

**A RESOLUTION TO BE SUBMITTED BY
LEGISLATOR MORTON, LORIGO, AND BURKE**

Re: Support for State Action Regarding Living Organ Donation

WHEREAS, there are more than 120,000 Americans waiting for organ transplants and each year the weight grows longer with less than one in seven patients able to find a willing and compatible donor; and

WHEREAS, in New York State and across the nation living organ donation rates have dropped in recent years leaving many in need of organ transplant waiting even longer; and

WHEREAS, several problems have been identified and need to be addressed in order to help increase the rate of organ donation including removing financial barriers to donation, and providing lifetime follow-up care to donors; and

WHEREAS, it has been determined that more long-term data on live donor outcomes is required to further mitigate risks to the donor's health and to help better educate the patients, their families, and the public about living donation; and

WHEREAS, the attached report has offered many possible avenues to alleviate the barriers to living organ donation including providing tax deductions for lost wages and child care costs for donors, provision of insurance for donors for at least a year after the procedure, and allowing Medicaid to cover paired kidney donation for paired exchanges based off of a national database as opposed to requiring in-state pairing; and

WHEREAS, easing the route to living organ transplant will help reduce the immediate and long-term costs associated with organ donation and can help increase the rate of donation by as much as twenty five percent (25%) thereby saving lives across our state; and

WHEREAS, the report cites costs of less than \$6,000 per donor per year which amounts to a budgetary impact of \$3.6 million across the entire State of New York; and

WHEREAS, associated research further indicates a cost savings of \$18 million accruing to the state through the elimination of expenses for the care for the donation recipient prior to transplant, as recurring treatments like kidney dialysis are no longer necessary, and the transplant recipients are able to return to work.

NOW, THEREFORE, BE IT

RESOVLED, that this honorable body action by New York State to independently examine the fiscal and practical implications of implementing the policies in the attached report and to work together to ease the process of organ donation; and, be it further

RESOLVED, that certified copies of this resolution be sent to the Western New York delegation to the New York State Senate and Assembly, the office of the Governor of the State of New York, Hon. Andrew M. Cuomo, the majority and minority leaders of both the New York State Senate and Assembly and any other party deemed necessary and proper.

Fiscal Impact: None for Resolution

WAITLIST ZERO

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Working Group Report In One Page

Working Group Background: Following a January meeting of NYC transplant leadership, a working group was tasked with developing state-level recommendations for transplant policy reform. The group was made up equally of patients and members of the medical community. We met six times over the course of three months to draft model legislation and a white paper laying out our recommendations.

Working Group Focus Areas: Our group chose six areas for improvement:

1. **Reimbursement of Donor Expenses:** Providing comprehensive, painless reimbursement for all expenses of kidney donation to donors beneath the top income quintile.
2. **Protecting Donor Health:** Minimizing health risks to donors by ensuring post-surgical insurance coverage.
3. **Educating Patients and their Families:** Ensuring: (a) all patients eligible for transplant receive a continuum of transplant education throughout their disease progression; and (b) education is effectively disseminated throughout a patient's entire support system.
4. **Raising Public Awareness:** Creating a state-of-the art website for living organ donation in New York State and a public campaign to launch the site and increase knowledge about living organ donation.
5. **Paired Kidney Donation:** Guaranteeing that Medicaid payment is not a barrier to paired kidney donation
6. **Long-Term Follow-up:** Recommends innovative solutions to make it easier and more attractive for donors to participate in follow-up rates and to improve follow-up generally.

Recommended Legislation: We narrowed these down to three legislative goals: (1) reimbursing donor expenses in a comprehensive and efficient way; (2) protecting donor health by providing post-surgical health insurance and encouraging long-term care; and (3) educating the public, patients, and their families by creating a NYS organ donation website, model educational materials, and publicly available data about transplant rates.

Legislative Impact: We expect, if passed, our legislation will increase live donation rates in New York by 25% per year, which would save more than 125 lives and \$18M in healthcare costs for state, federal, and private insurers. We calculate the legislation will cost \$3.5M annually without taking state savings into account.

Widespread Support: Our Report has already received broad stakeholder support in the New York transplant community, with endorsements from the Greater New York Hospital Association, Mt. Sinai, LiveOn NY, NYU, Stonybrook Medicine, and the Northeast Kidney Foundation. Polling indicates overwhelming public support for our policy recommendations.

NYS Living Donor Support Act Cost Estimate

Summary: The Living Donor Support Act reimburses living organ donors for the expense of donation, provides a year of health insurance to donors that don't have it, and educates the public, patients, and their families about organ donation. In total, these policies will require New York State spend approximately \$3.7M each year, yield a savings of \$2.6M per year, and require a net cost of \$1M per year.

Annual Cost	\$3,723,364
Annual Savings	\$2,567,505
Net Cost	\$1,155,859

Spending: The bulk of the bill's costs come from reimbursing expenses incurred by each of New York's anticipated 650 living organ donors about \$4,800 each (including administrative expenses), for a cost of \$2.8M. The remainder comes from providing the 11% of donors who are uninsured one year of comprehensive insurance (\$350K) and from creating and managing a statewide living donation website and other educational materials for donors (\$250K). This yields a total cost of \$3.7M

Annual Cost	\$3,723,364
Lost Wages	\$1,312,986
Other Financial Costs (Travel, Childcare, etc.)	\$1,811,310
1 Yr Health Insurance	\$349,068
NYS Educational and Website Management	\$250,000

Savings: Savings accrue from: 1. Medicaid cost-savings of transplant over dialysis; 2. Enabling kidney recipients to return to work and pay taxes; 3. Removing the currently existing tax deduction for living organ donors; and 4. Applying current federal travel reimbursement funding for transplant to the NY costs.

Annual Savings	\$2,468,505
Medicaid	\$1,180,575
Tax Collection	\$1,019,395
Removing Tax Deduction	\$129,250
NLDAC Reimbursement	\$139,285

NY LIVING DONOR WORKING GROUP

REPORT ON

**LIVE DONOR TRANSPLANT POLICY
AT THE STATE LEVEL**

<DRAFT>

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Introduction

The New York Living Donation Working Group arose out of a meeting between New York City transplant stakeholders in January, 2016 to develop strategies to alleviate the transplant shortage crisis in New York State. It was agreed that living donation needed special attention, and a Working Group to increase living donation was formed.

Our Working Group membership includes transplant professionals, donors, recipients, health policy experts, and family members of patients with kidney disease. We first met on March 21st, 2016, where we identified six key issues we felt needed to be addressed by state-level policy reform. We set up biweekly meetings through June to develop a legislative proposal and solicited opinion both within our institutions and from the transplant field more broadly about our ideas and our working drafts. In June, we finalized our legislative proposal and began working on this Report to disseminate our findings so that other states may be able to work from the same blueprint for a wide range of solutions to improve transplant policy.

A great deal of thoughtful effort and consideration went into these proposals. We are very proud of the result, thankful for all the help with their development, and determined to enact these ideas into policy.

NY Living Donation Working Group

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Executive Summary

The shortage of organs for transplantation is a social ill of dramatic proportions whose burden falls disproportionately on the most vulnerable Americans. More than 120,000 Americans are waiting for organ transplants— 100,000 need kidneys. Each year, the demand for kidney transplants exceeds supply by 18,000; the list grows ever-longer and more deadly. By comparison, the annual total of all homicides in the United States is only 12,000. When available, live donation is the best treatment for organ failure, yet fewer than one in seven patients on the waitlist find a willing donor.

Despite advances in paired kidney donation and patient desensitization, living organ donation rates have stagnated and actually declined in America in the 21st Century. Widespread agreement in the transplant field exists on many key questions surrounding how to effectively increase living donation. The transplant community universally recognizes the need to:

- Remove financial barriers to donation;
- Better educate the patients, their families, and the public about living donation;
- Provide donors lifetime follow-up care;
- Collect long term data on live donor outcomes; and
- Minimize risks to donor health.

Despite this consensus, much progress remains to be made on each of these goals. Over the spring and summer of 2016, our Working Group met more than half a dozen times to develop a statewide strategy to support living organ donors and increase living donation. This Report, along with the model legislation included as an appendix, represents the product of these meetings.

We hope these policies can be not only implemented in New York but also used as a starting point for other states' reform efforts. By allowing different centers, states, and regions to innovate on living donation, we hope to incubate and test policies that can then be enacted at a national level. Our Group focused our recommendations on the following six areas:

- 1. Reimbursement of Donor Expenses:** Experts across the transplant field have identified the need to remove financial disincentives to donation. ([Hayes, 2016](#); [LaPointe Rudow, 2015](#); [Salomon, 2015](#); [Delmonico, 2015](#); [Gaston, 2006](#)). Currently, travel expenses (within the United States) for qualifying donors are reimbursed by the federal National Living Donor Assistance Center (NLDAC) program as well as one private insurer, but lost wages, childcare, and caretaker expenses remain uncovered. A recent study found these expenses total an average \$4,200 per donor ([Rodrigue, 2016](#)). Partly as a result, while the need for kidneys disproportionately affects the poor, living donors are wealthier than the average American ([Gill, 2013](#)). While evidence is mixed, one study found that a tax deduction for the expenses of living donation increased unrelated donation by 52% ([Bilgel and Galle, 2015](#)). In a survey of NLDAC participants, 70% said they could not have donated but for the travel assistance. State payment of these expenses can increase the ability of a person to donate, minimize burdens faced by donors, and save money on expensive dialysis treatments.
- 2. Protecting Donor Health Insurance Coverage:** While medical expenses of the donor surgery are paid by the recipient's insurance, coverage of post-surgery complications is highly variable by insurer and long-term coverage of donation risks is inadequate. Because of donors' self-sacrifice, a generous approach to coverage is best. This Report recommends first that insurers be encouraged to develop standards for covering long-term risks of donation that are comprehensive and generous to donors. It also recommends no-fault compensation for donors who suffer surgical complications. Finally, it recommends states grant donors without health insurance at donation a year of free insurance as a bulwark against surgical risk.

3. **Expanding Access to Transplant Education for Patients and their Families:** Access to transplantation is severely curtailed by a lack of education. One study found 75% of transplant recipients felt inadequately educated about living donation. ([Waterman, 2006](#)) Another found that as many as 80,000 patients nationally who were eligible for transplant were unlisted. ([Schold, 2008](#)) A continuum of patient education is needed over time. This Report recommends the development of required transplant education materials— such as brochures, web, video, and social media content— for nephrologists to offer their patients over the lifetime of care—to familiarize patients and help them obtain a preemptive transplant. Public disclosure of the demographics and transplant status of nephrologist practices are also recommended to inform consumer choice and evaluate barriers to transplantation.

Moreover, practices at the transplant center can also be improved to educate not just the patient but also their family and support network. A study of home visit transplant education found it increased living donation by 60%, ([Rodrigue, 2007](#)) a finding that was subsequently replicated. ([Ismail, 2014](#)). The donor champion model pioneered at Johns Hopkins is another analogous effort that aims to spread the burden of seeking a transplant beyond the patient suffering from a kidney failure. ([Garonzik-Wang, 2012](#)) It takes a village to give a kidney: activating a broad network of support is the best way to increase the chance patients find a donor.

4. **Raising Public Awareness:** While substantial efforts exist to promote deceased donation and educate the public about registering as an organ donor, few analogous living donation efforts have been attempted. Broad baseline knowledge of the option of living kidney donation is important to help patients know to seek a transplant and lower barriers to talking to family members about the option of living donation. This Report recommends state-based public awareness campaigns to teach the public about living donation. In particular, a statewide living donation website that provide accurate information about living donation while highlighting the need among patients for donors can be an effective tool to increase public knowledge. They can also be designed to effectively support patient's own social media efforts to seek a transplant.
5. **Reforming Medicaid to Cover Paired Kidney Donation:** While the rise of paired kidney donation has helped ameliorate incompatibility as an obstacle to donation, access to this treatment is not evenly distributed. Currently reimbursement rules that confine Medicaid payments to in-state providers have prevented patients covered by Medicaid from national sharing with paired donation exchanges like the National Kidney Registry or UNOS KPD. This Report makes recommendations for how to reform payment requirements to fix this issue.
6. **Improving Long-Term Follow-Up:** Currently, although international recommendations call for lifetime post-donation follow-up, ([KDIGO, 2015](#)) only two years are required by the OPTN for American transplant centers. The most significant barrier centers report to longer follow-up is ability to maintain contact with donors and donor willingness to return to the center for treatment. Several approaches were discussed and recommended to try to solve these issues: First, reducing the difficulty of providing follow-up information by creating an easy process to obtain medical info through a donor physical or at a local testing facility. Second, developing a web-based donor registry to maintain up-to-date contact information and monitoring. Finally, trialing innovative approaches to improve compliance with follow-up care. For example, offering stipends to donors who submit their follow-up data is one approach worth studying.

These recommendations are implementable at the state level. We believe passage of our proposed legislation in New York state would increase living donor rates by 25% within a few years of passage—saving more than 1,250 lives and \$1.8B taxpayer dollars over the first decade of implementation. (See Appendix C—Impact Analysis). We estimate they would cost approximately \$6,000 per donor per year, or about \$3.6M in New York State.

Reimbursement for Donor Expenses

Proposal

That living organ donors be reimbursed for all expenses from donation, including lost wages, travel expenses, lodging, caretaker expenses, childcare, eldercare, prescriptions and other incidental costs of the donor surgery.

Summary: Experts across the transplant field have identified the need to remove financial disincentives to donation. (LaPointe Rudow, 2015; Salomon, 2015; Delmonico, 2015; Gaston, 2006). Currently, the federal National Living Donor Assistance Center (NLDAC) program reimburses travel expenses for donors who earn less than 3x a poverty level income. United Health Insurance also reimburses travel expense. But even there, lost wages, childcare, and caretaker expenses remain entirely uncovered. Recent studies have found these expenses total an average \$4,200 per donor (Rodrigue, 2015; Rodrigue, 2016). We recommend comprehensive and generous reimbursement of these expenses as close to the date they are incurred as possible, with the funds for reimbursement to come from state governments where possible and private insurers and transplant centers where necessary.

Need for Policy: While the need for kidneys disproportionately affects the poor, living donors are wealthier than the average American. (Gill, 2013). The stagnation and decline in living donation rates has disproportionately affected those in lower income strata. (Gill, 2015) While evidence is mixed, one study found that a tax deduction for the expenses of living donation increased unrelated donation by 52% (Bilgel and Galle, 2015). In a survey of NLDAC participants, 70% said they could not have donated but for the travel assistance. State payment of these expenses will increase donation and minimize burdens faced by donors.

Current Policy Background: While acquiring a kidney for valuable consideration is obviously forbidden by the National Organ Transplant Act, the Act explicitly allows the payment of donor expenses including lost wages, travel housing, and other expenses reasonably related to donation. Additionally, many states offer tax deductions or tax credits to cover the expenses of donation. For example, an American Legal Exchange Council model law passed by a number of states, including New York, allows for a tax deduction of up to \$10,000 for itemized lost wage, travel, and housing expenses. An Idaho law passed in 2006 allows for a \$5,000 lump sum tax credit regardless of claimed expenses.

Survey Results

- 84% of New Yorkers say donor expenses should be reimbursed. (Only 1% disagreed).
- 65% said the fear of having to pay their expenses made them less likely to donate.

Since 2007, the federal government has funded the National Living Donor Assistance Center (NLDAC) to pay for travel expenses for donors with income less than 3x the poverty line by providing a prepaid debit card restricted to certain types of expenses. This program has been very successful, with as many as 70% of participants reporting that they would not have been able to donate without assistance. But it has not been expanded to include lost wages. Additionally, over the last year the American Society of Transplantation and American Society of Transplant Surgeons have had discussions with private insurers about insurer funding for expanding the program. Recently

United Health publicized its decision to provide up to \$2,000 in travel expenses to donors to recipients covered by United insurance.

Implementation Details

- **Prepaid Expenses:** In order to make donation achievable for those of limited means, costs should be reimbursed very soon after they're incurred. Thus, we recommend following the NLDAC model of providing donors a limited-use prepaid credit card to use to cover most expenses (like travel or housing) with expense reconciliation post-donation.
- **Lost Wages Through Employer Payroll:** To the extent possible, lost wages should be paid through a donor's normal payroll process so they do not miss a paycheck, with employers being repaid by the state after the fact for the expense.
- **No Duplicative Coverage:** State-level coverage should be provided after federal programs have been exhausted.
- **Reimbursement Ceilings and Floors:** To best use limited resources, we recommend capping reimbursable lost wages at the 80th income percentile. (In New York, that is approximately \$124,000 as of the date of this report.) Additionally, we recommend non-wage expenses be capped at a total of one standard deviation above normal reimbursement levels for each component expense, though we do recommend flexibility to allow special circumstances to be demonstrated. Finally, we also recommend a floor of reimbursement at four weeks of the prevailing minimum wage for donors who are contractor laborers, do not have full-time employment, or otherwise cannot document their lost income.
- **Single Reimbursement Vendor:** For ease of use and efficiency, we recommend that reimbursement in a state be managed by a single vendor, such as the National Living Donor Assistance Center Program.

TABLE 1			
Reimbursable Costs			
Pre-Donation*		Average	Standard Deviation
	Direct Costs	523	942
	Donor Lost Wages	187	556
	Companion Lost Wages	76	311
Post-Donation**			
	Lost Wages	1,660	3,853
	Caregiver Lost Wages	377	1,486
	Direct Costs	1,157	1,909
	Service Expenses	225	768
	Donor Lost Wages	1,847	4,409
	Other Donor Costs	1,905	3,619
	Other Companion/Caretaker Costs	453	1,797
	Total Costs	\$4,205	
	Recommended Cap***	\$14,030	
* Rodrigue, 2015 ** Rodrigue, 2016			
*** Equals total cost plus total standard deviation			

Living Donor Insurance

Proposals

1. **Long-Term Coverage:** That complications of living organ donation be fully insured at minimal expense to the donor throughout their lifetime.
2. **Post-Surgical Insurance:** That kidney donors without health insurance when they donate be offered a year of free insurance.
3. **No-Fault Compensation for Complications:** That living donors who suffer surgical complications receive compensation through a convenient, no-fault process modeled after the National Vaccine Injury Compensation Program.
4. **Catastrophic Insurance:** That donors be provided life, disability, and long-term care insurance to cover the risks of surgery.

Summary: Currently, health coverage for donation-related conditions is inadequate, time-limited, and highly variable based on the recipient insurer. This leaves donors to suffer financially and medically based on their choice to save a life. It also confronts transplant centers with difficult, ad hoc, financially unsustainable choices about paying for donor health treatment, potentially years after donation.

While many complications can be directly attributed to surgery (see Table 2 below), living liver and kidney donation may contribute to psychosocial or other conditions whose origins are less clear (See [Dew, 2013](#)). We believe it is better to err on the side of generosity to donors than to be ungenerous and leave donors to bear an uncertain burden. Thus we recommend that donors: (1) be guaranteed comprehensive insurance coverage in the year after surgery; (2) receive donation-related care (broadly defined) at minimal cost by insurers over the course of their lifetime; and (3) have recourse to a no-fault compensation regime for complications of donor nephrectomy.

Need for Policy

- **Insurance:** Recipient insurance covers the medical costs of donation as well as some costs of treating surgical complications, but coverage for those complications varies significantly, which can leave donors to bear those risks out of their own pocket. Moreover, long-term risks of donation currently receive no coverage at all. These risks include a 1-2% increase in lifetime incidence of kidney failure, ([Muzaale, 2014](#) and [Grams, 2016](#)) and a 6% increase in preeclampsia for donors that later become pregnant ([Garg, 2015](#)). Additionally, limitations in follow-up lead to significant uncertainty as to the long-term scale and scope of the risks. (See [Steiner, 2014](#). See generally [Newell, 2015](#) and [Morrison, 2016](#)).

Survey Results

- 79% of New Yorkers say the health risks of donation decrease their willingness to donate;
 - 96% agree that donors should receive at least one year of free insurance coverage post-donation;
 - 63% believe donors should receive lifetime coverage.
- **No-Fault Compensation for Complications:** Currently, 18% of living kidney donors experience some form of surgical complication ([Friedman, 2010](#)); in 4% of donations,

complications are severe enough to require rehospitalization. Despite not receiving an individual medical gain from surgery, living donors fully bear the burden of potential complications. In analogous contexts of pro-social health treatment such as vaccination, a no-fault liability insurance process exists to reimburse any injuries from medical procedures that advantage society as a whole. A system modeled after worker's comp, that efficiently and fairly allocated pre-set amounts of compensation for donor complications, would alleviate some of the risks of donation. (See [Ratner, 2010](#)).

- **Catastrophic Insurance Coverage for Donors:** The Living Organ Donor Network program currently offers donors the ability to purchase life insurance and limited disability insurance for \$550. We recommend that a more comprehensive version of this guarantee be provided to donors for free as part of the cost of surgery, giving donors life, disability, and long-term care insurance for issues associated with their donor surgery.

TABLE 2	
Surgical Complications of Organ Donor Surgery	
Short term post donation complications	
Infection	
Pulmonary edema	
Bleeding requiring Transfusion	
reoperation	
Pulmonary emboli	
Neuropraxia from positioning	
Small bowel obstruction	
Hydrocele	
Incisional paresthesia, may need Neurontin	
Deep Vein Thrombosis	
Hypoadrenalism	
Chylous Ascites	
Ileus	
Aborted procedure	
Conversion to open procedure	
Short and Long term Psychiatric care r/t donation	
Processing of the donation process	
Grief counseling	
Anxiety	
Depression	
PTSD	
Long term "surgical" complications	
Hernia	
Bile duct repair	
Scar revision	

Transplant Education

Proposals

1. **Standardized Education Materials:** That all patients who could receive a transplant be provided high-quality educational materials by both their nephrologist and dialysis provider.
2. **Education and Outcome Transparency:** That state Departments of Health should collect data on referral, listing, and transplantation from providers and disseminate it to the public.
3. **Educating Patient Support Systems:** That programs that educate the patient's support system, such as home visits, be made easily accessible to all transplantable patients.

Summary: Educating transplant-eligible patients and their families has the most potential for increasing living donation of any policy intervention. The process of finding a living donor is a difficult one. Patients may feel embarrassed or ashamed about “asking for somebody’s organ.” Kidney failure disproportionately affects people with diminished access to the medical system, so they may have difficulty understanding information about donation or feel uncomfortable trying to convey that information to others.

Need for Policy: Starting transplant education early in a patient’s kidney disease progression is critical. We must educate not just the patient but also their entire support network.

- 75% of transplant recipients feel inadequately educated about living donation. (Waterman, 2006)
- Preemptive transplants last about 33% longer than transplants after a patient has begun dialysis, (Kasiske, 2002) but only 0.8% of patients diagnosed with kidney failure receive them (Davis, 2010).
- Home visit education that educates patients’ friends and family has been shown to increase living donation rates by more than 60% (Rodrigue, 2007; Ismail, 2014; Rodrigue, 2014).
- As many as 40% of patients eligible for kidney transplantation are not on the waiting list. (Schold, 2008) These patients are more likely to have low incomes, be people of color, and lack private insurance or college education. This implies a significant, fixable inequity in access to transplantation.

Recommendations—

- **Early Transplant Education:** The transplant education process should begin as early as possible. One way to ensure this would be to require that nephrologists and dialysis providers be mandated to automatically refer all patients eligible for a transplant to specialized transplant educators. Our Working Group strongly considered this policy but ultimately averred because we did not have time to develop sufficiently strict guidelines for transplant eligibility to be comfortable with a mandate. Instead, we focused on requiring dissemination of high-quality transplant educational materials by nephrologists and dialysis providers to all patients. We also recommend the publication of rates of waitlisting, transplantation, and living donation for different medical providers like nephrologists, transplant centers, and dialysis clinics.

Survey Results

- 66% of New Yorkers strongly agree they'd be willing to donate to a family member, but only one in seven find a living donor.
- 90% of New Yorkers believed all patients who need an organ should receive education from a transplant professional. Currently, as many as four in ten patients do not receive this education.

- **Educating the Patient's Community:** While patient education needs to improve, it takes a village to give a kidney. Requiring patients to do all the work of educating their friends and family demands too much and has proved impossible for most potential recipients. Part of the reason wealth correlates both with the ability to find donors and the propensity to donate is this educational disparity. Educating patient families through home visits has proven effectiveness. Donor champion approaches also strengthen support networks by empowering friends and family of patients to advocate on the potential recipients behalf. Social media tools can further help diffuse information across the broad community of people who could help a patient find a transplant. We recommend that transplant centers, nephrologists, and other educators implement tools to ensure that every eligible patient's friends and family are well-educated about transplant.

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Public Awareness

Proposals

1. **Living Donation Website:** That a central NYS website be developed to help both donors and recipients
2. **Public Awareness Campaign:** That a public awareness campaign focused on education about living donation be implemented across New York state.

Background: Public awareness of living donation is limited. Only 36% of New Yorkers have heard about living kidney donation in the past year, and the risks and benefits of donation are not well understood. An increasing number of searches for living donors occur over Facebook or other social media. Public appeals for donation often result in numerous offers to donate, ([Lamas, 2013](#)) implying that greater awareness of the need could significantly increase donation. While significant public awareness campaigns exist about deceased donation, few organizations exist on the scale of Organ Procurement Organizations, whose revenue comes entirely from deceased donation and who take the lead role in publicizing organ donation.

Survey Results

- **Weak Knowledge of Donation:** 38% of New Yorkers thought the risk of death during transplant surgery was greater than one in twenty.
- **Strong Willingness to Give:** 38% of New Yorkers said they would consider donating a kidney to a stranger.

Recommendations: *A web-based educational and pre-screening platform* may help expand access to transplantation. Creating a single official website for New York with state authority would give patients, donors, and doctors additional confidence in using the site. It would also allow stories of New Yorkers who've received and donated to be shared and be an effective portal for patients to engage with transplant centers. This could be modeled in part after websites like the California living donation site and [Informate](#), a website directed at educating Hispanic patients about transplant. (See [Gordon, 2016](#)) It could improve on those sites by including video content, stories of New York donors and recipients, ability to contact other patients and support groups, social media integration, and one-stop access to currently existing web content. Additionally, it could either use or replicate the Breeze transplant screening web tool, which has had significant success in increasing donor referrals by providing more accessible screening methods that are less time-intensive for transplant center staff.

A broad-based public awareness campaign could make it easier for patients to find a transplant once they need one. It could also be conducted in conjunction with the website launch to increase website adoption and use. Promoting the stories of New Yorkers in need of a transplant could both increase non-directed donation and help empower those patients to share their own stories within their social networks. These programs could build off the social media tools created by Johns Hopkins and ORGANIZE that help patients better tell their story. Because of New York's status as a multicultural state, the website and other materials should be accessible in languages like Spanish, and Mandarin.

Living Donor Follow-Up

Proposals

1. **Pilot Study:** That one or more NY transplant centers conduct a pilot study of offering donors research stipends for each year they submit follow-up data.
2. **Standardized Follow-Up:** That standard follow-up goals and public metrics be promulgated by the NY transplant community.

Background: Kidney donor follow-up is widely agreed to be inadequate. (See [Kasiske, 2015](#); [Ommen, 2011](#)). Although sequelae of transplant surgery are unlikely to materialize soon after donation, follow-up is required for only two years. Partly as a result, past studies of long-term effects of kidney donation have had short time horizons and may not properly state potential health consequences. (Steiner, 2014). Additionally, as much as 50% of donors' risk of kidney failure may be avoidable with lifestyle interventions if patients develop conditions like hypertension, diabetes, or chronic kidney disease— making follow-up care critical. Transplant coordinators have identified donor willingness as the primary barrier to long-term follow-up, so a stipend program may effectively encourage donor participation.

Recommendations: We recommend that the New York State Transplant Council develop guidelines for funded living donor follow-up beyond the national two-year requirement. We further recommend that a program be developed to test the effect of offering research stipends on donors' willingness to: (a) continue with follow-up over time and (b) reengage with follow-up after contact had been lost.

Paired Kidney Donation

Proposal

Ensuring Access to Medicaid Patients: That Medicaid payment requirements be amended to allow for payment to hospitals outside of New York state to allow paired kidney exchange to be available to New York ESRD patients on Medicaid..

Background: Paired kidney exchange allows patients with willing but incompatible donors to receive a transplant from a donor with their own incompatible recipient. These exchanges are most efficiently conducted in domino chains where a non-directed donor gives to a recipient at the beginning of the chain, whose donor gives to the second recipient, and so on until the chain concludes. Larger patient pools allow better matching for hard-to-match recipients, meaning that these chains are typically conducted nationally. Unfortunately, to date, Medicaid billing constraints have prevented out-of-state donor nephrectomies from being covered even though they benefit an NYS Medicaid patient.

Recommendation: We recommend that Medicaid billing rules be changed to allow Medicaid patients to participate in these exchanges and have access to national paired kidney donation.

Conclusion

This Report follows in the footsteps of many other academics and institutions that have developed consensus around important transplant reforms, particularly the Living Donation Consensus Conference held in Chicago in 2014. Our contribution has been to take these areas of consensus within the living donor transplant field and make them actionable at the state level through both legislation and concerted efforts by stakeholders including transplant centers, insurers, patient groups, and other nonprofits.

We plan to institute these recommendations into New York policy in the upcoming year. But just as importantly, we hope this Report will serve as the basis for other states and regions to implement these reforms as well. We have already received inquiries from other interested areas, and we believe that the process of change we are mapping out in New York can and should be replicated elsewhere. It is only by thoughtful experimentation and reform across the country that larger, much-needed national change can be tested and then enacted.

We hope that our Report will serve ultimately as a catalyst for a new set of transplant reform policies to safeguard living donors that can be enacted federally by the end of the year 2020, policies that make living donor transplants easy to ask for and easy to give. To accomplish this we must enact policies that recognize the valuable public service of living donors by lowering the cost of donating, providing lifetime health insurance and protection, and improving follow-up. We must also fully educate the public, patients, and their families about the incredible opportunities transplant offers to save lives and protect families. This report is a first step of a larger, transformative journey to support living organ donors, increase living donation, and end the deadly wait for transplants.

New York City
New York
September __, 2016

Working Group Members

Name	Background
Marian Charlton	Chief Transplant Coordinator Cornell Weill Kidney and Pancreas Program
Ira Copperman	Kidney Recipient Spouse President Transplant Support Organization
Dr. Bruce Gelb	Director of Kidney Transplantation Mary Lea Johnson Transplantation Center, NYU Langone Medical Center
Dianne LaPointe Rudow (Co-Chair)	Director Zweig Family Center for Living Donation, Recanati/Miller Transplant Institute, The Mount Sinai Medical Center
Pat McDonough	Kidney Donor Live Donor Transplant Coordinator Montefiore Einstein Center for Transplantation
Josh Morrison (Chair)	Kidney Donor Co-Founder and Executive Director Waitlist Zero
Chantal Onelian	ESRD Patient Parent Educator, Kidney Disease and Organ Donation Activist. Founder, Kidney for Thalya
Sedica Powell	Kidney Donor Advocate, National Kidney Foundation
Mike Sosna	Transplant Recipient Director Transplant Recipients International Organization – Long Island
Dr. Lloyd Ratner	Director Renal and Pancreatic Transplantation Columbia University/New York Presbyterian Hospital
David Rich (Legislative Advisor)	Executive Vice President Government Affairs, Communications, and Public Policy Greater New York Hospital Association
Brigitte Sullivan	Executive Director NYU Langone Transplant Institute

Supporting Institutions

The following institutions endorse the recommendations of this Report:



WAITLIST ZERO

[Other institutions]

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Appendix A: Draft Statutory Language

Statutory Draft Language for Financial Reimbursement

Summary

- Reimbursement, up-front where possible, for lost wages, travel, childcare, eldercare, housing expenses and cost of medicine.
- Reimbursement is managed through a contractor chosen by the state.
- Number of weeks for which lost wages can be claimed absent special circumstances are capped at four weeks for office-workers and eight weeks for those whose jobs require manual labor.

The public health law is amended by adding the following subsection:

§ 43-C. Reimbursement of Living Donor Expenses. 1. The department shall be authorized to pay for living donor expenses for all living organ donors who are full-time New York residents or donate to a recipient who is a full-time New York resident in New York. Living donor expenses shall be defined to be all financial costs incurred by any living organ donor that arise due to the act of living donation. These costs shall include but not be limited to: lost wages or sick days; travel, childcare, eldercare, and housing expenses; and costs of medicine and care associated with the donor surgery, including reimbursement for costs of care performed by relatives or friends of the donor. The state shall not reimburse wages or other expenses that were covered under paid medical leave by the employer or that are covered by other sources of reimbursement such as the federal National Living Donor Assistance Program. It shall reimburse living organ donors for the economic value of limited sick or vacation days expended by the living organ donor due to their donation.

2. Living donor expenses shall be reimbursed as close in time to their being incurred by the donor as practicable, including by pre-payment where achievable. Lost wages for living organ donors without full-time employment shall be defined as the greater of (a) demonstrated lost income due to organ donation or (b) the prevailing hourly New York state minimum wage multiplied by forty for each week in which the donor is incapacitated, such weeks for the

purpose of this clause not to exceed four in number unless special circumstances are demonstrated.

3. The department shall be authorized to contract, within amounts appropriated, for the management of the reimbursement process as provided herein. Factors such as cost, ease of use for the donor, and ease of use for transplant center hospitals shall be taken into consideration when awarding the contract. To the extent practicable, contractors should make reasonable efforts to distribute lost wage reimbursement through a donor's existing employer payroll process. Rules, regulations and guidelines as shall be necessary or appropriate to assure successful implementation of this program shall be promulgated by the department. Nothing contained in this section shall prohibit a program, with the approval of the department, from subcontracting for, or otherwise ensuring that the required services are available.

4. The department, at its discretion, shall be authorized to impose a cap on: (a) lost wages for donors making an income that either (i) ranks within the top quintile of incomes of New York State residents or (ii) exceeds \$124,000; or (b) for living donor expenses (including lost wages) above \$14,000 for any single donor. For living organ donors whose employment requires substantial manual labor, reimbursable time off work shall not exceed eight weeks except where special circumstances are demonstrated. For living organ donors whose employment does not require substantial manual labor, reimbursable time off work shall not exceed four weeks except where special circumstances are demonstrated.

5. This subsection shall be interpreted so as not to conflict with the federal National Organ Transplant Act (42. U.S.C. 274e).

The tax law is amended by deleting the following subsection

§ 612-(c)(38) (38) An amount of up to ten thousand dollars if a taxpayer, while living, donates one or more of his or her human organs to another human being for human organ transplantation. For purposes of this paragraph, "human organ" means all or part of a liver, pancreas, kidney, intestine, lung, or bone marrow. A subtract modification allowed under this paragraph shall be claimed in the

taxable year in which the human organ transplantation occurs.

(A) A taxpayer shall claim the subtract modification allowed under this paragraph only once and such subtract modification shall be claimed for only the following unreimbursed expenses which are incurred by the taxpayer and related to the taxpayer's organ donation:

(i) travel expenses;

(ii) lodging expenses; and

(iii) lost wages.

(B) The subtract modification allowed under this paragraph shall not be claimed by a part-year resident or a non-resident of this state.

Statutory Draft Language for Transplant Education

Summary

- Requires that state Department of Health approve and disseminate transplant education materials to nephrologists who are required to provide these materials to patients.
- Creates living donation website.
- Creates transparency requirements for transplant rates of patients who need a transplant

The public health law is amended by adding the following subsection:

§ 43-D. Transplant Education of Patients with kidney disease or end-stage renal failure. 1. For all patients with chronic kidney disease stage four or end stage renal disease, their nephrologist shall: (a) establish the transplant status of the patient (whether the patient is a candidate for transplantation pursuant to guidelines to be developed by the New York State Transplant Council) and (b) provide the transplant-eligible patient with the transplant education materials approved by the Council.

2. Dialysis facilities shall (a) establish the transplant status of the patient (whether the patient is a candidate for transplantation pursuant to guidelines to be developed by the New York State Transplant Council); (b) promptly provide transplant-eligible patient with the aforementioned transplant education materials approved by the Council; (c) maintain and make public a written policy defining delivery of transplant information to all patients, including when transplant information will be presented to new patients, what tools (brochures, video) are used, and who conducts annual follow-up education/contact with patient; and (d) designate one staff member to facilitate transplant education, evaluation referrals, submission of laboratory samples, and patient status changes.

3. The New York State Transplant Council shall approve and the Department shall disseminate transplant education materials described above, relying on the input of healthcare provider and consumer groups with expertise in the educational needs of potential transplant recipients; and other experts. These materials shall include online, video, print, and social media components and shall be designed to increase patient understanding about the

medical option of transplant and its desirability. These materials shall be designed to be accessible to New York residents of all cultural, linguistic, socioeconomic, and educational backgrounds. Failure by medical professionals or organizations to comply with the provisions of this section 43D shall constitute grounds for license revocation.

4. The transplant education materials shall include a website devoted to transplantation and living organ donation to be developed by private entities and approved by the department. This organ donation website shall include information about medical factors to consider for living donation, ways to find a living donor, New Yorkers in need of transplant, and opportunities to find a living donor, including on social media. The website shall direct patients to a staffed phone hotline. The website shall provide information about transplant centers that allows medically eligible patients to make an informed choice as to which transplant center to register. Such information shall include geography, number of transplants performed, year program was founded, average length of donation process, patient demography, average wait to receive living and deceased donor transplants and other information relevant to a patients. This website will allow for recipient and donor registration with transplant centers and shall be designed to be open-source and in such a way as to allow information promulgated in the website to be used by other scholars or public educators. Contact information for donors and patients who register through the site shall be maintained and kept current. Necessary follow-up activities post-transplantation for donors and recipients shall be coordinated through the website.

5. Nephrologists who treat more than 25 patients with kidney failure in a year shall provide to the department data indicating such facts as patient demography, the number of patients who received specialized transplant education, the number who were waitlisted for transplant, the number who received living and deceased donor transplants, and the average wait time between each of eligibility, education, wait-listing, and transplantation. This data shall be fully publicly available for research and evaluation purposes. The precise categories of information to be shared shall be determined per the recommendations of the New York State Transplant Council.

Living Donor Health Insurance

Summary

- Requires health insurers to cover complications associated with living donation.
- Makes available Medicaid Essential Plan coverage for living donors without health insurance in the year post-surgery.

Medicaid Coverage for Living Donors

The social services law is amended by adding the following subsection:

§ 365-o. Provision and coverage of services for living organ donors. The commissioner shall provide for coverage of health care services under the medical assistance program for living organ donors eligible for medical assistance under this article and (a) reside in New York State or (b) reside in other states but who donate organs to New York State residents, including through paired exchanges. Coverage shall include necessary pre-surgical, surgical, and post-surgical care; necessary follow-up care; care associated with any complications associated with the donation; and any necessary health care services associated with the donation, including ongoing monitoring. Efforts will be made to minimize costs of treatment incurred by the donor, per the voluntary recommendations of the New York State Transplant Council, which shall be responsive to representatives of transplant centers who provide services to living donors representatives of consumer groups with expertise in the needs of living donors; and other experts.

Commercial Insurance Coverage for Living Donors

Subsection (i) of section 3216 of the insurance law is amended by adding a new paragraph __ as follows:

(__) Every policy delivered or issued for delivery in this state which provides comprehensive coverage for hospital, medical, or surgical care shall make available and, if requested by a policy holder, provide coverage for health care services of a living organ donor who is a policy

holder, including but not limited to necessary pre-surgical, surgical, and post-surgical care related to a donation otherwise uncovered by the recipient insurer; necessary follow-up care; care associated with any complications associated with the donation; and any necessary health care services associated with the donation, including ongoing monitoring. Efforts will be made to minimize costs of treatment incurred by the donor, per the voluntary recommendations of the New York State Transplant Council, which shall be responsive to representatives of transplant centers who provide services to living donors; representatives of consumer groups with expertise in the needs of living donors; and other experts.

Subsection (k) of section 3221 of the insurance law is amended by adding a new paragraph __ to read as follows:

() Every group or blanket policy delivered or issued for delivery in this state which provides comprehensive coverage for hospital, medical, or surgical care shall make available and, if requested by the group policyholder, provide coverage for health care services of a living organ donor who is a group policyholder, including but not limited to necessary pre-surgical, surgical, and post-surgical care related to a donation otherwise uncovered by the recipient insurer; necessary follow-up care; care associated with any complications associated with the donation; and any necessary health care services associated with the donation, including ongoing monitoring. Efforts will be made to minimize costs of treatment incurred by the donor, per the voluntary recommendations of the New York State Transplant Council, which shall be responsive to representatives of transplant centers who provide services to living donors; representatives of consumer groups with expertise in the needs of living donors; and other experts.

Section 4303 of the insurance law is amended by adding a new subsection (__) to read as follows:

() Every contract issued by a medical expense indemnity corporation, a hospital service corporation or a health service corporation which provides comprehensive coverage

for hospital, medical, or surgical care shall make available and, if requested by a contract holder, provide coverage for health care services of a living organ donor who is a contract holder, including but not limited to necessary pre-surgical, surgical, and post-surgical care related to a donation otherwise uncovered by the recipient insurer; necessary follow-up care; care associated with any complications associated with the donation; and any necessary health care services associated with the donation, including ongoing monitoring. Efforts will be made to minimize costs of treatment incurred by the donor, per the voluntary recommendations of the New York State Transplant Council, which shall be responsive to representatives of transplant centers who provide services to living donors; representatives of consumer groups with expertise in the needs of living donors; and other experts.

Essential Plan Coverage for Uninsured Living Donors

Section 369-gg of title 11-D of article V of the social services law is amended by adding a new subparagraph (e) as follows:

(e) Notwithstanding the eligibility provisions of this paragraph, a person is eligible to receive health care services under this title if he or she donates organs to a resident of this state regardless of the state in which the donor resides and regardless of income. Such eligibility shall last for one year after the beginning of the provision of any necessary health care services related to the organ donation. Premium, copayment, or deductible requirements under this title shall not apply to living organ donors eligible to receive health care services under this subparagraph. The state shall assume any costs under this subparagraph that are not assumed by the federal government.

Appendix B—NYS Cost Projection

New York Cost Summary

Annual Cost	\$3,454,631
Lost Wages	\$1,211,401
Other Financial Costs (Travel, Childcare, etc.)	\$1,374,058
1 Yr Health Insurance	\$322,061
NYS Transplant Council	\$125,000
NYS Educational Materials	\$125,000

Annual Savings	\$2,121,100	Medicaid	Tax Collection
Standard	\$2,121,100	\$1,180,575	\$940,525
Optimistic	\$4,296,663	\$1,888,920	2,407,743
Pessimistic	\$1,009,313	\$708,345	\$300,968

Net Cost	\$1,333,532
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New York Budget Savings

<i>Decreased Medicaid Costs</i>						
	Annual NY Donors (avg. 2011-15)	% Increase in Donation	Medicare Savings per Donor	Medicaid Supplemental Coverage	% NYS Recipients on Medicaid*	Total
Optimistic	477	40%	300,000	25%	13%	\$1,888,920
Neutral	477	25%	300,000	25%	13%	\$1,180,575
Pessimistic	477	15%	300,000	25%	13%	\$708,345

*from 2014 USRDS fig 1.20 (national

<i>Increased Tax Revenue</i>						
	Number of NY Donors (2011-15)	% Increase in Donation	Percent Increase in Tax Payment	Years of Work	Mean NYS Tax Burden (2011)*	Total
Optimistic	477	40%	40%	6	5258	\$2,407,743
Neutral	477	25%	30%	5	5258	\$940,525
Pessimistic	477	15%	20%	4	5258	\$300,968

*<http://taxfoundation.org/article/annual-state-local-tax-burden-ranking-fy-2011>

Annual Savings	
Optimistic	\$4,296,663
Neutral	\$2,121,100
Pessimistic	\$1,009,313

Costs of New York Legislation

Per Donor Costs						
	2011-15 Avg. Tx	Expected % Increase	Number of Donors Reimbursed	Cost per Donor	Admin Costs	Total
Lost Wages	477	25%	596	\$1,847	\$110,127	\$1,211,401
Other Financial Costs (Travel, Childcare, etc.)	477	25%	596	\$2,095	\$124,914	\$1,374,058
Companion and Caretaker Costs	477	25%	596	\$453	\$27,010	\$297,111
1 Yr Health Insurance	477	25%	66	\$4,464	\$29,278	\$322,061
Donor Registry Stipend	0	25%	0	\$2,500	\$0	\$0

Donor Costs	\$3,204,631	2017 Costs	250,000
NY Transplant Council	\$125,000	Website Setup	125,000
Annual Website and Educational Materials	\$125,000	Other Education Materials	125,000
Total Annual Cost	\$3,454,631	Total 2017 Costs	\$3,704,631

Stakeholder Profitability

	2011-15 Transplants	Expected % Increase	Expected # Increase	Per Tx Revenue/Savings	Total Marginal Revenue/Savings	Total Fees	Net Profit
Transplant Center	477	25%	119	\$100,000	\$11,925,000	\$0	\$11,925,000
Insurer	333.9	25%	83	\$72,500	\$6,051,938	\$0	\$6,051,938
Pharma	477	25%	119	\$112,000	\$13,356,000	\$0	\$13,356,000

	Tx Cost	Immuno Cost	Annual Dialysis Cost	Years of Dialysis Coverage	Per Tx Savings
Insurer Savings	\$200,000	\$140,000	\$150,000	2.75	\$72,500

Appendix C— Impact Analysis

[to attach]

Appendix D— New York Survey Findings

[to attach]

NYS Living Donor Support Act

Background

Each year, nine hundred New Yorkers on the waiting list die or become too sick to transplant, which is 50% more than all the homicides in the state. Compared to the United States as a whole, New Yorkers are a third more likely to need an organ and 35% more likely to die due to the transplant shortage.

2016 saw excellent legislative progress in improving New York's deceased donation system, which previously ranked 50th in the country. But living organ donation is in equally great need of statewide legislation. The landmark living donor legislation below would immediately make New York the national leader in living donation policy and dramatically increase organ donation rates in the state.

Goals

- 25% increase in annual living organ donation rates.
- 1,250 lives saved over the next ten years.
- \$140 million in taxpayer savings over the next ten years.
- Living donors treated fairly and respected for their generous public service.

Bill Provisions

Reimbursement of Donor Financial Costs

- Reimburses donors for financial costs like lost wages that currently serve as a barrier to donation.
- Handles reimbursement efficiently through an outside contractor.
- Caps both number of weeks for which lost wages can be claimed and total reimbursements per donor.

Transplant Education

- Creates a living donation website.
- Empowers the Department of Health to approve and disseminate transplant education materials created by experts.
- Creates transparency requirements for wait-listing, transplant rates, and transplant eligibility.

Living Donor Health Insurance

- Ensures insurance coverage for conditions related to living donation.
- Makes available Medicaid Essential Plan coverage for living donors without health insurance in the year post-surgery.

Statutory Draft Language for Financial Reimbursement

Summary

- Reimbursement, up-front where possible, for lost wages, travel, childcare, eldercare, housing expenses and cost of medicine.
- Reimbursement is managed through a contractor chosen by the state.
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3. The department shall be authorized to contract, within amounts appropriated, for the management of the

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5. Nephrologists who treat more than 25 patients with kidney failure in a year shall provide to the department data indicating such facts as patient demography, the number of patients who received specialized transplant education, the number who were waitlisted for transplant, the number who received living and deceased donor transplants, and the average wait time between each of eligibility, education, wait-listing, and transplantation. This data shall be fully publicly available for research and evaluation purposes. The precise categories of information to be shared shall be determined per the recommendations of the New York State Transplant Council.

Living Donor Health Insurance

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Subsection (i) of section 3216 of the insurance law is amended by adding a new paragraph __ as follows:

(__) Every policy delivered or issued for delivery in this state which provides comprehensive coverage for hospital, medical, or surgical care shall make available and, if requested by a policy holder, provide coverage for health care services of a living organ donor who is a policy

holder, including but not limited to necessary pre-surgical, surgical, and post-surgical care related to a donation otherwise uncovered by the recipient insurer; necessary follow-up care; care associated with any complications associated with the donation; and any necessary health care services associated with the donation, including ongoing monitoring. Efforts will be made to minimize costs of treatment incurred by the donor, per the voluntary recommendations of the New York State Transplant Council, which shall be responsive to representatives of transplant centers who provide services to living donors; representatives of consumer groups with expertise in the needs of living donors; and other experts.

Subsection (k) of section 3221 of the insurance law is amended by adding a new paragraph __ to read as follows:

() Every group or blanket policy delivered or issued for delivery in this state which provides comprehensive coverage for hospital, medical, or surgical care shall make available and, if requested by the group policyholder, provide coverage for health care services of a living organ donor who is a group policyholder, including but not limited to necessary pre-surgical, surgical, and post-surgical care related to a donation otherwise uncovered by the recipient insurer; necessary follow-up care; care associated with any complications associated with the donation; and any necessary health care services associated with the donation, including ongoing monitoring. Efforts will be made to minimize costs of treatment incurred by the donor, per the voluntary recommendations of the New York State Transplant Council, which shall be responsive to representatives of transplant centers who provide services to living donors; representatives of consumer groups with expertise in the needs of living donors; and other experts.

Section 4303 of the insurance law is amended by adding a new subsection (__) to read as follows:

() Every contract issued by a medical expense indemnity corporation, a hospital service corporation or a health service corporation which provides comprehensive coverage

for hospital, medical, or surgical care shall make available and, if requested by a contract holder, provide coverage for health care services of a living organ donor who is a contract holder, including but not limited to necessary pre-surgical, surgical, and post-surgical care related to a donation otherwise uncovered by the recipient insurer; necessary follow-up care; care associated with any complications associated with the donation; and any necessary health care services associated with the donation, including ongoing monitoring. Efforts will be made to minimize costs of treatment incurred by the donor, per the voluntary recommendations of the New York State Transplant Council, which shall be responsive to representatives of transplant centers who provide services to living donors; representatives of consumer groups with expertise in the needs of living donors; and other experts.

Essential Plan Coverage for Uninsured Living Donors

Section 369-gg of title 11-D of article V of the social services law is amended by adding a new subparagraph (e) as follows:

(e) Notwithstanding the eligibility provisions of this paragraph, a person is eligible to receive health care services under this title if he or she donates organs to a resident of this state regardless of the state in which the donor resides and regardless of income. Such eligibility shall last for one year after the beginning of the provision of any necessary health care services related to the organ donation. Premium, copayment, or deductible requirements under this title shall not apply to living organ donors eligible to receive health care services under this subparagraph. The state shall assume any costs under this subparagraph that are not assumed by the federal government.