WAITLIST ZERO

OPEN PHIL REQUEST FOR FUNDING
EXIT GRANT

Summary: Waitlist Zero is seeking funding sufficient to continue operating for the next eighteen months. Over our three years in existence, we've achieved some moderate successes (recruiting living donors and HRSA funding for living donation), but our ability to pass transplant support legislation will determine whether or not Open Phil's investment achieved social returns equal to or greater than instead granting the money to GiveWell-recommended charities. Continuing to operate for eighteen months will give us two more chances to pass this legislation. We estimate that passage would increase live donor transplant in New York over the subsequent decade by 1,000 transplants, equivalent to a gain of approximately 8,000 QALYs. We would like Open Phil to provide a $100,000 exit grant, which would be 2/3 of the $150,000 necessary to run our operations for 18 more months.

Results from Past 24 Months: After an initial planning phase in 2014, WLZ received $200,000 from Open Phil, spread over two years. Our goal during this period was to be an advocacy organization representing kidney donors and aiming to enact transplant support policies that would make transplants easy to ask for and attractive to give. By building connections in the transplant field and advocating for consensus goals like reimbursement of donor lost wages and improved transplant education, we hoped to mobilize existing stakeholders by making cooperation on political goals easier and more attractive.

Our first campaign was a national effort to chance HRSA's policy towards living organ donation. It achieved intermediate success substantively and failed strategically. We successfully mobilized kidney donors and national stakeholders to request that HRSA (1) provide grant funding for living donation projects and (2) promote living donation as a policy goal. We achieved (1) and not (2), and HRSA has spent roughly $1M per year after our campaign (see chart of HRSA grants below in Appendix C). But this did not motivate national groups to work with us more closely or otherwise engage in further living donation advocacy efforts. We then failed to motivate federal legislators to put additional pressure on HRSA to promote living organ donation.

Our main lesson from this was to focus our energies on state-level reform because our capabilities were insufficient to achieve our goals when diffused nationwide. So we focused on building our power in New York State by building a "transplant collaborative" of leading transplant centers and other stakeholders with the immediate goal of passing transplant support legislation to reimburse donor expenses and improve transplant education. We successfully recruited stakeholder who put in genuine effort, but while we made significant progress, we failed to pass the bill in 2017.

Plan for the Next 18 Months: Our substantial investment in advocacy led to our legislation being included in the Senate budget and to a majority of Assembly legislators co-sponsoring it. This gives decent prospects for passage in 2018 and 2019 without the same level of effort as 2017, freeing up resources to focus on building a transplant education revenue model.

Multiple RCTs have demonstrated significant effectiveness for home visit transplant education, but this intervention has not been widely adopted in the U.S. We believe our New York "transplant collaborative" and partnership with Columbia provides us a supply of patients whose centers can bill for this education. Besides its substantive increase to transplant rates, the education can incorporate patient volunteers who will eventually be trained as paid educators. This will build a pool of constituents for advocacy work. Initial funding for such education exists at Columbia, and New York City is also a promising funder as well.

Finally, a key barrier to our policy goals has been lack of knowledge about living donation, particularly as a policy issue. Thus, over the next eighteen months, public awareness, particularly in the form of policy op-eds, will be more of a focus.

Funding Request: While Waitlist Zero has not achieved results that merit perennial support, our projects outstanding justify a final grant to allow both for a strong chance at passing important legislation and the ability to create a self-sustaining transplant policy reform nonprofit. If passed, transplant support legislation in New York would yield an estimated 8,000 QALYs over the following ten years (see estimate below in Appendix A), which, after a $100,000 exit grant, would work out to $43/QALY for Open Phil's total $350,000 investment over the life of the nonprofit. Additionally, longer term positive effects would be possible if either that legislation passes or a sustainable program to provide life-saving transplant education is created. Providing 2/3 of the $150,000 of funding necessary for a final 18 month period would allow sufficient runway to establish the transplant education piece and also give two more sessions in which to pass legislation.

Appendix A: Impact of Reimbursing Donor Expenses
Appendix B: Funding to Date
Appendix C: HRSA Living Donation Grants 2016-17
Appendix D: Good Samaritan Donor Candidates
Appendix E: Lessons Learned

Appendix A

Impact of Reimbursing Donor Expenses

Our New York legislation has two main components: reimbursing living donor expenses, broadly defined and requiring state-designed education materials be provided to all transplant eligible patients. An analysis by Judd Kessler, appended below, estimates that lost wage reimbursement, capped at $3,000 per donor, would yield a 20% increase in donation. There are limitations to this estimate (it was developed to justify a grant application and it makes an aggressive assumption that lost wage reimbursement would halve the discrepancy in the donation rate between the top income quintile and other income levels), but our reimbursement goes beyond lost wages, is capped at $14,000, and is expected to be $4,200 per donor.

Currently, as many as 40% of patients eligible for transplant go unlisted. If the education intervention causes 20% of them to be listed and they receive a living donor at the same rate as other patients, it would increase donation by about 10% ((2500 additions to the waiting list *. 8 * .2 * .14)/550 live donor transplants).

Thus, together we think it is realistic to expect our legislation would create a 20% increase in living organ donation in New York, leading to about 100 additional transplants per year with each transplant yielding roughly 8 QALYs, or about 8,000 QALYs gained over a ten-year period.

Appendix B

Funding to Date

Open Phil (2014 Planning Grant)	$50,000
Open Phil (2015 General Support)	$200,000
Novartis (2016)	$35,000
	$40,000
	$10,000
	$10,000
Other	$12,500
Total	**$357,500**

Appendix C

HRSA Live Donation Grants 2016-17

The following grants to living donation projects were made after our HRSA advocacy campaign and average about $2M a year for new living donation projects.

Grant	PI	Amount
1. Working Within an Integrated Learning Healthcare System to Improve Living Kidney Donation Knowledge across the CKD Continuum for all Racial Groups	Waterman (UCLA)	$1,343,808
2. Evaluating the Implementation of the Live Donor Champion Program	Segev (Hopkins)	$768,772
3. Informing American Muslims about Living Donation [I AM a LD]	Padela (U Chicago)	$824,309
4. Kidney Paired Donation: A Randomized Trial to Increase Knowledge and Informed Decision-Making	Beth Israel Deaconness (Rodrigue)	$1,096,150
		$4,033,039

Appendix D

Good Samaritan Donors

The following are results for good Samaritan donor candidates who were referred to a transplant center or the National Kidney Registry.

Donated	4
Scheduled to Donate	3
Donor process	8
Plans to donate	5
Not Presently Pursuing	3
Unknown	13
Decided against donating	2
Rejected	2

Candidate #	Outcome	Current Stage in Process
1	Decided against donating	
2	Decided against donating	
3	Donated	
4	Donated	
5	Donated	
6	Donated	
7	Donor process	Introduced to U Minn
8	Donor process	Close to approval; need to check on a few things
9	Donor process	Process broke down at Houston Methodist (through NKR). Restarting somewhere else, possibly Fort Worth or Texas Transplant institute
10	Donor process	
11	Donor process	Reviewing blood pressure and BRCA2 risk
12	Donor process	
13	Donor process	Hoping to get approval before holidays
14	Donor process	Close to approval from center; plans to donate in June when convenient with school
15	Not presently pursuing	
16	Not presently pursuing	Schedule of hospital visits and surgery were inconvenient with work

17	Not presently pursuing	
18	Plans to donate	Moved to SF. Feels settled in and wants donor referral
19	Plans to donate	
20	Plans to donate	Approved but timing didn't work
21	Plans to donate	rejected from Hopkins due to high blood pressure. Blood pressure under control so plans to donate in Chicago
22	Plans to donate	Moved to a new city (SF) and plans to donate once settled in
23	Rejected	rejected due to mental health issues
24	Rejected	Rejected from donating
25	Scheduled to donate	Scheduled to donate
26	Scheduled to donate	Scheduled to donate
27	Scheduled to donate	Surgery scheduled for January
28	Unknown	
29	Unknown	
30	Unknown	
31	Unknown	
32	Unknown	
33	Unknown	
34	Unknown	Referred to NKR
35	Unknown	
36	Unknown	
37	Unknown	
38	Unknown	
39	Unknown	
40	Unknown	

Appendix E

Lessons Learned

From the start, WLZ's goal was to focus transplant reform energies on achieving proven, consensus policy goals through tractable political processes. Representing living organ donors would allow us to lead this transplant reform movement.

Our progress with this strategy has been unsatisfactory. Living organ donors were hard to mobilize and not politically motivated. Public awareness of living organ donation was low, especially from a policy perspective, which left policymakers unmotivated about our issue. Transplant stakeholders had little energy for policy reform and were not especially hospitable to outside collaborators. We had anticipated trends in the field towards compensation and promoting living donation, but these failed to materialize.

As a result, in the next 18 months we expect to (1) reorient our strategy to more closely serve transplant centers with innovative services and (2) focus more of our political energies on directing elite media attention to transplant policy issues.

Mobilizing Living Donors and Patients: We found it difficult to mobilize patients to contact policymakers in sufficient numbers and with sufficient resilience to force action. Weak community and identity ties existed between most patients. Transplant support groups were helpful, but are small in number, serving maybe 150 patients consistently in New York State. Hospitals were unable to mobilize more than a few of their patients to support policy reform even in cases when strongly motivated to do so. Patients (donors and recipients) were interested in helping in the abstract but found legislative outreach unnatural and tended to lack the political consciousness necessary to be motivated by a desire to change transplant policy.

We have concluded that success in grassroots political advocacy will require building stronger ties of community and identity among patients (particularly donors). Our original strategy hoped to efficiently use resources by only focusing on the high marginal effectiveness of policy change. But this idea is alien to most constituents, whose political activities tend to be expressive rather than outcome-oriented. People will engage in political advocacy when it is a natural outgrowth of communal activities they already feel identified with. Thus, we now believe that the high-leverage advocacy work we started with needs to be anchored to more broad-based volunteering or employment to be viable. We hope that by using patients and donors as volunteer teachers and champions, our transplant education efforts will develop this community and grow their political consciousness.

Public Awareness: Awareness of living organ donation in general is quite low, so public interest in transplant policy questions is much lower still. We had not anticipated the size of the obstacle this would create for our advocacy efforts, since decision-makers are both themselves ill-informed about the issue and media have little incentive to draw attention to the policy question because their audience is uninterested. Even when press coverage arises, capitalizing on it is difficult. For example, a John Oliver segment on dialysis identified exactly the education problem our New York bill was aimed at solving. But it proved impossible to get further coverage on this provision or to motivate legislators to care about the previous coverage. Moreover, our strategy has been to pursue incremental policies with broad consensus. These policies are not especially newsworthy because they lack controversy. Even friendly journalists who are donors themselves or otherwise motivated to write about transplant have found it difficult to write pieces about transplant policy.

Improving public awareness of living organ donation requires a longer-term focus on increasing knowledge of living donation in general among the general public and of transplant policy reform among media elites. The home visit education model we're pursuing with Columbia includes a public awareness piece centered on individual campaigns to find donors for potential recipients. We will also orient more of our advocacy efforts to writing for publications that would inform other health policy writers about the issue.

Transplant Stakeholders: We entered the field believing that a living donation policy reform trend existed that we could participate in and hopefully accelerate. Leading professional societies had endorsed steps towards giving donors compensation, and publicly facing stakeholders embraced promoting living donation as part of their strategic plans. But after three years this trend has not emerged. Bracketing WLZ, the living donation field remains largely stagnant. Compensation and public awareness efforts failed to materialize, and professional associations have moved on to focus on funding for anti-rejection research. More broadly, other reform efforts have proven disappointing. For example, paired kidney donation has not seen significant increases, other transplant reform organizations have not remained in operation. The interesting developments that exist are the National Kidney Registry's Advanced Donation Program and the Arnold Foundation's funding of a lost wages reimbursement trial.

More generally, we have found that transplant centers are internally balkanized, incapable of decisive action, and lack motivation to reform. Perhaps more problematically, we have found at both the national and the state level that branding ourselves as a patient-representative group has led us to be distrusted as being outside the transplant profession in key ways. Patients have little power in the field or access to decision-makers, and this seems likely to continue.

To respond to this, WLZ plans to draw itself closer to the transplant profession, framing its work less as representing outside donors and more as a service provider to transplant centers, which are the center of gravity and power within the field.