



# NATIONAL KIDNEY REGISTRY

FACILITATING LIVING DONOR TRANSPLANTS

February 17, 2020

Frank Holloman  
Director, Division of Transplantation  
Healthcare Systems Bureau - Health Resources and Services Administration  
5600 Fishers Lane, Room 08W63 Rockville, MD 20857

RE: HRSA-2019-0001, Removing Financial Disincentives to Living Organ Donation

Dear Mr. Holloman:

As a living kidney donor myself, I applaud the efforts of HRSA to eliminate disincentives related to living kidney donation. We are hopeful that this public comment process will provide useful information that will allow HRSA to change its current plans and better protect living donors from the, often unknown, costs of giving the gift of life.

The National Kidney Registry (NKR) is the largest paired exchange program in the world and facilitates approximately 1,000 kidney transplants per year across nearly 100 transplant centers in the United States. The NKR is also the leading provider of **comprehensive living kidney donor protections** in the United States. Our Donor Shield program, along with our other donor protection programs, protect approximately 25% of all U.S. living kidney donors. In other words, the NKR is already eliminating disincentives to living donation efficiently and on a massive scale. These donor protections go far beyond the lost wage reimbursement program that is being planned by HRSA, and these donor protections are already available to donors at roughly half of all U.S. transplant centers.

Not only are the NKR donor protections helping patients realize life-saving transplants by increasing the number of transplants, and not only is this right thing to do for generous living donors who give the gift of life, but these donor protections have the potential to **save the federal government \$10 billion dollars** over the next decade.

Based on our actual experience eliminating disincentives, we can achieve 100% adoption of the NKR's Donor Shield protections if we have HRSA's full support. A 100% adoption rate will increase living donor transplants in the U.S. by at least 15% which equates to approximately **1,000 additional living donor transplants per year**. Life expectancy on dialysis for a patient that can qualify for a transplant is about 15 years, and dialysis related costs are about \$90,000 per year. The savings for one additional living donor transplant is about \$1.2 million (15 years x \$90K x present value factor) less the cost of the transplant (\$200,000), yields a net savings to our government of \$1 million dollars for each additional living donor transplant. 1,000 additional living donor transplants per year delivers \$1 Billion in savings annually. Over 10 years, our government can save \$10 Billion dollars.

With HRSA's full support, the NKR can provide Donor Shield protections (described below along with other NKR programs that are eliminating important disincentives to living donation) to all donors in the United States by the end of 2020. The cost to achieve the \$10 Billion in savings is approximately \$3,000 per transplant, or an inconsequential \$21 Million per year. **This equates to a return on investment of over 10,000%**. Imagine the enthusiasm of an investor that could get a Billion dollar return on a \$21 Million dollar investment while saving/improving lives.

## **Donor Shield (no income limits for eligibility)**

- Lost Wage Reimbursement: up to 4 weeks and up to \$1,500/week
- Travel & Lodging Reimbursement: up to \$2,000
- Donation Life Insurance: \$500,000 principle amount
- Donation Disability Insurance: \$1,500/ week up to 52 weeks reimbursed
- Legal Support: Unlawful termination & health insurance issues
- Coverage for Uncovered Complications: Post-discharge surgical complications not covered by the recipient's health insurance. Also includes related lost wages and travel/lodging reimbursement.

## **Remote Donation**

To date, 57 of the NKR Member Centers have joined the Remote Donation Network which allows donors to undergo surgery at a center near their home when their intended recipient is at a hospital in a distant city. This dramatically lowers the cost of the donor's travel & lodging and makes the donation process much easier for the donor – they can recover at their home as opposed to recovering in a hotel in a distant city. The same GPS technology used to safely ship living donor kidneys for NKR swaps (over 3,000 without failure) is used to reliably transport the remote donor kidneys to the recipient center.

## **Family Voucher**

The Family Voucher program allows donors to donate to a stranger (start a chain) and provide up to 5 vouchers for family members in the unlikely event that they may need a kidney transplant in the future. I donated my kidney in 2015, starting an 8-deep chain, while providing a voucher for my daughter, who received a kidney transplant in 2007 and is doing well post-transplant. I would not have donated my kidney if not for the family voucher program.

## **Standard Voucher**

The Standard Voucher program allows donors to undergo surgery when it is convenient for them and generate a voucher for their friend or family member that is in imminent need of a transplant. This is especially useful when the donor is the recipient's caretaker or when the donor has an inflexible work schedule (e.g. in the military and has limited leave time, teacher, judge, etc.). This program also allows donors to help more than one person in need of a transplant by starting a chain, while providing a voucher to their intended recipient.

## **Prioritization for LD kidney**

All living donors in the U.S. are prioritized for a deceased donor kidney through the OPTN in the unlikely event they ever need a transplant. All donors that donate in an NKR swap are prioritized for a living donor kidney via the NKR in the unlikely event that they ever need a kidney transplant. Prioritization for a living donor kidney is important to donors because living donor kidney transplants have better outcomes and generally last 2-3 times longer than deceased donor kidney transplants.

## Life Insurance Predatory Pricing

After donating my kidney, I purchased additional life insurance to protect my family. Because I only had one kidney, all the Life Insurance underwriters doubled or tripled my premiums, even though research clearly shows that living donors live longer than the general population. **So donating a kidney will cost me \$160,000 over the next 10 years.** Another colleague at the NKR, who also donated a kidney, cannot even purchase additional life insurance because he is a living donor. This is a significant disincentive to living donation.

Life insurance companies are the direct financial beneficiaries when a living donor steps forward to donate a kidney and removes a patient from dialysis. If the dialysis patient has a life insurance policy, the resulting transplant dramatically reduces the patient's mortality rate, creating a substantial savings for the insurance company. Said differently, the industry that financially benefits from the generosity of living donors, turns right around, and doubles or triples the donor's life insurance premiums.

The NKR is working with other donor organizations to lead an effort to initiate a \$1+ Billion-dollar class action lawsuit on behalf of all living donors who have been abused by the Life Insurance industry. We encourage HRSA to lead the effort to get legislation passed, similar to the 2018 Idaho law that protects living donors in Idaho from the **life insurance industry's disgraceful business practices**. We need HRSA's leadership to help eliminate this critical disincentive for living donation.

## Summary

NKR is already providing comprehensive living donor protections efficiently and on a massive scale. These protections go far beyond the lost wage reimbursement program planned by HRSA, and these NKR protections are already available to donors at roughly half of all transplant centers in the United States. We have recently seen several large transplant centers abandon their interest in Donor Shield because of HRSA's plans for a limited, inferior and untested, lost wage reimbursement program. Donors who show up at one of the 10 HRSA pilot centers will not be systematically informed that they are losing access to donation life insurance, donation disability insurance, legal support, and coverage for uncovered complication. **HRSA's plans are unwittingly hurting living donors** and undermining the principle of informed consent. As a donor myself, I have experienced firsthand many of the disincentives to living donation and have a responsibility help protect future donors. We urge HRSA to partner with the NKR to bring much needed comprehensive donor protection to every living donor in the United States by the end of 2020. In doing so we can do the right thing for donors, increase the number of life-saving transplants and put our government on a path to save \$10 billion dollars over the next decade.

Sincerely,



Garet Hil  
Founder & CEO  
National Kidney Registry  
Living Kidney Donor