

# WAITLIST ZERO

## CASE STATEMENT

For many, kidney failure is a lonely disease. Without a transplant, patients require several days of dialysis treatments each week, which are often painful and so exhausting that only one dialysis patient in five can maintain full-time employment. Complications regularly ensue: after five years of treatment, barely more than a third of the patients who started dialysis will have survived.<sup>1</sup> Medicare guarantees health coverage for kidney failure, but the non-medical costs of living with a debilitating disease are significant enough to tax anyone's support network tremendously.

Kidney transplantation is the preferred treatment – adding years of healthy life – but our society's treatment of donation begs for reform. Despite hundreds of millions spent on deceased donor organ procurement, the average wait for a deceased donor kidney is about four-and-a-half years.<sup>2</sup> Living kidney transplants perform better than deceased ones, but the American health system does not systematically support living donor procurement. Donors bear the costs of their own donations, like lost wages, childcare expenses, and travel, while patients and their families do not receive systematic education or help finding a transplant.

This neglect has made asking for the un-repayable gift of living organ donation into a cruel burden. Here's how one patient, John Mendes, described his eight-year wait for a transplant: "It was like a dead body in the room every time one of my friends came over. Both of us knew it was there, but neither of us would talk about it. It was always like: he wasn't offering, and I wasn't asking."

Our healthcare system can do better. The mission of WaitList Zero is to expand institutional support for living donation – to make it easy for patients to ask for a kidney and easy for donors to give. Achieving this would end the shortage of kidney transplantation, which costs as many as ten thousand lives each year in the United States.

### The Problem

**Scale**— The kidney shortage is large and growing. In the past decade, the total number of kidney transplants has stagnated, but last year, twenty thousand more patients were added to the waitlist than received a transplant.<sup>3</sup> That list is already over a hundred thousand patients names long, and as many as eighty-two thousand more people medically eligible for transplant are never even listed.<sup>4</sup>

**Disproportionate Impact on Minority Groups**— These unlisted patients are disproportionately more likely to be of African descent, lower income, and not to have graduated college. In general, kidney failure disproportionately affects

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<sup>1</sup> [2013 USRDS Atlas](#) V. 2, p. 267

<sup>2</sup> [Id.](#), p. 284

<sup>3</sup> OPTN Data Series, <http://optn.transplant.hrsa.gov/converge/latestData/step2.asp?> Figure reached by subtracting annual waitlist additions (36,395 in 2013) by the total transplants (16,416)

<sup>4</sup> See Schold, Srinivas et al., *The Overlapping Risk Profile Between Dialysis Patients Listed and Not Listed for Renal Transplantation* (2008), which finds that one quarter of the waitlist not listed for transplant has better medical prognoses than the bottom third of those waitlist. There are approximately 340K patients on dialysis not on the waitlist, implying 85K additional transplant candidates.

underprivileged populations – one third of End Stage Renal Disease (ESRD) patients are African American<sup>5</sup> – and these patients also find it more difficult to find a transplant. Even when they are listed, African Americans wait, on average, one-and-a-half years longer for transplant than Caucasians do.<sup>6</sup>

**Health Effects**— Transplants can buy decades of life for ESRD patients. After one year as a functioning graft, the half-life of a living donor transplant is about twenty-five years; by comparison, a deceased donor transplant is about fifteen. Besides an increased risk of infection necessitated by immunosuppression, transplant recipients can live normal lives. Living donation is also safe for kidney donors: more than 95% report satisfaction with their decision to donate.<sup>7</sup> For donors, mortality in surgery only occurs in 3 out of 10,000 cases;<sup>8</sup> the hospital stay is typically a couple of days, and most return to office work after a few weeks. There is no change in life expectancy, and long-term health harms materialize in fewer than 1% of donors.<sup>9</sup>

**Cost Savings**— In addition to saving years of life, transplants are also substantially cheaper than dialysis. Each year on dialysis costs Medicare about \$90K<sup>10</sup> per patient it covers, while transplants cost an average of \$30K<sup>11</sup> per year. The ESRD entitlement takes up about 6% of Medicare’s entire budget.<sup>12</sup>

## The Solution

**Need for a New Approach**—In 1984, the National Organ Transplant Act established the American system of deceased donor organ transplantation, forgoing significant institutional development for living donation. No major legislation has been passed since then, but the facts have changed considerably.

Then	Now
1. Living donation was too novel for long-term donor outcomes to be known.	1. More than a hundred thousand people have donated over a span of decades.
2. Living donation required painful open nephrectomy surgery.	2. The procedure is performed laparoscopically.
3. Deceased organ procurement was novel, the public under-informed, and collections procedures underdeveloped.	3. The deceased donation field is mature, and 77.2% of all persons medically eligible to donate do so. <sup>13</sup>

<sup>5</sup> American Kidney Fund, Kidney Disease Risk Among African Americans, <http://www.kidneyfund.org/kidney-health/are-you-at-risk/african-americans.html>

<sup>6</sup> OPTN Data Series, <http://optn.transplant.hrsa.gov/converge/latestData/step2.asp?>

<sup>7</sup> Dew, Zuckoff et al. Prevention of Poor Psychosocial Outcomes in Living Organ Donors: From Description to Theory-Driven Intervention Development and Initial Feasibility Testing (Prog. Transplant, 2013).

<sup>8</sup> Segev, Muzaale et al. Perioperative Mortality and Long-Term Survival Following Live Kidney Donation (JAMA, 2010).

<sup>9</sup> Muzaale, Massie et al. Risk of End-Stage Renal Disease Following Live Kidney Donation (JAMA, 2014).

<sup>10</sup> 2013 USRDS Atlas, v.2, 416

<sup>11</sup> Id., p. 419

<sup>12</sup> Id., p. 328

<sup>13</sup> National DSA Dashboard, available at <http://www.aopo.org/userfiles/file/DonationData/DSA%20Dashboard%20-%20Comprehensive%20Data%20Through%20June%202014..xls>

Even if it were possible to convert 77% of potential deceased donors to 100%, it would not come close to ending the shortage.

### ***Effective, Uncontroversial, and Affordable Interventions to Promote Living***

**Donation:** Several interventions are well-supported by evidence but have not been funded at scale by the federal government. Currently, there are significant disincentives to donation that can be removed, and patient and public knowledge about living donation is weak, creating a tremendous potential for change. Two of the high quality interventions are:

- ***Removing Disincentives:*** Donation-related expenses eat up a month or more's worth of donor salaries,<sup>14</sup> and complications from surgery are not always covered. Removing the financial disincentives and providing health insurance would make donation easier and reduce the burden of asking.
- ***Patient Education:*** Randomized control trials have found that home visits to educate patients and their families can increase living donor transplant rates by 20-30%.<sup>15</sup>

**Expanded Donor Support:** Because kidney donation is a field where supply is low but demand is high, many have advocated for a regulated organ market as a way to erase the shortage, while others have expressed concerns that such a market would exploit and commodify poor donors and crowd out existing reasons for donation. We embrace a middle approach that would achieve the goal of ending the shortage and is also politically feasible. This approach is centered around (1) ensuring donors will be no worse off for donating and (2) treating donors as honored public servants.

1. ***Donors No Worse Off:*** No matter what policies are enacted, kidney donation will always require the brave choice to voluntarily undergo surgery at no direct medical benefit to oneself. Nevertheless, we owe it to donors to make them whole for the downsides of donation, including its inconvenience, discomfort, and health risks. Such benefits are almost certainly needed to increase living donation to the needed levels.
2. ***Donation as Public Service:*** Soldier, doctors, teachers, police officers, and firefighters are all valued public servants, and there is a time-honored tradition of providing long-term benefits to acknowledge this service in the form of pension coverage or, most notably, with the GI Bill. This doesn't cheapen or commodify their service; it merely makes it possible. Kidney donors as a class deserve the same treatment, possibly through the provision of an annuity, health insurance, or other form of support.

***Lifting the Burden on Patients***—These principles would shift the system from one where seriously ill patients are supposed to find a living donor, with virtually no support for either party, to a system that approaches the need for living donors realistically and systematically. If patients know that living donation will not burden the donor, asking will not feel like such an impossible request. Potential donors, who already have an interest in

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<sup>14</sup> See, e.g., Klarenbach, Gill, Economic Consequences Incurred by Living Kidney Donors: a Canadian Multi-Center Prospective Study (Am. J. Transplant. 2014).

<sup>15</sup> Rodrigue, Cornell, Increasing Live Donor Kidney Transplantation: A Randomized Controlled Trial of a Home-Based Educational Intervention (Am J. Transplant, 2007); see also Ismail, Luchtenburg, et al. Home-Based Family Intervention Increases Knowledge, Communication and Living Donation Rates: a Randomized Controlled Trial (Am J. Transplant, 2014).

helping, will now have their fears assuaged and feel excited to give. Patient and public education programs will create a receptive environment to help donors and patients learn about the benefits of donating.

## The Path to Change

***Incremental and Feasible***—The solution we describe saves the government money and is bipartisan in its appeal, two features that are absolutely essential for policy change in the current legislative environment. It also builds incrementally and does not require risky discontinuities in policy. For example, paying for lost wages is affordable (about \$30M/year with all current donors<sup>16</sup>), uncontroversial, creates evidence of the effectiveness of providing support to donors, and moves incrementally towards our vision; it can be extended easily into providing health insurance to donors or providing an annual stipend for donors to increase their participation in follow-up studies.

***Venue-Independent***— Almost as important, many of these policy changes can be pursued in a variety of arenas such that rejection by one decision-maker does not halt progress. For example, lost wages can be reimbursed: (1) at the federal level through (a) omnibus legislation; (b) legislative appropriation in response to an agency request; (c) agency grants from preexisting programs; or (d) change in Medicare reimbursement policies; (2) at the state level through (a) legislation or (b) change in insurance regulation; or (3) at the private actor level through (a) insurance company reimbursement policy or (b) non-profit funding.

***Coalition for Change***— Finally, a large and diverse coalition can be mobilized behind these efforts. Patients, donors, and transplant professionals each have a direct stake in increasing transplantation, but each group is decentralized and only transplant professionals have been even partially politically mobilized to date. Insurers (because of cost-savings) and pharmaceutical companies that manufacture immunosuppressants each have a financial stake. Finally, these issues disproportionately affect people of color, but support for market-based solutions have typically come from the libertarian right, thus creating the possibility for advocates on both sides of the aisle.

## Our Work

***Overview:*** As a new organization entering the field, we need to pursue projects that both achieve substantive results in the short-term and build our capacity for change in the long run. We have selected three areas of focus: (1) political advocacy; (2) donor representation and recruitment; and (3) mobilization of religious congregations.

***Political Advocacy:*** Our general vision of political change is described above. We've taken our first step towards achieving that vision through our HRSA Living Donation Parity Campaign. Currently, because of the risk of donation, the Health Resources and Services Administration (HRSA) manages deceased donation policy within the federal government as well as some living donation efforts. It is uncomfortable with efforts explicitly aimed at increasing living kidney donation and excludes projects to do so from its grantmaking.

To persuade HRSA to change this policy, we have recruited leading patient groups as allies in our campaign; we are gathering signatures for institutional and individual letters

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<sup>16</sup> \$5K/yr\*6K donors.

of support in favor of our position, and will use those as the platform for mobilizing legislative support, media coverage, and editorial campaigns.

Our goals with this campaign are twofold. First, we believe it is a good way to introduce us and our issue to stakeholders and legislators: it is an easy ask, with broad community support that will not cost additional funds. Second, we want to begin pushing an omnibus “Living Donation National Organ Transplant Act,” and we believe pushing HRSA to accept living donation promotion is a useful first step for giving those policies a future home in the federal government.

***Voice of Donors:*** Our group was founded by two Good Samaritan kidney donors, and we believe situating our group as an advocate for donor interests is useful in helping us lead the movement to end the waitlist through living donation. The major criticism of donor-support based measures is that they are bad (exploitative, commodifying) for donors. Successfully representing the voice of donors will lend tremendous moral authority to the reform effort.

We want to build this constituency by two main activities: (1) we aim to recruit past donors to our Donor Advisory Board, raise public awareness about their stories, and push for policies that respond to their concerns; (2) we want to recruit additional Good Samaritan Donors and mobilize them politically, since we think they are powerful advocates for our cause. Without any non-profit support in America, the annual number of such donors has tripled in the past ten years (admittedly from a low amount), and in England, where a small non-profit does promote Good Samaritan donation, such donors make up 10% of all living kidney transplants<sup>17</sup> (in the U.S. it’s closer to 3%<sup>18</sup>). We think that apart from the political appeal of this strategy, the direct impact of recruiting even a few extra donors justifies investment in the program.

***Religious Support:*** Religious communities have played a prominent role in many bioethical issues such as stem cell research, IVF, and removal of life support. Winning the support of communities of faith, or at the least preventing opposition, is an important step towards enacting donor benefits. Further, many people find organ donation itself repugnant, let alone benefits for organ donors. Thus, the endorsement of moral authorities, such as members of the clergy is very valuable.

We plan to build support for living donation within communities of faith by reaching out to individual congregations and parishes, and inviting them to commit to a set of best practices related to promoting living donation and be listed as a One Body Congregation. This will give a visible sign of support from the religious community, help recruit additional living donors, support ESRD patients, and lay the groundwork for additional political mobilization.

The creation of a label for congregations that commit to a set of best practices and public endorsement of a cause, has already been used by gay rights advocates, proponents of traditional views of marriage, and environmental groups throughout various religions and denominations.

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<sup>17</sup> Kidney Activity, available at [https://www.organdonation.nhs.uk/statistics/transplant\\_activity\\_report/current\\_activity\\_reports/ukt/kidney\\_activity.pdf](https://www.organdonation.nhs.uk/statistics/transplant_activity_report/current_activity_reports/ukt/kidney_activity.pdf)

<sup>18</sup> OPTN Data Series, <http://optn.transplant.hrsa.gov/converge/latestData/step2.asp?>

## Conclusion

**Personnel:** WaitList Zero was founded by two Good Samaritan kidney donors interested in policy change. Thomas Kelly is a political science PhD candidate at UC-Berkeley whose research focuses on lobbying and advocacy in the American political system. WaitList Zero in part grew out of his efforts to recruitment of several friends to become kidney donors, and Thomas published [an editorial](#) in the Washington Post online in connection with his donation. Josh Morrison is a lawyer trained at Harvard Law School where he was an editor of the Harvard Law Review. He previously served as General Counsel and Director of Strategic Initiatives at the Alliance for Paired Donation and is a co-author of a forthcoming article in the Journal of Law and Contemporary Problems, “State Organ-Donation Incentives Under the National Organ Transplant Act.”

**Funding Requirements:** Prior to creating WaitList Zero, we raised \$70K for the organization’s initial planning period. Our goal in our current round of fundraising is to raise \$900K, which is intended to provide a stable level of funding for three years while we grow the organization.

**Conclusion:** End-stage renal disease is a major health problem, and its best treatment, living kidney donation, has been underinvested in by both the government and the nonprofit world. While unfortunate for the thousands of Americans that have died due to low rates of living kidney donation, we believe that this means resources invested in living kidney donation can yield large gains. There is a large and diverse group of stakeholders that would benefit from growth in living donation—Medicare, patients, transplant professionals—and there are clear and cost-effective policy interventions available. WaitList Zero will bring leadership and attention to the issue and in doing so, be a key driver in the movement to end the organ shortage.