

A conversation with Josh Morrison, September 15, 2015

Participants

- Josh Morrison – Executive Director, Waitlist Zero
- Alexander Berger – Program Officer, U.S. 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 to follow up on a grant. Conversation topics included program activities, fundraising, its staff and board, and plans for the future.

Program activities

Health Resources and Services Administration (HRSA) advocacy campaign

HRSA is the agency within the U.S. Department of Health and Human Services responsible for overseeing organ donation. Mr. Morrison has been spending approximately 70% of his time working on Waitlist Zero's HRSA advocacy campaign. This work includes relationship and coalition building with government and nongovernment stakeholders, including medical professionals, the media, and others. A coalition of fifteen organizations has been formed for the purposes of the campaign. In general, Waitlist Zero believes that stakeholders are taking the organization's mission and demands seriously.

Inclusion of living donation projects in HRSA's grant program

Waitlist Zero has made more progress than initially expected on pushing for HRSA to award grants to projects promoting living donation. It appears that HRSA's next request for proposals (RFP) will consider awarding grants to living donation education projects, but not for projects that focus directly on increasing living donations. Initially, Waitlist Zero had believed that the RFP would be announced prior to the coalition's meeting with HRSA. It now appears that this will occur in October 2015.

Creation of a Living Donor Breakthrough Collaborative

In the spring of 2015, Waitlist Zero was more optimistic about the likelihood of HRSA funding the creation of a Living Donor Breakthrough Collaborative than it is now. Its efforts have met with moderate success: the idea was not a major topic at the stakeholder meeting with HRSA, but it was discussed and generally well received. Four out of the five other stakeholders at the meeting expressed some openness to it. Waitlist Zero does not expect HRSA to provide funding for this initiative within the next year.

Public awareness campaign

Mr. Morrison has been spending approximately 20% of his time working on Waitlist Zero's public awareness campaign. Waitlist Zero believes current levels of public awareness about living donations are very low.

Waitlist Zero is preparing a grant application to mount a pilot public awareness campaign. Initially, the campaign would be disseminated in Maine, and later in New York. It would involve the creation of a national website connecting individuals seeking potential living donors with individuals wishing to become living donors, as well as the development of branded infographics and other educational materials.

Waitlist Zero expects that these campaigns will encourage more people to become living donors, more patients to seek out living donors, and help it gain support for state legislative campaigns. In addition, it is developing a significant amount of expertise in the areas of public awareness, patient education, and legislative reform. Eventually, it hopes to develop a funding stream by providing services in these areas to transplant centers and other institutions seeking to increase living donation rates.

State legislative campaigns

Mr. Morrison has been spending approximately 10% of his time working on state legislative campaigns. Waitlist Zero has been working on a potential campaign in Maine, and is not very satisfied with its progress thus far. Initially, it wished to pass legislation that would require:

1. Payment of lost wages and travel expenses to living donors
2. Health insurance for one year for living donors
3. Education on transplant opportunities for those needing a transplant (including the funding of home visits)
4. The creation of a living donor registry and stipends for donors

Waitlist Zero's main collaborator in Maine is willing to advocate for legislation in two of the four areas: payment of lost wages and funding of home visits. Mr. Morrison believes it is relatively likely that these pieces of legislation will pass. If the campaign were to result in legislation in all four areas, it could serve as a model for other states.

Transplant Education Council (TEC)

Thomas Kelly, Co-Founder and Board Chair of Waitlist Zero, is responsible for Waitlist Zero's Transplant Education Council work. This project aims to develop a set of voluntary consensus standards to improve the quality of transplant education initiatives.

Initially, the standards might only apply to transplant centers. If there are sufficient resources, standards for primary care physicians and nephrologists could also be developed. Waitlist Zero believes that federal regulations might mean that federal government programs might be required to adhere to the standards unless there is a conflicting rule already in place, or the program has a valid reason to opt out.

Development of standards

In the development phase, drafts of the standards will be circulated among stakeholders in order to obtain and incorporate their feedback. The drafts will also be discussed in monthly phone calls. It is hoped that the inclusive nature of this process will help produce a final version that is representative of stakeholder perspectives. This drafting process also gains legitimacy by adhering to American National Standards Institute (ANSI) standards.

A final draft of the standards should be complete by the end of 2015. In order to be enacted, the standards would be subject to a voting process and various applications to the federal government.

Adoption of standards

Initial efforts to encourage adoption of the standards will be challenging, so Waitlist Zero will first target transplant centers who have been the most engaged in the process, or in the organization's efforts. In the following years, it will encourage other centers to adopt the standards. It is hoped that as more centers begin to adopt the standards, others will feel encouraged to do so as well. The Living Donor Breakthrough Collaborative could also be an important vehicle for disseminating and encouraging adoption of the standards.

Note on the relative importance of public awareness and TEC activities

Initially, Waitlist Zero believed that focusing on political advocacy would be the most effective pathway to accomplishing its goals. Its experiences in public awareness and transplant education have demonstrated that capacity building in the field is also an important priority.

Outreach to faith communities

Waitlist Zero has deprioritized efforts to facilitate living donations between congregation members in faith organizations. Although this type of work is valuable, Waitlist Zero does not currently have the staff capacity to pursue this work.

Living donor community building

As Waitlist Zero was not able to hire the candidate they had identified for work on living donor community building, this program has been temporarily deprioritized. The organization considers this to be an important initiative, and would prioritize it if the necessary funding were secured.

Fundraising

Mr. Morrison has not spent a significant amount of time on fundraising and intends to prioritize this work for the rest of 2015. Waitlist Zero hopes to raise an additional \$150,000 by the end of 2015, and has a two-year fundraising target of \$500,000.

Other than grants from the Open Philanthropy Project and one individual donor, Waitlist Zero has not received any additional funding yet.

However, **Waitlist Zero has made good progress in identifying potential funding opportunities**, including three large pharmaceutical companies, applying to HRSA for a grant around living donor education, and other foundations with an interest in transplantation.

Staff and board updates

Staff updates

Waitlist Zero used funds it had earmarked for communications work to hire Stephen Rice, who had previously delivered high quality work as a part-time volunteer. His tasks include overseeing the redevelopment of the website, developing written and graphic communications, helping with the public awareness campaign, and writing the grant application for the pilot public awareness campaign. Mr. Rice lives in Portland, Oregon, which is a manageable challenge.

Thomas Kelly is working approximately 10-15 hours/week, and is currently transitioning to a more independent role focused primarily on the TEC work.

A volunteer with political advocacy experience, who is also a kidney donor, is doing some unpaid work. Should the necessary funding become available, and depending on the quality of her work, Waitlist Zero would consider offering her a paid position.

Board updates

Waitlist Zero plans to recruit two additional board members by the end of 2015. The organization will likely also create a board of advisors; it has gotten positive responses from a number of potential members. Many of the board members of Save Lives Now New York (SLNNY), which is in the process of dissolving, will join Waitlist Zero's board of advisors.

Upcoming plans

Five-year plan

Waitlist Zero hopes to achieve the following goals within the next five years:

- Enactment of federal laws requiring educational home visits for all patients who are medically eligible for transplant, a significant amount of health insurance for donors, and stipends for donor follow-up.
- Presence of a robust donor community program. The program would serve the donor community, who would contribute to the program by acting both as sources of authority and as constituents.
- Presence of an ongoing public discussion on transplantation, with Waitlist Zero being an influential voice in this discussion.
- Improved practices in the field as a result of the Living Donor Breakthrough Collaborative and TEC work, with Waitlist Zero continuing to push for additional improvements.

Plans for the fourth quarter of 2015

In the fourth quarter of 2015, Mr. Morrison plans to divide his time in the following way: 60% on fundraising (including potentially applying for a HRSA grant), 20% on communications, and 20% on the Living Donor Breakthrough Collaborative and other programs. Waitlist Zero is working on a relatively large number of projects given its size, so it may have to scale back some of these efforts.

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