

## **A conversation with Josh Morrison, April 25, 2016**

### **Participants**

- Josh Morrison – Co-Founder and Executive Director, Waitlist Zero
- Alexander Berger – Program Officer, US Policy, Open Philanthropy Project

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

### **Summary**

The Open Philanthropy Project spoke with Josh Morrison of Waitlist Zero as part of a grant update. Conversation topics included Waitlist Zero's top priorities, board of directors, funding, and staffing updates.

### **Top priorities**

#### **Priority 1: Create New York state legislation and living donation hub**

Waitlist Zero's goals in this area are:

- To get the state legislature to pass transplant support legislation that can serve as a model for other states.
  - A near-term goal is to get good language for legislation introduced so that Waitlist Zero can then ask legislators to support a specific bill.
- To increase the influence of the living donation community in New York's transplant community. This would increase the number of transplants done and put Waitlist Zero in a better position to achieve major changes.

Early in 2016, Waitlist Zero met with New York transplant leaders to discuss the possibility of getting state funding to create a breakthrough collaborative modeled on a previous federal effort for deceased donation conducted from 2003-06. This was unsuccessful, partly because the group requested funding late in the budget cycle and partly because Waitlist Zero was trying to move too fast and did not get the necessary support from within the transplant field.

This effort resulted in the creation of a living donation working group including many leaders in the New York state transplant community, which Mr. Morrison co-chairs with Dianne LaPointe Rudow, Director of the Center for Living Donation at Mount Sinai Hospital. The working group aims to produce draft legislation to be introduced at the end of the current term (in mid-June) and get it passed early in the next term. This seems to be an achievable goal in part because CEOs of hospitals and transplant centers have asked the Greater New York Hospital Association (GNYHA) to prioritize organ donation, and GNYHA seems willing to support the cause. Mr. Morrison believes that GNYHA is relatively influential in Albany. However, there is a

risk that Waitlist Zero's allies will decide this is not a high priority and stop working on it.

### **Priority 2: Federal campaign work**

Waitlist Zero previously aimed to get members of Congress to write letters in support of increasing living donation to the Health Resources and Services Administration (HRSA), which would support Waitlist Zero's goal of creating a living donation breakthrough collaborative. This effort was unsuccessful, in part because many legislators who are interested in kidney donation believed that it was important for the Living Donor Protection Act to be passed first.

Mr. Morrison's impression is that the Living Donor Protection Act was introduced organically several years ago by New York Congressman Jerrold Nadler and then gained the support of advocacy groups. It was recently reintroduced and now has bipartisan sponsors in both the House and Senate. It has broad support in the transplant field and several groups have claimed it as a priority. Despite this support, the bill has gained few additional co-sponsors in the past 2 years. Mr. Morrison's impression is that stakeholders meet with members of Congress to discuss this issue, but fail to follow up.

The Living Donor Protection Act would be more likely to pass than other legislation because it is fairly uncontroversial, has strong support in the field, and does not require government funding, but it seems to currently have too few co-sponsors to move forward.

Supporting the Living Donor Protection Act may introduce Waitlist Zero to legislators who are interested in kidney disease who could be rallied in support of future living donation legislation. Mr. Morrison aims to get the support of about 5 new co-sponsors in May and 20 in June. Waitlist Zero has attempted to contact the health aides of 10-12 legislators so far and has spoken with 4-5 of them. These health aides have expressed support but none of the legislators have become co-sponsors.

### **Priority 3: Create a website for potential living donors**

As part of its goal of integrating into the New York transplant community, Waitlist Zero plans to create a website that would increase publicity for living donation and gain more potential donors, ideally in a way that is repeatable. It plans to pilot an advertising method wherein potential donors would be directed to the website by billboards advertising campaigns such as "Transplant for Thalya." The website would educate potential donors about living kidney donation and enable them to input their information to determine their eligibility to donate, at which point they would be referred to a transplant center for further testing.

This process would reduce the amount of work that the transplant centers need to do to process potentially eligible donors, bring potential donors to the center who would not have otherwise donated, and increase the likelihood that those who arrive at a transplant center are informed and able to donate.

### **Division of time between priorities**

Mr. Morrison currently spends approximately 55% of his time on New York state work, 30% on federal campaign work, 10% on the website, and 5% on everything else. He would like to increase his time spent on federal campaign work, but overall thinks that this breakdown adequately reflects the importance of each activity.

### **Board of directors**

The board of directors typically meets about every 3 months. Mr. Morrison would like to expand the board to get a variety of perspectives. Diane Brockington recently joined the board, and Mr. Morrison hopes to add another member in the next 3 months. Progress on this has been slower than he expected.

### **Funding**

Waitlist Zero expects to receive a total of about \$135,000 in 2016. This does not include a pledge for a large donation that may not come through. At a fundraising event in Washington, D.C., Waitlist Zero raised a net \$1,000 and gained some kidney donor contacts and volunteers. Novartis has donated \$15,000 for polling in New York, \$10,000 for branding (which could include projects such as billboards to generate website traffic), and \$10,000 for the website.

Waitlist Zero has a few potential large donors and potential opportunities in New York, but fundraising has been deprioritized because Waitlist Zero has about a year's worth of funding and because recent fundraising efforts have not been very fruitful. Mr. Morrison would like to make progress on Waitlist Zero's goals before putting a large effort into fundraising.

### **Staffing update**

An employee who had been working remotely for Waitlist Zero recently left the organization, leaving Mr. Morrison the only employee. Though the employee had added significant value, especially early on, managing a remote employee doing open-ended work was increasingly challenging, and Mr. Morrison believes it would likely have been better if the relationship had ended sooner.

Waitlist Zero is not currently hiring, but Mr. Morrison anticipates that if they do so in the future they will prioritize hiring someone in New York and focus on establishing a clear job description and set of responsibilities from the beginning.

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