, more closely matched, donor. To donate a kidney, one must simply be willing, healthy, and motivated. With more stories that showcase doctors “walking the walk,” there is a potential to sway the public attitudes and opinions of those opposed to organ donation. And this change in perceptions and attitudes is necessary for many awaiting a kidney transplant.

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