

A conversation with Josh Morrison, August 25, 2017

Participants

- Josh Morrison – Co-Founder & 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 Mr. Morrison of Waitlist Zero (WLZ) to get updates on the \$200,000 general support grant it made to WLZ in August of 2015. Conversation topics included the Living Donor Support Act, WLZ's plans for a home visit education initiative, and how WLZ staff have allocated their time recently.

The Living Donor Support Act

2017 legislative session

For the first half of 2017, WLZ focused most of its efforts on attempting to get the Living Donor Support Act (LDSA) passed through the New York State legislature. The bill got close but did not end up passing this session.

The main reason that the bill did not pass was that it was voted on outside of the normal budget process. Bills that go through this process require active support in order to pass, but the bill was new and organ donation is not a high-profile issue, so it did not receive the necessary support to pass in the Assembly.

Senate

The New York State Senate Majority Leader and other important senators sponsored the LDSA, and the bill was included in the Senate's draft of the budget, which some lobbyists have told WLZ is nearly equivalent to having the bill passed.

Assembly

Because support for the LDSA in the Senate was assured, WLZ focused its efforts on the New York State Assembly. It got 78 out of 150 Assembly members to sponsor the LDSA, but this was not enough to pass because it needed to get referred out of committee first. The bill ultimately failed in the Assembly Ways and Means Committee because it did not have the support of the chair because it was outside the normal budget process.

WLZ's work to promote the bill

Public relations (PR) work

WLZ worked with hospital PR departments to develop a publicity strategy, which included identifying patient spokespeople, and having stakeholders be responsible

for pitching stories to certain news outlets. Mr. Morrison thinks this is roughly what a PR agency would have done.

This strategy was ultimately ineffective for several reasons:

- It was difficult to get the hospital PR departments to prioritize work on this.
- There was insufficient demand from news outlets.
- It was difficult to find transplant center patient spokespeople, because transplant centers do not stay in touch with their patients.

Mr. Morrison thinks that significant press coverage might have created a sense of urgency that would have helped the bill get over final hurdles.

Endorsements

WLZ got several national groups to endorse the bill, including:

- The National Kidney Foundation
- American Liver Foundation
- American Society of Transplant Surgeons
- American Society of Transplantation
- Donate Life America

Next steps

WLZ's goal now is to ensure that the LDSA is included in the New York state executive budget proposal going into 2018. The executive budget is written between September and Thanksgiving, with input from both the legislature and the governor's office.

Assembly budget

WLZ is confident that the LDSA will be in the Assembly's budget proposal, given the amount of support the bill has in the Assembly, and the fact that the prior chair of the Ways and Means Committee is stepping down. Of the three top candidates to be the new chair of the Ways and Means Committee, two are already sponsors of the LDSA, and WLZ has supporters in the districts of all three candidates, so the committee is quite likely to be in favor of the LDSA.

Governor's budget

The major remaining challenge is getting the LDSA into the governor's budget. WLZ met with the governor's office in mid-August to discuss the prospects of the LDSA.

Some things that might influence the outcome would be:

- **Getting news coverage about the organ donation situation in New York.** New York is the state in the US with the third highest number of people waiting for organ donations, but it has the lowest percentage of residents registered as organ donors. Mr. Morrison believes that a major

New York newspaper writing about this issue and about the LDSA would help get the bill passed.

- **Encouraging people to send letters to the governor's office in support of the bill.**

Collaborative projects

WLZ works closely with several other organizations, and has quarterly collaborative meetings with the New York transplant leadership.

Creation of a kidney transplant consortium

In New York, the government and major organ transplant centers contribute money to the New York Cardiothoracic Transplant Consortium (NYCTC) and the New York Center for Liver Transplantation (NYCLT). These organizations help decrease the rate of organs discarded, host planning sessions between different transplant centers, and lobby to change rules for liver transplantation, among other things. NYCTC and NYCLT each receive ~\$140,000 from transplant centers and ~\$450,000 from the state each year.

WLZ is in the process of trying to create a similar organization for kidney transplantation. WLZ may receive some funding for this, but Mr. Morrison does not know for sure or how much.

Health Resources and Services Administration (HRSA) grant

Along with Mt. Sinai Health Systems, Columbia University Medical Center, and NYU Langone Medical Center, WLZ applied for a grant from HRSA for living donation. It will find out more about the grant in several months.

Home visits

In the next six months, WLZ will focus its energy on establishing a home visit education program.

This work is particularly important because WLZ has been trying to encourage others to start programs, and has reached the conclusion that if they do not do home visit education, no one else will. A robust home visit program could also become a sustainable revenue source, and help strengthen the base community of donors by giving community members a clear project and more shared experiences. Having a stronger and more extensive community may improve outcomes for WLZ's future policy work as well.

WLZ is working on this project with Dr. Kasi McCune, a transplant surgeon at Columbia.

Time allocated to different projects

For most of 2017, until late June when the legislative session ended, WLZ's main focus was on the LDSA. Its other work during that time included laying the

groundwork for the kidney collaborative, talking to transplant centers about the HRSA grant, and thinking about its business plan for home visits.

Since the end of the legislative session, WLZ has divided its energy as follows:

- **~50% kidney collaborative and home visits**
 - Mr. Morrison grouped these two together because the relationships from the collaborative are what allows WLZ to have a customer base for home visits.
- **~20% remaining New York state legislative work**
 - This proportion will likely increase during the period when the executive budget is being written.
- **~20% generalizing the campaign to other states**
 - WLZ is working to create a template for the work it has done in New York that can easily be implemented in other states. There is some interest in such work in California, Colorado, Connecticut, Maryland, and Wisconsin.
- **~10% other work**
 - Most of WLZ's remaining work is counseling people who are considering becoming Good Samaritan kidney donors. About 250 people have signed up with WLZ, and Mr. Morrison would guess that ~10-20% of these have donated. This is approximately the same percentage as the National Kidney Registry gets.

Funding

General funding

WLZ has ~\$27,000 in the bank and is currently spending about ~\$8,000 per month. WLZ expects to receive ~\$25,000 in funding from private donors this year.

Funding for home visits

Mr. Morrison and Dr. McCune will approach Novartis to try to get funding for their home visits work. Novartis has funded WLZ in the past.

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