

## **A conversation with Waitlist Zero, January 28, 2015**

### **Participants**

- Josh Morrison – Executive Director, Waitlist Zero
- Thomas Kelly – President, 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 and Thomas Kelly.

### **Summary**

The Open Philanthropy Project spoke with Josh Morrison and Thomas Kelly of Waitlist Zero to follow up on a grant made by Good Ventures in September 2014 (<http://www.givewell.org/labs/causes/organ-transplantation/planninggrant>). Conversation topics included updates on Waitlist Zero's organizational structure, personnel, funding, policy advocacy goals, and other projects.

### **Update on organizational development**

Waitlist Zero obtained 501(c)(3) status in September 2014.

During the initial part of the planning phase, Waitlist Zero's founders were considering an organization with a staff of about five people that would include:

- An executive director
- An assistant

As well as staff members in charge of:

- Communications
- Development
- Policy work

Waitlist Zero based this model on conversations with groups with more advocacy experience. At the time, the founders also believed they might recruit more high-level talent, including someone else to serve as executive director.

Some useful lessons learned by the founders during the start-up phase include:

- Logistics (e.g., setting up a website) took longer than expected.
- Some basic practices (e.g., setting clear agendas for scheduled calls between the founders) should have been implemented earlier.
- It was important for the founders to become stricter about deadlines and to give each other more critical feedback.
- It has been difficult for Waitlist Zero to get useful outside feedback. The founders seek out advice from the people they work with and others in the field, but most people with useful advice on kidney transplantation do not know much about political advocacy, and vice versa.

- During the early start-up phase in particular, the work was emotionally challenging and unpredictable. Over time, the work has become more predictable and consistent.

### **Shift from Strategic Master Plan to Minimum Viable Products**

During their planning phase, the founders expected that a robust, well-presented strategy proposal would be recognized as valuable and attract outside support. The founders discussed policy with experts to improve their strategic thinking.

Due to discussions with Open Philanthropy Project staff and others, however, Waitlist Zero decided that producing an in-depth, well-sourced strategic plan would be a less valuable investment of time and effort than working on practical "minimum viable products" (though the founders were confident that they could write such a plan if needed). Engaging interest, implementing real projects, and achieving policy, advocacy, or coalition-building successes seem to be more important indications of an organization's potential than producing a thorough strategic plan.

### **Outreach to other groups**

It has been easier for Waitlist Zero to get other transplant-focused groups interested in its advocacy approach than to get advocacy groups in related fields interested in transplants.

Organizations that have expressed interest in working with Waitlist Zero include:

- Donate Life America (DLA)
- The John Brockington Foundation
- American Association of Kidney Patients
- Transplant Recipients International Organization (TRIO)

Waitlist Zero has made an effort to facilitate community involvement in its work. Other projects by intellectuals in this field tend to not involve communities beyond the initial project group.

Waitlist Zero has found it important to make specific requests of the groups it engages. For example, when initially reaching out to African-American groups and churches, Waitlist Zero was not able to present clear "asks." Waitlist Zero's campaign directed at the Health Resources and Services Administration (HRSA) now serves as a well-defined project around which to build a coalition of other groups.

### **Changes to the board of directors**

The current members of Waitlist Zero's board of directors are Thomas Kelly and several of his initial cofounders for the project.

Waitlist Zero plans to revamp the board shortly. Waitlist Zero expects the initial board of directors to be relatively small and will likely ask members to serve two-

year terms. It may be beneficial to have the board of directors consist primarily of donors and recipients.

Mr. Kelly has returned to graduate school, and as a result currently works about 10-15 hours a week for Waitlist Zero in a volunteer capacity. This decision was made for several reasons:

1. Although Waitlist Zero expects to receive more funding eventually, it wanted to ensure that it could maintain one full-time employee (i.e., Mr. Morrison) for as long as possible, rather than two full-time employees for half as long.
2. When Waitlist Zero initially divided projects between the founders, Mr. Morrison was put in charge of the HRSA campaign, which now seems like the most promising project to continue to pursue.
3. By returning to finish his Ph.D. now, Mr. Kelly could go on the academic job market in the fall of 2015.

### **Merger with Save Lives Now New York (SLNNY)**

SLNNY plans to dissolve and transfer its assets to Waitlist Zero. Mr. Morrison is currently drafting the paperwork for the merger, which is planned to occur in mid-March. Reasons for the merger include:

- The head of SLNNY is in favor of the merger.
- The dissolution process offers Waitlist Zero an opportunity to engage more closely with SLNNY's board of directors, which includes the heads of major transplant centers in New York.
- SLNNY has an office in Manhattan (provided to them *pro bono* by a law firm), which Waitlist Zero will be able to use.

### **Funding**

Waitlist Zero currently has enough funding for another three months of operations. At the beginning of April, it expects to have at least three additional months of funding. Expected sources of future funding include:

- About \$7,000 of SLNNY funds that Waitlist Zero will acquire in the merger.
- Waitlist Zero will host a kickoff event in early March, which will include the heads of major transplant organizations in New York and previous donors to New York transplant causes. Waitlist Zero hopes that this event will produce its main sources of individual fundraising.
- A few other individual donor prospects.

Waitlist Zero expects to present a proposal for funding to the Open Philanthropy Project in a few months, once it has raised between \$50,000 and \$100,000 in individual pledges.

Waitlist Zero has submitted applications for start-up funding to some other foundations. One major foundation was interested in transplants but not in living donation.

## Policy goals

### Reorientation of Policy Goals

The mission of WaitList Zero is to end the kidney waitlist by increasing living kidney donation. The founders spent a great deal of time investigating potential solutions to the waitlist. An initial area of investigation was the potential of cash incentives for living kidney donors to increase living kidney donation. Waitlist Zero has decided that promoting cash incentives for living kidney donation is not the right focus for the organization for several reasons:

1. Ethical concerns with cash incentives—namely commodification, exploitation, and crowding out—make pursuing an alternative solution more attractive, if that solution could end the transplant shortage.
2. Because organ transplantation is a sensitive and controversial issue, and because a strong coalition around the issue does not already exist, it is particularly important to achieve consensus among advocacy groups in order to be politically effective. Waitlist Zero believes that a more incremental strategy, involving less controversial steps, will be more successful in this regard than a direct push for incentives. (For example, the statement of principles (<http://www.waitlistzero.org/content/principles>) for Waitlist Zero’s Coalition to Promote Living Kidney Donation was originally created at the suggestion of the American Association of Kidney Patients [AAKP], which did not want to be associated with support for cash incentives.)
3. When envisioning a path to incentives, the founders believed a lengthy “pilot” phase would be required, during which particular types of incentives would be tested at a small scale. This was not ideal for several reasons:
  - It could be difficult to mobilize political support for the pilot program.
  - Even with support, a pilot program would be politically controversial. Waitlist Zero was unsure whether its potential advocacy efforts would be able to overcome attempts by opponents to weaken and delay such a program.
  - If subsequent debate over the pilot phase determined it to be unsuccessful, the main program would not move forward.
  - Even if the pilot program were successful, Waitlist Zero’s main policy goals would only be reached several years later.

#### *Transplant support*

There is greater discomfort with efforts to increase living donation, even without donor incentives, than Waitlist Zero initially expected. Waitlist Zero has found that some coalition members on its HRSA campaign have been reluctant to fully support living donation.

As a result, Waitlist Zero has shifted its advocacy focus from donor incentives to living donation in general. The founders believe that there are useful policies that promote living donation without using donor incentives. For example, “transplant

support” policies offer a middle-ground position between the controversial version of incentives and the status quo.

Transplant support policies aim to make it easy for patients to request a transplant and easy and attractive for donors to give. Steps towards this could include:

- Supporting patients with transplant by educating them, their families and the public about transplant’s safety, ease, and life-saving potential.
- Supporting donors by paying lost wages and travel expenses for donation, providing health insurance to donors, and giving donors a stipend each year they participated in follow-up care and study.

Waitlist Zero has successfully convinced other groups of the value of transplant support, including some groups that oppose donor compensation.

#### *Founder’s views on transplant support vs. donor incentives*

Mr. Morrison finds transplant support more attractive than direct compensation in some ways (though he does believe a system of donor incentives would be better than the status quo). It is important to ensure that there is no social stigma associated with living donation. He believes that improved transplant support policy could be enough to meet organ demand.

Mr. Kelly supports non-compensation strategies (e.g., patient education) and believes that incremental policy steps are useful. He believes it is theoretically possible to develop a compensation system that satisfies normative concerns, but it’s not the right approach for Waitlist Zero. He believes that non-compensation methods could significantly increase the availability of organs but may not entirely meet the demand.

#### *Transplant education reimbursement by the Center for Medicare and Medicaid Services (CMS)*

Waitlist Zero’s next policy goal is to attempt to have CMS fully reimburse transplant education programs (e.g., home visits). Mr. Kelly is investigating the current state of policy on this issue. In particular, Waitlist Zero is trying to determine whether there is currently a way for education providers to be reimbursed, e.g., if they do the proper paperwork (a consulting firm that Waitlist Zero spoke to suggested this is possible).

Waitlist Zero expects to submit a completed proposal to CMS near the end of the second quarter of 2015. The proposal will include a letter proposing interventions and a literature review, for which CMS specifies the type of data it would like to see (e.g., randomized control trials). Waitlist Zero will ask influential people in the field to sign the application letter. This may be a particularly effective issue to mobilize around.

#### **Health Resources and Services Administration (HRSA) Campaign**

HRSA is the agency within the US Department of Health and Human Services (HHS) responsible for organ donation. HRSA is in charge of the government contract with the United Network for Organ Sharing to maintain the transplant waiting list, as well as a few other contracts. HRSA's total annual budget is about \$9 billion, and the organ transplantation division has an annual budget of \$25 million. Some other federal agencies are involved in kidney health as well (e.g., CMS spends about \$36 billion annually treating kidney failure.)

The goal of Waitlist Zero's HRSA campaign is to increase living kidney donation, which HRSA has been reluctant to support in the past. The campaign asks HRSA to:

1. Remove the exclusion on living donation from its grant-making policy. This exclusion is inconsistent with the policy of the National Institutes of Health and the Agency for Healthcare Research and Quality, both of which have given grants to support living donation.
2. Include living donation goals in its annual performance report (issued each year on July 31<sup>st</sup>).

The statute under which HRSA grants are issued does allow for grants to support living donation. However, this statute was passed in 2003 and authorizes the grants for 5 years. While HRSA continues to receive appropriations for grants and to issue them pursuant to this statute's language, there is some ambiguity as whether the statute's language remains legally binding. The statute also gives the HHS secretary discretionary power in approving grants.

In the short-term, the campaign could shift about \$3 million of HRSA's \$7 million annual grant budget to living donation. Because this money would come from HRSA's existing grant budget, it would not require extra appropriations and has not already been allocated to any other group. Living donation is currently underfunded, with only a few million dollars in the field.

In the long-term, it is important that HRSA support living donation because it will be responsible for implementing the sorts of future policy changes for which Waitlist Zero advocates.

The founders believe that HRSA is a good target for Waitlist Zero's first advocacy campaign, offering an opportunity for Waitlist Zero to present its main policy position clearly. Waitlist Zero will also have the opportunity to achieve broader organizational goals in the course of implementing the key steps of the campaign (e.g., introducing Waitlist Zero to the field, building a coalition with other non-profits, partnering with legislators, promoting the campaign to the public, attracting media attention, etc.).

#### *Building a coalition and initial HRSA meeting*

Waitlist Zero consulted others in the field (e.g., other non-profits, bioethicists) and found its campaign concept to be generally supported and uncontroversial.

On October 14<sup>th</sup>, Waitlist Zero and other patient and donor groups (e.g., AAKP, TRIO, the Living Kidney Donor Network) sent a letter of inquiry about the grant program to HRSA. As a result, a meeting with HRSA in Maryland was scheduled in January.

Before the January meeting, Waitlist Zero began putting together a coalition of other non-profit groups interested in promoting living kidney donation. It also ran a promotional social media campaign and organized living donors to send letters of support to Bob Walsh, Director of HRSA's Division of Transplantation.

The January meeting with HRSA went well. Coalition members with more government experience felt very positively about the meeting. HRSA said that it is open to reconsidering both policies and is willing to meet again in the future. Mr. Walsh emphasized that he had not been present for the decision to exclude living donors. HRSA wanted Waitlist Zero to meet next with the Advisory Committee on Organ Transplantation. Waitlist Zero requested a public meeting instead, and will likely end up having a stakeholder meeting.

HRSA raised two main objections at the meeting:

1. It suggested that transplant centers would pursue living donation on their own, without support from grants, because it is more profitable.
2. Living kidney donation should not be incentivized by policy because it is a personal choice.

Waitlist Zero hopes to grow the coalition formed around this campaign and believes it could serve as umbrella group for future advocacy efforts. Waitlist Zero is currently drafting a letter in support of living donation, and hopes to get signatures of support from the Congressional contacts of some coalition members.

## **Other projects**

### **Non-directed donor education initiative**

For its non-directed donor education initiative, Waitlist Zero plans to locate non-directed donors, provide them with useful materials and help them create a presentation, and then secure speaking opportunities for them to talk about non-directed donation. This program is intended to:

- Raise awareness about kidney donation (in particular non-directed donation).
- Make non-directed kidney donation more attractive.
- Mobilize donors as a constituency group for Waitlist Zero.

### **The OneBody program**

Waitlist Zero's OneBody program aims to help kidney patients find living donors within their faith communities.

It has been difficult to generate interest in the program from congregations. Some ministers have expressed interest, but have not gotten involved. Waitlist Zero still

believes the OneBody program could be effective, but may take a long time to produce results. In March, Waitlist Zero plans to invite ministers and kidney patients to an educational kickoff brunch in Oakland to discuss the program.

Waitlist Zero has discussed the program with advocacy groups trying to gain the support of churches in other areas (e.g. environmental issues, gay rights, veterans' issues). During a conference at Duke University, Waitlist Zero found that it had worked on this strategy of outreach to religious groups more than any of the transplant groups present, except for Renewal (an organization that connects Jewish patients with Jewish donors). Other transplant groups have expressed support and interest in the strategy (e.g., DLA asked Waitlist Zero to share its materials on engaging religious groups).

Waitlist Zero has contacted three health care sharing ministries (HCSMs), organizations that share health care costs among members of religious communities, about the OneBody program. Waitlist Zero thought that HCSMs might be more likely to promote living kidney donations to members because of their financial stake in the issue. So far, only one HCSM has responded, asking to discuss the issue in September.

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