

The American Living Organ Donor Fund: Removing Financial Barriers to Benevolent Actions

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INTRODUCTION

An online fundraising campaign brought in three hundred dollars. Friends from church pooled just a bit more than that for the cause. But the total was not enough to cover six weeks of 46 year-old Stephanie Washington's expenses as she recovered at her sister's home in Hayward, California from kidney donation surgery to help her niece, a gunshot victim. "She knew that God would provide, but I knew that we had to put some plans in place," said Washington's sister, Faye Herald, who didn't anticipate the obstacles potential donors encounter. Washington ran her own cleaning service, and if she didn't go to work- she wouldn't get paid. She provides for two children, a daughter at Howard University and a 14 year-old son. Money is tight, but she never considered not donating; if she did not, she feared her brother's 24 year-old daughter would soon die. What she didn't know when she first considered donating is what many Americans don't either: while a transplant recipients' health insurance covers the medical expenses of donors, coverage does not include transportation, lodging, childcare or lost wages. The National Organ Transplant Act of 1984 made it illegal to compensate organ donors. Herald thought that some charitable assistance had to be available, and with some research, she discovered the newly established American Living Organ Donor Fund, founded late last year by bioethicist and health care attorney Sigrid Fry-Revere to remove financial disincentives that accompany such a benevolent act.

ANALYSIS

"Why should a living donor who is saving a life by giving part of their body go into debt or use up their savings?" Fry-Revere asked. She received a completed application from Herald on behalf of her sister that included documentation that Washington was self-employed, along with a client list and bank statements. Fry-Revere approved it, and one day after Washington was discharged from a San Francisco hospital following January 6th surgery, she received a check from the fund to cover two months of rent and household bills. "It's such a blessing and relief," Washington said by phone from her sister's home. "I can relax, and that's one of the reasons my recovery is going so good. I don't have to worry."

According to the American Journal of Nephrology, living donors incur an average of five thousand dollars in out-of-pocket expenses. Sometimes, costs total as much as four times that. However, the Census Bureau reports that only eight percent of households can afford such a cost without dipping into savings or going into debt. Twenty percent of American households have no discretionary funds. "This is awesome," Herald said about Fry-Revere's new non-profit, funded initially by a successful Kickstarter campaign. "She is doing a great thing."

Fry-Revere was once a potential donor herself. In 2010, she thought she had plans in place to donate

a kidney to a friend who experienced organ failure as a child due to a bout with strep throat and fever. His mother donated a kidney then; when it failed, he received a cadaveric kidney that lasted two decades. Having two transplants already, chances were nil that he would receive another organ by waiting on the UNOS list. Fry-Revere believed that she was his solution, as she was medically compatible. She planned surgery during the Christmas holidays, so that her husband and college-aged sons could take time away from work and school to help her recover at their ten-acre Northern Virginia farm. What she had not considered was the factor driving her current philanthropy: personal expenses. The University of Michigan Transplant Center coordinator told her that an eight-week recovery plan was required; however, her caregivers could only be home for a month. Unable to tend to daily tasks of property maintenance, she also would need to hire a farmhand. With the expense being unanticipated and unaffordable, she was quickly eliminated from the process. Fry-Revere's friend died one year after her declined offer. "I was dumbfounded," she said. "They would rather let him die than give me time to figure out how to take care of myself."

She has been lobbying Congress to amend the National Organ Transplant Act with more provisions and financial support for living donors. Fry-Revere said she believes funding donors' out-of-pocket costs would save exponentially more money than continuing to cover long-term dialysis and other medical expenses for the thousands of patients awaiting a kidney. The most expensive patients, perhaps, could more easily receive organs from live donors; in turn, they would be removed from the UNOS waiting list. "Here's a real savings opportunity," she said. "This is a win-win solution that saves money and saves lives". In the meantime, her organization has the resources to assist 17 qualifying donors, and Fry-Revere is working to raise more. "There are probably potential donors who would be willing if they knew they would be getting some type of assistance," Washington said.

CONCLUSION

Living donors are desperately needed, as more than 120,000 Americans are listed on the United Network for Organ Sharing (UNOS) waiting list. Those awaiting kidneys number 103,000; these patients are ones that could be helped through living donation. More than one million people have died as a result of end stage renal disease since 1980; Fry-Revere points out that this number is more than the approximate total of 623,000 military deaths in World Wars I and II, Korea, Vietnam, the Persian Gulf, Afghanistan and Iraq combined. "We are small peanuts right now," Fry-Revere laughed. "It's a drop in the bucket, but it helps our morale and helps educate people." It wasn't small peanuts for Stephanie Washington, or for her niece who is recovering well.

For more information on the American Living Organ Donor Fund:
<http://www.helpingdonorssavelives.org/>

For more information about Sigrid Fry-Revere's related work: <http://ethical-solutions.org/>