

A conversation with Josh Morrison, October 20, 2016

Participants

- Josh Morrison – Co-Founder and Executive Director, WaitList Zero
- Alexander Berger – Program Officer, US Policy, Open Philanthropy Project
- Nicole Ross – Operations Associate, Open Philanthropy Project

Note: These notes were compiled by the Open Philanthropy Project and give an overview of the major points made by Mr. Morrison.

Summary

The Open Philanthropy Project spoke with Mr. Morrison of WaitList Zero as part of an update on our 2015 grant. Conversation topics included legislation proposed by WaitList Zero in New York state, the Kidney for Thalya campaign, and WaitList Zero's current budget and fundraising status.

Current activities

Mr. Morrison currently divides his time roughly as follows:

- 50-70% on the New York state legislative campaign.
- 20% on the Kidney for Thalya public awareness campaign.
- Some time on a campaign lobbying the United Network for Organ Sharing (UNOS) to incorporate an advanced donation program into its deceased donor waiting list.
- Some time on other minor tasks (e.g., talking to potential donors who contact WaitList Zero, writing a recent article for Vox).

New York legislation

WaitList Zero has drafted legislation intended to increase living kidney donation that it expects the chairs of the health committees of the New York Senate and Assembly to introduce on November 15th (the earliest date to introduce legislation for the 2017 session).

One of WaitList Zero's main focuses over the next couple of months will be to get the program included in the governor's budget, which would make it easier to get the program funded than if the bill were only passed by the legislature. Mr. Morrison thinks there is a 50% chance or less of the program getting included in the governor's budget. WaitList Zero plans to advocate for this till roughly January 1st when legislative session starts.

Goals of the bill

WaitList Zero aims to increase living donation by 25% in New York State (roughly 125 transplants per year). Mr. Morrison thinks that compensating donors for lost wages and travel will likely be an important factor. One study showed that New York's tax deduction for donors increased living unrelated donation by 50%. This

compensation accounts for most of the cost of the bill.

The bill also provides a year of health insurance for donors. Mr. Morrison thinks the main impact of this provision will come from making transplant centers more likely to accept donors that they would currently reject because of their lack of insurance (rather than from incentivizing potential donors who would donate if they had insurance).

WaitList Zero hopes that this bill will serve as a model for other states, as well as make federal reforms more likely to succeed.

Removal of patient education component

The final bill does not include the originally planned patient education component, which included home visits and a requirement that dialysis companies refer patients to independent advisers to help them evaluate transplant options. After the bill is passed, WaitList Zero plans to advocate to get funding for home visits at the city level and through transplant centers.

Kidney for Thalya public relations campaign

WaitList Zero is currently running Kidney for Thalya, a public awareness campaign to find a kidney donor for a teenage girl in New York City. WaitList Zero aims for this campaign to:

1. Result in five kidney donations.
2. Serve as a prototype for a broader pilot program involving 3 to 5 more potential transplant recipients to test whether this outreach model is scalable and repeatable.

WaitList Zero plans to promote Kidney for Thalya through the press and media outlets as well as on social media. It is making a short social media video to promote the campaign, which Mr. Morrison estimates will cost between \$10,000 and \$15,000. WaitList Zero plans to use this video as a template to make future video work cheaper. The website itself will cost roughly \$1,000.

WaitList Zero's goal is to systematize the process of campaigns for kidney donation. If the pilot proves successful, Mr. Morrison thinks it will make it easier to persuade transplant centers and insurers of the value of this process, and that they might be willing to fund such campaigns in the future.

Donor intake system

Donor outreach campaigns, like Kidney for Thalya, often lead to more donor inquiries than transplant centers can process. The National Kidney Registry (NKR) has two intake systems to help handle large volumes of requests, including a free version that WaitList Zero plans to use. The system has potential donors fill out the intake information online, and then allows WaitList Zero to connect them to volunteers to discuss and confirm their intention to donate and connect them with a transplant center.

Advanced donation program

NKR's advanced donation or "voucher" program allows donors to donate a kidney now on behalf of an intended recipient who will need a kidney later; the donated kidney is used for someone currently in need of a transplant, and the donor's intended recipient receives a voucher that gives them priority when they need a kidney in the future. WaitList Zero thinks this option will help incentivize donors who respond to the campaign, and want to make Thalya their intended recipient, to donate.

WaitList Zero's goal is to be able to offer advanced donation as an option during outreach to potential donors across the board, which it thinks would make donor outreach more effective. (NKR's voucher program has a limited reach, as NKR only does roughly 300 transplants a year.) WaitList Zero sent a request to the UNOS ethics committee asking it to consider incorporating an advanced donation program. UNOS asked for a more detailed proposal, which WaitList Zero is now putting together a group of academics and others to produce. Mr. Morrison estimates this will take roughly two years.

Federal work

WaitList Zero is not currently focused on federal level work. It plans instead to build momentum at the state level, such as in New York, to make its federal advocacy more effective later on. WaitList Zero's New York work has turned out to focus less on grassroots support and more on more inside game. WaitList Zero largely delegates grassroots work to the other groups it works with (e.g. patient groups).

Budget and fundraising

WaitList Zero has received some funding from Novartis, which includes:

- \$10,000 for a website about living donation as part of the Kidney for Thalya project (including the video component).
- \$25,000 for polling about living donation in New York, and for branding and creating content based on the polling. WaitList Zero's polling in New York showed favorable attitudes towards living donation and has been useful as an advocacy tool. The polling also provided useful information on people's willingness to donate, perception of risks, etc.

Open Philanthropy's last tranche of \$100,000 to WaitList Zero came through in June.

WaitList Zero has roughly \$25,000 in outstanding pledges from individuals.

WaitList Zero expects to have roughly \$90,000 in cash on hand at the end of this year. At WaitList Zero's current spending rate of between \$75,000 and \$80,000 per year, it has funding to last till roughly the end of 2017 or slightly beyond without raising more funds. WaitList Zero has been fairly conservative in its budgeting and has tried to maintain an adequate runway.

Board and staff

Mr. Morrison is WaitList Zero's only current full-time staff member. He does not plan to hire at least through end of this year.

WaitList Zero recently added David Trinh to its board.

*All Open Philanthropy Project conversations are available at
<http://www.openphilanthropy.org/research/conversations>*