

WAITLIST ZERO

REQUEST FOR FUNDING

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Overview

Ending the kidney transplant shortage is possible and would represent one of the great public health achievements of the 21st century. Each year twenty thousand more Americans are added to the waiting list than receive a kidney transplant. Each transplant from a living donor saves about 8 Quality Adjusted Life Years (QALYs).¹ Because transplant is the rare place where lifesaving treatment saves significant costs to the federal government, any effective reform program would be self-funding.

Although we do not believe it would be feasible to enact a policy providing frank incentives for donors, interest group consensus in the field can be marshaled for passage of transplant support policies that we believe would eventually be sufficient to close the gap. These policies might include comprehensive transplant education for the public, patients, and their families as well as a package of benefits to donors worth in the low-mid five figures. Home education programs have already been shown in multiple randomized control trials to increase living kidney donations to program participants by ~20 percentage points, so simply scaling that intervention to cover everyone medically eligible for transplant could eliminate a third of the gap.

¹ See [Kelly and Morrison, 2014](#). But see [Matas et al., 2004](#) for a 3.5 QALY estimate.

Sufficient transplant support would end the shortage and provide a model for transplant policy in other countries, which face similar shortages.

Since the beginning of 2015, WaitList Zero has made rapid progress. We have assembled a Coalition to Promote Living Kidney Donation² of ten nonprofits, (the Coalition) including leading patient groups. We have built strong relationships with both the American Society of Transplantation, the largest association of transplant professionals, which has asked us to help them recruit a patient advisory council, and Donate Life America, the umbrella group for public education about organ donation, which has spoken with HRSA on our behalf. We recruited hundreds of living kidney donors to sign an open letter in support of our policy platform, and we expect to be able to further organize those individuals in the future.³ We are currently working with the Health Resources and Services Administration (HRSA), the target of our first federal campaign, to plan a stakeholder meeting on living kidney donation. Within the next two years, we expect that campaign to result in HRSA reallocating ~\$3.5 million a year in existing research funding from efforts aimed at promoting deceased donation to ones aimed at living donation, which we believe to be much more cost-effective. Within the next year, we expect the campaign to lead HRSA to launch a Living Donation Breakthrough Collaborative, based on the model of the Organ Donation Breakthrough Collaborative that it initiated in 2003,⁴ which resulted in about 5K additional deceased-donor kidney transplants.⁵ A Living Donor Collaborative is eminently feasible and could lead to the scale-up of extremely cost-effective interventions like home visits.

This progress has presented us with tremendously exciting opportunities for growth. We intend to raise \$600K to support our next two years of work, which represents our full core operational budget (\$500K) along with \$50K each to launch two projects that we believe will have an outsized effect on our success. (See Appendix A—Budget). We are asking the Open Philanthropy Project (OPP) for half of our two-year full budget, \$300K.

Planning Period: September to December 2014

Last September, the OPP disbursed a \$50K grant for a four-month planning period to develop a nonprofit devoted to decreasing the transplant shortage by making donation more attractive to donors:

“The key deliverable from the project [was] a detailed plan for such an organization, including a convincing theory of change and an assessment of the human and financial resources required to execute

² See [Statement of Principles, 2015](#) for the policies members sign onto to join the Coalition. See also Appendix C: Sample Coalition Statement of Responsibilities for expectations signed onto by member organizations.

³ We have already received ~150 detailed questionnaires from them about their experiences and policy suggestions.

⁴ The Collaborative became the nonprofit [Organ Donation and Transplantation Alliance](#) in 2006.

⁵ Total deceased donor kidney transplants in the five years between 2003 and 2007 were 49,191 [8668+9359+9913+10660+10591], compared to an expected 43,974 given the average rate of increase from 1998-2003 [((8668-8034)/(2003-1998)+8668)*5].

it; [OP] also hope[d] to see evidence of support or buy-in from relevant constituencies (e.g. funders, patients, transplant groups).”⁶

We decided to create an organization representing kidney donors whose mission is to end the transplant shortage through increased support for living donation.

During this period, we also conceived, investigated, and launched our initial advocacy campaign, to persuade HRSA to fully support living donation by allowing living donation projects to receive the same grant funding treatment as deceased donation.⁷

Decision Process and Outcome: During that four-month period (in addition to preparatory work performed over the previous two months), we consulted experts in the transplant, bioethics, political advocacy, and community organizing fields. Based on what we learned in those conversations, we decided to focus strategically on: (1) organizing existing interest groups to advocate for change and (2) representing living kidney donors as a constituency. The key rationale for prioritizing organizing existing interest groups is that we believe this is a low-salience, potentially controversial policy area where developing consensus and marshaling support will be key to success. We've decided to prioritize representing living kidney donors as our core constituency because (a) they are a potentially sympathetic group, (b) we can effectively claim to represent them because we are living kidney donors, (c) we've had more success so far reaching and mobilizing them than we have with other groups (e.g. patients), and (d) no other group currently exists to mobilize them.

Approaches Considered and Rejected: We tested and rejected several other strategies, including organizing patients directly, reaching out to communities of color as allies, and recruiting non-directed donors—these measures failed to gain traction and seemed better achievable by recruiting partner organizations. We additionally explored putting on a publicity-grabbing event with recent non-directed donors dedicating their donation to policy reform demands but rejected it as premature without a clear agenda and institutional capacity for pushing the issue forward beyond the event. We explored and rejected explicitly orienting our mission towards incentives. (See Appendix B: Evolution of Our Thinking on Incentives).

Operational Track Record: January 2015 to Present

We are very excited about our progress to date. In the past fifteen weeks, we have celebrated successes in the following areas:

Coalition-Building—*Coalition to Promote Living Kidney Donation*: We have assembled our growing Coalition of (currently) ten active member organizations, including the American Association of Kidney Patients (AAKP).⁸

⁶ [GiveWell, 2014](#).

⁷ See [HRSA Campaign, 2015](#) for a public description of the campaign.

⁸ Coalition membership currently includes: AAKP, Dialysis Advocates, Donate Life Northwest, The John Brockington Foundation, Living Kidney Donor Network, Northeast Kidney Foundation, Renal

- **Strategic Partnerships:** We have formed strategic partnerships with the American Society for Transplantation (AST), the largest transplant professional association in the country and Donate Life America (DLA), the national umbrella group responsible for public education about organ donation.
 - AST has met with HRSA on living donation issues at our request and will partner with us on a joint stakeholder meeting invitation to HRSA. They have also asked us for help with setting up a professional-patient summit meeting, surveying patients and donors in our Coalition about compensation, and recommending members for an AST Patient Advisory Counsel.
 - DLA has asked HRSA to support our campaign, agreed to join our stakeholder meeting invitation, and offered help with soliciting congressional support for our campaign.
- **Transplant Roundtable:** We presented our campaign at the Transplant Roundtable⁹ and, in addition to our Coalition's support, acquired important signatories like DLA and the National Kidney Registry (NKR) to the Roundtable's letter to Congress in support of HRSA funding.
- **Transplant Education Council:** We have begun assembling a Transplant Education Council of leading nonprofits, transplant education scholars, and professionals that will disseminate best practices (like home visits and the donor champion model) and build capacity for patient education efforts.

Representing Donors—

- **Donor Letter of Support:** We have built a contact list of living kidney donors by having over 500 sign a letter online in support of our platform. Our goal is to collect 1,000 signatures by June 1st, which would represent nearly 1% of all American kidney donors.
- **Donor Questionnaire:** Over a hundred donors have submitted detailed questionnaires to us about their experience donating and how transplant policy could be improved.

Campaign Successes—

- **HRSA:**
 - Our Coalition had a promising initial meeting with HRSA in January.
 - We conducted a successful social media campaign that yielded (among other things) 7,500 petition signatures.¹⁰

Support Network, Transplant Recipients International Organization, Transplant Support Organization, and WaitList Zero.

⁹ The Roundtable is an informal trade association meeting quarterly and representing transplant interests: members include the National Kidney Foundation, American Society of Transplantation, Transplant Recipients International Organization, American Association of Kidney Patients, American Society of Transplant Surgeons, Association of Organ Procurement Organizations, American Society of Nephrology, Dialysis Patient Citizens, and the United Network for Organ Sharing, among others. See, e.g., [Transplant Roundtable, 2013](#).

¹⁰ See [Change.org Petition, 2015](#).

- During the public comment period of the most recent Advisory Committee on Transplantation¹¹ (ACOT) meeting, nearly all comments made concerned living donation, the majority of which (five) were initiated by our efforts.¹² The ACOT chair suggested forming a special subcommittee on living donation issues as a result.
- **Patient Education**
 - We have attained pro bono representation from a well-regarded Washington lobbying firm for our campaign.
 - We acquired an opinion letter from a transplant billing consultancy indicating that transplant education expenses are reimbursable. (Most transplant education programs do not apply for Medicare reimbursement and view themselves as cash-constrained).

Two Year Plan: 2015–16

Summary: Two years from now we expect to be nationally recognized as both the leading organization in living kidney donation policy and the authoritative representative of living kidney donor interests. We will have a significant role in the new Living Donation Collaborative created as a result of our successful HRSA campaign. We will have driven significant resources to home visit transplant education and built a Patient Education Counsel to expand transplant education capacity.

In addition, we will have received national news coverage for the first living kidney donor conference and will be close to achieving model living donation legislation in New York State with similar campaigns initiated in other states that contain key federal legislators.

HRSA Campaign and Living Donor Collaborative: We chose this as our first campaign because it combined a principled stance, significant opportunity for coalition-building, and a moderately important substantive goal that could feasibly be achieved without significant new federal funding or legislation.

- **Coalition-Building:** The HRSA campaign has already allowed us to successfully launch our Coalition to Promote Living Kidney Donation (see Operational Track Record, below). The next step in the campaign is setting a stakeholder meeting with HRSA to discuss living donation policy. This will likely be held in mid-to-late July. Because this meeting will be attractive to potential attendees throughout the transplant field, it will serve as an effective recruitment tool for our Coalition. Moreover, congressional lobbying before that meeting will build our legislative capacity and relationships.

¹¹ The Advisory Committee on Transplantation is a group of external advisors that provides recommendations to the Secretary of Health and Human Services on a variety of transplant issues.

¹² See Advisory Committee on Transplantation March 2014 Minutes, [Forthcoming](#).

- **Substantive Goals:** As our campaign has evolved, it has developed two substantive goals: first, to redirect \$3.5M in HRSA grant funding each year to living donation projects and, second, to persuade HRSA to sponsor a Living Donation Breakthrough Collaborative.
 - *Grant Funding:* Each year, HRSA budgets \$7M for grants to increase solid organ donation. Currently, none of these grants are allowed to go to living donation projects. Last year, no new grants were offered. If grants are offered and half go to living donation projects, we expect most grants to go to transplant education efforts. Because of Request for Proposal timing, we are unsure if grants made this year will respond to our campaign but feel confident any grants made in future years will do so.
 - *Living Donation Breakthrough Collaborative:* In 2003, an Organ Donation Breakthrough Collaborative was sponsored by HRSA. It gathered transplant elites, set and monitored best practices, and resulted in substantial increases in donation, which we estimate at ~5K. (Total transplants in the five years between 2003 and 2007 were 48K compared to an expected 43K given the average rate of increase from 1998-2003.) We would expect similar increases from a Living Donation Collaborative. Moreover, we believe the stakeholder meeting, the attendees of which we will have a strong voice in selecting, can be made to form the basis of such a collaborative.

Patient Education: Most End Stage Renal Disease (ESRD) patients are essentially uneducated about transplant, which is why as many as a quarter of all ESRD patients are medically eligible for transplant yet are never listed.¹³ One education methodology, transplant professional home visits to educate patients and their families, has had two randomized control trials (RCTs) showing dramatically increased living donation compared to in-center transplant education (52%/30% and 44%/9% respectively).¹⁴ Requiring this kind of education for ESRD patients could more than double the number of annual living donor transplants.¹⁵

Policy Goals: Our goal is (1) to direct significantly more funding to these programs by clarifying Medicare reimbursement policy and (2) to build capacity for new programs by creating a Transplant Education Council to set best practices and certify adoption. Ideally, Organ Procurement Organizations (OPOs), large, well-funded nonprofits that handle deceased donation logistics, could be major vehicles of living donor education. (See the New York legislative campaign below for further discussion about creating a home visit education requirement for all transplant patients.)

¹³ [Schold et al., 2008.](#)

¹⁴ See [Rodrigue et al., 2007](#) and [Ismail et al., 2014.](#)

¹⁵ (35K (patients added to waiting list each year))*20% = 7K. If the program were applied to all those medically eligible for transplant, not just those on the waitlist, the potential benefit might be ~20% larger.

Center Adoption Target: Currently, about five transplant centers pursue some form of home visit program. We hope to expand this number to twelve in two years with at least one OPO also participating.

Donor Mobilization: No nonprofit currently represents the interests of living kidney donors. Those interests are crucial to living donation policy, because: (1) the number of donors is the constraining factor on transplantation rates; (2) arguments against fully pursuing living donation inevitably rely on claims about donor welfare; and (3) because donors have unique moral authority in the transplant field. As a group founded by living donors, WaitList Zero is uniquely positioned to fill this niche.

Member Recruitment: Despite relatively limited effort and without publicity, we have already achieved a surprising level of success in building a living donor constituency (see Operational Track Record above). We intend to continue recruiting donors to support our policy platform, asking them to share their stories, identifying and utilizing passionate volunteers, and interviewing donors who have experienced complications or are otherwise unsatisfied. Our goal is to have an active donor membership of 2,000 (accounting for approximately 1.6% of all living donors since recordkeeping began in the U.S. in 1988) by the end of 2016.

Donor Conference: A major project we intend to launch in Q4 of 2015 is to hold the first living donor conference in mid-to-late 2016. We intend to use the conference to promulgate and publicize our policy platform, organize donors, and receive national media coverage. We will also tie this into political campaigns we are pursuing contemporaneously.

State Legislative Campaign: Organ donation is a low-salience issue affecting a relatively small and politically marginalized community. Given the tight federal legislative window, we believe constituent pressure is needed for federal legislation to pass. Additionally, as a new organization, it will take time to build federal legislative relationships.

Political Rationale: We believe that the best way of building local constituencies in key federal legislative districts (e.g. those of members of the relevant appropriations committees) is to conduct successful state campaigns mobilizing transplant interest groups at the state level (transplant centers, OPOs, local patient chapters, etc.) that can build relationships with federal legislators during the state campaign and then target them directly for the federal campaign. These campaigns would provide achievable wins that further our policy platform and have some substantive value. They would also create precedent and pressure for federal legislation (and ideally, evidence of effectiveness).

New York Campaign: Our first state campaign will be in New York State, given our headquarters here, our good relationships with several important transplant centers and nonprofits, and our support from individuals who succeeded in passing statewide transplant legislation in the past. Our goal will be to achieve legislation within two years from when the campaign is launched (in Q3 of 2015) and to fund this campaign largely from local transplant centers and national professional

associations (whose removing disincentives agenda will be advanced). The campaign will then serve as a model for similar campaigns in other states.

Bill Components: We anticipate that the legislation will consist of: (1) paying lost wages and other costs of donation; (2) requiring comprehensive transplant education for all medically eligible patients; and (3) providing patients with one year of free health insurance post-donation. It may also create a living donor registry or otherwise try to integrate OPOs into living donation. We hope the bill can largely be financed by fees on interest groups benefitting from transplantation (insurers, immunosuppressant manufacturers, and transplant centers), but that approach is fairly speculative at this point.

Funding Needs

Given our rapid progress to date, we need to raise significant funds to capitalize on the opportunities available.

Our fundraising goal for 2015 is \$600K, which provides two years of our core operational budget as well as a significant portion of two major projects. We think a two-year time frame would allow WaitList Zero to demonstrate a sustained track record of success, achieve meaningful policy wins, and build a diversified funding base. We are requesting 50% of this funding from OPP.

Providing a full level of funding at this level would be \$300K; a minimal level of funding would be \$114K. (See Appendix A).

Appendix A

Budget

Core Budget	
Josh's Comp¹	82
Thomas Comp²	18
Junior Staff Comp³	50
Communications Consultant	20
Development Consultant	15
Office	13
Website	10
Travel	12.5
Events	10
Other	20
Total	250

¹ Full comp assumes a base salary of \$75K/yr+health insurance + FICA.

² Compensation of cofounder, Thomas Kelly- Thomas has so far spent approximately 10-20 hours per week on Waitlist Zero business since leaving employment, devoting 70% of his time to patient education and 20% to One Body. Full pays buys a quarter of his time at a \$75K/yr rate.

³ We have a strong candidate for a junior position currently working as an unpaid consultant. \$45K/yr annual salary is what we think would be sufficient to bring her on full-time.

NYS Legislative Budget		
	Y1	Y2
Field Director	75	80
Outside Lobbyist	25	25
Travel	2.5	2.5
Events	5	5
Other	5	5
Total	107.5	112.5

Donor Conference Budget	
Event Planner	25
PR Firm	10
Travel and Lodging	40
Venue	20
Other	10
Total	105

Appendix B

Evolution of Our Thinking on Incentives

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Our History of Supporting Incentives

General Incentive Rationale: Before founding WaitList Zero, both of its creators (Thomas Kelly and Josh Morrison) were attracted to transplant policy by the potential of financial incentives to end the kidney shortage. The safety and convenience of laparoscopic nephrectomy¹ implied a price existed that would end the shortage. The cost-savings of transplant to the federal government (conservatively estimated at \$120K/procedure²) implied that this shortage-clearing price would reduce government expenditures on kidney failure, which are substantial.³ The kidney shortage causes tremendous suffering⁴ and affects a sizable

¹ The procedure has a 0.03% mortality rate and average hospital stay of two nights. Most office workers return to work in 2-3 weeks. Long-term complications occur in less than 1% of donors.

² See [Matas et al., 2004](#) (\$95K in savings at the time, equivalent to \$120K in 2015). This figure likely underestimates savings – when amortized over five years, the annual cost of transplant to Medicare (surgery and annual immunosuppressants) is about \$30K and dialysis is about \$85K. A living donor transplants lasts an average of fourteen years.

³ Coverage for patients with kidney failure is guaranteed by Medicare, regardless of patient age. Kidney failure accounts for 6% of Medicare's total budget, \$32.9B. [USRDS, 2012](#).

population,⁵ so anything that would end the shortage while saving government funds seemed both morally urgent and politically achievable.

Our Background with Incentives: Josh met his first employer in the transplant field, Mike Rees of the Alliance for Paired Donation, at a conference at Duke about incentives for organ donation, which also led to a law review piece co-authored by Josh about incentives on the state level. Josh and Thomas first met in person at a Princeton conference on incentives, where Josh proposed the idea of an academic open letter in support of pilots of incentives, which he and Thomas were two co-authors of and on which Josh had a leadership role in its early stages. Both founders continue to believe that making donation more attractive to donors would be effective at increasing living donation and could be structured to avoid risks of exploitation and commodification.

Change in Our Thinking: Nevertheless, our thinking about incentives has evolved substantially, and we have decided to eschew incentives as an explicit goal of our organization.⁶ Specifically, we have come to believe that: (1) the shortage can be significantly reduced or even ended without compensation; (2) directly and explicitly aiming towards incentives for organ donation would significantly undermine our organization's ability to end the shortage; (3) intermediate, near-term, policy achievements are possible whose passage would (a) substantially increase transplantation; (b) be impossible for an organization publicly committed to incentives; and (c) significantly improve the achievability of explicit incentives if we prove incorrect about (1) above and explicit incentives are what is needed to end the shortage.

Incentives Landscape in the Transplant Field

Summary: Support for some type of incentive for organ donation has increased and has expanded beyond its libertarian origins. However, opposition remains strong and intractable. Both sides of the debate have moderated, and we see a growing consensus on certain transplant support goals across both sides. We believe we can harvest this consensus to yield powerfully pro-transplant political achievements, but that taking a position on incentives would wreck our ability to do so.

⁴ Dialysis treatment is unpleasant, exhausting, and unhealthy. Fewer than 20% of dialysis patients maintain full employment (admittedly the average age of ESRD onset is 65). The five-year survival rate of patients on dialysis is 36% (though patients eligible for transplant are a somewhat healthier cohort—typically with a prognosis of longer than five years of survival on dialysis). By comparison living donor transplant lasts an average of about fourteen years, and recipients lead normal, healthy lives.

⁵ Approximately 100-160K patients are currently medically eligible for transplant. See [Schold, 2008](#). Each year, 20K more enter the waiting list than receive a transplant.

⁶ This document focuses on strategic considerations, but we also believe there are normative problems with a frank incentive approach, including potentially reducing the social esteem of donation (commodification) such that people who would currently decide to be living or deceased donors decide not to do so (crowding out). Our program of transplant support avoids these normative concerns.

Moderating Trend of Pro-Incentive Positions: Our work on the open letter in support of incentives⁷ (the Open Letter) prior to founding WaitList Zero and our engagement with transplant professional societies have informed our understanding of what pro-incentive actors believe possible, which involves *a pilot stage*⁸ and *does not include cash incentives* as an explicit goal. We believe this reflects an underlying political reality that should guide our behavior.

- **Open Letter:** The Open Letter was able to secure support from elite bioethicists and transplant figures largely drawn from the political left. This was encouraging because support in the past had been confined to the libertarian right. At the same time, this support was contingent on a request for pilot trials of non-cash incentives. A stronger position could not have gathered elite signatories.
 - Moreover, this stance was not without controversy—a counter-letter swearing off incentives altogether was assembled with signatories of similar stature⁹ (the Delmonico Letter). It called for the removal of disincentives while drawing a hard line against incentives.
 - Neither the pro-incentive or anti-incentive letters received significant media coverage, despite efforts to attain publicity for the Open Letter.
- **AST/American Society of Transplant Surgeons (ASTS) Incentives White Paper:** Josh attended a workgroup on incentives held by the professional societies in June 2014. The white paper¹⁰ from this conference calls for an “arc of change” starting with optimizing the current system, moving rapidly to removal of disincentives,¹¹ and then proceeding (at an undefined point) to pilots of incentives.
- **Key Individuals:** For years, Sally Satel has been the figure most associated with making the pro-incentive case. Her most recent editorial¹² advocated for the demands of the open letter: trials of non-cash incentives, a significant moderation of past positions. Similarly, economist Al Roth, who won a Nobel Prize in part for his work in the transplant field, had not previously taken a public position on incentives but now endorses state-level experimentation to gather evidence.¹³

Anti-Incentive Interests Remain Strong But Have Moderated: Anti-incentive forces remain quite potent:

⁷ [Open Letter, 2014](#).

⁸ After analyzing a political strategy of passing pilots as the primary path to incentives we found it to have significant drawbacks. Kelly and Morrison, 2014. Available upon request.

⁹ [Delmonico, 2015](#).

¹⁰ [Salomon et al., 2015](#), 2015. See also [NY Times Room for Debate, 2014](#).

¹¹ These included clearly pay for lost wages and other out-of-pocket expenses and probably for donor loved ones who needed an organ. Lifetime health insurance was postulated as potentially attractive without being firmly endorsed.

¹² [Satel, 2015](#).

¹³ [Roth, 2015](#).

- ***Delmonico Letter***: While American transplant professional societies have elected pro-incentive leadership over the last few years, a solid core of well-regarded transplant professionals signed the Delmonico Letter.
- ***Major Stakeholders Against Incentives***: Influential nonprofits such as the National Kidney Foundation (NKF)¹⁴ and the AAKP have hardline anti-incentive positions.
- ***Targeting More Living Donation Can Be a Taboo***: There is also discomfort with explicitly targeting increased living donation among professional associations like AST, transplant educators like Explore Transplant, and governmental agencies like HRSA, which imply further obstacles for incentives.
 - This discomfort may stem from transplant professionals' role in obtaining informed consent from patients who do not medically benefit from surgery. In their professional interactions with potential donors, it is inappropriate to treat donors as a resource, and this protective attitude is then transmitted to public policy.

Broad Support for Donor Benefits: Even those who are anti-incentive support a significant increase in benefits for donors compared to the status quo.

- ***Paying Financial Costs of Donation Is Broadly Accepted***: As mentioned above, even anti-incentive literature concedes a desire to pay for the financial costs of donation, usually estimated at \$5-6K on average.
- ***Strong Incentive Opponents Endorse Healthcare Provision***:
 - ***AAKP***: As part of joining our Coalition to Promote Living Kidney Donation, the AAKP endorsed the Coalition Statement of Principles,¹⁵ which calls for the provision of healthcare for donors.
 - ***Key Figures***: A leading opponent of incentives, Gabe Danovitch, co-authored an article calling for lifetime health coverage for donors along with a \$5,000 payment to compensate for the inconvenience of donation.¹⁶
 - ***The Delmonico Letter*** endorses “lifelong follow-up for all living donors, with guaranteed provision of any donation-related medical care not fully covered by donors' own health insurance.”

Many Stakeholders Are Cautious and Do Not Take a Position: Many organizations in the transplant field are skittish and avoid a clear stance on incentives. Some groups like Explore Transplant, NKR, and Renewal view themselves as essentially apolitical. Others, like DLA or certain OPOs and transplant centers, are already politically engaged in promoting transplantation, but seek to avoid controversy. We believe that it is possible to rally political support from both groups, but only for goals with significant consensus in the field where achievement would benefit organizational goals directly. These groups will not sign onto a coalition whose avowed goal is promoting incentives.

¹⁴ [National Kidney Foundation, 2003.](#)

¹⁵ [Statement of Principles, 2015.](#)

¹⁶ [Gaston et al., 2006.](#)

Orthogonal Policies with Broad Support: In addition to the donor benefits policies described above, there is also broad political consensus for two other policies of interest to us: increased transplant education and expanded donor follow-up, although some of the support for increased donor follow-up comes from those hostile to living donation who appear to believe increased follow-up will reveal greater risks from donation. While these goals sound anodyne, appropriately developed education and follow-up efforts are complementary to donor benefit goals and can dramatically increase transplantation on their own.

Increased Transplant Education: A deficit in education about transplantation clearly exists. As much as one quarter of all dialysis patients are medically eligible for transplantation, but are never listed for the deceased donor transplant waiting list.¹⁷ Living donation education is even worse than that provided about deceased donation. No large-scale public education campaigns exist about it, and ESRD patients who often lack medical sophistication are the ones responsible for informing potential donors about transplantation and asking them to give. Both of these tasks are daunting.

This implies that better education is possible, and indeed, two different methodologies have been increasing in popularity among sophisticated centers. The first is a donor champion model that seeks to inform and recruit a member of an ESRD patient's social circle to act as their champion in the transplant search.¹⁸ This model is promising, but lacks clear evidence of effectiveness to date. The second model involves home visits by transplant professionals to educate patients and their families about transplant. Two separate RCTs of home visits have found dramatic increases in living donation compared to in-center transplant education¹⁹ (which many ESRD patients already do not receive). In both trials, an additional twenty percent of the treatment population received living donor transplants than the control group. Mandating this type of education just for patients currently on the waiting list could yield as many as 16K transplants.

Increased Donor Follow-Up: Currently, transplant centers are only required to follow donors for two years post-transplant. There is a widespread belief in the transplant field that more information about donors could provide a better understanding about the risks of donation. The increased interest in living donation has led to a corresponding desire for better safety information.²⁰ Transplant centers indicate that the major obstacle to this follow-up is donor willingness to make and attend appointments, sometimes caused by donor relocation. A policy that mandated high lifetime follow-up rates for transplant centers and incentivized donors to do their follow-up could achieve attractive transplant field goals, create more certainty around donor outcomes, and provide annual stipends for kidney donors. We support increased donor follow-up as a matter of transparency and fairness. However, while providing stipends to donors who attend follow-up

¹⁷ [Schold et al., 2008](#).

¹⁸ See, e.g., [Garoznik-Wang et al., 2012](#).

¹⁹ See [Rodrigue et al., 2007](#) and [Ismail et al., 2014](#).

²⁰ See Advisory Committee on Transplantation March 2014 Minutes, [Forthcoming](#).

appointments should increase living donation, increased follow-up in isolation increases the regulatory burden on transplant centers and may decrease living donation.

Transplant Support

There is broad consensus for removing financial costs, alleviating medical risks of donation, educating patients about transplant, and providing long-term follow-up.

Transplant Support Policies: We believe this opens a political opportunity for consensus support of our political program of transplant support. It includes: (1) paying costs of donation; (2) provision of 5-10 years of free health insurance to avoid gaps in coverage; (3) lifetime donor follow-up care and study, with donors receiving an annual stipend of a few hundred dollars for each year they participate in the study; (4) home visit transplant education for all medically eligible patients and their families; (5) expanded public education around living donation. These benefits would be worth in the low to mid tens of thousands of dollars, and potential donors would be informed about them in the homes of their loved ones by professional transplant educators.

Transplant Support Is Politically Feasible: Predictions about political feasibility are highly uncertain, but given consensus in the field behind many of these goals, the cost-saving nature of transplant increases, a stepwise political roadmap to legislation, and our rapid progress to date, we believe federal passage of this program is possible within a 4-6 year timeframe.

Transplant Support Will Be Effective: The amount of benefits provided by transplant support provides a strong reason to donate given the relative safety and convenience of donation. This reason will be offered to people who already have a strong stake in donating to a family member or loved one. The provision of these benefits will make seeking a living donor transplant significantly easier for ESRD patients, because it reduces the burden implicit in the request for a donation. It is impossible to specifically quantify the results of a fairly novel program, but several pieces of evidence indicate that it will have a powerful impact:

- **Home Visits Alone Are Effective:** Each year, 36K patients enter the kidney waiting list, while 17K receive a transplant (11.5K deceased; 5.5K living).²¹ If home visits find living donor transplants for an additional 20% of that figure, that alone would double annual living donor transplantation.²²
- **Lost Wages Alone Might Increase Donation:** Some evidence exists that relatively small amounts of reimbursement can have an impact.
 - Seventy percent of participants in the National Living Donor Assistance Center (which pays travel costs for donors who make less

²¹ UNOS website. < <http://www.unos.org/index.php> > retrieved April 2, 2014.

²² This may undercount the number affected because it does not include patients who currently are not listed. It might over count because it assumes study-conditions would apply universally.

than 3X the poverty line) self-report that they would not have donated but for the support.²³

- Living donation rates decline directly with income despite lower income populations having higher incidence of ESRD.²⁴
- During the recession, donation rates declined in the bottom three income quintiles, stayed flat in the 2nd highest, and grew in the highest quintile.²⁵

Transplant Support Improves Prospects for Future Political Change: Achieving increases in living donor transplantation through better treatment of donors can only strengthen further attempts to end the shortage. If providing benefits works substantively and is cost-effective, the case for providing more benefits will only become stronger. If kidney donation retains high social esteem and strong informed consent, the fears of incentive opponents will seem far more remote. An organization that brought about significant and life-saving policy change will have great resources and credibility to advocate for further policy.

Even if further expansion of the transplant support model is insufficient to end the shortage and frank incentives were to prove necessary (which we do not believe to be the case), the case for incentives would be stronger than it is today because opponents would not be able to claim that the transplant support model would be sufficient.

Response to Counterarguments

Our model of political change involves organizing interest groups around moderate and overlapping policies to achieve political success. One challenge to our anti-incentives argument is that this moderate model is misguided and that a more radical messaging model would be superior. We lay out two stylized approaches below and argue why our approach is superior in the kidney transplant space.

Coalition-Building Model: Our model of political change involves mobilizing a growing coalition by achieving concrete and escalating political victories. Victories are achieved by demonstrating power to decision-makers. Power stems from interest groups being mobilized within the coalition to fight for the desired policy. This is a moderate, incremental strategy that requires identifying a zone of overlap between interest groups and gathering them together to push for policies within that zone. Incremental wins are necessary to prove to the coalition's constituent members the effectiveness of their efforts on behalf of the coalition. Value is added by solving the collective action problem that each constituent interest group faces in promoting its preferred policy.

²³ See NLDAC Press Release, 2013.

²⁴ Technically the average income of their zip code. See [Gill et al., 2014](#)

²⁵ Id.

Policy Persuasion Model: An alternative model aims to change opinion towards a policy. Here, the public, elites, and interests are persuaded by normative appeal to change their policy goals and/or the priority of those goals. Tactics vary by the target of persuasion—for example, a campaign to persuade elites may involve making the case in an academic arena; the public might be targeted through political theater. By changing background beliefs, the hope is that interest groups will then mobilize for the newly popular policy on their own (or that the first, coalition-mobilization, strategy can then be run with greater success).

Coalition-Building Should Be Prioritized: As it pertains to our issue area, we believe the coalition-building model is superior.

- ***Past Efforts at Persuasion Have Failed:*** The debate on incentives is long-standing and stagnant. Academic gatherings like the Princeton or Duke conferences have not yielded meaningful results. The Open Letter was able to gather admirable signatories but failed to gain meaningful public attention.
- ***Awareness of the Problem Is Low:*** Kidney failure has a highly concentrated impact on a relatively small, marginalized group. The public has little self-interested reason to devote attention to the issue, so the media has little incentive to cover it. Correspondingly, given the low initial information base, a persuasion strategy requires significant public education whose success is at best unpredictable.
 - Such an education strategy would also be hampered by controversy in its early stages if its ostensible goal were incentives.
- ***Political Change is Newsworthy; Suffering Is Not:*** The coalition model generates its own media coverage through incremental political success. The persuasion model requires engaging public sympathy by demonstrating the suffering of others, which is non-unique to our issue.
- ***Beliefs About Organ Donation May Not Be Amenable to Persuasion:*** Beliefs about kidney incentives overlap with feelings of repugnance in other contexts.²⁶ As a biomedical innovation, transplantation can raise a yuck factor that could stymie awareness-raising. Moreover, transplant raises uncomfortable questions about the sacrifices of the donor and one's own willingness to donate to a loved one. These may also make public attention difficult to attain.
- ***Friction and Legislative Capacity:*** In the current legislative arena, the only kind of legislation likely to succeed is either (a) important enough to warrant a very significant partisan mobilization or (b) totally uncontroversial. Given low public awareness, significant mobilization is unlikely, so consensus presents a better strategy.
- ***The Coalition-Building Function Is Necessary Given the Interest Group Space:*** The interests in favor of increased transplantation are disempowered and decentralized. They have not acted effectively to promote transplant policy in the past, in part because the natural leader, NKF, did not prioritize

²⁶ [Leider and Roth, 2010](#). See generally Roth, 2007.

transplant interests over dialysis ones.²⁷ Transplant interests are not politically agile and do not feel able to forthrightly endorse the goal of increased living kidney donation.

- ***Achieving Consensus Will Be Difficult, and Consensus is Important:*** Opinions among bioethicists, transplant professionals, and other elites in the field are well-informed, mixed towards incentives, and unlikely to be dramatically changed through rational argument. An issue that continues to be controversial will have very poor prospects in a tight legislative environment.
- ***The Marginal Value of Coalition-Building Is Especially High for New Groups:*** Convincing existing organizations and interest groups to support our cause lends us credibility and supporters at an early stage. As the organization matures and builds its own brand, these factors may be less important.

Pursuing Incentives Is Inconsistent with Coalition-Building

- ***Major Players Oppose Incentives:*** NKF²⁸ and AAKP both oppose incentives. DLA is at best determinedly agnostic. Excluding these groups eliminates the chance to speak authoritatively on behalf of patients or to utilize their significant legislative resources and constituencies.
- ***Membership Organizations Avoid Controversy:*** Membership organizations (like professional associations or support groups) have a strong incentive to avoid controversies that can divide their membership. Even groups like AST and ASTS who have taken steps to support incentives,²⁹ have only endorsed intermediate steps like removing disincentives and establishing pilots. TRIO also officially endorses pilots for incentives but is skittish about promoting it for similar reasons. If our group wants to represent kidney donors, we should avoid alienating members of that constituency when possible.

Conclusion

A program of transplant support can win significant backing throughout the transplant field. This program can dramatically increase transplantation within a very attractive time frame. If success can be achieved, the prospects for future changes necessary to end the shortage will be greatly improved. Directly pursuing incentives is unlikely to be successful and can only stymie progress towards achievable, significant goals.

²⁷ [NY Times, 2009](#). See also [Becker, 2010](#).

²⁸ [National Kidney Foundation, 2003](#).

²⁹ See [NY Times: Room for Debate, 2014](#). AST/ASTS Incentives White Paper available upon request.

Appendix C

SAMPLE COALITION STATEMENT OF RESPONSIBILITIES

[Name of Organization] (“Member”) is proud to support efforts to increase living kidney donation and intends to play a critical role in the Coalition to Promote Living Kidney Donation, particularly its campaign to collaborate with HRSA on increasing support for living donation as well as future campaigns to increase transplant support via removal of donor disincentives, provision of health insurance to donors, increased education for the public, patients, and their families, and expanded donor follow-up study and care.

To assist with planning and implementing the work of the Coalition, Member commits to:

Public Affiliation

- 1) Being listed as a Coalition Member on the WaitList Zero website and in other communications material.
- 2) Announcing its joining the Coalition in a newsletter or other email or social media communication to its membership.

Legislative Campaign Support

- 1) Meeting with federal legislative contacts together with other Coalition members to request support for Coalition efforts.
- 2) Participation in Coalition Hill Days and other legislative education efforts.
- 3) Inclusion of living donation issues in other discussions with legislative staff.

Solicitation of Support for the Campaign

- 1) Soliciting living kidney donors and other membership to register support for efforts to increase living kidney donation.
- 2) Inviting groups Member works with to join the Coalition.

Policy Development

- 1) Providing advice on policy questions the Coalition considers and helping to design living donor transplant policy.

Organizational Involvement

- 1) Designating one staff member as point person responsible for the working with the coalition, including solicitation of member support.
- 2) Participating in a monthly meeting to discuss campaign strategy.
Joining additional Coalition projects to which it has unique expertise and can offer a unique contribution.

Appendix D

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Appendix E

Glossary

AAKP: American Association of Kidney Patients

ACOT: Advisory Committee on Transplantation

AST: American Society of Transplantation

ASTS: American Society of Transplant Surgeons

Delmonico Letter: An open letter which takes a hard line against incentives for living donation, written in response to the pro-incentive Open Letter,

DLA: Donate Life America

ESRD: End Stage Renal Disease

HRSA: Health Resources and Services Administration

NKF: National Kidney Foundation

NKR: National Kidney Registry

NOTA: National Organ Transplant Act of 1984

Open Letter: The open letter in support of transplant incentives, two of whose co-authors were Josh Morrison and Thomas Kelly

OPO: Organ Procurement Organization

OPP: Open Philanthropy Project

QALY: Quality Adjusted Life Year

RCT: Randomized Control Trial

USRDS: United States Renal Data System