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Paired Kidney Donations in Light of the National Organ Transplant Act: A Bioethical Analysis

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An abstract of A thesis submitted to the Faculty of the James T. Laney School of Graduate Studies of Emory University in partial fulfillment of the requirements for the degree of Master of Arts in Bioethics 2017

Abstract

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One phenomenon that has emerged out of the practice of live kidney donation is paired kidney exchanges. Paired kidney exchanges provide a transplant option for candidates who have a living donor who is medically able, but cannot donate a kidney to the intended candidate due to an incompatible blood type, HLA crossmatch, or both. In the exchange, an arrangement occurs between two incompatible donor pairs whereby the donor from each pair gives a kidney to a donor recipient from the other pair. For example, suppose A wants to donate to his brother, B, and suppose C wants to donate to her sister, D. A is not a match for B, but is a match for D. Similarly, C is not a match for D, but is a match for B. The four parties enter into a paired kidney exchange agreement whereby A agrees to donate to D and C agrees to donate to B.

Most astonishing about the paired kidney exchange model is the lack of protection afforded to exchange participants. That is, in the United States, no law, policy, or safeguards are in place to deter bad actors from falsely inducing one party to donate a kidney and later reneging on their promise to reciprocate. As such, this thesis will analyze the bioethical issues that must be addressed if the paired kidney exchange model will serve as a strategy for overcoming barriers to patients suffering from end stage renal disease.

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Introduction

On December 23, 1954 Dr. Joseph E. Murray of the Peter Bent Brigham Hospital in Boston changed the course of medicine when he performed the first living kidney donation between Richard and Ronald Herrick, identical twin brothers.¹ Over sixty years following this watershed moment, bioethics continues to entertain ongoing public debate about the ethical, social, logistical, and medical dimensions of organ transplantation. As an evolving field of therapeutic pursuit, organ transplantation continuously challenges legislators, bioethicists, legal scholars, the medical community, and kidney waiting list patients to pursue ethically, legally, and logistically sound strategies to best facilitate organ supply in response to increasing demands.

Though the quality of medical care afforded to individuals suffering from organ failure has dramatically improved since the first organ transplant, advances in technologies, improvements in medications, and policies governing organ procurement and donation raise new hurdles for all transplant participants. Specifically, external challenges and limits, such as the severe organ shortage; strict federal statutes that explicitly prohibit compensation to the donor; debate over criteria for determining when death has occurred such that a deceased person's organs might be removed; society's moral reluctance and fear of embracing policies that may increase donors at the expense of reducing the human body to a source of replacement parts; technological advances; and time restraints before the individual in need of a transplant becomes too ill for transplantation intensify the complexities associated with organ donation. Consequently, the organ transplantation process requires creative methods to overcome such challenges.

¹ Joseph Murray, "Reflections on the First Successful Kidney Transplantation," *World Journal of Surgery* 6 no. 3 (1982): 372-76, doi: https://doi.org/10.1007/BF01653562.

Out of all transplantable organs, the kidney requires special attention because the gap between the supply and demand in the United States far exceeds the gap for any other organ.² Of the 116,770 individuals currently on the U.S. national waiting list, 82.9 percent of those are waiting for a kidney..³ Due to the increasing demand and relatively static supply, the wait time for a cadaveric kidney can take up to five years..⁴ In response, major improvements in living kidney donations during the past few decades have allowed live kidney donations to become standardized transplantation practice, which offers both a life-saving alternative to the deceased donor waiting list as well as a mitigating response to the kidney shortage in the United States..^{5,6}

One phenomenon that has emerged out of the practice of live kidney donation is paired kidney exchanges. Paired kidney exchanges provide a transplant option for candidates who have a living donor who is medically capable of donating an organ, but the organ itself is incompatible with the intended recipient either because of blood type, HLA crossmatch, or both. In the exchange, an arrangement occurs between two incompatible donor pairs whereby the donor from each pair gives a kidney to a donor recipient from the other pair. For example, suppose A wants to donate to his brother, B,

⁴ Gary Becker and Julio Elías, "Introducing Incentives in the Market for Live and Cadaveric Organ Donations," *Journal of Economic Perspectives* 21 no. 3 (2007): 3-24, DOI: 10.1257/jep.21.3.3.
⁵ "Data," U.S. Department of Health and Human Services, last modified September 28, 2017, https://optn.transplant.hrsa.gov/data/.

² "Organ Donation Statistics," U.S. Government Information on Organ Donation and Transplantation, accessed September 4, 2017, https://www.organdonor.gov/statistics-stories/statistics.html.

³ "Organ Procurement and Transplantation Network," U.S. Department of Health and Human Services, last modified September 28, 2017, https://optn.transplant.hrsa.gov.

⁶ According to the Living Kidney Donor Network, many waitlisted kidney patients wait more than five years. "The waiting list has doubled in size over the past 10 years - and it continues to grow… However, only 1% of the deaths result in organs that could be used. Even if all of these organs were able to be recovered, it would not alleviate the shortage." "Living Kidney Donors Network Mission," Living Kidney Donors Network, accessed September 5, 2017, http://www.lkdn.org/mission.html.

and suppose C wants to donate to her sister, D. A is not a match for B, but is a match for D. Similarly, C is not a match for D, but is a match for B. The four parties enter into a paired kidney exchange agreement whereby A agrees to donate to D and C agrees to donate to B.

Perhaps the most astonishing aspect of paired kidney exchange and kidney chain models, however, is the lack of protection afforded to the participants as the entire foundation depends on the good faith of all participating parties.⁷ Specifically, in the event the exchange does not occur simultaneously, all participants must trust the second donor will carry out his or her promise to donate even after his loved one has already received a kidney. Thus, the current system of paired kidney exchange, and by extension kidney chains, crumbles when one intended donor acts in bad faith by inducing the first party to donate and then backs out of the promise. To date, no formal safeguards exist in United States state laws, regulatory frameworks, or in hospital policies that explicitly address efforts to deter bad actors from reneging on their promise to donate.⁸ Neither do host institutions of paired kidney exchanges include vetting processes designed to identify and exclude nefarious actors from participating in the kidney exchange system. What is more, the National Organ Transplant Act (NOTA) remains silent as to the remedies available for the victims of a breach of this type of contractual arrangement.

This paper will argue that the paired kidney exchange model is both efficient and integral to encourage live organ donations, especially in light of the severe organ shortage. However, a bioethical and brief legal analysis of current practices in paired

⁷ See Part I.C.2 for a detailed explanation of paired kidney chains.

⁸ Unless stated otherwise, all discussion of law and policy is limited to federal and state jurisdictions of the United States.

kidney donations reveals that the failure to address fundamental safeguards in the exchange process eclipses participants' abilities to make fully informed decisions about their healthcare. Namely, without appropriate regulatory protections in place, participants in the exchange, the healthcare providers, and kidney transplant centers must rely on the good faith and good intentions of the parties involved. Because the underlying premise of the organ procurement models in the United States assumes all parties enter paired kidney exchanges with good intentions, when one party does engage in the morally egregious acts of fraud and deception, very little, if anything, can be done to help the harmed party or parties.

This thesis will discuss two sets of bioethical issues that must be addressed if the paired kidney exchange model and its variations will continue to serve as integral options for kidney patients in need of transplants when their living potential donors are deemed incompatible or unsuitable. First, it will address issues inherent to the paired kidney exchange model. This includes an analysis of the model against the backdrop of the ethical principles of autonomy, beneficence, nonmaleficence, and justice. Because there are at least four participants directly involved in the exchange (and several more if in a paired kidney chain), a complete analysis requires consideration of all parties, including the unique ethical dilemmas paired kidney exchanges present to physicians and other healthcare providers.

Second, this thesis will offer potential solutions to overcoming the problems inherent to the paired kidney exchange model. This includes a proposal for specific performance as a remedy for breaching paired kidney exchange contracts; an analysis of the UCLA model, which follows a "pay to play" voucher system; and consideration of an organ market. Each potential solution raises its own bioethical issues, which will be discussed. Ultimately, this thesis will argue that a remedy of specific performance offers the most morally sound solution to the current and potential problems plaguing the organ procurement and transplantation process. Though not a morally perfect solution, a remedy of specific performance deters nefarious actors seeking to infiltrate the paired kidney donation system while at the same time best balances the principle of autonomy with the principles of beneficence and non-maleficence. In light of the severe organ shortage plaguing the United States, the explicit legal prohibition on organ markets, and the widespread political and social endorsement of paired kidney exchanges and chains, the failure to incorporate a specific performance remedy subjects the already vulnerable transplant and donor populations to harm and threatens to eviscerate the current organ procurement and transplantation network.

Part I will begin by providing a history of organ donations in the United States, from the first successful live organ donation to present day paired kidney donations. This section will include a discussion of current trends in living organ donation, such as paired kidney chains and the UCLA kidney donation voucher system. Part II will briefly describe laws, regulations and policies currently in place that govern live organ donations in the United States. It will begin with an analysis of federal statutes, such as the National Organ Transplant Act, and proceed to discuss hospital and transplant center policies. Included in this discussion is will the vetting processes for potential donors and recipients employed by hospitals that facilitate paired kidney exchanges. Part III will briefly discuss the legal concerns with the current state of laws governing organ donation. Part IV will apply a bioethical analysis of the paired kidney exchange model in light of

the inadequate laws, policies, and regulations that currently govern organ procurement and transplantations in the United States. The prevailing issues that will be discussed include: informed consent, patient autonomy, distributive justice, the healthcare providers' obvious duty to desist from maleficent acts, and the expectation that allocation maximizes the expected net amount of overall good. These principles will be considered within the specific framework of NOTA, established by Congress to deliberately create a national transplant law founded on the basis of "altruism".⁹ Through applying a bioethical analysis, this section will touch on legal, social, and political issues inherent to current practices. Part V will offer potential solutions to the current paired kidney exchange system. Included in this section are proposed changes to NOTA to establish more ethical practices, a proposal to switch to a voucher system, and consideration of an organ market. Because each proposal raises its own unique ethical issues, this section will also provide an in-depth analysis of implications and consequences of each option. Finally, Part VI will conclude by summarizing the argument for why the incorporation of a remedy of specific performance into the National Organ Transplant Act, which governs paired kidney exchanges, presents the most ethical approach to managing the organ procurement and transplantation network in the United States and why it best protects all participants in paired kidney exchanges.

The Kidney.¹⁰

Though severe organ shortage is an issue that pervades all types of organs - from hearts to lungs to livers – kidneys merit special attention because of their unique status

⁹ As will be discussed below, the terms "altruism" and "altruistic" are effusive and applied differently in a variety of contexts. Though these terms appear repeatedly in the legislative history of NOTA, the precise definitions of altruism and altruistic remain unclear.

¹⁰ For more information on the kidney and renal failure, see Appendix 1.

when viewed in the context of live organ donations and transplantations. Namely, compared to other transplantable organs or donatable tissue, it resides in a category of its own in terms of its number, nature, and characteristics. That is, a healthy person is born with two kidneys; the number of kidneys in the human body is finite over the course of a person's life; the kidney cannot regenerate; kidney donation involves transplantation of the whole kidney, rather than a portion of the kidney; and a healthy individual can survive with only one kidney. By contrast, all other organs or tissue used for transplantations, grafts, or donations neatly fall into one of three categories.

The first category involves donations that are minimally invasive and can be donated by a single donor multiple times. Items such as blood, bone marrow, peripheral blood stem cells, post birth placenta and amniotic membrane, and even hair fall into this category..^{11,12} These donataive materials do or have the potential to regenerate. Whereas some procedures, such as bone marrow donation, require anesthesia and may necessitate a recovery time of several day, most donations that fall into this category require very little recovery time and cause little to no long term physical harm or impact on the donor.

The second category constitutes partial organs that can be donated by a live donor. Whereas some of these partial organs can regenerate and regain full function, such as a segment of the liver, others do not have the ability to regenerate. Organs that can be donated in part and do not have the ability to regenerate include: a lobe of one lung; a portion of the pancreas; and in extremely rare instances, a portion of the intestine...¹³ The

¹¹ "The Living Donation Process," U.S. Government Information on Organ Donation and Transplantation, accessed September 2, 2017, https://www.organdonor.gov/statistics-stories/statistics.html.

 ¹² "Donation Frequently Asked Questions," U.S. Department of Health and Human Services, accessed September 2, 2017, https://bloodcell.transplant.hrsa.gov/donor/donating/donation_faqs/index.html#2.
¹³ "Types of Living Donation," United Network for Organ Sharing, accessed September 1, 2017, https://transplantliving.org/living-donation/facts/organs/.

transplantation process for organs that fall into the second category requires general anesthesia, large incisions, and a longer recovery time.

The third category constitutes organs that can only be donated from a cadaveric donor. Organs that fall into this category include: the heart, skin, and tissue.¹⁴ Most organs from deceased donors must be transplanted to the recipient almost immediately because organs remain healthy only for a short period of time after removal from the donor.¹⁵ By contrast, tissue such as corneas, the middle ear, skin, heart valves, bone, veins, cartilage, tendons, and ligaments can be stored in tissue banks and used later to restore sight, cover burns, repair hearts, replace veins, and mend damaged connective tissue and cartilage in recipients..¹⁶ As of 2014, faces from deceased donors can be used for face transplants.

Kidney Shortage

Though living donors can safely donate one of their kidneys, kidneys remain the most needed organ. Of all the organs people in the United States are awaiting, kidneys make up 82.9 percent of needed organs. Second is the liver, which makes up only 12.3 percent.¹⁷ Furthermore, according to the U.S. Department of Health and Human Services, as of August 2017, 96,815 individuals are awaiting a kidney.¹⁸ Moreover,

¹⁴ In exceptionally rare circumstances, a domino transplant makes some heart-lung recipients living heart donors. "When a patient receives a heart-lung "bloc" from a deceased donor, his or her healthy heart may be given to an individual waiting for a heart transplant. Extremely rare, this procedure is used when physicians determine that the deceased donor lungs will function best if they are used in conjunction with the deceased donor heart." Ibid.

¹⁵ "The Deceased Donation Process," U.S. Government Information on Organ Donation and Transplantation, accessed September 2, 2017, https://organdonor.gov/about/process/deceased-donation.html#transport.

¹⁶ "What Can Be Donated," U.S. Government Information on Organ Donation and Transplantation, accessed September 2, 2017, https://organdonor.gov/about/what.html.

¹⁷ U.S. Government Information on Organ Donation and Transplantation, "Statistics."

¹⁸ U.S. Department of Health and Human Services, "Organ Procurement and Transplantation Network."

approximately every 14 minutes someone is added to the waiting list..¹⁹ This culminates into roughly 3,000 individuals added to the kidney waiting list each month..²⁰ At the same time, approximately 13 people die each day while waiting for a life-saving kidney transplant..²¹

The growing waiting list for kidneys generates several potential issues that undercut some of the medical advances made by the advent of organ transplantation. Because improvements in available drugs and dialysis machines allow waiting list patients to live longer, the number of individuals waiting for kidneys rapidly outpaces the number who previously would have been removed from the list either because they passed away or became too ill for a transplant. One way transplant centers have attempted to adapt to the growing waiting list and increased waiting time for kidneys is through relaxing the criteria for donor eligibility, i.e. allowing individuals who are older or sicker, including drug users and those with infectious diseases, to donate.²² As a result, the overall quality of the donated organ has decreased..²³ Moreover, organ recipients today are, in some cases, sicker than people who received organs in the past, thereby raising questions about the efficiency of a waiting list and whether the current system does, in fact, maximize the benefits and lifespan, or amount of time the donated organ can successfully function in the recipient's body, of each precious organ.²⁴ This reality raises questions about

 ¹⁹ "Organ Donation and Transplantation Statistics," National Kidney Foundation, last updated January 11, 2016, https://www.kidney.org/news/newsroom/factsheets/Organ-Donation-and-Transplantation-Stats.
²⁰ Ibid.

²¹ Ibid.

²² Eric Cohen, "Organ Transplantation: Defining the Ethical and Policy Issues," Staff Discussion Paper, The President's Council on Bioethics, accessed September 1, 2017,

https://bioethicsarchive.georgetown.edu/pcbe/background/staff_cohen.html. See also Susan Scutti, "Old Kidneys may be a new answer to organ shortage," *CNN*, last updated December 15, 2016, http://www.cnn.com/2016/12/15/health/old-kidneys-work-for-transplants/index.html

²³ Ibid.

²⁴ Ibid.

whether the current laws that govern organ transplantation are sufficient and efficacious in light of developments and recent trends in organ procurement, donation, and transplantation.

Part I: Present-day trends

In response to the severe organ shortage and technological advances that render live kidney donations possible, several methods of living organ transplantation have emerged. Perhaps the most common is the paired kidney exchange and its multiple variations. The following section will briefly review the development of the paired kidney exchange model and proceed to discuss prevalent models of living kidney donations commonly facilitated by the National Kidney Registry, transplant hospitals, United Network for Organ Sharing, and other prominent kidney registries.

1. <u>History and development</u>

The earliest recorded paired exchange transplants were organized in 1991 in South Korea by Dr. Park.²⁵ For nearly a decade, only Dr. Park and his transplant team in South Korea employed the paired kidney exchange model to facilitate transplants for incompatible donor - recipient pairs.²⁶ By 1999, paired kidney donation transplants spread to Europe, then by 2000 to the United States, and by 2007 to Australia.²⁷ When first performed in the United States, hospitals organized paired kidney exchanges independently among their own patients, but soon databases and registries emerged to organize exchanges on a greater scale.²⁸ In 2000, the first prototype for kidney matching

²⁵ Blake Ellison, "A Systematic Review of Kidney Paired Donation: Applying Lessons from Historic and Contemporary Case Studies to Improve the U.S. Model," *Wharton Research Scholars Journal* 107 (2014):2-27,

http://repository.upenn.edu/cgi/viewcontent.cgi?article=1113&context=wharton_research_scholars. ²⁶ Ibid at 2.

²⁷ Ibid at 7.

²⁸ Ibid at 2.

software entered the fold, which takes into account many of the variables involved in a kidney transplant, such as blood type, HLA crossmatch, etc..²⁹ Using advanced algorithms, the computer program analyzes data from the pool of potential donor and recipient pairs to determine the most compatible matches..³⁰ As a result, paired kidney exchanges expanded into three-way and four-way paired kidney donations and eventually to nation-wide kidney chains. Today, the landscape for kidney paired donations in the United States includes several single-center programs, multicenter consortia, and the United Network for Organ Sharing, a registry operated by the organization that administers deceased donation in the United States. The first large swap in the United States occurred in 2012 and involved 60 participants..³¹ An even larger swap was completed in 2014 and involved 70 participants..³²

2. <u>Two-Way Paired Kidney Exchange</u>

Perhaps the simplest of the paired kidney donation models is the two-way paired kidney exchanges. Originally proposed by in 1986 by F.T. Rapaport, the two-way kidney exchange model provides a transplant option for two incompatible pairs with reciprocal incompatibilities.³³ The donor from the first pair donates to the recipient of the second pair, and the donor from the second pair donates to the recipient of the first pair.³⁴

Consider, for example, Patient B and Patient D, two patients in need of a new kidney. Donor A wants to donate his kidney to his cousin, Patient B, and Donor C wants to

²⁹ "About Us," Alliance for Kidney Paired Donation, accessed September 7, 2017, https://paireddonation.org/about-us/.

³⁰ Blake Ellison, "A Systematic Review of Kidney Paired Donation," at 2.

³¹ Ibid.

³² Ibid.

³³ F.T. Rapaport, "The Case for a Living Emotionally Related International Kidney Donor Exchange Registry," *Transplantation Proceedings* 18 no 3 (1986): 5-9.

³⁴ Ellison, "A Systematic Review" at 2.

donate her kidney to Patient D, her sister. Within each patient-donor dyad, the donor's kidney is incompatible with the patient's immune system, but it is suitable for the patient in the other pair.³⁵ Thus, the two pairs enter into a simultaneous kidney swap, whereby Donor A donates his kidney to Patient D and Donor C donates her kidney to Patient B. In effect, this cross-couple exchange provides those in need of a kidney with a match and circumvents the need to join the hundreds of thousands of individuals in the United States on kidney donation and transplantation waiting lists.



3. Transplant Chains.³⁶

Another trend that has emerged the transplant field is a cooperative practice called transplant chains. In short, the paired kidney exchange model unfurls into a kidney chain when sparked by a non-directed donor.³⁷ That is, when a non-directed donor chooses to donate to a recipient of an incompatible pair, he or she triggers a string of transplants in which the non-compatible intended donor of the recipient proceeds to donate to a patient unknown to him or her who has been identified as a match. The loved one of the second

³⁵ Alvin E. Roth, Tayfun Sonmez, and M. Utku Unver, "Kidney Exchange," *The Quarterly Journal of Economics*, 119, no. 2 (2004): 457-488. http://www.jstor.org/stable/25098691.

³⁶ For more Information on Kidney chains, see Appendix 3

³⁷ A non-directed donor is an individual who has a desire to donate one of his or her kidneys, but does not have an existing recipient to receive the donation. Often non-directed donors are referred to as "altruistic donors." As explained in Part IV, however, defining the term "altruism" is problematic as it has many different definitions and implications depending on the context in which it is used. For example, according to some definitions altruistic acts require selfless motivations to drive the act while others contend altruistic acts can be selfishly motivated. Further, altruism can be defined as either normative or autonomous, where normative altruism includes common-place acts of helpfulness governed by social rewards and punishments and autonomous altruism is not influenced by these. As such, unless the terms "altruism" "altruistic" is part of a name or title, this paper will employ the term non-directed donor. For further discussion on altruism, see Svetlana Feigin, Glynn Owens, and Felicity Goodyear-Smith, "Theories of human altruism: a systematic review," *Annals of Neuroscience and Psychology* 1, no. 1 (2014) http://www.vipoa.org/neuropsychol.

recipient will then donate to an unknown yet compatible individual in need of a kidney, and the chain will continue in this way. To date, the longest kidney chain to take place in the United States included 68 people - 34 donors and 34 recipients - at 26 hospitals nationwide..³⁸

4. <u>Domino Paired Donation Chain (DPD) and non-simultaneous extended</u> <u>altruistic donor (NEAD) chains.³⁹</u>

A non-directed living donation is a type of donation whereby the donor does not identify a specific recipient. Also known as "anonymous," "unspecified," "community," "good Samaritan," or "altruistic" donors, these individuals choose to donate their kidney to a complete stranger in need of a kidney.⁴⁰ Initiation of an exchange by a non-directed donor allows two more KPD exchange options: domino-paired donation chains (DPD) chains and non-simultaneous extended altruistic donor (NEAD) chains.⁴¹

In a DPD chain, the non-directed donor donates to the recipient of an incompatible pair, the donor of which either continues the chain by donating to another incompatible recipient, or ends the chain by donating to the waitlist.⁴²

Non-directed donor Donor 1 Not compatible Recipient 1 Recipient 2

³⁸ "Longest Kidney Chain Ever Completed Wraps up at UW Hospital and Clinics," University of Wisconsin Madison School of Medicine and Public Health, last updated April 14, 2015, http://www.uwhealth.org/news/longest-kidney-chain-ever-completed-wraps-up-at-uw-hospital-and-clinics/45549.

³⁹ For more information on DPD and NEAD chains, see Appendix 4.

⁴⁰ "Living Donors," National Kidney Registry.

⁴¹ Ellison, "A Systematic Review" at 3.

⁴² Ibid.

A non-simultaneous, extended, altruistic-donor, or NEAD chain differs from a DPD because the transplants are not executed simultaneously.⁴³ A NEAD occurs when a nondirected, or altruistic, donor donates to a person awaiting a transplant. That recipient's incompatible donor donates to another individual awaiting a transplant.⁴⁴ In effect, this approach to organ transplantations involve clusters of simultaneously performed transplantations, or single transplantations, in which the donor at the end of each cluster or single transplantation serves as a "bridge donor." ⁴⁵ Each living donor gives to a stranger, and the goal of the NEAD is to continue the chain for as long as possible. The chain ceases when a recipient's incompatible donor cannot or does not donate his or her kidney.



The most recent development to emerge out of the growing practice of paired kidney exchanges and kidney chains is the UCLA kidney voucher program. The program, which began in 2014, allows for living donors to donate a kidney in advance of when a loved one might require a kidney transplant.⁴⁶ In effect, a donor donates his kidney *now* and selects a recipient for a *future* donation. Once the donor donates, his loved one receives a

 ⁴⁴ "The NEAD Chain – Altruistic Donation," National Kidney Center, accessed September 4, 2017, http://www.nationalkidneycenter.org/treatment-options/transplant/a-chain-of-hope/nead-chain/.
⁴⁵ Michael Rees et al., "A Nonsimultaneous, Extended, Altruistic-Donor Chain," *The New England Journal*

of Medicine 360 (2009): 1096-1101, http://www.nejm.org/doi/full/10.1056/NEJMoa0803645#t=article. ⁴⁶ Erika Edwards, "Will 'kidney coupons' revolutionize transplants?," 22 News, last updated July 11,2016,

⁴³ Ibid.

http://wwlp.com/2016/07/11/will-kidney-coupons-revolutionize-transplants/.

voucher that can be used if and when she needs a living kidney donation.⁴⁷ When the need for a kidney arises, the national kidney registry will find the next available kidney chain and insert the recipient into the chain so that she receives the next compatible kidney. This pay-to-play program seeks to encourage family members and friends to donate to someone in immediate need and, in turn, set up their loved ones to immediate access to a kidney when they eventually need one.

The rules of the UCLA voucher program are straightforward. A donor can add up to five people onto a voucher. Potential voucher recipients must have kidney disease and the voucher can be used only by the first person who needs it.⁴⁸ Further, vouchers are not transferable and they cannot be sold to another person nor can they be withdrawn. In the event the listed recipient(s) die before they can use it, the voucher expires and the donor simply becomes a non-directed donor.⁴⁹ Finally, the transfer center will conduct a complete human leukocyte antigen (HLA) typing on all voucher recipients. That way, when the time comes for the voucher recipient to submit the voucher, the transplant center can ensure the individual submitting the voucher is indeed the intended recipient.

To date, thirteen transplant centers across the United States participate in this program and more are expected to join. While the program is structured to encourage more live kidney donations, thereby increasing the number of kidneys into the system, at this point many questions remain as to whether this model can function effectively as it expands. It is unclear, for example, exactly how the voucher program is monitored and by whom the program is enforced. Moreover, champions of the program have yet to

 ⁴⁷ Kristen Fischer, "Donate a Kidney Now, Get a Voucher for One Later," *Healthline News*, last updated July 15, 2016, https://www.healthline.com/health-news/donate-kidney-now-get-one-later#3.
⁴⁸ Ibid.

⁴⁹ Ibid.

address ways to prevent those with kidney disease from paying individuals to donate their kidneys and provide them with vouchers. As noted above, payment for organs is prohibited and directly violates the National Organ Transplant Act.

Part II: Laws, Regulations, and Policies that Govern Live Organ Donation⁵⁰

Over the past several decades, numerous laws, regulations, and medical protocols governing organ donation, procurement allocation, and transplantation have emerged in the United States. Between 1968 and 2008, three primary Congressional Acts have established the foundation for the legal, moral, and medical framework of organ transplantation: (1) The Uniform Anatomical Gift Act of 1968; (2) the Uniform Determination of Death Act of 1981; and (3) The National Organ Transplantation Act of 1984. In 2007, Congress added an important corollary to the National Organ Transplantation Act called the Charlie W. Norwood Living Organ Donation Act, which explicitly states that criminal penalties do not apply to paired organ donations..⁵¹ Moreover, between 1968 and 2017, Congress enacted several minor but important acts that have supplemented and helped shape the current status of organ procurement and donation in the United States.

A. Uniform Anatomical Gift Act

First, in 1968, the National Conference of Commissioners on Uniform State Laws drafted the Uniform Anatomical Gift Act of 1968 (UAGA). The UAGA is a set of model regulations and laws concerning organ donation that all 50 states have since adopted.⁵²

⁵⁰ This section provides only a brief overview of the laws, regulations, and policies governing living organ donation. This author plans to engage in future project involving a complete legal analysis of paired kidney donations and proposed changes to NOTA.

⁵¹ 42 U.S.C. § 274e(a) (1991). "The preceding sentence does not apply with respect to human organ paired donation." Ibid.

⁵² "The Ethics of Organ Transplantation," University of Minnesota Center for Bioethics (2004), www.bioethics.umn.edu.

Prior to the passage of UAGA, organ transplantation policy was determined at the local level by states.⁵³ This legislation served as a guideline for state governments to apply uniform principles and procedures for the donation and receipt of transplantable organs.

Notably, the 1968 Act does not allude to any prohibition of financial incentives or other forms of compensation related to deceased donor organ procurement and donation. Instead, when drafting the Act, Congress believed the matter should be left to "the decency of intelligent human beings" to manage the issue..⁵⁴ In adopting the 1968 version of UAGA, some states incorporated modifications that do explicitly prohibit organ sales..⁵⁵ In 1987, the UAGA was amended to explicitly prohibit the sale of human tissue with the exception of blood, sperm, or human eggs..⁵⁶ Designed to avoid morally problematic inducements to hasten a potential donor's death, the UAGA expressly prohibits the purchase and sale of organs if removal of the organ is intended to occur after death. This prohibition, however, does not apply to organ sales by living donors if the organ removal is to occur before death. In adopting the 1987 amendment, some states modified the Act to apply to live organ donations too..⁵⁷

B. Uniform Determination of Death Act

The second major piece of legislation pertaining to organ procurement is The Uniform Determination of Death Act of 1981 (UDDA). The UDDA established the following criteria for declaring someone dead: "An individual who has sustained either

⁵³ Goodwin, "The Veneer of Altruism."

⁵⁴ Robyn Shapiro, "Legal Issues in Payment of Living Donors for Solid Organs," *Human Rights Magazine* 30 no. 2 (2003),

 $https://www.americanbar.org/publications/human_rights_magazine_home/human_rights_vol30_2003/spring2003/hr_spring03_livingdonors.html$

⁵⁵ Ibid.

⁵⁶ see e.g. Uniform Anatomical Gift Act (1987), 1995 N.M. HB 482.

⁵⁷ Shapiro, "Legal Issues in Payment of Living Donors for Solid Organs."

irreversible cessation of circulatory and respiratory functions, or irreversible cessation of all functions of the entire brain, including the brain stem, is dead.".⁵⁸ Though the UDDA does not directly address live organ donation practices, it marks a significant piece of legislation because it broadened the definition of death to include brain death. In doing so, the National Conference of Commissioners on Uniform State Law and the state legislatures that adopted the UDDA permit physicians to retrieve organs from individuals declared brain dead even though circulatory function may remain intact..⁵⁹ More commonly known as the "dead donor rule," this is fraught with ethical concerns as it has forced the medical community and society to develop criteria for declaring patients dead while their organs are still alive.

C. National Organ Transplant Act

Finally, the most significant and relevant piece of legislation for the paired kidney exchange discussion is the National Organ Transplantation Act (NOTA) of 1984. The National Organ Transplant Act is the federal law that addresses nation's critical organ donation shortage and aims to improve the organ matching and placement process in the United States.⁶⁰ Since 1984, NOTA has governed the national registry for organ transfer and allocation.

NOTA emerged in part as a federal reaction to plans formulated and promoted by doctor Barry Jacobs. Jacobs, who lost his license to practice medicine due to fraud,

⁵⁸ American Medical Association and the American Bar Association, "Uniform Determination of Death Act," *National Conference on Commissioners of Uniform State Law* (1981).

 ⁵⁹ F.L. Delmonico, "The Concept of Death and Deceased Organ Donation," *International Journal of Organ Transplantation Medicine* (2010): 15-20, https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4089217/.
⁶⁰ "Organ Donation Legislation and Policy," U.S. Department of Health & Human Services, accessed September 4, 2017, http://organdonor.gov/legislation/.

decided to pursue a career as an organ broker..⁶¹ In 1983, the Washington Post published an interview with Jacobs in which he detailed his plans to recruit living organ sellers from third-world countries..⁶² In response, Congress enacted NOTA in part to prevent Jacobs' plan or any similar type of plan from occurring..⁶³ More broadly, NOTA aimed achieve three primary goals: "to articulate a national health policy for organ transplantation, to ensure equitable allocation of donor organs, and to increase the number of organs available for transplantation.".⁶⁴ To carry out these goals, the Act explicitly forbids the knowing acquisition, receipt, or transfer of any human organ for "valuable consideration for use in human transplantation if the transfer affects interstate commerce.".⁶⁵ If individuals are caught selling or buying organs, they may be subject to a jail term, or a fine may be levied against them.

To aid in their objectives, the NOTA directed the Secretary of the Department of Health and Human Services to establish a nationwide Organ Procurement and Transplantation Network (OPTN) designed to maintain a national registry for organ matching. Further, NOTA called for the network to be operated by a private, non-profit organization under federal contract..⁶⁶

Seeking to avoid the poor becoming "a source of spare parts for the rich," Congress, in effect, eliminated the possibility of contracting for organs by preempting common-law

⁶¹ Michele Goodwin, "The Veneer of Altruism," *The Virtual Mentor* 14 no. 3 (2012): 256-63, http://journalofethics.ama-assn.org/2012/03/msoc1-1203.html.

⁶² Ibid.

⁶³ Ibid.

⁶⁴ Chad Wilson, "Working the System: Should Patients in Need of an Organ Transplant Be Able to Join Multiple Waitlists?" *Indiana Health Law Review* 8 (2011): 230-56 at 236. https://mckinneylaw.iu.edu/ihlr/pdf/vol8p229.pdf.

⁶⁵ 42 U.S.C. § 274e(a) (1991).

⁶⁶ "History & NOTA," U.S. Department of Health & Human Services, accessed September 4, 2017, https://optn.transplant.hrsa.gov/governance/about-the-optn/history-nota/.

requirements of contract.⁶⁷ That is, under United States contract law, a legally enforceable contract must be supported by legal consideration, i.e. a bargained-for exchange, such as a promise for a promise, or a promise for a performance..⁶⁸ Here, because transferring or receiving an organ does not constitute consideration, the exchange amounts to no more than a gift..⁶⁹

At the outset of NOTA's passage, it remained unclear if paired exchanges constituted "valuable consideration" and thus illegal under NOTA. Whereas some organizations performed paired kidney exchanges, many transplant centers refused to participate, fearing legal ramifications. Recognizing the potential for paired kidney donations to help alleviate the kidney shortage, medical organizations held several consensus conferences to discuss the legal, ethical, and medical implications of paired kidney donation.⁷⁰ Ultimately, members of the medical community pressured Congress to pass the Charlie W. Norwood Living Organ Donation Act of 2007, which creates a legal carve-out to the anti-contractual provisions by recognizing the validity of a contract that governs a paired organ transfer.⁷¹ Congress reasoned that a paired kidney donation constitutes two simultaneous gifts rather than consideration.

Deeply problematic, however, is the statute's silence as to how a paired organ transfer contract should be enforced in the event one of the parties' breaches. That is, without a

⁶⁷ Ibid.

⁶⁸ Robert Scott & Jody S. Kraus, *Contract Law And Theory* (LexisNexis, 2007).

⁶⁹ A gift, by definition, is a voluntary conveyance of land or transfer of goods, from one person to another, made gratuitously, and not upon any consideration of blood or money. "The Law Dictionary," Black's Law Dictionary, accessed September 8, 2017, http://thelawdictionary.org/gift/.

⁷⁰ Ellison, "A Systematic Review of Kidney Paired Donation," at 9.

⁷¹ See 42 U.S.C. § 274e(a) (1991). "The preceding sentence does not apply with respect to human organ paired donation." Ibid.

remedy or strict method of enforcement in place the practice of paired kidney donation in the United States risks collapse.

D. Transplant Hospital Policies

It is important to note that hospitals that facilitate paired kidney exchanges and kidney chains employ a vetting process for potential kidney recipients and potential donors. To be eligible to donate, an individual must first participate in a series of health screenings that test for high blood pressure, diabetes, hepatitis, HIV, cancer, or any other disease or condition that may compromise a kidney recipient. Once the donor completes the initial round of testing and it has been preliminarily determined that he or she is a physically and mentally stable adult, the intended donor will then participate in a series of tests.⁷² This first round of testing includes: extensive lab tests to determine blood and tissue typing for compatible matching, urine and blood tests to rule out viruses or diseases, testing for certain cancers, and, if applicable, pregnancy tests.⁷³ After passing the first round of tests, a potential donor will advance to a second round of testing, which includes heart tests and x-rays. Additionally, he or she will participate in a series of evaluations by a nephrologist, therapist, live donor administrator, a psychologist, and whatever other type of testing the transplant center deems necessary. Only after it has been determined by the transplant team that the potential donor is physically, emotionally, mentally, and financially fit to donate, the paired kidney exchange will proceed.

Part III: Legal Concerns

 ⁷² "Kidney Donor Process," Alliance for Paired Kidney Donation, accessed August 27, 2017, http://paireddonation.org/donor-information/.
⁷³ Ibid.

While it is understandable that Congress sought to reconcile the dire kidney shortage with NOTA's prohibition of compensation for organs, the legal fiction created by the 2007 amendment is deeply problematic. An exchange of a good for another good (or the promise of a good) without using money is a barter. Paired kidney donation, or the exchange of a kidney for another kidney (or the promise to donate a kidney) is inarguably a barter. The 2007 attempt to reframe a paired kidney donation as a simultaneous gift exchange rather than a quid pro quo transaction creates a legal fiction that blatantly discounts the reality. More importantly, deeming a kidney donation a "gift" fails to protect against desperate and possibly unethical actor-promisors seeking to obtain a matching kidney for a directed recipient. By legal definition, a gift is "a voluntary transfer of property by one person to another without any consideration or compensation therefor."⁷⁴ Moreover, a valid gift must have three elements: donative intent, actual delivery by donor, and acceptance by the donee.⁷⁵ To constitute a gift, rather than a loan or a transaction, there must be an absence of consideration or any expectation of compensation. The element of "donative intent" captures this no compensation or consideration requirement and directly contradicts the motivations behind the donors in a paired kidney exchange paradigm.

Consider, for example, D1, R1, D2, and R2. D1 donates his kidney to R2 with the understanding and expectation that D2 will reciprocate and donate her kidney to R1. By overlooking D1's detrimental reliance on D2's promise that she will donate her kidney to R1, Congress disregards the fact that a paired kidney exchange is, at its core, a quid pro quo transaction. Without D2's promise to donate to R1, D1's loved one, it is highly

⁷⁴ 39 American Jurisprudence Proof of Facts 2d at 733.

⁷⁵ Ibid.

unlikely D1 would donate to R2. Should D2 renege on her promise to donate to R1 after D1 has already donated his kidney to R2, Congress's categorization of a paired kidney donation as a "gift" offers no equitable or fair remedy to D1 and R1. Unlike an actual gift, which yields no expectation for a reciprocal action, the paired kidney exchange "gift" warrants an enforcement remedy because without one, the alleged "altruistic" nature of "gifting" lacks sufficient strength to assure a just outcome in the event a nefarious actor enters the exchange.

The appropriate solution in the case of paired kidney donations first requires a recognition that a paired kidney donation constitutes a quid pro quo exchange. To preserve the integrity of the exchange, Congress must make equitable remedies available to those harmed by nefarious actors attempting to scheme the system. Because monetary compensation can be both an impracticable and an inadequate remedy to an individual dying from kidney failure, certain instances warrant a balancing of the equities to determine the appropriate remedy. The more egregious the impropriety, collusion, and ill will demonstrated by the transgressing parties, the stronger the argument for a remedy of specific performance becomes.

Perhaps the most egregious scenario arises not from a paired kidney exchange, but from a situation where an individual becomes the direct beneficiary of his misconduct. Suppose, for example, an individual named Rob learns he needs a kidney. Rob learns Victor is a compatible kidney match. Rob begs Victor to donate his kidney, but Victor refuses. Desperate, Rob kidnaps and drugs Victor, and offers a surgeon a large sum of money to perform the transplantation. The surgeon happily obliges and the kidney transplant is a success. Upon awaking from the surgery, Rob enjoys a relatively quick and simple recovery, and happily proceeds to lead his normal life. Victor, by contrast, experiences several complications post-transplant and ultimately learns that he will now need a kidney because the transplant caused his only working kidney to fail. Furious that he was drugged, stolen from, and significantly harmed, Victor demands the immediate return of his kidney.

In balancing the equities, a court may find Victor has a legitimate claim for specific performance. First, Victor's stolen kidney is highly unique in that it consists of his DNA, matches all 6 HLA antigens, and no other kidney, other than Victor's failing one, is exactly like it. Second, payment of monetary damages, regardless of the amount, fails to provide adequate compensation. Victor needs a kidney to live, not money. Given the 5-year kidney waitlist and the national average of 4,500 people who die each year while waiting, Victor's only realistic hope of survival is a court order mandating the return of his stolen kidney. Finally, the malice aforethought exhibited by Rob warrants a punishment in the form of harsh restitution. So egregious were Rob's actions of plotting, kidnapping, drugging, and robbing Victor of his kidney, the restitution model of punishment not only penalizes the wrongdoer, but also makes the victim whole again. Anything short of the return of Victor's kidney fails to achieve justice.

A similar form of reasoning applies in the context of paired kidney exchanges wherein the donor and recipient collude to fraudulently induce a donor. For example, prior to the kidney exchange, suppose D2 and R2 conspire to deceive R1 and D1 by making them believe they intend to participate in a paired kidney exchange. They concoct circumstances that require D1 to donate to R2 several days before D2 must donate to R1 and plot to renege once R2 has received a kidney from D1. Assuming D2 and R2's plan works, R1 and D1, like Victor, have a legitimate case for specific performance. Just as the malice aforethought exhibited by Rob in the plotting, kidnapping, drugging, and robbing of Victor's kidney tip the scales of equity in favor of specific performance, so too does the calculated fraudulent inducement demonstrated by D2 and R2. In both cases, the nefarious actors have the willful intent to obtain a kidney in a dishonest way, the actors acted on their intentions, which ultimately resulted in harm. Though D2 and R2 did not physically capture R1 and D1, they engaged in a form of collusion and fraud so deplorable that it ultimately achieved the same outcome: an individual losing his kidney against his will.

Part IV: Ethical Concerns

Framing the Issue

A common theme in medical advancements often goes as follows: a new technology, technique, method, or approach enters the fold. The introduction of the new technology improves or cures the immediate issue. Yet the new technology activates unintended consequences, thereby raising a host of new issues to be addressed and resolved. In the context of organ donation, technological advancements, such as improved dialysis methods and refined anti-rejection medication bring new challenges to the organ supply and demand ratio. Consequently, with more people surviving for longer periods of time while waiting for a new kidney, the demand for kidneys has increased drastically.⁷⁶ Moreover, though progress in dialysis and anti-rejection medication have fostered greater hope for individuals suffering from renal failure, so too have they cultivated a novel form

⁷⁶ See e.g. Maduell Moreso et al., "High-Efficiency post dilution online hemodiafiltration reduces all-cause mortality in hemodialysis patients," *Journal of American Society of Nephrology* 24 no.3 (2013): 487–497, https://www.ncbi.nlm.nih.gov/pubmed/23411788.

of human suffering that comes with torturous and unpredictable periods of waiting filled with uncertainty as to whether the day for a new kidney will ever arrive. As observed by the President's council on Bioethics, society must address "the complicated paradoxes of medical progress: treatment success in one area increases the demand for other kinds of treatment, especially for age-related diseases; and the possibility of treating once-untreatable diseases makes the failure to treat them in every case seem like a "crisis" rather than real but limited medical progress."⁷⁷

The paired kidney exchange model offers one approach to mitigating the stress and burdens that attach to waiting for a kidney by constructing a donation mechanism that alleviates the compatibility requirement. At the same time, it creates layers of ethical issues pertaining to the rights and duties of all parties involved. Namely, when a party to the paired kidney exchange reneges on his or her promise to donate after already inducing the other party to donate, what obligations are owed and to whom? Moreover, should claims to bodily integrity be considered absolute? Or should a nefarious actor's claims to bodily integrity diminish when he or she falsely induces another party to donate a kidney? As already discussed in the previous section, the law fails to consider such layered issues and scenarios or provide an appropriate remedy. Thus, this section aims to provide an ethical analysis to supplement important components of live organ donation the law has overlooked.

At the outset, it is imperative to note that not all instances of reneging on a paired kidney exchange agreement should be considered equally. Organ donations, and especially live organ donations, do not occur in a vacuum and often externalities can and

⁷⁷ Eric Cohen, "Organ Transplantation: Defining the Ethical and Policy Issues."

do play a role in the success or failure of a transplantation. For example, a scenario whereby one of the intended donors falls ill with cancer before he can donate should be treated differently from a scenario where one of the intended donors willfully induces the first donor to donate and subsequently decides not to follow through on his promise to donate a kidney. Thus, the presence or absence of willfulness and malicious intent dictate the appropriate approach to analyzing and managing a failed paired kidney exchange due to one party reneging. The following permutations involving Donor 1 (D1), Recipient 1 (R1), Donor 2 (D2) and Recipient 2 (R2) will flesh out the range of possible ways a party to a paired kidney donation may renege. This spectrum spans from willful malice aforethought to latent illness that renders the intended donor unfit to donate.



Case One of reneging involves unequivocal malice aforethought. That is, D1 and R1 collude to create a scenario to ensure D2 donates to R1 before D1 must donate to R2. After fraudulently inducing D2 to donate to R1, D1 and R1 flee, leaving D2 with only one kidney and R2 without the promised kidney. Moreover, as a result of R1 and D1's willful misconduct, the doctors, nurses, and healthcare staff were tricked into violating their oath to do no harm. In this case, because R1 and D1 acted collusively to fraudulently induce D2, both ought to be considered culpable in their efforts to cheat the paired kidney exchange system. Depending on each party's degree of participation in furthering the fraud, R1 and D1 could be equally culpable, R1 may be more culpable that

D1 as R1 benefited most from the transaction, or D1 may be considered more culpable if he masterminded the fraud.

Consideration of the most just approach to rectify the injustice raises two immediate possibilities. The first option involves R1 returning a matching kidney to R2. Simply stated, through their actions, R1 and D1 became thieves the moment D2 donated to R1 and R2's kidney became the stolen good. That is, because R1 and D1 never intended to uphold their end of the bargain and because they acted collusively to induce D2 to donate, the act of fraud, for all intents and purposes in this scenario, becomes morally and legally equivalent to the act of thievery. Given the stolen property is exceedingly rare and uniquely specific to the original host, a just form of restitution requires either the thief to return the stolen kidney to the original host, i.e. D2, or to find and provide an exact kidney replacement for D2. Lawfully obtaining an exact match is highly unlikely as the waitlist for cadaveric donors is approximately five years and the chances that a match for R2 will suddenly appear and volunteer his or her kidney is highly improbable. The remaining option, therefore, requires R1 to return D2's kidney back to D2. Because R1 reaped the benefits of the theft by acting with willful maleficence, R1's return of D2's kidney achieves one form of justice.

Though this outcome returns all parties to the status quo ante, there are three glaring drawbacks. First and most importantly, it requires D2 to undergo a second operation, thereby increasing the risk of complications and further harm to D2. Second, though R1 is the wrongdoer, a second surgery may place him in a position that is worse than the position he was in before the surgery. Whereas a retributive theory of punishment may argue further harm to R1 is justified in light of the magnitude of his crime, a

rehabilitative theory may find that a less harsh approach, such as education and therapy, is more just and appropriate. Third, R2 remains in the same position as before the proposed exchange: in need of a kidney. Extremely problematic is the reality that D2 is now powerless to help R2 because she no longer has a "spare" kidney to donate, and thus cannot participate in a different paired kidney exchange. What is more, with each passing day R2 becomes sicker and the opportunities to find a new potential donor and undergo a transplant decrease.

A second possible approach to rectifying the injustice involves a remedy of specific performance imposed upon D1 to achieve the terms of the original agreement. D2 donated her kidney to R1 under the explicit and expressed condition that D1 would donate his kidney to R2. Had D1 not promised to donate his kidney to R2, D2 would not have placed herself at risk to undergo surgery and forfeit her kidney to R1. As mentioned above, obtaining an equal replacement kidney is highly improbable given the shortage of cadaveric kidneys and scarcity of voluntary living donors. Thus, to place R2 in the position she would have been in had all parties behaved according to their promise, D1 must donate to R2.

Because D1 actively participated in falsely inducing D2 to act, a remedy that mandates D1 to carry out the terms of the original agreement would yield a fair and just outcome. Here, the primary purpose of specific performance is not punishment, but rather to make the harmed party whole again. To build a punishment scheme designed to directly reflect R1 and D1's degrees of culpability would be unproductive in that the goal of a specific performance remedy in the paired kidney exchange context is to place the parties in the same position they would have been in had R1 and D1 not acted with willful malicious intent to defraud R2 and D2. While R2 and D2 may subsequently seek punitive damages or jail time for R1 and D1, specific performance merely seeks to make the harmed parties whole. Because R1 and D1 did willfully and maliciously collude to defraud D2 and R2, at minimum they bear moral responsibility to right the wrong.

Whereas the first approach, which calls for R1's specific performance, constitutes the purest form of restitution, this second approach, which calls for D1's specific performance, constitutes the most just and equitable solution in light of the totality of the circumstances. Unlike in the first approach, D2 and R1 would not need to undergo a second surgery. Further, while the first approach results in an outcome where D1 and D2 have two working kidneys and R1 and R2 have no working kidneys, the second proposed option conforms with what was originally planned – D1, D2, R1, and R2 each end up with one working kidney. Given the nature of kidneys- finite and non-regenerative – and given D1 and R1's voluntary and collaborative efforts to defraud D2 and R2, a stronger equitable argument in this case calls for D1 to donate to R2 rather than R1 return the kidney to D2.

Like Case One, Case Two involves malice aforethought. However, in this permutation, malicious donor 1 acts independently to fraudulently induce D2 to donate first. To highlight the distinction between Case 1 and Case 2, D1 with be referred to as DM1, which stands for Malicious Donor 1. DM1 does not act collusively with or even informs R1 of his intent to renege on his promise. Rather, DM1, acting independently, fraudulently induces D2 to donate to R1. Following D2's donation, DM1 flees, leaving R2 without the promised kidney. Here, DM1 is the only party acting with malice aforethought while R1 remains completely innocent. Furthermore, unlike in Case One, in
Case Two the only just form of restitution would require DM1 to fulfill his original promise to donate his kidney to R2. Because R1 is an innocent party rather than a coconspirator, it would be inequitable to force R1 to return D2's kidney. Moreover, it could be argued that requiring R1 to return the kidney constitutes an immoral and cruel and form of punishment because it forces R1 to suffer the consequences of DM1's willful misconduct.

Case Three becomes more complicated as neither D1 nor R1 engage in malice aforethought or act collusively. Here, no willful misconduct by R1 or D1 occur, but circumstances require R2 to donate to D1 first. When the time comes for D1 to donate to R2, D1 cannot carry out his promise. Several potential external factors may result in a Case 3 scenario. Perhaps D1 suffers a heart attack after D2 has already donated to R1 and before D1 can donate to R2. Suppose the transplant team begins the kidney extraction procedure only to discover one of D1's kidneys is failing, rendering D1 no longer suitable to donate. Perhaps the transplant team accidentally contaminates the kidney before it can be implanted into R2. Irrespective of the externality that renders D1 unfit to donate, the critical factor that distinguishes Case Three from Cases One and Two is the absence of willful intent. That is, absent purposeful actions to defraud D2 and R2, the claim that just D1 or D1 and R1 are morally responsible for the harm to D2 and R2 significantly weakens.

Clearly, a range of possible scenarios can occur whereby third party actors or outside factors disrupt the exchange. These cases are particularly difficult because neither R1 or D1 engaged in deceit or nefarious actions, rather unanticipated and extremely unfortunate circumstances render the completion of the paired kidney donation impossible. Neither R1 nor D1 acted willfully or nefariously, and therefore to punish R1 and D1 would be unfair and unjust. At the same time, R2 and D2 find themselves in positions worse than they were in Cases 1 and 2 because they can no longer be made whole. That is, with only one kidney left, D2 can no longer participate in a different paired kidney to save R2 and R2 remains sick and in need of a kidney. Moreover, in this case, D1 did not willfully breach his obligation to donate and cannot be required to donate.

Though not perfect, the quickest and most feasible solution in this case involves joining R2 to another paired kidney chain. Several kidney chains can occur simultaneously across the country at any given time. National databases such as the National Kidney Registry use sophisticated software that take into account factors such as blood type and HLA crossmatches to pair and link donors and recipients in a chain.⁷⁸ R2's data could be entered into the database and intervene in the next available kidney chain in which the donor is a match. This, however, raises a new layer of questions and ethical issues concerning Q, the individual in the kidney chain who, but for R2's interference, would have received the next available kidney. Broadly, the new moral analysis asks whether one's position in a kidney chain is an immutable right, whether one can make entitlement claims, whether the criteria used to determine a kidney patient's placement in the chain is fair, and how optimization is defined and achieved in light of the unpredictability of renal failure. More specifically, the new moral analysis asks whether R2's claim to the next available kidney supersedes that of Q. While on one hand Q will argue demoting his position in the kidney chain to remedy a broken arrangement for which he took no part in is unjust and deprives him of access to a lifesaving

⁷⁸ "How it Works," Kidney Link, accessed September 7,2017,

http://www.kidneylink.org/PairedDonationHowItWorks.aspx.

procedure, R2 will argue her claim to the next available kidney prevails because D2 has already donated on her behalf. That is, R2 will argue she was the catalyst of D2's donation to R1, and therefore because she is partially responsible for one donation, her claim to the next kidney supersedes that of Q's. This, of course, assumes no one has already donated on Q's behalf.

Philosophical underpinnings

This section will discuss the bioethical principles of autonomy, beneficence, nonmaleficence, utility, and justice as applied to paired kidney exchanges. It will conclude by analyzing the role of altruism and how it comports with the paired kidney exchange model. However, before delving into the ethical challenges concerning specifically the paired kidney exchange paradigm, it is important to first consider the bioethical context in which organ transplantation resides and the moral arguments that surround it. At the heart of the issue is the question of how human dignity and integrity of the human body comport with living organ donation broadly and paired kidney exchanges specifically. Those on one end of the spectrum argue engaging in a paired kidney sechange is morally good as those with two healthy kidneys need one of their kidneys less than those with no working kidneys. While this argument may prove compelling in some utilitarian schemes, it drastically oversimplifies the moral worth of the body as it assumes the body has meaning only because it is useful and that the body is simply a tool individuals have rather than what individuals are.⁷⁹ The opposing viewpoint claims donating a kidney to

⁷⁹ Eric Cohen, "Organ Transplantation: Defining the Ethical and Policy Issues."

induce another to donate is a morally reprehensible act as it reduces the human body to sellable (or barter-able) parts and thus is an affront to the donor's human dignity.⁸⁰

What is deemed right, wrong, moral, immoral, or best for society will depend on the philosophical perspective through which something is perceived. Deontological and utilitarian ethics, two prominent moral theories that are highly relevant to the discussion of paired kidney donation offer different reasoning and justifications for or against participation in the paired kidney donation model. The following will briefly discuss the primary rationales employed by the deontological utilitarian moral theories as they apply to living kidney donations with a specific focus on paired kidney donations.

Deontological Ethics

A Kantian version of the deontological perspective might be interpreted as prohibiting the sale of organs because it contradicts Kant's second formulation of the categorical imperative, which states that a person is an end in him or herself with dignity..⁸¹ Various interpretations of Kantian philosophy, however, differ over whether Kantian deontology endorses an absolute ban on all forms of living organ donations or if certain circumstances permit the voluntary participation in an organ exchange, such as the paired kidney exchange model. Whereas some, such as ethics scholar Nicole Gerrand, argue Kant expressly forbids the voluntary donation of one's organs, even if the donation is obtained in the absence of coercion, others maintain it is permissible..⁸²

⁸⁰ Nicole Gerrand, "The Misuse of Kant in the Debate about a Market for Human Body Parts," *Journal of Applied Philosophy* 16 no. 1 (1999): 59-67, http://onlinelibrary.wiley.com/doi/10.1111/1468-5930.00108/abstract.

 ⁸¹ Immanuel Kant, *Lectures on Ethics*, L. Infield trans. (Indianapolis and Cambridge: Hackett, 1963): 165.
 ⁸² Ibid.

espoused by Kant. The primary argument centers around Kant's notion of personhood. According to Kant, the most important way a person can exhibit rationality is by acting in accordance with moral law.⁸³ This capacity gives humans dignity, which distinguishes humans from things, all of which have a price.⁸⁴ Because a person's dignity is inextricably linked to the "capacity to exhibit humanity by acting rationally" and morally, Kant prohibits the treatment of the human body and its parts as means to an end.⁸⁵ He argues, "...man is not his own property and cannot do with his body as he will. The body is part of the self; in its togetherness with the self it constitutes the person."⁸⁶ Because the human body, and by extension its parts, constitutes part of the person, to sell or give away a body part for someone else to make use of would transform his body, and so his person, into a thing.⁸⁷ Furthermore, this ties into one formulation of Kant's categorical imperative, which asserts, "so act that you treat humanity, whether in your own person or in the person of any other, always at the same time as an end, never merely as a means."⁸⁸ That is, treating a human body part, such as a kidney, as an instrument for another's use violates the categorical imperative because the kidney of one person is being treated by another as a means to an end.

Others, however, argue that organs such as the kidney do not necessarily fall into Kant's category of "integral parts" and thus may be permissible to donate under certain conditions, such as a paired kidney exchange. According to a Kantian conception of a

⁸³ Tim Jankowiak, "Immanuel Kant," *Internet Encyclopedia of Philosophy*, accessed October 4, 2017, http://www.iep.utm.edu/kantview/.

 ⁸⁴ Gerrand, "The Misuse of Kant in the Debate about a Market for Human Body Parts," at 62.
 ⁸⁵ Ibid.

⁸⁶ Ibid at 60, citing Immanuel Kant, *Lectures on Ethics*, 166.

⁸⁷ Ibid.

⁸⁸ Immanuel Kant, *Groundwork of the Metaphysics of Morals*, trans. Mary Gregor (Cambridge: Cambridge University Press, 1996): 429.

duty of mutual aid, "we have a duty to respond to the true needs of rational beings when fulfilling such needs places little burden on us."⁸⁹ Those who believe Kantian logic approves living kidney donation contend that organ donation does not run contrary to Kantian ethics so long as certain conditions are met. First, the choice to donate is completely voluntary and no coercion or external pressure influences the individual to donate. Second, the organ to be donated, in this case the kidney, and the surgical procedure involved does not pose a grave risk to the donor. Third, donating the kidney is permitted so long as it does not threaten the moral personality of the donor, including his or her use of rational powers..⁹⁰

Taking it one step further, Kantian reasoning can be applied to support an argument for specific performance in the event D1 reneges after willfully inducing D2 to donate. Given that the paired kidney exchange is a contract memorializing a promise to act in exchange for a promise to act, the concept of duty becomes imperative once one of the parties donated. Kant emphasizes the significance of refraining from false promises in *Groundwork of the Metaphysics of Morals* where he explains that refraining from making promises one has no intention of keeping is a perfect duty toward others. To demonstrate how false promises defy the categorical imperative, he creates a scenario wherein an individual in need of money knows he will never repay a loan. Yet, recognizing he will never receive a loan if he does not firmly promise to repay it, he promises a loan-giver that he will repay it. Kant states that the maxim of his action is, "When I believe myself

http://anesthesiologyethics.homestead.com/files/a_kantian_argument_for_a_duty_to_donate_one_s_own_organs.pdf. ⁹⁰ Archimedes Articulo, "Living Organ Donation, Beneficent Helping, & the Kantian Concept of Partial Self-Murder," *Open Journal of Philosophy* 4 (2014): 502-09. doi: http://dx.doi.org/10.4236/ojpp.2014.44052.

⁸⁹ Jean-Christophe Merle, "A Kantian Argument for a Duty to Donate One's Own Organs. A Reply to Nicole Gerrand," *Journal of Applied Philosophy* 17 (2000): 97,

to be in need of money I shall borrow money and promise to repay it, even though I know that this will never happen.".⁹¹ Such a maxim, Kant explains, violates the first formulation of the Categorical Imperative because it cannot be universalized without contradiction and therefore cannot become a universal law..⁹² That is, to universalize the maxim of making false promises would destroy all trust in society. Moreover, falsely promising to repay one's loan infringes upon what belongs to someone else because the promisee parts with her money in the mistaken belief that the promisor intends to repay the loan..⁹³

Applying Kant's logic to the current legal structure governing paired kidney donations, infiltration of fraudulent actors making false promises would contradict the live organ donation structure. Without any form of repercussion in place to deter willful deception and without any protective legal safeguards to eliminate the potential for false inducement, there is nothing to stop those desperate for a kidney from committing fraud and deception; i.e. falsely inducing a party to a paired kidney to donate and reneging on the return promise to donate. This also violates Kant's second formula, which, as discussed above, is to treat humanity in yourself and others as an end and never merely as a means. If R1 has already gained a benefit from D2, then D1's failure to fulfill his obligation to R2 equates to treating D2 as a mere means to R1's advantage. Furthermore, because the non-fulfillment of duties constitutes a violation of someone else's freedom of

⁹¹ Immanuel Kant, "AA IV," in *The Cambridge Edition of the Works of Immanuel Kant: Practical Philosophy*, translated and edited by Mary J. Gregor and Allen Wood (Cambridge: Cambridge University Press,1996): 422.

⁹² Ibid.

⁹³ Kant, Groundwork of the Metaphysics of Morals at 429.

choice, Kant might argue that one should be required to fulfill these duties under penalty of law.⁹⁴

<u>Utilitarian</u>

The classical utilitarian approach seeks to maximize the greatest amount of good for the greatest number of people. This approach, a key branch of consequentialist thought, analyzes consequences for their value and is informed by the calculated benefits or harms for an action or intervention based on the actual harms or benefits.⁹⁵ In the context of live organ donations broadly and paired kidney donations specifically, voluntary donating one's organ to participate in a paired kidney chain would be morally good because the consequences of donating would not only result in saving more lives, but more importantly, each life saved would achieve a level of utility that could not be realized without a transplant.⁹⁶ By extension, some in the utilitarian camp would argue that offering financial compensation or financial incentives to encourage kidney donors is ethically meritorious so long as it results in achieving the greatest amount of good, which many argue equates to benefiting the greatest number of individuals.⁹⁷

Returning to paired kidney exchanges, Case 1 highlights the distinction between a utilitarian and non-utilitarian outcome. As previously discussed, two options exist for remedying the situation. The first involves R1 returning the stolen kidney to D2 and the second requires D1 to follow through on the exchange contract and donate to R2. Through a utilitarian lens, the second option ranks superior to the first. The greatest good

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⁹⁴ Sharon Byrd and Joanchim Hruschka, "Kant on Why Must I Keep My Promise," *Chicago-Kent Law Review* 81, no. 1 (2005): 50.

 ⁹⁵ Jharna Mandal, Dinoop Ponnambath, and Chandra Parija, "Utilitarian and deontological ethics in medicine," *Tropical Parasitology* 6 no. 1 (2016): 5-7, https://dx.doi.org/10.4103%2F2229-5070.175024.
 ⁹⁶ David Flamholz, "A Penny for Your Organs: Revising New York's Policy on Offering Financial Incentives for Organ Donation," *Journal of Law and Policy* 14 (2006): 360.
 ⁹⁷ Ibid.

afforded to the greatest number of people would result in the allocation of D2's healthy kidney to R1 and the allocation of D1's healthy kidney to R2. That is, everyone ends up with one healthy kidney as opposed to two people winding up with two healthy kidneys and two individuals left with zero working kidneys.

Bioethical Principles

Autonomy

The right to make independent decisions about one's healthcare represents the hallmark of medical ethics in the United States. This principle of respect for autonomy expresses the right of a competent patient to accept or refuse medical care, even if such care is lifesaving.⁹⁸ The underlying presumption holds that autonomous persons are often in the best position to determine what would be good and bad for them.⁹⁹ However, as with all guiding bioethical principles, respect for autonomy is not absolute and in certain instances, moral and societal constraints can limit an individual's claims to autonomy. As such, paired kidney exchanges sit at the unique intersection of society's paternalistic interests in protecting the individual from himself and the autonomous right of the patient to engage in a contractual exchange for kidneys.

Because a paired kidney exchange involves at least two parties agreeing to undergo a surgery that yields no physical benefit and results in at least some physical harm, many questions arise concerning how to best balance autonomy with societal or state interests in protecting the individual from himself. Moreover, an ethical analysis of autonomy in a

⁹⁸ Benjamin Hippen, Lainie Ross, and Robert Sade, "Saving Lives Is More Important Than Abstract Moral Concerns: Financial Incentives Should Be Used to Increase Organ Donation," *Annals of Thoracic Surgery* 88 no. 4 (2009): 1053-1061, doi: 10.1016/j.athoracsur.2009.06.087.

⁹⁹ Jukka Varelius, "The value of autonomy in medical ethics," *Medical Health Care Philosophy* 9 no. 3 (2006): 377–388. doi:10.1007/s11019-006-9000-z.

paired kidney exchange model can become highly complex because at least four independent primary parties are involved, all of whom equally claim to have their personal autonomy respected. If misunderstandings or disagreements ensue, one person's rights can easily infringe on those of another's. In a two-way paired exchange, for example, D1, D2, R1, and R2 each warrant respect for their personal autonomy and possess the strong presumptive right to do as they please with their bodies..¹⁰⁰ However, when D1 enters into the paired kidney exchange agreement with the willful intent to fraudulently induce D2 to donate, D1's autonomous interests and actions clash with those of D2. The resolution of this case will ultimately turn on the full realization of one party's autonomous claims at the expense of the other's. Either D1 and R1 may engage in deception without repercussion, which is a direct affront on both D2 and R2's dignity and autonomy..¹⁰¹ Or D1 must fulfill his contractual obligation over his objection so that D2 and R2's claims to securing the promised kidney, as grounded in justice, can be fully realized..¹⁰²

Additionally, autonomy claims of the surgeon(s) and the rest of the healthcare team warrant consideration as they are moral agents who can conscientiously object to participating in practices that offend their values. That is, a transplant surgeon whose values fundamentally disagree with the concept of a paired kidney exchange cannot be forced to operate.

¹⁰⁰ Stephen Wilkinson, "The Sales of Human Organs," *Stanford Encyclopedia of Philosophy*, updated October 22, 2015, https://plato.stanford.edu/entries/organs-sale/.

¹⁰¹ David Bakhurst argues lying is morally wrong because it is an affront to a person's dignity and autonomy. David Bakhurst, "On lying and Deceiving," *Journal of Medical Ethics* 18 (1992): 63-66, http://jme.bmj.com/content/medethics/18/2/63.full.pdf.

¹⁰² D2 entered into the contract and donated her kidney with the understanding that D1 would donate his kidney. Entering into the contract with the intent to fraudulently induce, made D1's consent uninformed. For further discussion on autonomy and contracts see Richard Craswell, "Remedies When Contracts Lack Consent: Autonomy and Institutional Competence," *Osgoode Hall Law Journal* 33 (1995): 209.

An unfiltered view of the principle of autonomy supports the notion that R1, D1, R2, and D2 have the right to do as they please with their own bodies and therefore should not be hindered on the condition the exchange presents no substantial harm to third parties. Central to the argument for a full realization of each party's autonomy is the contention that free choice should dictate the provision of organs and those individuals who desire to donate, sell, or barter a "redundant organ" should be allowed to do so...¹⁰³ As noted by Dr. Benjamin Hippen, "free societies typically do not interfere with competent adults making choices that affect their lives and do not significantly harm themselves or others.".¹⁰⁴ So long as all four parties enter into the paired kidney exchange voluntarily and without the presence of bribery, coercion or any other unjust circumstance, they should be free to engage in the exchange...¹⁰⁵ As competent individuals and owners of their own bodies, they may bind themselves to a contract that forces them to undergo a surgery that either results in relinquishment of one kidney (donors) or the relinquishment and receipt of a kidney (recipient).

At the same time, legal and societal constraints place limits on autonomy and thus a productive bioethical analysis of autonomy must occur within the context of and in light of these boundaries. In the United States, society will impose paternalistic limits to a person's claim to autonomy either to protect the individual from him or herself, to protect society, or because limited resources prevent the individual from pursuing a specific course of action. For example, debate around the morality of physician assisted death represents a clash between the full realization of a patient's autonomous rights and the

¹⁰³ Cohen, "Organ Transplantation: Defining the Ethical and Policy Issues."

 ¹⁰⁴ Hippen, Ross, and Sade, "Saving Lives Is More Important Than Abstract Moral Concerns: Financial Incentives Should Be Used to Increase Organ Donation," at 1055.
 ¹⁰⁵ Ibid.

state's interest in upholding reverence for life, which includes stopping the terminal patient from ending his or her own life. In most states, the scale tips in favor of human reverence for life as physician assisted death is outlawed in 44 states..¹⁰⁶ Rather, most states have made the determination that the reach of a patient's autonomy abruptly ceases when self-determination impedes on respect for life and human dignity. A second example exemplifies the public health reason for limiting autonomy via immunization laws and requirements for students who wish to attend public school. Any student seeking daycare and school entry must adhere to state and local vaccination requirements. Though parents may opt to homeschool or seek out private schools without such entry requirements, most opt to comply with the vaccination laws in part to ensure their children are not at risk and in part to ensure the community is at a reduced risk for vaccine-preventable diseases..¹⁰⁷

Returning to living organ transplantation models, the opportunity for paternalism increases as kidney transplantation models more closely resemble organ markets. One of the main arguments for limiting an individual's autonomous right to sell his kidney is to protect the individual from himself. As noted by Dr. Hippen, "autonomy must be understood within a social context. In a society in which great disparities exist in wealth and opportunities, the claim that poor people should have the right to sell their kidney as one more option to escape poverty denies any social responsibility we may have to

¹⁰⁶ Tom Beauchamp, "The Right to Die as the Triumph of Autonomy," *Journal of Medicine and Philosophy* 31 no. 6 (2006): 643-654, http://dx.doi.org/10.1080/03605310601096619. Currently 6 states, California, Colorado, Oregon, Vermont, Washington, Montana, and the District of Columbia, have legalized physician-assisted suicide. By contrast, 44 states consider physician assisted suicide illegal. "State-by-state guide to Physician Assisted Suicide," ProCon.org, last updated February 21, 2017, https://euthanasia.procon.org/view.resource.php?resourceID=000132.

¹⁰⁷ "State Vaccination Requirements," Centers for Disease Control and Prevention, last updated January 29, 2016, https://www.cdc.gov/vaccines/imz-managers/laws/state-reqs.html.

prevent such a tragic option."¹⁰⁸ That is, to protect individuals from making decisions contrary to what is perceived to be in their best interest, such as selling an organ, curbing their autonomy is justified. By contrast, in organ transplant models such as paired kidney exchanges and the UCLA voucher program, society has greatly expanded the opportunity for individuals to realize their claims to autonomy to a fuller extent.

Informed Consent

The principle of respect for autonomy forms the basis for the practice of informed consent. In any research or clinical setting, following proper protocols to ensure the patient or participant is both acting voluntarily and fully aware of the reasonably foreseeable risks, potential outcomes, and alternative resolutions are essential to the integrity of patient autonomy.¹⁰⁹ In the context of a living donations broadly and paired kidney exchanges specifically, it is exceptionally important for donors to thoroughly undergo the necessary steps of informed consent as the donors are agreeing to participate in a highly invasive procedure that affords no direct physical benefits to them. As noted in the *Clinical Journal of the American Society of Nephrology*, "without ensuring valid informed consent on the part of prospective donors, the ethical tension between the responsibility to help transplant candidates and the well-founded concern about harming donors cannot be resolved by appealing to donor autonomy."¹¹⁰ Insofar as the goal is to protect this unique class of patients from unanticipated harm, ensure the right to self-

¹⁰⁸ Hippen, Ross, and Sade, "Saving Lives Is More Important Than Abstract Moral Concerns: Financial Incentives Should Be Used to Increase Organ Donation," at 1058.

¹⁰⁹ "What are the elements of the Informed Consent document?" UNT Health Science Center, last updated June 18, 2015, https://www.unthsc.edu/research/protection-of-human-subjects/informed-consent/what-are-the-elements-of-the-informed-consent-document/.

¹¹⁰ Peter P. Reese, Arthur L. Caplan, Aaron S. Kesselheim, Roy D. Bloom, "Creating a Medical, Ethical, and Legal Framework for Complex Living Kidney Donors," *Clinical Journal of the American Society of Nephrology*, (2006): 1148–1153, http://cjasn.asnjournals.org/content/1/6/1148.full.

determination, and preserve bodily integrity, the doctrine of informed consent requires three elements: adequate provision of information to the patient, adequate capacity for decision making, and freedom from coercion..¹¹¹ These elements are designed not only to protect the individual patient's health, welfare, and rights to autonomy but also to safeguard the integrity of the medical profession in general.

For paired kidney exchanges, informed consent applies to three important and distinct relationships. The first application involves the physician patient relationship. In bioethics, the doctrine of informed consent requires physicians to respect patients' autonomy by giving them the information needed to understand the risks and benefits of a proposed intervention, as well as the reasonable alternatives (including no intervention), so that they may make independent decisions..¹¹² The 1972 case *Canterbury v. Spence* codifies this sentiment in the landmark opinion: "The scope of the physician's communications to the patient…must be measured by the patient's need, and that need is the information material to the decision ... [A]ll risks potentially affecting the decision must be unmasked.".¹¹³ In paired kidney exchanges, the potential that one party will renege or be found unable to participate is foreseeable by almost any standard...¹¹⁴ Thus, in the current state of paired kidney exchanges, a physician must clearly explain to the participants the foreseeable risks, complications, and alternatives to a kidney transplant,

¹¹¹ Mary Olbrisch, Sharon M. Benedict, Deborah L. Haller, James L. Levenson, "Psychosocial Assessment of Living Organ Donors: Clinical and Ethical Considerations," *Progress in Transplantation* 11 no. 1 (2001):40-49, https://psych.vcu.edu/Portals/37/Documents/LivingDonor.pdf.

¹¹² Laura Sedig, "What's the Role of Autonomy in Patient- and Family-Centered Care When Patients and Family Members Don't Agree?" *AMA Journal of Ethics* 18 no. 1 (2016): 12-17, http://journalofethics.ama-assn.org/2016/01/ecas2-1601.html.

¹¹³ Canterbury v. Spence, 464 F.2d 772 (D.C. Cir 1972): 786-87.

¹¹⁴ In some states the legal standard for disclosure is that which a reasonable medical practitioner would provide. Other states only require the practitioner provide information about reasonably foreseeable risks and alternative treatments. See e.g. NY Pub Health L § 2805-D (2014).

which includes the possibility that one party may either renege or become medically impaired, thereby crumbling the entire paired exchange. Simply stating the foreseeable risks, however, fails to achieve adequate informed consent. Because the law affords no remedy to a harmed party as the result of a willful paired kidney exchange contract breach, a foreseeable worst case scenario must be conveyed to both donors and participants. That is, if D1 reneges even after D2 has already donated, R2 will have no guaranteed back up recourse for another kidney and D2 will no longer be able to participate in another paired kidney exchange because his kidney has already been removed.

The second aspect of informed consent applies to the relationship between the recipient and the donor who has agreed to donate on behalf of the recipient. In living donations, ethical questions frequently arise about the extent to which the intimate bonds of family and friendships affect a potential donor's autonomous choice when agreeing to become a kidney donor. Whereas some take no issue with a competent individual agreeing to undergo a harmful procedure to help a friend or family member, others maintain that donors' consent is compromised by their emotional attachment to the recipient. A potential donor's desire to help a friend, family member, or specified recipient may overshadow his or her understanding of the risks associated with the procedure. As noted by Carl Elliot in an article published in the Journal of Medical Ethics, "genuine worries about exposing a subject to harm are channeled into a debate about freedom of choice."¹¹⁵ The worry is that the obligation to help a kidney patient in

¹¹⁵ Carl Elliot, "Doing harm: living organ donors, clinical research and The Tenth Man," *Journal of Medical Ethics* 21 (1995): 91-96, 93.

https://www.ncbi.nlm.nih.gov/pmc/articles/PMC1376630/pdf/jmedeth00295-0028.pdf.

need, especially if the patient is a friend or family member, eclipses a donor's judgment, competency, and ability to fully understand and appreciate the risks of a kidney donation. Suppose, for example, the donor is the mother of a child in need of a kidney. Some may claim that to offer a mother the chance to donate a life-saving kidney to her child is coercive or denies full autonomous choice because no parent could refuse the offer.¹¹⁶ Elliot continues, "the bonds between parent and child are so tight, it was said, that they constrict a parent's ability to make a free choice about risking the chance of harm."¹¹⁷ Others, however, contend the self-sacrifice aspect of donation does not necessarily equate to coercion or the lack of voluntary participation. Just because a mother's unyielding love for her child motivates her to participate in a paired exchange to save her child does not automatically mean her freedom of choice has been compromised. Rather, it is incumbent upon the transplant centers and transplant teams to analyze each participant on a case-by-case basis to ensure the donors are acting out of their own volition.

Third, because all four parties agreed to enter into an exchange that succeeds only if donors commit to perform donor duties and recipients agree to their recipient duties, it is important all donors and recipients involved are fully informed about the stipulations in the agreement. Though technically NOTA precludes these agreements from being called contracts, which, by definition, require an exchange for valuable consideration, contractual guidelines involving informed consent are still necessary for a successful paired kidney exchange. Specifically, when a participant in the exchange is accused of breaching a promise, as in Cases 1 and 2, some of the first inquiries include: what were the terms of the agreement and whether a meeting of the minds was achieved? That is,

¹¹⁶ Ibid.

¹¹⁷ Ibid.

did all four parties understand the agreement in the way it was intended to be understood? To achieve this common understanding, all parties must be properly informed of all relevant information, including the intentions of the other parties engaging in the agreement. An understanding of each party's intention, in addition to information from the medical provider about the act of donation or receipt of a kidney, the reasonably foreseeable post-operative complications, foreseeable out-of-pocket expenses, realistic post-operative expectations about returning to work, foreseeable lifestyle changes, and future medical expenses are essential to each party's full realization of autonomy in making an informed decision about their healthcare.

Beneficence

The principle of beneficence refers to a normative statement of a moral obligation to act for the others' benefit, helping them to further their important and legitimate interests, often by preventing or removing possible harms.¹¹⁸ In a clinical setting, healthcare providers have a duty of care that extends to the patient, professional colleagues, and to society..¹¹⁹ In the context of paired kidney exchanges, a complete analysis of beneficence must be viewed in conjunction with other bioethical principles, such as non-maleficence, justice and autonomy, and requires consideration of both the donors' and the recipients' best interests. For the recipient, beneficence implies an active attempt to advocate strongly for the best medical treatment for patients with end stage renal disease, which for many means transplantation.¹²⁰ As discussed in an article published in the *Journal of*

 ¹¹⁸ Tom Beauchamp, "The Principle of Beneficence in Applied Ethics," *Stanford Encyclopedia of Philosophy*, last updated October 3, 2013, https://plato.stanford.edu/entries/principle-beneficence/.
 ¹¹⁹ Frank Kinsinger, "Beneficence and the professional's moral imperative," *Journal of Chiropractic Humanities* 16 no. 1 (2010): 44-46, https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3342811/.
 ¹²⁰ Peter Reese, Arthur Caplan, Aaron Kesselheim, and Roy Bloom, "Creating a Medical Ethical, and Legal Framework for Complex Living Kidney Donors," *Clinical Journal of American Society of Nephrology* 1 (2006): 1148–1153, doi: 10.2215/CJN.02180606.

American Nephrology, "a kidney transplant from a living donor—ideally performed as the initial modality of RRT—provides the best outcome for a patient with ESRD," or end stage renal disease.¹²¹ First, it allows the recipient to avoid the three-to-five year waiting period on the deceased donor waiting list. Second, Live donor kidney lasts about 15-20 years, while the average deceased donor kidney lasts 10-15 years.¹²² Third, unlike in the case of a deceased donor, surgery can be timed for the optimal health of the recipient and for donor convenience..¹²³ Fourth, compared to deceased-donor transplants, recipients of living-donor kidneys enjoy better outcomes because the kidney is transplanted immediately after removed from the donor, thereby improving the efficacy and chances that the transplanted organ will function immediately. Certainly then, performing a lifesaving kidney transplant fulfills the healthcare providers' obligation to the recipient of beneficence as a transplant is almost always in the recipient's best interest.

The same, however, cannot be said for the donor. Removing a kidney from a healthy person clearly does not physically benefit the recipient. Not only is the transplant team subjecting the recipient to a highly invasive and non-therapeutic surgery, but also it is removing a healthy organ from the recipient's body. Should the one remaining organ suffer from failure in the future, the recipient will find him or herself on a waiting list for a new kidney, thus subjecting either another living donor to the same risks or chancing death while awaiting a cadaveric donor. Thus, the principle of beneficence must balance against respect for donor and patient autonomy.

¹²¹ Robert Gaston, Vineeta Kumar, and Arthur Matas, "Reassessing Medical Risk in Living Kidney Donors," *Journal of the American Society of Nephrology* 26 (2015):1017–1019, doi: 10.1681/ASN.2014030227.

 ¹²² "The Benefits of Living Donation," UC Davis Health, accessed September 23, 2017, http://www.ucdmc.ucdavis.edu/transplant/livingdonation/donor_benefits.html.
 ¹²³ Ibid.

On one end of the spectrum are those who argue the donor does benefit greatly from the donation because he or she enjoys significant psychological gains by aiding an emotionally related family member or friend.¹²⁴ In conducting the transplantation, healthcare team is, in effect, aiding the donor in his or her quest to achieve psychological and emotional fulfillment. A paired kidney exchange scheme further fosters this objective because it allows the donor to circumvent the hurdle of donor compatibility. So long as the donors choose to donate a kidney voluntarily and the physician does not actively solicit kidneys from potential donors, the transplant physician is justified in removing the kidney as he or she is providing physical benefits to the recipient and psychological benefits to the donor.¹²⁵

The stronger argument, however, contends that a living donation affords little-to-no physical benefit to the donor, but claims to autonomy and the presence of informed consent can outweigh reasonable physical harm incurred by the donor. That is, a bioethics analysis requires a balancing of the principles and "one may conceptualize the 'opposing' demands placed by beneficence and nonmaleficence as weights balancing like a seesaw on a fulcrum of autonomy."¹²⁶ When a potential donor expresses a strong desire to donate to a loved one, for example, her autonomy can potentially outweigh the principles of beneficence and non-maleficence so long as she is properly informed. As discussed in the *Clinical Journal of the American Society of Nephrology*, "without ensuring valid informed consent on the part of prospective donors, the ethical tension

¹²⁴ Hippen, Ross, and Sade, "Saving Lives Is More Important Than Abstract Moral Concerns: Financial Incentives Should Be Used to Increase Organ Donation," at 1058.

¹²⁵ Active solicitation for organs by a physician may be perceived by some as a form of coercion or, at least, constitutes attempts to curb donor autonomy.

¹²⁶ Reese, Caplan, Kesselheim, and Bloom, "Creating a Medical Ethical, and Legal Framework for Complex Living Kidney Donors," at 1150.

between the responsibility to help transplant candidates and the well-founded concern about harming donors cannot be resolved by appealing to donor autonomy."¹²⁷ Even though engaging in a paired kidney donation affords a donor no physical benefits and may even harm the donor, participation can be a morally acceptable practice when the donor fully understands the risks, alternatives, and potential outcomes and still maintains the position that he or she wants to donate to help a specified recipient.

Non-maleficence

Just as the principle of beneficence requires healthcare providers to act in the best interest of their patients, the principle of non-maleficence, or "do no harm," charges the healthcare team to avoid, as much as possible, inflicting harm on the patient. Considered the axiom of medical ethics, the charge to do no harm or "Primum non nocere" affords four primary purposes in the clinical setting.¹²⁸ First, it maintains the integrity of medicine by casting it as a moral enterprise. Essentially, it is designed to serve as a check on physicians to ensure medical skill is not put to wrongful use. As noted by Robert Timko in his book *Clinical Ethics: Due Care and the Principle of*

Nonmaleficence, "physicians are obliged to use their knowledge and expertise or exercise their authority only in ways which meet the needs of a particular patient and do no harm to either the patient or community well-being."¹²⁹ As such, a physician generally should not recommend or partake in a procedure or therapy that generates harm unless the action is necessary to prevent even greater harm. Second, the principle of non-maleficence

¹²⁷ Ibid.

¹²⁸ Albert Jonsen, "Do No Harm," *Annals of Internal Medicine* 88 no. 6 (1978): 827-832, doi: 10.7326/0003-4819-88-6-827.

¹²⁹ Robert Timko, *Clinical Ethics: Due Care and the Principle of Nonmaleficence* (Lanham: University Press of America, 2001): 133.

ensures the physician appropriately exercises clinical judgment and engages in due care. It charges physicians to be competent, knowledgeable, and informed about current the therapies and techniques pertinent to their patients. Failure to abide by due care can result in harm to the patient. Third, the charge to do no harm requires the healthcare provider to engage in a risk-benefit analysis. Though in the clinical context harm typically refers to the violation of a patient's health and wellbeing, it also includes any action that results in "prolonged diminished ability to respond to physical, psychological, or social challenge.".¹³⁰ When a degree of harm is inherent to a particular medical intervention, a calculus of the risks and benefits of the intervention as applied to all parties involved must ensue. The procedure with the best chance of success and the lowest risk of harm should prevail. In a paired kidney exchange, for example, the net benefits to each party should exceed the net harms. Finally, the principle of non-maleficence requires a benefit-detriment equation. Here, "do no harm" prohibits the physician from inflicting harm not associated with a compensating benefit..¹³¹

When competent individuals request and consent to procedures that are risky, painful, harmful, and provide no physical benefit to the patient, it raises significant ethical issues for the healthcare providers involved. Complicating the matter is the dominant role autonomy plays in the American healthcare framework, which favors acceding to the patient's wishes even if the course of action may veer from the patient's best health interests. In the context of living organ donations, one way the medical community accommodates the clash among autonomy, beneficence, and non-maleficence is through

¹³⁰ Ibid at 135.

¹³¹ Albert Jonsen, "Do No Harm: Axiom of Medical Ethics" in *Philosophical and Medical Ethics: Its Nature and Significance* edited by Stuart F. Spicker and Trstram Engelhardt (Dordrecht: Reidel, 1977), 29f.

framing these three principles as a calculus to be understood in tandem with a benefit-toharm ratio ..¹³² This calculus occurs on a case-by-case basis and takes into account the anticipated medical and psychosocial benefits in relation to the anticipated medical and psychosocial harms..¹³³ Put another way, "the principle of non-maleficence is not absolute and requires to be weighed against the duty of beneficence and respect for autonomy.".¹³⁴

In living organ donation broadly and paired kidney donations specifically, the riskbenefit calculus can become quite complex as the procedure is designed for one side, the recipient, to enjoy the physical benefits while the other side, the donor, loses the physical benefit of a second healthy kidneys.¹³⁵ Thus, "assessment of risk and benefit for living donors has always occurred against a backdrop of complex interactions that cannot be reduced to either paternalism or unrestrained autonomy."¹³⁶ A rigid assessment of do no harm rejects any form of live organ donation or blood donation because these procedures cause physical damage to the donor and affords the donor no physical benefit..¹³⁷ A paired kidney exchange model crumbles under a framework that affords the risk of harm greater weight than the benefits of living kidney donations.

By contrast, a more relaxed perspective takes the position that the removal of a kidney from a donor is justified because the general risk to the donor is relatively small

¹³² Hippen, Ross, and Sade, "Saving Lives Is More Important Than Abstract Moral Concerns: Financial Incentives Should Be Used to Increase Organ Donation," at 1058.

 ¹³³ "Living Non-directed Organ Donation," Organ Procurement and Transplantation Network.
 ¹³⁴ David Price, *Legal and Ethical Aspects of Organ Transplantation* (Cambridge: Cambridge University)

Press, 2000), 254.

¹³⁵ Jonsen, "Do No Harm" at 827.

¹³⁶ Gaston, Kumar, and Matas, "Reassessing Medical Risk in Living Kidney Donors," 1017.

¹³⁷ See e.g. Gretchen Cuda-Kroen, "Organ Donation Has Consequences Some Donors Aren't Prepared For," *NPR*, updated July 2, 2012, http://www.npr.org/sections/health-shots/2012/07/02/155979681/organ-donation-has-consequences-some-donors-arent-prepared-for.

and the benefit to the recipient is large and likely life-saving. Moreover, despite the potential post-operative complications, many studies conclude the overall risk of shortterm and long-term complications and death is quite low. Several U.S. studies and reports have found "in general, the operative procedure is well tolerated, standardized and relatively safe, independent of whether the kidney is removed by open or laparoscopic surgery."¹³⁸ According to a 2015 conducted by the Johns Hopkins University School of Medicine and the Johns Hopkins School of Public Health, of the 133,824 living kidney donors from 1987 to 2015, the median risk of kidney failure was only 1 case per 10,000 donors at 5 years after donation and only 34 per 10,000 donors at 20 years after donation.¹³⁹ Furthermore, a 2015 paper published in the Journal of the American Society of Nephrology reported that donors lived as long (or longer) as the general population, had a relatively stable glomerular filtration rate (GFR) over many years without increased rates of end stage renal disease, had similar risks of hypertension and proteinuria as nondonors, and had excellent quality of life.¹⁴⁰ A paired kidney exchange model thrives in a framework that recognizes these statistics as evidence that the benefits to living kidney donations generally outweigh the risks.¹⁴¹

Justice

The primary purpose behind the enterprise of organ procurement and transplantation is to benefit a population of critically ill patients. Two factors that are necessary to

¹³⁸ Heiner Wolters and Thorsten Vowinkel, "Risks in Life After Kidney Donation," *Nephrology Dialysis Transplantation* 27 no. 8, (2012): 3021-23, https://doi.org/10.1093/ndt/gfs150.

¹³⁹ Allan Massie et al., "Quantifying Postdonation Risk of ESRD in Living Kidney Donors," *Journal of the American Society of Nephrology* 28 no.9 (2017): 2749-55, doi: 10.1681/ASN.2016101084.

¹⁴⁰ Gaston, Kumar, and Matas, "Reassessing Medical Risk in Living Kidney Donors," 1017-1019.

¹⁴¹ For a more in-depth discussion of the risks associated with living kidney donations, see Appendix 5.

ensure a morally sound kidney allocation system are utility and justice..¹⁴² Whereas utility refers to the maximization of net benefit to the community, justice refers to "fairness in the pattern of distribution of the benefits and burdens of an organ procurement and allocation program.".¹⁴³ Though both utility and justice are distinct components of what NOTA calls an "equitable" allocation system, both must act concordantly to achieve a moral allocation model..¹⁴⁴

Justice requires balancing the perspectives of recipients, donors, transplant centers and society as a whole, which can vary significantly in terms of the proper allocation of living organs..¹⁴⁵ Broadly, it requires that all parties are treated fairly and afforded consideration as independent individuals rather than as members of a particular group, race, or class. According to NOTA's mandate for the establishment of the Task Force on Organ Procurement and Transplantation, for example, NOTA was explicitly designed to advocate for "equitable access by patients to organ transplantation and for assuring the equitable allocation of donated organs among transplant centers and among patients medically qualified for an organ transplant." ¹⁴⁶ As such, the principle of justice concerns not only with the aggregate amount of medical good that is produced, but also with the method in which that good is distributed among all potential beneficiaries. Whereas utility takes only quantity and probability of the various outcomes into account, justice requires consideration of both medical need and medical benefits, with a strong

¹⁴² "Ethical Principles in the Allocation of Human Organs," Organ Procurement and Transplantation Network, updated June 2015, https://optn.transplant.hrsa.gov/resources/ethics/ethical-principles-in-the-allocation-of-human-organs/.

¹⁴³ Ibid.

¹⁴⁴ Ibid.

¹⁴⁵ Bradley Wallis, Kannan Samy, Alvin Roth, and Michael Rees, "Kidney Paired Donation," *Nephrology, Dialysis, Transplantation* (2011): 4, doi: 10.1093/ndt/gfr155.

¹⁴⁶ Public Law 98-507, October 19, 1984. National Organ Transplant Act 98 Stat. 2339 cited in "Ethical Principles in the Allocation of Human Organs," Organ Procurement and Transplantation Network.

preference for aiding the medically sickest patients..¹⁴⁷ As discussed in the 2015 Organ Procurement and Transplantation Network "Ethical Principles in the Allocation of Human Organs" report, "factors to be considered in the application of the principle of justice are: medical urgency; likelihood of finding a suitable organ in the future; waiting list time; first versus repeat transplants; age; and geographical fairness.".¹⁴⁸

From a policy standpoint, the principles of justice and utility as applied to the kidney shortage and distribution may at times conflict. Depending on what is perceived as the greatest medical good, models such as the paired kidney exchange, kidney chains, the UCLA voucher program, and even an organ market may achieve justice but not utility. For example, if achieving the maximum life span for a donated kidney is considered maximizing good, then a paired kidney exchange where the donors are young and healthy and the recipients are elderly and sickly, may achieve justice but does not maximize utility. On the other hand, if maximizing the number of living organ donors is considered the greatest good, then paired kidney exchanges may achieve both justice and utility. That is, when increasing kidney donor supply and removing more individuals from the cadaveric donor waiting list are considered great medical goods, these models can be viewed as mechanisms toward achieving maximum benefit. In a scheme where the potential harms to the donor are considered relatively minimal, the paired kidney exchange and its variations achieve the greatest net good by creating a way for more potential donors to donate.

 ¹⁴⁷ "Ethical Principles in the Allocation of Human Organs," Organ Procurement and Transplantation Network.
 ¹⁴⁸ Ibid.

Justice, too, requires a multifaceted examination when applied to paired kidney exchanges because the analysis depends on how the exchanges are organized and the breadth and scope of the donor and recipient pools. On a national level, a simple twoparty paired kidney exchange may fall short of achieving justice because factors such as medical need and probability of beneficial medical outcomes are vastly overlooked. Given that the purpose and design of the paired kidney exchange is to allow donors to help an acquaintance, friend, or family member despite their incompatibility. If the loved ones in need of a kidney happen to be the sickest and worst off recipient candidates, then perhaps the paired kidney exchange can achieve justice. If the loved ones do not fall into the "worst off" category, then it can be argued that paired kidney exchanges favor only those who have healthy loved ones who are willing and able to donate a kidney. That is, under a paired kidney exchange scheme, a semi-sick loved one will receive a kidney from his loved one while a kidney recipient candidate whose medical need for a kidney surpasses the semi-sick individual will be overlooked because she does not have a person willing to donate on her behalf. The same can be said for paired kidney chains and the UCLA program as a necessary component for participation is the availability of a friend or family member who is willing to donate a kidney on the recipient's behalf.

Furthermore, from an institutional perspective, greater utility and justice can be achieved when transplant centers across the United States work collaboratively either to match incompatible pairs across multiple transplant centers or to shift from paired kidney exchanges to paired kidney chains to increase the participant pool. For example, one transplant center has two donor-recipient pairs that are compatible with one another and can participate in a two-way exchange internally. At most, two kidney patients could benefit from this exchange. Suppose, however, Pair 3 from another transplant center is awaiting a compatible pair so they can participate in an exchange. As it turns out Pair 1 would be a match for Pair 3. Similarly, Pair 4 from a different hospital is a match for Pair 2. Suppose instead of Pairs 1 and 2 exchanging internally within their transplant center, all four pairs are entered into a national pool. Pair 1 is then matched with Pair 3 and Pair 2 is matched with Pair 4. When multiple transplant centers can participate in paired kidney exchanges together to increase the pool size, it maximizes the number of individuals that will receive kidneys. As noted in the *Journal of Nephrology Dialysis, and Transplantation*, "if centers are doing some internal exchanges without making those pairs available to the national pool, that means those exchanges, de facto, had higher priority than, for example, children at other centers.".¹⁴⁹ A paired kidney allocation system that is restricted only to a single hospital fails to fully achieve utility and justice in distribution and allocation of available kidneys.

<u>Altruism</u>

In the United States, the prevailing public policy underlying organ donation is described as one of "encouraged voluntarism" or "altruism".¹⁵⁰ This concept appears frequently in documents characterizing the United States' organ transplant policy, ranging from NOTA's legislative history to journal publications to policy statements by major organ procurement organizations like UNOS and the American Society of Transplantation.¹⁵¹ However, a closer look at the use and application of "altruism"

¹⁵⁰ Aparna Dalal, "Philosophy of organ donation: review of ethical facets," *World Journal of Transplantation* 5 no. 2 (2015): 45, doi: 10.5500/wjt.v5.i2.44; Arthur Caplan, "Bioethics of Organ Transplantation," *Cold Springs Harbor Perspectives in Medicine* (2014):1, doi: 10.1101/cshperspect.a015685.

¹⁴⁹ Wallis, Kannan Samy, Alvin Roth, and Michael Rees, "Kidney Paired Donation," 5.

¹⁵¹ See e.g. "AST Position Statement on Directed and Non-Directed Donation," American Society of Transplantation, accessed September 8, 2017, https://www.myast.org/ast-position-statement-directed-and-

reveals the concept is fraught with interpretive discrepancies and the actual definition is unclear and often applied with inconsistency.¹⁵² Before delving into an analysis of how a paired kidney exchange model comports with the United States' commitment to facilitating an altruistic organ procurement system, this section will first highlight prevailing definitions and interpretations for what does and does not constitute altruistic organ donation.

a. Prevailing definitions

The term altruism, coined by Auguste Comte, French philosopher and founder of positivism, is defined as a theory of conduct that regards the good of others as the end of moral action..¹⁵³ If "good" is understood to mean pleasure, happiness, and the absence of pain, then a moral agent has an obligation to further the pleasures and alleviate the pains of other people..¹⁵⁴ In the medical field, the concept of altruism has permeated policy as one of the dominating concepts in understanding acts of donation, which follows the idea that donation is a free and unrewarded gift..¹⁵⁵ As applied to organ donation, altruism is often narrowly defined as an absence of monetary exchange and commercialization..¹⁵⁶ Other altruistic donation definitions include "giving without

non-directed-donation; "Living Non-Directed Organ Donation," Organ Procurement and Transplantation Network, updated December 2015, https://optn.transplant.hrsa.gov/resources/ethics/living-non-directed-organ-donation/; *National Organ Transplant Act: Hearing on H.R. 4080 Before the Subcommittee on Health and the Environment of House Committee on Energy and Commerce*, 98th Congress 16-29 (1983). ¹⁵² Greg Moorlock, Jonathan Ives, and Healther Draper, "Altruism in organ donation: an unnecessary requirement?" *Journal of Medical Ethics* (March 2013): 1-5, doi:10.1136/medethics-2012-100528.

 ¹⁵³ Editors of Encyclopaedia Britannica, "Altruism," Encyclopaedia Britannica, accessed August 29, 2017, https://www.britannica.com/topic/altruism-ethics.

¹⁵⁴ Moorlock, Ives, and Draper, "Altruism in organ donation: an unnecessary requirement?" ¹⁵⁵ Michael Steinmann, Peter Sykora, Urban Wiesing, "Altruism in medical donations reconsidered: the reciprocity approach" in: Michael Steinmann, Peter Sykora, Urban Wiesing, eds. *Altruism reconsidered: exploring new approaches to property in human tissue* (London and New York: Routledge, 2016).

¹⁵⁶ Marie-Chantal Fortin, Mrianne Dion-Labrie, Marie-Josée Hébert, and Hubert Doucet, "The enigmatic nature of altruism in organ transplantation: a cross-cultural study of transplant physicians' views on altruism," *BMC Research Notes* 3 no. 216 (2010) https://doi.org/10.1186/1756-0500-3-216.

expectation of reward" or simply the "opposite of a commerce-based system."¹⁵⁷ Though on their face these definitions appear clear, in fact they leave open questions about whether conditional donations, the presence or absence of impartiality and objectivity in the donor's intentions, the interjection of third parties seeking to compensate the donor, and donors with competing motivating factors fall inside or outside the scope of organ donation altruism. As will be demonstrated below, many of the kidney exchange models permitted under NOTA (and state law equivalents) and endorsed and facilitated by organizations such as UNOS and the National Kidney Registry contradict some of the prevailing definitions of organ donation altruism and comport with others.

b. Conceptual Difficulties with the term "Altruism"

At the outset, it is also important to establish that an altruistic donation and a morally good donation are not always synonymous. For example, suppose the prevailing definition of altruism is the absence of monetary exchange and commercialization. In one community, made up of predominately European immigrants, several individuals suffer from kidney failure and need kidney transplants. Upon learning that the community is in dire need of kidney donors, one healthy member of the community decides she wants to help by donating her kidney. After receiving medical clearance to donate, this intended donor also offers to pay for all associated hospital expenses for herself and for the unknown recipient – from pre-operation check-ups, to hospital expenses, to follow-up appointments - and expects nothing in return. She even requests

¹⁵⁷ Ibid; Michael Steinmann, Peter Sykora, Urban Wiesing, "Altruism in medical donations reconsidered: the reciprocity approach" in: Michael Steinmann, Peter Sykora, Urban Wiesing, eds. *Altruism reconsidered: exploring new approaches to property in human tissue* (London and New York: Routledge, 2016): 13-50.

complete anonymity so the recipient will never learn of her identity. Her only request is that the recipient is not of European descent. Though "altruistic" according to the no monetary compensation definition, this single-conditioned donation is hardly moral as it denies an entire group of people consideration for a kidney solely because they are of European descent.¹⁵⁸

Similarly, a donation that is legally permitted under NOTA does not necessarily mean the donation is altruistic according to some definitions.¹⁵⁹ Academic thinkers have offered a diverse range of perspectives on what does and does not constitute altruistic organ donation, leaving paired kidney donation (or one of its variations) to qualify as altruistic acts under some definitions while excluding it from others. Some, for example, contend objectivity and impartiality are necessary conditions of altruism such that acting in the interest of a loved one simply because he is a loved one is not considered altruism.¹⁶⁰ Thus, under this definition, paired kidney donations involving loved ones, though legally permissible, often fail to achieve altruism. For example, suppose B loves his sister, S, and wants to donate his kidney to her. Unfortunately, S is not a match for B. Similarly, W wants to donate her kidney to her husband, H, who is suffering from kidney failure. They too, are not matches for one another. However, B is match for H and W is a match for S. Clearly, members of both parties do not act with objectivity and impartiality when they agree to engage in a paired kidney exchange. In fact, but for his sister needing a kidney, B would never donate kid kidney to H. Similarly, but for her husband needing

¹⁵⁸ For purposes of simplicity, this hypothetical also assumes that no member of the community is a criminal nor has any member of this community done anything to harm this individual or her family. Further, several members of this community are matches for the donor.
¹⁵⁹ Ibid.

¹⁶⁰ See e.g. T. Nagel, *The Possibility of Altruism* (London: Oxford University Press, 1970).

a kidney, W would never donate to S. Thus, under the definition of altruism that requires objectivity and impartiality, only anonymous and non-directed paired kidney exchanges would constitute altruistic donations.

Other definitions, however, maintain altruistic acts may include certain forms of partiality so long as the actor's actions are motivated by the intentions or desire to help another.¹⁶¹ For example, a kidney donation from one friend to another may be considered altruistic if feelings of sympathy, compassion, concern and care motivate a donor to donate. What remains unclear, however, is whether and how many motivating factors other than the desire to help another are allowed such that the donation is still considered altruistic. Thus, a paired kidney donation or a directed kidney donation to a loved one may or may not fall under the altruism umbrella depending on permitted motivating factors. Another definition of altruism is "behaviour that is intended to meet the needs of others, where there is no immediate self-interested reason to help, and where there is no institutional requirement that one should."¹⁶² For example, a father's donation of a kidney to his sick child would not be considered altruistic because it falls within the realm of institutional obligation for a father to care for his son. Finally, other interpretations consider altruism as behavior "that is motivated by concern for the welfare of the recipient of some beneficent behaviour, rather than by concern for the welfare of the person carrying out the action."¹⁶³ This definition leaves open the possibility for

 ¹⁶¹ See e.g. Lawrence Blum, *Friendship, altruism and morality* (London: Routledge & Kegan Paul, 1980).
 ¹⁶² David Miller, "Are they my poor?: The Problem of Altruism in the World of Strangers," Critical Review of International Social Political Philosophy 5 no. 4 (2002): 106–27, http://dx.doi.org/10.1080/13698230410001702762.

¹⁶³ Nuffield Council on Bioethics, *Human bodies: donation for medicine and research* (London: Nuffield Council on Bioethics, 2011).

some form of reward to accompany altruistic intent since several motivations, including the desire to help others, may prompt an actor to act.¹⁶⁴

C. Varying Understandings of Altruism and their Application to Living Donor Models

The above-mentioned interpretations offer just brief glimpse of the varying definitions that are applied to paired kidney donation. Clearly, the altruism definitions that allow for partiality and motivations other than the sole desire to help another best align with models such as paired kidney donations and the UCLA voucher program. For those more stringent definitions that exclude all forms of directed kidney donations to family, friends and loved ones, the next question becomes whether the absence of altruism categorically deems that model of donation impermissible or if other ethical principles, such as beneficence and non-maleficence can outweigh altruism's absence. Because this paper argues that paired kidney donations are morally good, either the working definition of altruism should allow for some forms of partiality such that paired kidney donations and other forms of directed donation are considered altruistic or other principles should outweigh altruism to render paired kidney donations permissible.

From a legal standpoint, NOTA codifies the concept of altruism in its "valuable consideration" prohibition, which imposes a prophylactic ban on the exchange of anything that might resemble emotional, monetary, or psychological value..¹⁶⁵ Yet, in 2007 with the enactment of the Charlie W. Norwood Act, the law carved out an exception for paired kidney donations by explicitly stating the ban on exchange for valuable

¹⁶⁴ Moorlock, Ives, and Draper, "Altruism in organ donation: an unnecessary requirement?"

¹⁶⁵ See 42 U.S.C. § 274e (1991).

consideration does "not apply to human organ paired donation."¹⁶⁶ As demonstrated by the paired kidney exchange, kidney chain, and UCLA models, these "altruistic" donors do yield valuable return. Namely, many who opt to donate through a paired kidney exchange model do so because they want to help a friend, family member, or loved one obtain a kidney. And when their loved ones receive a kidney, the donors presumably benefit from the joy, happiness, love, and more valued time with the recipient. Arguably, if these paired kidney exchange donors did not want any "valuable consideration" in return, they could have simply donated their kidneys as anonymous non-directed donors to their transplant center of choice. Clearly, Congress's decision to create a paired kidney donation exception in NOTA, though a good way to increase living donor participants, created uncertainties about NOTA's definition of altruism that continue to this day. As such, questions for future research and consideration include: where to legally draw the demarcation between altruistic and non-altruistic acts? Ought the legal definition of altruism be informed by an ethical analysis? What factors should be used and how should they be weighed in deciding whether a donation should be deemed altruistic?

Despite definitional discrepancies involving a multitude of interpretations, it is widely believed that all forms of organ donation, including paired kidney donations, must be tethered to the concept of altruism. Specifically, many individuals and organizations involved in organ procurement and transplantation contend the role of altruism is essential to the welfare of the society.¹⁶⁷ This conviction is largely rooted in the fear of promoting an instrumental view of human beings, and a desire to prevent the

¹⁶⁶ "H.R. 710 — 110th Congress: Charlie W. Norwood Living Organ Donation Act." www.GovTrack.us, accessed September 8, 2017, https://www.govtrack.us/congress/bills/110/hr710.

¹⁶⁷ Dalal, "Philosophy of organ donation: review of ethical facets," 44.

commodification of human body parts..¹⁶⁸ A stringent definition and application of an altruism requirement, which requires both an intent to meet the needs of others where there is no immediate self-interested reason to help and prohibits all forms of valuable consideration, protects against the introduction of financial incentives because they inherently fail to meet the core altruism requirements. Moreover, altruism is necessary to overcome the ethical issue of nonmaleficence in living organ donation. As such, some make the bold claim that when organ donation is incentivized by monetary compensation, "there is nothing to outweigh the harm implicated by the necessary invasion of bodily integrity, but that where donation is involved the pure altruism of giving, together with the potentially beneficial consequences of donating, is sufficient to tip the scales in favour of allowing it.".¹⁶⁹

On the other end of the spectrum are those who contend that policies adhering to more stringent definitions of altruism that prohibit exchange of any valuable consideration, such as NOTA, reflect irrational and antiquated modes of thinking that fail to maximize the number of organ transplantations to save the most number of people suffering from renal failure. Two primary arguments comprise the prevailing qualms with an altruistic-based organ procurement system..¹⁷⁰ First, a system based on altruism rather than commercialization significantly limits the number of living kidney donors, and thus the number of kidney recipients. Specifically, those who argue for compensating donors cite the urgent organ shortage plaguing the United States and

¹⁶⁸ See e.g. United States Task Force on Organ Transplantation, "Organ Transplantation: Issues and Recommendations, Department of Health and Human Services (1984): 1623. "Society's moral values militate against regarding the body as a commodity." Ibid.

¹⁶⁹ David Price, "Legal and Ethical Aspects of Organ Transplantation," 396.

¹⁷⁰ Raanan Gillon, "Commerce and Medical Ethics," Journal of Medical Ethics 23 no. 2 (April 1997).

lament the unnecessary loss of human life.¹⁷¹ Though Congress added an addendum to NOTA in 2007, which permits paired kidney exchange, the reality that thousands of people still die each year while awaiting a kidney transplant suggests that even with the 2007 paired kidney donation exception, NOTA's "no valuable consideration" scheme does not efficiently shrink the gap between kidney supply and demand.¹⁷² As such, either relaxing the "no valuable consideration" clause or establishing a carefully crafted and ethically sound regulated organ market would encourage more people to donate because potential donors would not be deterred by short or long-term financial burdens as a consequence of their decision to donate.¹⁷³ Specifically, incentives that cover all medical costs associated with the transplantation, travel expenses, and lost wages, which are all prohibited by NOTA, may encourage those who want to donate but cannot afford to.¹⁷⁴ Second, the lack of clear and consistent application of altruism in the context of organ donation undermines the integrity of its role in policy governing organ procurement and transplantations. Though creating an addendum to NOTA that explicitly excludes paired kidney donations from the category of "valuable consideration," arguably increases efficiency and the number of transplants, it calls into question both the underlying definition of altruism that informed NOTA and weakens the philosophic justification of the "no valuable consideration" requirement.

Perhaps the biggest criticism of altruistic-based organ transplant policies is the misapplied prioritization of prohibiting valuable consideration rather than aiming to save

¹⁷¹ Benjamin Hippen, Lainie Ross, and Robert Sade, "Saving Lives Is More Important Than Abstract Moral Concerns: Financial Incentives Should Be Used to Increase Organ Donation," 1055.

¹⁷² Organ Donation Statistics, U.S. Department of Health and Human Services, accessed October 1, 2017, https://www.organdonor.gov/statistics-stories/statistics.html.

¹⁷³ "Incentives for Organ Donation: Proposed Standards for an Internationally Acceptable System," *American Journal of Transplantation* 12 no. 2 (2012): 306-12, doi:10.1111/j.1600-6143.2011.03881.x. ¹⁷⁴ Ibid.

as many lives as possible. That is, altruistic-based systems lead to unnecessary deaths because the overemphasis on filtering out donations that are deemed non-altruistic that bigger picture is entirely overlooked, i.e. individuals in need of kidneys are dying due to a severe organ shortage. As noted by Raanan Gillon, former editor of the Journal of *Medical Ethics*, "there is a danger in being too ready to offer blanket condemnation of commerce in health care in lofty favour of altruism and social solidarity that health care may suffer."¹⁷⁵ Specifically, policies such as NOTA are accused of stifling efforts to save lives via kidney donations simply because a proposed exchange does not comport with the law's definition of altruism or consideration. As noted by Michele Goodwin, "The prohibition against any procurement mechanism's use of 'valuable consideration," including specialized exchanges, incentives, and payments, most likely contributes to thousands of unnecessary deaths each year.¹⁷⁶ These deaths are the unfortunate byproducts of our federal legislative commitment to a purely altruistic organ procurement regime." Those who agree with Goodwin maintain that altruistic-based systems ultimately cause more harm than good.

A second criticism highlights the far-reaching effects of policies like NOTA. Namely, by outlawing non-altruistic forms of donations, NOTA induces Americans to seek kidneys in countries with more lax organ donation policies, a reality that yields outcomes that directly contradict and undermine the driving factors and purpose of the NOTA's prohibition on "valuable consideration". As noted by Goodwin, the United States' altruistically-focused policy "contributes to the very exploitation of people of color in developing countries it sought to prevent. The U.S. demand for organs spills over

¹⁷⁵ Gillon, "Commerce and Medical Ethics," 67-8.

¹⁷⁶ Goodwin, "The Veneer of Altruism."
into other nations, where individuals' poverty and vulnerability make them the voiceless conspirators in a very dangerous enterprise."¹⁷⁷ This also leads to the growth of dangerous, unregulated, and exploitative black market exchanges that ultimately undermines the health and dignity of patients abroad as well as in the United States.¹⁷⁸

Finally, as discussed above, there are many definitions and interpretations of altruism. Inconsistent application of altruism when used as a gatekeeper of permissible kidney exchanges reduces the concept of altruistic organ donation to an arbitrary and illogical policy. Because a kidney transplant approval, in most cases, is the arbiter of a waitlist patient's fate, when policies like NOTA permit exchanges that afford the donor certain benefits but reject others, they lose merit and clout. For example, the UCLA gift certificate program discussed above awards a gift certificate to a future recipient of the donor's choice. This coupon for a highly valued, rare, and life-saving kidney arguably does constitute "valuable consideration." As described by the UCLA newsroom: "currently, some potential altruistic donors are reluctant to donate a kidney for fear that a family member might need one in the future..¹⁷⁹ But if the gift certificate approach is successful, altruistic donors could donate a kidney and their spouse or child would receive a gift certificate for a future transplant." Yet, proposals to enact programs that

¹⁷⁷ Ibid. "Frequently, Americans obtain organs from executed political prisoners in China, as well as from destitute men and women in India, Pakistan, South Africa, and Brazil. American patients pay brokers upwards of \$150,000 for kidneys and as much as \$250,000 for hearts." Ibid. ¹⁷⁸ Ibid.

¹⁷⁹ Enrique Rivero, "Gift certificate' enables kidney donation when convenient and transplant when needed," *UCLA Newsroom*, July 11, 2016, http://newsroom.ucla.edu/releases/gift-certificate-enables-kidney-donation-when-convenient-and-transplant-when-needed.

provide donors with other types of rewards, such as tax breaks or health insurance coverage, are immediately rejected.¹⁸⁰

Furthermore, other U.S. policies exclude altruistic requirements altogether and unequivocally permit the sale of human biologics. The reproduction market, for example, represents a prime development that allows the commercialization of human tissue and reproductive material on one hand while upholding a system designed to preserve human dignity and limit the potential for exploitation on the other. As noted by Goodwin, "the proscription is over-inclusive in prohibiting well-meaning programs that involve no financial exchanges and chilling innovation, and it is under-inclusive in tolerating markets for babies, ova, sperm, embryos, and commercialized cell lines and human tissues."¹⁸¹ Challenges to the altruistic-based NOTA are understandable especially in light of the permission of other markets that allow the sale of human material without any requirement of altruism.

Part V: Potential solutions to the current paired kidney exchange system

A. Specific performance

One approach to improving the paired kidney exchange model involves restructuring NOTA such that it secures, provides greater predictability, and ultimately better preserves the integrity of the paired kidney exchange system. The most efficient way to do so requires stringent remedies that deter malicious actors and mitigate any temptations to cheat the kidney transplant and procurement system. The current policies and infrastructure, predominantly based on the trust and good intentions of all participating

¹⁸⁰ For further discussion about tax breaks as a method to incentivize organ donations and why these proposals are rejected, see Thomas Petersen and Kasper Lippert-Rasmussen, "Ethics, Organ Donation and Tax: a Proposal," Journal of Medical Ethics 38, no. 8 (2012): 451-457.

¹⁸¹ Michele Goodwin, "The Veneer of Altruism."

parties, fail to address repercussions and consequences if a party acts with malice aforethought to fraudulently induce another party to give up a kidney. As such, the paired kidney exchange model remains vulnerable to the threat of desperate or nefarious actors infiltrating the system.

In United States contract law, the most preferred remedy following a contractual breach is money damages, which mandates the breaching party to financially compensate the harmed party. Assuming the breach is a total breach, the harmed party would recover damages in an amount equal to the sum or value the plaintiff would have received had the contract been fully performed. When money damages fail to make the harmed party whole, the court may resort to the equitable remedy of specific performance, which requires the breaching party to perform in accordance with the terms of the contract.¹⁸² Though specific performance is a remedy of last resort, it remains necessary when the contract-in-question falls into the category (or categories) of highly unique, extremely rare, unavailable in the marketplace, or with sentimental value.¹⁸³ Because items that fall into one of these categories typically cannot be quantified, money damages do not adequately provide a fair form of substitutional relief, and thus cannot achieve justice. Yet, specific performance straddles a fine line between making the harmed individual whole on the one hand and violating individual rights to privacy, personal autonomy, and bodily integrity on the other.¹⁸⁴

¹⁸² Deepa Varadarajan, "Tortious Interference and the Law of Contract: The Case for Specific Performance Revisited," *Yale Law Journal* 111 (2005): 737, https://www.yalelawjournal.org/pdf/368_32gzf4ik.pdf.
¹⁸³ Alan Schwartz, "The Case for Specific Performance," Yale Law Journal 89(1979): 272-273.
¹⁸⁴ R. Alta Charo, "Legislative Approaches to Surrogate Motherhood," in *Surrogate Motherhood: Politics and Privacy*, ed. Lawrence Gostin (Bloomington and Indianapolis: Indiana University Press, 1990): 93.

Undoubtedly, the kidney falls into at least one of the categories. First, the severe organ shortage proves the kidney is extremely rare. Second, an organ market does not exist so the kidney cannot be found in the marketplace. Third, though a donor's kidney may not have sentimental value in the traditional sense, in most cases the availability of a new kidney is the primary decider between life and death, which affords it a value that cannot be converted into a standardized monetary value. Thus, after D1 falsely induces D2 to donate and subsequently reneges on his promise, D2 and R2 become the harmed parties to the contract. An award of money damages fails to make D2 and R2 whole because without the promised matching kidney, R2 will die. Given this exchange occurred in a United States jurisdiction, any amount of money will not save R2's life.¹⁸⁵ Moreover, D1's (and R1's) fraud stole D2's ability to enter into a different paired kidney exchange contract to save R2 because D2 now only has one working kidney. Further, though inserting R2 into the next available kidney chain is a plausible option, it raises questions of justice and fairness, especially to the original intended recipient in the chain. As such, adding a remedy of specific performance to NOTA creates a harsh, yet fair and just remedy for those wronged by nefarious actors. Moreover, it serves to deter fraud and deception.

Bioethical Issues with Specific Performance

The concept of self-determination, which guarantees a person is the master of his or her own destiny, constitutes a fundamental value of the United States legal system.¹⁸⁶

¹⁸⁵ It is important to note that technically it would be possible for the parties to travel to a country like Iran, which allows organ markets, to obtain and purchase a replacement kidney. However, this raises a new set of ethical issues regarding the procurement methods and regulations in these countries, which exceed the scope of this paper.

¹⁸⁶ Paula Walter, "The Doctrine of Informed Consent: To Inform or Not to Inform?" *St. John's Law Review* (1997): 546.

Just as in western bioethical discourse, deference for individual autonomy marks the starting point for major decision-making that affect rights and liberties. It is from this framework that integral laws ranging from the doctrine of informed consent to the Fourteenth Amendment, the Thirteenth Amendment, and several other policies championing personal dignity and individual liberties have developed and prospered.

One such area is contract law. Contracts are considered tools for realizing individual self-determination by means of voluntarily entering legally binding agreements..¹⁸⁷ In the event of a breach, strong hesitation and even opposition by courts to award a remedy of specific performance stem from the notion that an individual has the right to be free from non-consensual interference with his or her person..¹⁸⁸ As discussed in *Union Pac*. *Ry. Co. v. Botsford* "[n]o right is held more sacred, or is more carefully guarded by the common law, than the right of every individual to the possession and control of his own person, free from all restraint or interference of others, unless by clear and unquestionable authority of law.".¹⁸⁹ This sentiment is shared by the bioethics structure, which recognizes bodily integrity, informed consent, and the right to self-determination as central components of autonomy..¹⁹⁰ Thus, when D1 refuses to donate his kidney after deceiving D2 into temporarily ceding her autonomy and the rights that derive therefrom,

normenbegruendung/intern/publikationen/gutmann/55_gutmann_-_contract_and_autonomy.pdf. ¹⁸⁸ See Cruzan, 497 U.S. at 269 (citing Union Pac. Ry. Co. v. Botsford, 141 U.S. 250, 251 (1891) ("No right is held more sacred, or is more carefully guarded, by the common law, than the right of every individual to the possession and control of his own person from all restraint or interference of others, unless by clear and unquestionable authority of law."))

¹⁸⁹ Union Pac. Ry. Co. v. Botsford, 141 U.S. 250, 251, 11 S. Ct. 1000, 1001 (1891).

¹⁸⁷ Thomas Gutmann, "Theories of contract and the concept of autonomy," Centre for Advanced Studies in Bioethics (2013), https://www.uni-muenster.de/imperia/md/content/kfg-

¹⁹⁰ Jukka Varelius, "The value of autonomy in medical ethics," *Journal of Medicine, Health Care, and Philosophy* (2006) doi: 10.1007/s11019-006-9000-z.

it produces an unavoidable clash of autonomous rights that strike at the heart of both the legal and bioethical frameworks.

For any type of organ donation, an invasion of the body is inevitable. To successfully donate a kidney, the donor must undergo an invasive surgery whereby the physician slices into the lower abdomen and extracts a kidney.¹⁹¹ Likewise, to successfully receive a kidney, the recipient must undergo invasive surgery that involves incisions to the lower abdomen, blood vessel attachment, and connection of the bladder to the donated kidney.¹⁹² In optimal living donation or paired kidney exchange cases, the healthcare team follows appropriate informed consent protocols, the donors and recipients agree to donate or receive a kidney without external coercive pressures, the donors follow through on their promise, and thus the bodily integrity of all parties remain intact. However, when willful fraudulent inducement causes one of the donors to detrimentally rely on the false promise, as in Case 1, it is inevitable that one of the parties' autonomous rights, personal dignity, and claim to bodily integrity will shrink. Either D2, the donor who has already donated, will suffer the theft of her kidney as the consequence of malicious false pretenses concocted by D1 and/or R1, or D1, the nefarious actor who acted with malice aforethought to induce D2 to donate, must give up his kidney, even if against his stated will. Recall, however, that D1 had originally agreed to donate his kidney to R2 in the paired kidney exchange contract.

On one hand, the fundamental right to bodily integrity includes the right to refuse unwanted medical treatment, even if such refusal is not in the best interest of the patient's

 ¹⁹¹ "Laparoscopic Donor Nephrectomy," University of California San Francisco, accessed September 21, 2017, https://transplant.surgery.ucsf.edu/conditions--procedures/laparoscopic-donor-nephrectomy.aspx.
 ¹⁹² Ibid.

health and well-being. As stated in Cruzan v. Harmon, "the doctrine of informed consent arose in recognition of the value society places on a person's autonomy and as the primary vehicle by which a person can protect the integrity of his body. If one can consent to treatment, one can refuse it. Thus, as a necessary corollary to informed consent, the right to refuse treatment arose."¹⁹³ D1's appeal to bodily integrity in his refusal to donate his kidney to D2 holds significant weight not only because of deep legal and bioethical precedent, but also because he garners no benefit from undergoing the donation procedure. As discussed in Steele v. Hamilton City Community Mental Health *Board*, "[o]nly when a court finds that a person is incompetent to make informed treatment decisions do we permit the state to act in a paternalistic manner, making treatment decisions in the best interest of the patient."¹⁹⁴ In D1's case, not only is the kidney removal unwanted, but also extracting a perfectly healthy kidney runs contrary to D1's best interests. Thus, when analyzed in a vacuum, the principles of autonomy, informed consent, and non-maleficence strongly tip the scales in favor of respecting D1's bodily integrity and refraining from performing the unwanted kidney removal.

Additionally, even a court ordered document proscribing the doctor to perform the kidney removal places the entire healthcare team in a precarious position. First, the doctrine of informed consent rests upon the "respect for the individual's right to be free of unwanted bodily intrusions no matter how well intentioned." D1's outright refusal to undergo surgery, despite having previously agreed to it by signing the paired kidney exchange contract, invokes the doctrine of informed consent and thus calls upon the healthcare team to halt all surgical proceedings. Second, as discussed above, the

¹⁹³ Cruzan v. Harmon, 760 S.W.2d 408, 417 (Mo. 1988).

¹⁹⁴ Steele v. Hamilton Cty. Community Mental Health Board, 736 N.E.2d 20 (Ohio 2000) at 21.

principles of beneficence and non-maleficence often inform valid arguments against living donation of any vital organ because the risk of harm outweighs the benefits. Given healthcare practitioners are required to act in the best interests of their patients, performing a non-therapeutic operation on a patient who has explicitly refused contradicts the ethical principle of beneficence as applied to the patient refusing the transplant. Moreover, in short, the principle of non-maleficence requires that health practitioners endeavor to prevent or reduce harm. Here, reducing harm to the patient, D1, means abstaining from performing the surgery. In balancing non-maleficence and beneficence, the scale undeniably appears to tip in favor of not performing the surgery as the risks to the patient-donor is high and the physical benefits to the patient-donor is extremely low.

On the other hand, when multiple patient-parties are involved and interconnected, a comprehensive bioethical analysis cannot simply consider just one patient in a vacuum. Rather, all parties' claims to autonomy, beneficence, non-maleficence, justice, and any other moral claim require recognition and must inform the overall bioethical calculus. Situations like Case 1 and Case 2, for example, pit D1's and R1's appeals to autonomy, beneficence, and non-maleficence directly against those claims of D2 and R2. A scheme that fails to provide a remedy of specific performance elevates D1's claim to autonomy and bodily integrity by permitting him to violate D2's trust and infringe upon D2's claims to bodily integrity, informed consent, and autonomy. D1 will then turn around and successfully use those same appeals to defend his own autonomy. D1 also reaps the benefits of the principles of non-maleficence and beneficence when he uses them as defenses against fulfilling his promise even though he fraudulently induced D2 to take

the same risks and undergo the very harm he is seeking to avoid. By contrast, a scheme that includes a remedy of specific performance presents a framework that appreciates the delicate balance and co-dependent relationships among all four patient-parties. In this calculus, the interests of the harmed party prevail over those of the nefarious actors. That is, D1's claims to autonomy, bodily integrity, non-maleficence, and beneficence shrink to the point where justice can be achieved. Thus, for example, in Cases 1 and 2, D1's ethical arguments allowing him to revoke his consent pale and lose their power. In effect, a remedy of specific performance prevents D1 from using appeals to autonomy, bodily integrity, beneficence, and non-maleficence as shields to justify his refusal to carry out a promise to donate his kidney.

Furthermore, from a global perspective, failure to award a remedy of specific performance rewards the nefarious parties and significantly burdens the harmed parties. R1 walks away with D2's healthy kidney, R2 remains in need of a kidney, D2's kidney was essentially stolen from her, which means D2 no longer has the option to participate in a different paired kidney exchange to help save R2. Because under NOTA a paired organ donation is nothing more than simultaneous gift swaps, D1 leaves the exchange without any significant repercussions. Absent a strict remedy of specific performance, the exchange system endorses dishonest behavior and conveys a message to those desperate for a kidney that acting on willful intent to commit fraud can result in a new kidney. Additionally, it violates the integrity of the promise-for-promise paradigm. From a deontological standpoint, the sanctity of a promise is a well-established and deeply engrained moral principle. As discussed above, in *Fundamental Principles of the Metaphysics of Morals* Kant highlights promise-keeping as one of the four illustrations of

the categorical imperative. Failure to keep a promise would make the promise itself "impossible, as well as the end that one might have in view in it, since no one would consider that anything was promised to him, but would ridicule all such statements as vain pretences.".¹⁹⁵ If breaches in paired kidney exchange agreements becomes widespread, the entire practice will self-destruct. Without any type of guarantee that all parties enter the exchange with honesty and full intent to follow through, why would anyone participate? Though a remedy of specific performance could not guarantee the receipt of a kidney as donors may be forced to withdraw due to health reasons or other extenuating circumstances, it could at least filter out the nefarious actors.

Regarding the bioethical principles from the perspective of the healthcare practitioners, it is important to note that principles are prima facie, rather than absolute requirements. As such, some principles may balance out or override competing ethical principles. For example, in the case of a directed kidney donation, the prevailing position contends the life-saving benefit to the recipient in conjunction with the psychological benefit afforded to the donor outweigh the risks of harm to the donor.¹⁹⁶ Through this analysis, the healthcare team can morally justify imposing limited harm on the patient-donor to benefit the patient-recipient. By contrast, in D1 and D2's case, failure by the healthcare team to perform a court-ordered kidney extraction from D1 arguably results in a risk-benefit calculus that bolsters the autonomy of the nefarious actor while it diminishes the autonomy and claims to bodily integrity by the harmed party. That is, the healthcare team has already removed D2's kidney and transplanted it to R1. Taking no

¹⁹⁵ Immanuel Kant, Fundamental Principles of the Metaphysics of Morals, trans. Thomas Kingsmill Abbott (Internet Edition), http://caae.phil.cmu.edu/cavalier/80130/part1/sect4/KantReading.html.

¹⁹⁶ Hippen, Ross, and Sade, "Saving Lives is More Important than Abstract Moral Concerns," at 1056.

further action means the transplant team actively (but not knowingly) participated in the violation of D2's bodily integrity and autonomy as D2 agreed to the kidney removal only under the strict condition that D1 would reciprocate to R2. Now that the transplant team knows about this violation and that they helped facilitate kidney theft, carrying out the second half of the exchange over D1's objection is justified as the interest of restoring D2's autonomy and bodily integrity interests overrides the interest in preserving D1's. Further, D1 already provided consent to have his kidney removed when he signed the paired kidney exchange agreement. Thus, absent any significant change in circumstances post signing of the exchange agreement that render D1 medically unfit to donate his kidney, a moral justification for removing the kidney does exist.

B. UCLA Gift Certificate program

As discussed above, the UCLA model is a relatively new model for transplantation and began in 2014 at Ronald Reagan UCLA Medical Center. It has since spread to about thirty hospitals around the country, including UCSF, Georgetown, Emory and Cornell..¹⁹⁷ Because it emulates a "pay-to-play" formulation, its special feature is that it shields donors and recipients from the possibility of a potential donor reneging. That is, the donor must first donate his kidney before the intended recipient may receive one. Prior to donation, the donor lists his intended recipient on the informed consent form. Then, just as one would with a gift certificate, the future recipient may redeem the kidney when the appropriate time arrives, which, according to the National Kidney Registry Rules, is

¹⁹⁷ Fran Kritz, "Kidney voucher program counts on karma to improve donation," *CNN*, updated September 15, 2017, http://www.cnn.com/2017/09/15/health/kidney-voucher-partner/index.html.

"when transplantation is indicated as a therapeutic modality for end-stage kidney disease."¹⁹⁸

Widespread adoption of the UCLA model may foster a more efficient method of facilitating paired kidney exchanges and kidney chains on the national level because it benefits the recipient community in two distinct ways. First, it helps those in immediate need of a kidney transplant because the promise of the gift certificate incentivizes potential donors to donate now. That is, donors can provide kidneys to those in immediate need while at the same time help their loved ones via the voucher for when they need a kidney in the future. Also, every time someone receives a kidney from a living donor, it almost inevitably moves another person up a notch on the deceased donor list. Second, it benefits the donors' loved ones who will eventually need a kidney transplant because they can trade in the gift certificate and redeem their kidney when they need one in the future.¹⁹⁹ Additionally, the gift certificate allows donors the freedom undergo surgery at a time that best accommodates their schedules. As noted by Dr. Jeffrey Veale, transplant surgeon at UCLA who helped initiate the voucher program, "a friend or family member could donate a kidney now, before a major anticipated life event — such as traveling, changing employment or getting married — and their intended recipient who is nearing Dialysis would receive a gift certificate to redeem for transplantation when needed."²⁰⁰ Most notably, this model overcomes common barriers of live kidney donation - namely time restraints and compatibility - because it provides

¹⁹⁸ "Kidney Voucher," UCLA Health.

¹⁹⁹ As of 2016, nine other kidney transplant centers have begun implementing the voucher program. "Kidney Transplant Coupons/Vouchers Are Spreading Across the Country - Guaranteeing Some Patients Transplants," KidneyBuzz, accessed September 8, 2017,

https://www.kidneybuzz.com/kidney-transplant-coupons/vouchers-spreading-across-the-countryguaranteeing-transplants-for-some/. ²⁰⁰ Ibid.

donors flexibility in that they could potentially donate their kidneys several months or years before the recipients are ready to redeem their new kidney.²⁰¹ According to Veale, "While kidney transplant exchanges help resolve biological incompatibility between donors and recipients, the 'voucher' program helps resolve chronological incompatibility."²⁰²

Bioethical Issues with UCLA Gift Certificate Program

At the same time, however, the UCLA gift certificate program does raise a host of new ethical issues. First, some who contend altruism prohibits emotional or psychological benefits may argue it undermines the United States' commitment to operating kidney exchange programs on the basis of altruism. As discussed in Part IV, those who contend objectivity and impartiality are necessary conditions of altruism would categorically reject the gift certificate program because donors donate for the specific purpose of obtaining a gift certificate that a loved one can later "cash in" for a new kidney. Just like a paired kidney exchange, at the core of the UCLA gift certificate program is a barter system. Donor 1 donates his kidney under the condition that Donor 2 will later donate her kidney to Donor 1's loved one. The motivations of participants in a paired kidney exchange or voucher program are clear: they want to save the life of a family member, friend, significant other, etc. According to those who define altruism as a behavior intended to meet the needs of others where there is no self-interested reason to help, the UCLA voucher program does not comport with altruism because the donor does

²⁰¹ See e.g. Enrique Rivero, "'Gift certificate' enables kidney donation when convenient and transplant when needed." Here, a grandfather, knowing his grandson would need a kidney transplant in the future, donated his kidney. Upon donation, the grandfather received a voucher for his grandson to be used when he needs a transplant.

²⁰² Jeffrey Veale, "Give a Kidney, Get a Kidney," *The Wall Street Journal*, August 2016, https://www.wsj.com/articles/give-a-kidney-get-a-kidney-1470265583.

hold an interest in helping the intended recipient. If the donor did not he or she would donate the kidney without requesting a voucher for a future intended recipient. Alternatively, the donor would donate anonymously through a NEAD chain, domino chain, or any other variation of kidney donation where the donor does not know or desire to help the recipient.

Second, if not carefully crafted, the stipulations in the donor agreement could raise issues of informed consent. While the program is designed to encourage immediate donations while also providing the donors' loved ones access to kidneys in the future, nothing is guaranteed. Therefore, it is imperative that all parties involved are aware that having the donor give a kidney right now in no way guarantees that a compatible kidney will be found in the future for the intended recipient. Without explicit disclosure to the donor and future recipient of the possibility that a compatible kidney in the future cannot be guaranteed, transplant facilities could be at risk for failing to disclose material risks.

Third, as the UCLA model grows across the United States, it is inevitable that at least two sets of kidney waiting lists will develop: the priority list and the general list. Those who are fortunate enough to befriend or be related to someone willing to donate for a gift certificate will join the priority list while those without will remain on the general list. Just as in security lines at an airport, those approved for TSA pre-check enjoy an expedited security screening process where the lines are shorter and with fewer people. Those without pre-check, by contrast, must wait for longer periods of time as there are many more people. While everyone in the airport security lines will ultimately make it through to their gates, not everyone on the kidney waiting list will receive a kidney. Currently, the average waiting time for a kidney transplant in the United States is roughly five years..²⁰³ Creation of the gift-certificate "pre-check" line significantly reduces the chances that those on the general waiting list will receive a kidney. This calls into questions issues of distributive justice. Though the UCLA model will likely generate more organ donations, it remains to be seen whether the increase in donors will outpace the demand. If not, waitlist patients are essentially hopeless without someone who is willing to donate a kidney into the system.

Another potential problem with the UCLA model as it currently operates is the lack of safeguards to prevent a black market. The UCLA voucher program website lists several stipulations that must be agreed upon by the intended donor, intended recipient, and the National Kidney Registry designed to ensure "ethical and efficacious management of gift certificates for future kidney transplantations." According to the stipulations, once the donor has identified the intended recipient, the voucher may not be reassigned and the voucher expires if the intended recipient dies before he or she can redeem it..²⁰⁴ Moreover, the stipulations clearly state "to avoid the transfer of vouchers for monetary gain, redemption must be limited to the intended recipient as identified in the informed consent document. The intended recipient is required to have government photo identification.".²⁰⁵ Furthermore, blood typing and tissue typing of the recipient must be confirmed before the voucher is redeemed..²⁰⁶ However, the stipulations fail to account for the possibility that potential donors could be bought. For example, suppose R1 is born with a kidney defect and his parents know he will need a kidney transplant in

https://www.uclahealth.org/transplants/kidney-exchange/giftcertificateprogram. ²⁰⁵ Ibid. ²⁰⁶ Ibid.

²⁰³ National Kidney Foundation, "The Kidney Transplant Waitlist – What You Need to Know," accessed September 12, 2017, available at https://www.kidney.org/atoz/content/transplant-waitlist.

²⁰⁴ "Kidney Voucher," UCLA Health, accessed September 16, 2017,

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the future. Members of his family are ineligible to donate their kidneys in exchange for a voucher due to their own health reasons. As a result, they seek out someone willing to donate a kidney in exchange for monetary compensation. That individual could potentially donate through the voucher program, identify R1 as the intended recipient, and the family could compensate him "under the table" for his "donation." In this case, the rules and safeguards established by the UCLA program and the National Kidney Registry do not detect or prevent these parties from carrying out a cash-for-kidney exchange. Because the design of the voucher program detaches both the chronological and compatibility aspects of kidney donations, individuals can potentially engage in a market with much more ease. Thus, the features that makes the UCLA model more accessible and more convenient for potential donors is the very feature that makes it susceptible to exploitation and abuse.

C. Organ market

Another potential solution to reducing the wide gap between the supply and demand of transplantable organs is to permit financial compensation and financial incentives to potential organ donors. Such incentives could include: tax breaks, guaranteed health insurance, college scholarships for a donor's children, deposits into retirement accounts, etc..²⁰⁷ Proponents of an organ market contend that saving lives is more important than abstract moral concerns..²⁰⁸ Quite simply, the gap between the supply and demand for organs continues to increase, past efforts to remedy the organ shortage have either proven

²⁰⁷ See e.g. Sally Satel, "Death's Waiting List," *The New York Times*, May 15, 2006, http://www.nytimes.com/2006/05/15/opinion/15satel.html.

²⁰⁸ See Ben Hippen's argument in "Saving Lives Is More Important Than Abstract Moral Concerns: Financial Incentives Should Be Used to Increase Organ Donation," at 1054-56.

inadequate or unlikely to succeed, and a highly-regulated system with financial incentives will increase the number of willing and capable donors.

Additionally, commercial activity within the organ transplant system already exists in that "transplant programs pay organ-procurement organizations for exclusive rights to organs, and then bundle the acquired body parts with medical services for sale to patients, often at the maximum price the market will bear."²⁰⁹ Thus, the claim that current transplant policy is purely altruistic or an exchange of simultaneous "gifts" is a façade. Rather, organs that may begin as gifts are ultimately exchanged for valuable consideration.²¹⁰. As noted by legal scholar Julia Mahoney, "only the first link in the distribution chain is a gratuitous transfer - when the individual source agrees to make a solid organ available for transplant. Subsequent transfers generally entail the exchange of valuable consideration for rights to possess, use, and exclude others from organs."²¹¹ Moreover, the main costs associated with transplants are doctors' fees, hospital fees, and drug fees, all of which are determined by markets. Why, many organ market proponents ask, "is it legitimate for these to be the results of markets and not the organs themselves?"²¹²

Moreover, many organs, including kidneys, are purchased in underground economies or black markets abroad.²¹³ The World Health Organization identifies Colombia, India, Pakistan and the Philippines as four of the leading global hot spots for buying and selling

²⁰⁹ Julia Mahoney, "Altruism, Markets, and Organ Procurement," *Law and Contemporary Problems*, 72 no. 17 (Summer 2009): 23.

²¹⁰ Ibid at 23-24.

²¹¹ Ibid at 23.

²¹² Gerald Dworkin, "Markets and Morals: The Case for Organ Sales," *Morality, Harm, and the Law* (Boulder: Westview Press, 1994), 158.

²¹³ Nancy Scheper-Hughes, "Keeping an eye on the global traffic in human organs," *Lancet* 10 (May 2003): 1645-48, doi:10.1016/S0140-6736(03)13305-3.

human organs.²¹⁴ Though organ selling is illegal in these countries, patients from around the world continue to purchase kidneys in these nations.²¹⁵ To date, only the relatively wealthy can afford to fly across the world in search of a kidney on the black market when there are not enough kidneys available from cadavers. Many of these organs are placed on the market by organ brokers who purchase organs from individuals living in urban slums and other poor areas.²¹⁶ Thus, the argument that an organ market will disadvantage and exploit the poor as justification for an absolute ban on an organ market in the United States fails to recognize that greater exploitation occurs around the world and many wealthy Americans contribute to it. A regulated organ market in the United States could provide a safe alternative to underground markets, thereby decreasing the number of American patients who fuel the exploitative international organ trafficking. As noted by Dr. Hippen, "because organ trafficking continues unfettered by existing laws prohibiting the practice, those who are authentically committed to reducing organ trafficking can find the most straightforward solution in reducing the incentive for recipients in wealthy, developed countries to economically support trafficking."²¹⁷

Calls for some form of an organ market come from individuals spanning a variety of disciplines, communities, and classes. Over the past two decades, reports and proposals for potential solutions to the organ shortage have appeared in op-ed pages, bioethics journals, and medical journals.²¹⁸ As one organ recipient explained in an op-ed article in

²¹⁴ Leigh Turner, "Medical tourism' initiatives should exclude commercial organ transplantation," *Journal of the Royal Society of Medicine* 101 no. 8 (2008): 391–394,

https://www.ncbi.nlm.nih.gov/pmc/articles/PMC2500247/.

²¹⁵ Ibid.

²¹⁶ Ibid.

²¹⁷ Hippen, Ross, and Sade, "Saving Lives Is More Important Than Abstract Moral Concerns: Financial Incentives Should Be Used to Increase Organ Donation," at 1055.

²¹⁸ See e.g. J. Radcliffe Richards, "Commentary. An Ethical Market in Human Organs," *Journal of Medical Ethics* 29 (2003): 139-40.

the New York Times, "Paradoxically, our nation's organ policy is governed by a tenet that closes off a large supply of potential organs — the notion that organs from any donor, deceased or living, must be given freely... The verdict is in: relying solely on altruism is not enough. Charities rely on volunteers to help carry out their good works but they also need paid staff. If we really want to increase the supply of organs, we need to try incentives — financial and otherwise."²¹⁹ Of course, instituting a regulated organ market would require a radical overhaul of NOTA, which, as noted above, explicitly prohibits the sale or acquisition of an organ for valuable consideration. However, proponents of allowing financial incentives are quick to point out that markets for human eggs, sperm, and surrogate mothers already exist, thereby deflating one of the underlying principles behind NOTA – to refrain from reducing the body to nothing more than a host of sellable parts. Moreover, they contend "paying for organs, from the living or deceased, may seem distasteful. But a system with safeguards, begun as a pilot to resolve ethical and practical aspects, is surely preferable to the status quo that allows thousands to die each year."²²⁰

Bioethical issues with organ market

Proposal to divert from the current organ donation system, which prohibits the exchange of an organ for valuable consideration, have been met with much criticism and pushback.²²¹ First, an organ market defies society's proclaimed commitment to altruism. Congress made it abundantly clear that any efforts to create an organ market are absolutely outlawed through NOTA's explicit prohibition of "any person to

²¹⁹ Satel, "Death's Waiting List."

²²⁰ Sally Satel, "Death's Waiting List."

²²¹ Julia Mahoney, "Altruism, Markets, and Organ Procurement," 17.

knowingly acquire, receive, or otherwise transfer any human organ for valuable consideration for use in human transplantation.".²²² Records of NOTA's legislative history reveal a prevailing fear that permitting financial compensation for organs would "result in the collapse of the nation's system of voluntary organ donation.".²²³ Second, though endorsed by economists and legal scholars, medical ethicists have denounced proposals to compensate sources of transplantable organs or their survivors as unethical and impracticable..²²⁴ Namely, they contend the commercializing and commodification of human body parts would objectify them to nothing more than spare parts used to generate profit..²²⁵ This, in turn, would crowd out altruistic transfers and increase the already high costs of transplantation. As Mahoney notes, opponents of a market system contend "paying for organs would inject commerce into a sphere where market values have no place and would transform a system based on generosity and civic spirit into one of antiseptic, bargained-for exchanges.".²²⁶

Third, concern over exploitation of vulnerable populations deters many from entertaining the prospect of organ sales. Individuals willing to exchange their organs for valuable consideration might be in desperate financial or emotional straits.²²⁷ An organ market, it is feared, would advantage economically privileged kidney patients over those

^{222 42} U.S.C § 274e

²²³ H.R. Rep. no. 98-575, at 22-23 (1983).

²²⁴ See e.g., Arthur L. Caplan, Am I My Brother's Keeper? The Ethical Frontiers of Biomedicine
(Bloomington and Indianapolis: Indiana University Press: 1997): 95-96; Nicholas L. Tilney, Transplant: From Myth to Reality (New Haven and London: Yale University Press, 2003): 267-74.

²²⁵ Julia Mahoney, "Altruism, Markets, and Organ Procurement," 22.

²²⁶ Julia Mahoney, "Altruism, Markets, and Organ Procurement," 17.

²²⁷ Bourree Lam, "Is there a Moral Way to Fix America's Kidney Shortage?" *The Atlantic*, January 22, 2015, https://www.theatlantic.com/business/archive/2015/01/is-there-a-moral-way-to-fix-americas-kidney-shortage/384710/.

who were not wealthy, and potentially exploit or injure desperate organ sellers.²²⁸ As noted by Arthur Caplan, "watching your child go hungry while you lack a job and a wealthy person waves a wad of bills in your face is not exactly a scenario that inspires confidence in the valid choices that the poor would make in a market for body parts.".²²⁹ This also infringes on autonomy of the poor. Caplan continues, "talk of individual rights and autonomy is hollow if those with no options must "choose" to sell their organs to purchase life's necessities. Choice requires options as well as information and some degree of freedom.".²³⁰

Worldwide consensus on the matter reflects the legal and ethical aversions to organ compensation. With the exception of India in the 1980s and Iran beginning in 1988, almost no other country permits financial incentives to donate organs..²³¹ Moreover, many in the medical profession contend the very nature of an organ market violates the practice of medicine..²³² Because the principle of "do no harm" serves as a central ethical tenet of the medical profession, "the only morally defensible way to remove an organ from someone is if the donor chooses to undergo the harm of surgery solely to help another, and if there is sufficient medical benefit to the recipient."²³³ Existence of an organ market places medical professionals in precarious positions because "doctors and nurses would be using their skills to help people harm themselves for money."

²²⁸ Jed Adam Gross, "E. Pluribus UNOS: The National Organ Transplant Act and Its Postoperative Complications," *Yale Journal of Health Policy, Law, and Ethics* 8 no. 1 (2013): 147-187 at 179.

²²⁹ Arthur Caplan, "Bioethics of Organ Transplantation," *Cold Springs Harbor Perspectives on Medicine* 4 no. 3 (March 2014), doi: 10.1101/cshperspect.a015685.

²³⁰ Ibid.

²³¹ Becker and Elías, "Introducing Incentives in the Market for Live and Cadaveric Organ Donations" at 3.

²³² Hippen, Ross, and Sade, "Saving Lives is More Important than Abstract Moral Concerns," at 1059.

²³³ Caplan, "Bioethics of Organ Transplantation," at 1057.

On the other side of the debate are those who claim autonomous and competent adults have a strong presumptive right to do as they please with their own bodies, especially where this is not substantially harmful to third parties..²³⁴ As such, respect for bodily autonomy charges others to recognize the individual "as sovereign over his own body" and respect the right of competent individuals to sell parts of their body..²³⁵ Given society's acceptance of the sale of blood, semen, ova, hair, and tissue, a precedent exists for individuals claiming the right to dispose of their organs and other bodily parts if they so choose..²³⁶ Recognition of this autonomy not only affords the individuals respect for their right to dictate their own healthcare decisions, but also provides a tremendous benefit to others, i.e. a lifesaving kidney.

Moreover, allowing individuals to either barter or sell a body part increases the societal level of well-being because permitting the sale of organs will lead to increased organ transplants, thereby mitigating the organ shortage and ultimately save lives..²³⁷ Those who espouse this argument contend, "the saving of lives is a good end and organ sale is then defensible as a means of achieving that positive end.".²³⁸ Because transactions are voluntary, individuals who opt to sell their kidney are presumably doing so because they believe they are better off without the kidney and with the money than without the money and with the second kidney..²³⁹ As such, allowing a regulated organ market not only recognizes the autonomy of the individual but also achieves a moral good from a utilitarian perspective because it yields greater goods for a greater number of people.

²³⁴ "The Sale of Human Organs," *The Stanford Encyclopedia of Philosophy* (Spring 2014),

https://plato.stanford.edu/archives/spr2014/entries/organs-sale/#ArgBasPriResForAutLibNotSelOwn. ²³⁵ Gerald Dworkin, "Markets and Morals: The Case for Organ Sales," 156.

Gerald Dworkin, "Markets and Morals: The Case for Organ Sales," 156

²³⁶ Ibid.

²³⁷ Ibid.

²³⁸ "The Sale of Human Organs," The Stanford Encyclopedia of Philosophy.

²³⁹ Gerald Dworkin, "Markets and Morals: The Case for Organ Sales," 156.

V. Conclusion

As the demand for organs increases, it is essential to ensure that new and innovative laws, policies and strategies of increasing organ supply are bioethical, feasible, and sustainable. Cutting edge biomedical research and technology propel biomedicine and surrounding fields toward alternative therapies, including xeno-transplantation, the creation of extra-corporeal artificial organs, stem cell medicine, and various nano-based therapies. Once some or all of these technologies are realized, it may render the paired kidney exchange and other contemporary transplant models moot. Currently, however, such research is either speculative or in the early stages of development, and thus the present-day transplant systems such as paired kidney exchanges warrant continued analysis and steps toward improvement. Namely, until new technologies or approaches become safe and available for human use, serious discussions about the most ethical, fair, and just system to protect all parties involved and ultimately decrease the imbalance between kidney supply and demand are necessary.

Despite the ethical issues involving the paired kidney exchange model and its variations, they should continue to become an integral aspect of living kidney donations in the United States. The evolution of the paired kidney donation model into NEAD and DPD chains and the recent development of the UCLA voucher program reflect creative methods designed circumvent hurdles such as timing and donor compatibility to encourage more living donors. However, without the implementation of certain safeguards, the organ procurement and transplant system in the United States remains vulnerable to nefarious actors infiltrating the transplant networks and raising doubts about the safety, stability, and trustworthiness of the systems in place. Most vulnerable are the kidney patients awaiting transplants, potential living kidney donors, transplant centers, and the transplant and healthcare teams.

As such, to protect the autonomy of all participants in the healthcare team while upholding the balance between beneficence and non-maleficence within the legal parameters of NOTA, the most ethical solution to best secure the paired kidney exchange model involves revising NOTA to include a remedy of specific performance. As highlighted in the pages above, living kidney donation practices exist within a delicate framework with many compounding hurdles working against hopeful kidney transplant recipients. Perhaps most vexing are factors such as the national organ shortage, finding donor compatibility, time, the recipient's deteriorating health conditions, and legal statutes restricting the ways in which organs can be obtained. Absent a strong objective remedy in place, individuals desperate for a kidney (or individuals desperate to help a loved one obtain a kidney) can take advantage of the system, which is premised on the good faith and trust that all participating parties will act in accordance with proclaimed promises. Not only does the incorporating of a harsh, but equitable deterrent to reneging protect the autonomy of each participant in, but also, preserves the integrity of the paired kidney exchange structure at the systemic level.

The argument for why a remedy of specific performance offers the most ethical safeguard to paired kidney exchange follows a similar logic to why making false promises, especially to gain an advantage over another, constitutes unethical behavior. That is, to promise with the intention of reneging on the promise undermines and contradicts the act of promising. When the purpose of the promise becomes hollowed and meaningless, the act of promising can no longer become universalized as there is no

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way to distinguish a real promise from a lying promise. As a consequence, the entire infrastructure of promise-giving and promise-keeping crumbles because people can no longer trust one another nor can they trust the systems in place that govern based on the premise that individuals keep their promise.

Similarly, in the paired kidney exchange context, if individuals can lawfully lie about their intentions to donate a kidney when they enter into a paired kidney exchange agreement and cause others to act upon their lies, the entire paired kidney exchange model will fade until it disappears altogether. Namely, without any safeguard in place to guarantee an intended donor's honest commitment to following through on his promise, no party will ever agree to donate first out of fear that the other party will renege. Thus, the only form of paired kidney exchanges that will remain are exchanges conducted simultaneously. That is, D1 will agree to donate to R2 if and only if D2 agrees to donate to R1 at the exact same time. Though this permutation represents ideal execution of paired kidney exchanges as it eliminates the opportunity for an intended donor to defraud and renege, the simultaneous kidney swap is not the most efficient approach as it drastically limits the number of pairs who can participate due to logistical reasons. For example, donor schedules, recipient schedules, schedules of the transplant centers and the transplant surgery teams, the health status of all participants, and, in many cases, geographic location will all have to align for the simultaneous kidney exchange to take place.

The remedy of specific performance functions as a form of insurance or an extra protective measure designed to keep all donors and recipients honest and transparent about their intentions. As such, adding the remedy of specific performance to NOTA reifies what the ethical calculus requires. That is, equipping the law with a mechanism to deter fraudulent behavior preserves human dignity and protects individual autonomy by ensuring current and future paired kidney exchange participants can make free, rational choices without fear their choices are based on lies or fraud. Under the current version of NOTA, a nefarious actor can lawfully renege on a promise to donate his kidney despite entering into the agreement with blatant immoral intentions and later acting on them. This also prohibits the transplant team performing the first transplantation from acting in the best possible interest of their patient as lurking in the background is the possibility that the second donor will subsequently retract his or her promise. Even if the transplant team obtains the requisite informed consent from the first donor by explaining the potential risk that the second donor will renege, many transplant surgeons may still insist on performing the transplant either simultaneously or second, which, all other things being equal, offers a better guarantee they are doing everything in their power to act in the best interest of their patients and to do no harm.

Of course, to apply a strict application of specific performance toward any instance in which an intended donor does not follow through on his or her promise would be overly harsh and could cause more ethical issues than resolutions. It is therefore necessary to identify the types of circumstances where a remedy of specific performance should not apply. First, as mentioned above, only after one party has completed the act of donating the kidney should the remedy of specific performance be triggered. Thus, specific performance should not apply when one of the intended donors backs out of the agreement before any of the donors has donated. Prior to any party donating, all intended donors still have both of their kidneys and the intended recipients are each still in need of a kidney transplantation. No one yet has detrimentally relied on another's promise, no permanent or severe damage has been done, and the intended donors may still participate in different paired kidney exchanges to save their recipient. To force any of the intended donors to donate a kidney against their will would be a gross violation their bodily integrity and claims to autonomy.

Additionally, such a harsh application of specific performance places the transplant teams in an ethically precarious position because it would require them to override the patient's informed consent, inflict all the harm associated with kidney donations on the patient, and fail to act in the best interest of the patient or even in the best interest of patients who participate in paired kidney exchange programs. Unlike application of specific performance to D1 in Case One, where temporarily shrinking D1's claims to autonomy and bodily integrity can be justified because D1's specific performance is the most plausible solution to right the wrong caused by D1 and R1's fraudulent actions, the application of specific performance prior to any donative action is not necessary because D1 and R1 did not collude or act willfully to cause permanent harm. Though withdrawing from a paired kidney exchange agreement at any point before either party donates may delay the other party from securing a new pair, the harm does not rise to the level of shrinking the withdrawer's claims to autonomy and bodily integrity. Any physician or transplant team that helps facilitate a forced kidney removal when the remedy of specific performance is not warranted violates the principles of informed consent, nonmaleficence, and patient autonomy. Though the transplant team may provide benefits to the kidney recipient, the gross misconduct and violation of the other ethical principles vastly outweigh any benefits afforded to the kidney recipient.

Other instances wherein a remedy of specific performance is not justified include occasions where the recipient falls ill and becomes medically ineligible to receive a kidney. This may occur before the first donor already donated or after. Moreover, cases where either the first or second donor falls ill and becomes medically ineligible to undergo the transplant surgery or to donate a kidney. As mentioned above in the section on specific performance, the best solution in situations where no willful misconduct is at play and the first donor has already donated involves finding and inserting the waiting recipient into the next available kidney chain.

The argument that adding a specific performance remedy clause to NOTA serves as the most ethical solution does not completely discount the other options discussed. Both the establishment of an organ markets and the widespread implementation of the UCLA gift certificate program offer viable solutions to the kidney shortage issues. The ethical problems with either alternative, however, vastly surpass the number of ethical and legal issues with specific performance. Perhaps the biggest and most pressing hurdle to implementing a regulated organ market is the need to completely overhaul NOTA and the UAGA as they explicitly outlaw the sale of organs. Moreover, the primary ethical argument maintains an organ market will become a pathway for wealthy purchasers to take advantage of or coercing vulnerable individuals into selling their organs. This paternalistic approach endorses legal constraints on individual autonomy to protect individuals from themselves, especially those members of society who are poor, gullible, mentally disabled, or easily manipulated. Furthermore, those ethically opposed to the organ market contend that the harm outweighs the benefits in an organ market framework. Using data from Iran and India, two countries that permit organ markets,

they maintain the non-directed donor "gains significant psychological benefits by aiding an emotionally related family member or friend. In contrast, data (from Iran and India) show that the paid vendors do not reap the benefits they expected (improved financial circumstances)."²⁴⁰ Though widely accepted, this moral argument falls short, particularly when viewed from a utilitarian perspective, because it holds the potential to provide the greatest amount of good for the greatest number of people. Assuming strong safeguards are in place to ensure participation is voluntary and to prevent coercion or taking advantage of vulnerable populations, an ethical policy regulating a national organ market is certainly plausible.

Regarding the widespread application of the UCLA voucher program, there are still many legal and ethical wrinkles that require further consideration and revisions before it can surpass specific performance as the most ethically sound option. While on one hand the UCLA program overcomes the paired kidney exchange and need for specific performance hurdle by requiring donors to donate before recipients may receive a kidney, it fails address the concerns raised by those who oppose the organ market. Namely, because the donor is so untethered from the recipient – both through time (the donor can donate years before the recipient needs a kidney) and through compatibility (the donor's kidney does not need to be compatible with the recipient), a large ethical concern looms regarding the solicitation, coercion, and manipulation of vulnerable populations. Assuming the legislature seeks to remain far away from an organ market system, strong protections must be put into place to prevent those suffering from kidney disease from paying members of the vulnerable population to donate their kidney and provide them

²⁴⁰ Hippen, Ross, and Sade, "Saving Lives is More Important than Abstract Moral Concerns," at 1058.

with a voucher to be used when needed.

Appendix 1: The Kidney

The kidneys consist of two bean-shaped organs located on both sides of the spine under the diaphragm and behind the liver and stomach.²⁴¹ They are reddish-brown in color and measure about 4.5 inches long, 2.5 inches wide, and 1 inch thick.²⁴² Their primary function is to remove waste from the body through the production of urine. They also help regulate blood pressure, volume, and electrolyte composition.²⁴³

Kidney failure, or renal failure, occurs when the kidneys cannot adequately remove waste and maintain the correct electrolyte balance.²⁴⁴ Acute renal failure, which is often associated with trauma, burns, acute infection, or obstruction of the urinary tract, is characterized by inability to produce urine and an accumulation of wastes. Treatment depends on the cause and often includes antibiotics and reduced fluid intake. Chronic kidney, failure, by contrast, typically occurs as a result of many systemic disorders and often results in many secondary issues such as fatigue, a decrease in red blood cells, diminished urine output, anemia, and often complications of hypertension and congestive heart failure. Transplant patients most commonly have diseases from one of the following categories: glomerular diseases; diabetes; polycystic kidneys; hypertensive nephrosclerosis; renovascular and other vascular diseases; congenital, rare familial, and metabolic disorders; tubular and intestinal diseases; neoplasms; re-transplant graft failure; and other. Treatment for chronic kidney failure may involve the use of diuretics, restricted protein intake, and, if all else fails, dialysis, transplantation, or both.²⁴⁵ Long-

 ²⁴¹ "Organ Procurement and Transplantation Network," U.S. Department of Health and Human Services, last modified September 28, 2017, https://optn.transplant.hrsa.gov/data/organ-datasource/kidney/.
 ²⁴² Ibid.

²⁴³ Ibid.

²⁴⁴ Ibid.

²⁴⁵ Ibid.

term survival is markedly improved among patients who receive a kidney compared with patients who remain on the waiting list for such an organ.²⁴⁶ Figures from the Organ Procurement and Transplantation Network reveal that patients receiving kidneys from living donors have higher survival rates than patients receiving kidneys from cadavers..²⁴⁷

Appendix 2: History of Living Kidney Donations

To provide a context for the United States' progress in procuring and transplanting organs and the laws and policies that surround this procedure, it is important to first highlight significant advances and developments in transplant history. This timeline will not only provide a sense of the pace at which organ donation and nephrology have advanced in the past sixty years, but also set expectations for anticipated progress and future developments in the field. As will be discussed below, the development of first the dialysis machine and later immunosuppressant drugs marked major turning points in the field because on one hand they greatly expanded the number of potential kidney recipients and provided hope to those awaiting a transplant while on the other they unleashed a series of new legal, ethical, and logistical problems pertaining to fair and just kidney allocation. Additionally, the rapid pace at which advances and developments in the field occurred drastically outpaced the laws and regulations governing the practice. As will become clear in Part II, the law still lags behind in adjusting to new models and trends in kidney transplantation.

1. <u>Dialysis</u>

²⁴⁶ R. Wolfe et al., "Comparison of mortality in all patients on dialysis, patients on dialysis awaiting transplantation, and recipients of a first cadaveric transplant," New England Journal of Medicine 41 no. 23 (1999): 1725-30, https://www.ncbi.nlm.nih.gov/pubmed/10580071.

²⁴⁷ For example, the five-year survival rate for transplants performed between 1995 and 2002 was 90.5 percent for living donors compared to 82.5 percent for cadaveric donors. Elisheva Berman et al., "The Bioethics and Utility of Selling Kidneys for Renal Transplantation," Transplantation Proceedings 40 no. 5 (2009): 1264-70, https://www.ncbi.nlm.nih.gov/pmc/articles/PMC2504358/.

Prior to 1954, the only way to treat kidney disease involved dialysis. Dr. Willem Kolff, considered the father of dialysis, developed the first dialyzer, or artificial kidney, in 1943.²⁴⁸ The first long-term success for the Dutch physician's dialyzer occurred in 1945 when a 67-year-old woman in uremic coma regained consciousness after 11 hours of hemodialysis with Kolff's dialyzer.²⁴⁹ For the next decade, Kolff's dialyzer and subsequent versions became standard procedure to treat kidney disease.²⁵⁰

In the late 1940s, following World War II, Kolff continued his research in the United States. He provided blueprints for his kidney machine to George Thorn at the Peter Bent Brigham Hospital in Boston..²⁵¹ This led to the manufacture of the next generation of Kolff's dialyzer, a stainless steel Kolff-Brigham kidney, which helped treat acute renal failure..²⁵² Then, in 1960 Dr. Belding Scribner invented the Scribner shunt, which connected the patient to the dialyzer using plastic tubes, one inserted into an artery and one into a vein..²⁵³ This breakthrough device was the first of its kind to prolong the lives of end stage renal disease patients by allowing patients to survive longer periods while waiting for an organ to become available.

Though the Scribner shunt is no longer used today, it is remarkable because it opened the door to better methods of access to the circulatory system. As a result, dialysis machines today can perform the basic function of the kidneys by essentially washing the patient's blood, which increases the amount of time a kidney patient can survive while

²⁵³ Ibid.

²⁴⁸ "The History of Dialysis," Davita Kidney Care, accessed September 2, 2017,

https://www.davita.com/kidney-disease/dialysis/motivational/the-history-of-dialysis/e/197. 249 Ibid.

²⁵⁰ Ibid.

²⁵¹ Ibid.

²⁵² Ibid.

awaiting a kidney..²⁵⁴ On average, patients can remain on dialysis between 5 to 10 years as they await a kidney transplant..²⁵⁵ As of December 2016, for example, approximately 468,000 individuals were reportedly on dialysis..²⁵⁶ Dialysis patients today receive treatment approximately three times per week, for about four hours at a time. Though dialysis may prolong their life, patients must endure painful side effects from dialysis treatment, including burning, bloating, infections, low blood pressure, fatigue, and nausea..²⁵⁷ Because their health drastically declines while on dialysis, the majority of patients on dialysis do not receive new kidneys because the long wait time works against their deteriorating condition..²⁵⁸

2. Live Kidney Transplant

A turning point in organ transplantation occurred in 1954 when Dr. Joseph Murray performed the first successful kidney transplant at the Peter Bent Brigham Hospital in Boston.²⁵⁹ Because the donor and recipient were identical twins, the organ did not appear foreign to the recipient's body, which did not reject it. Kidney transplantation, however, did not become commonplace until the development of immunosuppressant drugs that could prevent rejection of transplanted organs.²⁶⁰ Following the introduction of Purinethol and Imuran in the 1960s immunosuppression became the standard of care..²⁶¹

http://www.nationalkidneycenter.org/treatment-options/transplant/history-of-transplants/.

²⁶⁰ Immunosuppressant drugs are drugs or medicines that lower the body's ability to reject a transplanted organ. Another term for these drugs is anti-rejection drugs. There are 2 types of immunosuppressant drugs: 1. Induction drugs: Powerful antirejection medicine used at the time of transplant and 2. Maintenance drugs: Antirejection medications used for the long term. "Immunosuppressants," National Kidney Foundation, accessed September 2, 2017, https://www.kidney.org/atoz/content/immuno.

²⁵⁴ Ibid.

²⁵⁵ Ibid.

²⁵⁶ Ibid.

²⁵⁷ Goodwin, "The Veneer of Altruism."

²⁵⁸ Ibid.

²⁵⁹ "History of Transplants," National Kidney Center, accessed September 3, 2017,

²⁶¹ Becker and Elías, "Introducing Incentives in the Market for Live and Cadaveric Organ Donations" at 3.

As a result, it became possible to closely match donor and recipient tissue. Further advances in immunosuppressant drugs ultimately increased the number of kidney, lung, liver, heart, and other organs that could be transplanted.²⁶² In 1962, for example the first successful cadaveric transplant used a deceased donor kidney. The kidney worked for almost 2 years.²⁶³ Then, in 1966, doctors performed the first successful liver transplant.²⁶⁴

3. <u>Immunosuppressant drugs</u>

Another major breakthrough occurred in the 1980s with the development of Cyclosporine..²⁶⁵ This drug dramatically improved the success rate for transplant recipients as well as patient outcomes..²⁶⁶ As a result, the first successful heart-lung transplant occurred in 1981. In 1986, the first xenotransplantation was performed..²⁶⁷ A baboon heart was transplanted into Baby Faye and worked for 20 days..²⁶⁸ Also, because of the new drugs, doctors performed the first artificial heart transplant..²⁶⁹

The late 1980s and 1990s produced new techniques, new medications, and new patient information that have helped make kidney transplants a safer, more effective and more routine procedure..²⁷⁰ For example, during this time physicians discovered how to split organs into pieces, and the first split liver transplant in 1996 allowed one cadaveric

²⁶² "History of Transplants," National Kidney Center.

²⁶³ Ibid.

²⁶⁴ Ibid.

²⁶⁵ Thomas Starzl, "History of Clinical Transplantation," *World Journal of Surgery* 24 no. 7 (2000): 759-82, https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3091383/.

²⁶⁶ Ibid.

²⁶⁷ Ibid. ²⁶⁸ Ibid.

²⁶⁹ Ibid.

²⁰⁰ ID10.

²⁷⁰ Megan Fix, "Kidney Transplantation: Past, Present, and Future," accessed September 3, 2017, https://web.stanford.edu/dept/HPS/transplant/html/history.html.

liver to be used among multiple transplant patients..²⁷¹ More importantly, expansion of the living donor pool occurred during this period. Whereas in the 1960s and 1970s living donation opportunities were afforded only to those genetically related to the recipient, during the 1980s and 1990s the donor pool broadened to friends, non-relatives, and eventually to complete strangers..²⁷² As a result of the broadening of the potential donor pool, by 2001, the number of living organ donations passed cadaveric donations..²⁷³

Appendix 2: Kidney Statistics

To place into historical context the escalating gap between the supply and demand for organs since organ transplantation became common practice in the 1970s and 1980s, the following statistics will highlight a few key data points that demonstrate both progress in organ transplantation as well as major hurdles the transplant community continues to face. Namely, even though the science and medical community have developed better drugs, new trends in organ donation models, and greater ability to perform more complex organ transplantations, the gap between the supply of organs and the demand for kidneys continues to increase.

According to the Institute of Medicine, in 1988, there were 16,026 individuals on the waiting list for an organ transplant; by 1995 the waiting list had increased almost 275 percent to 43,937.²⁷⁴ By 2013, the waiting list for kidneys exceeded 100,000 patients

²⁷¹ Ibid.

²⁷² See e.g. Daphne Sashin, She gave him a kidney, he gave her his heart," CNN, last updated February 12, 2015, http://www.cnn.com/2015/02/11/living/soul-mate-stories-kidney-donor-match-irpt/index.html.
²⁷³ Fix, "Kidney Transplantation: Past, Present, and Future."

²⁷⁴ Institute of Medicine, *Organ Donation: Opportunities for Action* (The National Academies Press, Washington, DC, 2006) at 19.
even though 16,900 transplants had occurred that year..²⁷⁵ In 2016, 19,061 kidney transplants were performed nationally..²⁷⁶

Between 1990 to 2005, the number of kidney transplants escalated from 10,000 in 1990 to over 13,700 in 2005, with approximately half the transplants in 2005 coming from live donors.²⁷⁷ Part of the increase in live kidney transplants "can be attributed to the growing use of laparoscopic nephrectomy (the name for the surgical procedure for removing a kidney), a minimally invasive procedure with equivalent recipient outcomes and lower donor morbidity relative to traditional open nephrectomy."²⁷⁸

At the same time, however, the growth in demand for kidneys during this ten year period drastically exceeded the supply. Whereas approximately 7,000 individuals were on the waiting list for a kidney in 1990, 65,000 persons were waiting for a kidney by the beginning of 2006. According to Becker and Elias, "part of the increase can be attributed to technological progress that reduced the cost of organ transplants and made them safer during the past 15 years. A larger part can be attributed to the sustained increase in waiting time to receive an organ due to the inability of the current system to procure enough organs."²⁷⁹ By 2006, on average, an individual would remain on the waiting list for about five years. The median waiting years is shorter than the average because some individuals on the list died before they could receive a kidney, some became too ill to undergo transplant surgery, some opted to remain on kidney dialysis, and others chose to

²⁷⁵ Editorial Board, "Ways to Reduce the Kidney Shortage," *The New York Times*, September 1, 2014, https://www.nytimes.com/2014/09/02/opinion/ways-to-reduce-the-kidney-shortage.html?_r=0.
²⁷⁶ "Giving Life a Second Chance Through Organ & Tissue Donation," Gift of Life Donor Program, accessed August 28, 2017, http://www.donors1.org/learn2/organs/kidney/.

²⁷⁷ "Data," United Network for Organ Sharing, accessed August 27, 2017, https://www.unos.org/data/.

 ²⁷⁸ Becker and Elías, "Introducing Incentives in the Market for Live and Cadaveric Organ Donations" at 4.
 ²⁷⁹ Ibid.

go abroad for transplantation..²⁸⁰ In 1990, for example, 1,000 people died while on the waiting list. From 2003-2005, by contrast, between 3,5000 and 4,000 individuals on the waiting list died each year. Moreover, in 2005, over 1,070 people were removed from the waiting list because they became too ill to undergo transplant surgery..²⁸¹ In 2014, 4,761 patients died while waiting for a kidney transplant..²⁸²

Appendix 3: Kidney Chains

Logistically, many networks must work together to successfully implement a chain. First, people interested in participating in Kidney Paired Donation (whether donors or recipients, incompatible or compatible) are entered into a Kidney Paired Donation database. The information submitted to the database includes their blood type, HLA antigen typing, and other basic medical information. Sophisticated algorithms are then used to identify and match compatible donors and recipients within the registry...²⁸³ National registries, such as the National Kidney Registry, incorporate data from hospitals and transplant centers across the country to maximize the probability of linking nonmatching pairs of patients and willing donors. As a result, matching donors and recipients may be located on opposite sides of the country. It is important to note that in most cases, the matched donors and recipients do not travel to another transplant center. Rather, the respective surgeries are performed at a transplant center close to the homes of the matched donor and recipient, and the donor's kidney is shipped to the recipient's transplant center.

²⁸⁰ Ibid at 5.

²⁸¹ Ibid at 7.

²⁸² "Organ Donation and Transplantation Statistics," National Kidney Foundation.

²⁸³ Living Donor Kidney Center, Weill Cornell Medical College, last visited August 23, 2017, http://cornellsurgery.org/patients/services/livingdonor/kpd-procedures.html.

Appendix 4: DPD and NEAD Chains

Although transplant programs initially did not recruit non-directed living organ donors, in recent years non-directed living donor transplants have been widely accepted and encouraged. Specifically, over the past decade several transplant organizations across the country have funded large transplantation awareness campaigns designed to encourage individuals to become donors and partake in the "miracle of transplantation."²⁸⁴ Past and current efforts to encourage individuals to become organ donors include greater dissemination of information about the risks and benefits of becoming an organ donor on social media; production of heartwarming videos highlighting individual stories about how the organ donor saved a recipient's life; face-to-face dialogues, delivered by culturally sensitive and ethnically similar community messengers who were health care providers, transplant recipients, persons awaiting transplants, donors and donor family members; and involvement of religious organizations to help promote and encourage potential donors.²⁸⁵

For example, in 2014, non-directed living donors comprised 184 or 3.32 percent of the 5,536 living donor kidney transplants performed.²⁸⁶ To keep track of number of nondirected donors, the Organ Procurement and Transplantation Network (OPTN), through its contract with the United Network of Organ Sharing (UNOS), requires transplant centers to report the relationship between the donor and recipient for every organ

²⁸⁴ "Encouraging Organ Donation: Removal of Disincentives & Consideration of Incentives," American Society of Transplantation, accessed September 4, 2017, https://www.myast.org/about-ast/presidents-blog/encouraging-organ-donation-removal-disincentives-consideration-incentives.

²⁸⁵ Clive Callender and Patrice Miles, "Minority Organ Donation: The Power of an Educated Community," *Journal of the American College of Surgeons* 210 no.5 (2010):708-717, https://www.ncbi.nlm.nih.gov/pmc/articles/PMC2861044/.

²⁸⁶ "Living Non-directed Organ Donation," Organ Procurement and Transplantation Network.

transplanted.²⁸⁷ These relationships must be reported through one of 12 categories or subcategories as described in the following table:

Major Category	Subcategories	Relationship
Biological, blood related	6	Parent, child, identical
		twin, full sibling, half
		sibling or other relative
Non-biological	2	Spouse, life partner
Non-biological, unrelated	4	Paired donation,
		anonymous donation,
		domino, or other unrelated
		directed

Relationships Between Donor and Recipient

Appendix 5: Risks associated with living kidney donations

Though living kidney donation is a relatively safe procedure, it still poses major risks to the donor. It simply cannot be overlooked that the transplant team must subject a relatively healthy donor to an extensive surgical procedure that provides no benefit to him or her. First, removing a kidney is an invasive surgery that brings about "all the usual complications, some serious, such as infection, blood clots in the lungs, or injury to other organs, and some not so serious, such as incisional pain or excessive scarring.".²⁸⁸ As with any surgery, post-operative complications are often unpredictable and can inflict otherwise healthy individuals..²⁸⁹ Furthermore, other recognized risks include side effects associated with allergic reactions to the anesthesia, pneumonia, hemorrhaging, the

²⁸⁷ Ibid.

²⁸⁸ Mark F. Anderson, The Future of Organ Transplantation: From Where Will New Donors Come, To Whom Will Their Organs Go?" *Health Matrix* (1995), 80.

²⁸⁹ Kelly Lobas, "Living Organ Donations: How Can Society Ethically Increase the Supply of Organs?" *Seton Hall Legislative Journal* 30 (2006), 489.

need for blood transfusions, infection of the wound or urinary tract, and even death..²⁹⁰ The risk of surgical complications in living donor surgery is a 5 percent to 10 percent risk and the risk of death is 0.5 percent to 1 percent..²⁹¹

Moreover, because the term "risk" reflects both the probability and the magnitude of harm, cost, or burden to the recipient, all potential harms must be accounted for in the risk-to-benefit analysis. In addition to potential physical risks that likely could cause harm, a donor may also incur psychological harm. In fact, for many donors, the psychological and emotional aspects of recovery are much more difficult and lengthier than the physical recuperation.²⁹² First, following donation, an organ donor may experience negative psychological symptoms. Often these emotions manifest through feelings of regret, resentment, anger, anxiety or depression..²⁹³ Treatment for these conditions can be lengthy, costly, and could possibly include the use of medications with risks and side effects.²⁹⁴ Additionally, it is possible the recipient's body rejects the donor's kidney or the kidney does not function properly in the recipient's body. Thus, "if exchange partners decide to share information and if any recipient in a kidney exchange has an unfavorable outcome, it could have an adverse psychological impact on donors."²⁹⁵ Finally, it is important to mention that the transplant recipient may also suffer some aspects of psychological harm. Not every transplant candidate is enthusiastic

- ²⁹² "Living Donor Psychological Recovery," Living Donor 101, updated January 1, 2015, http://www.livingdonor101.com/psychrecovery.shtml.
- ²⁹³ Ibid.

²⁹⁰ Ibid.

²⁹¹ Dalal, "Philosophy of organ donation: review of ethical facets," 45.

²⁹⁴ "Medical and Psychological Risks," Living Donation California, accessed September 15, 2017, http://livingdonationcalifornia.org/how-living-donation-works/medical-and-psychological-risks/.

²⁹⁵ Sommer Gentry, Ron Shapiro, and Dorry Segev, "Kidney Paired Donation Programs for Incompatible Living Kidney Donors and Recipients," J. Steel (ed.), *Living Donor Advocacy* (2014), 24, doi 10.1007/978-1-4614-9143-9_2, 17.

about the prospect of receiving an organ from a living donor because of the feelings of guilt for placing another person at risk..²⁹⁶ Others are uncomfortable with receiving kidneys from live donors either because they feel unworthy or because they do not want to feel indebted to another person for the rest of their lives. Often, recipient guilt heightens when another family member or friend either donates to them, or, in the context of paired kidney exchange and UCLA programs, donates on their behalf, particularly when the donor has other family members for whom they are responsible, such as children, elderly parents, or a spouse..²⁹⁷

Additionally, financial harm constitutes another major aspect of harm assessment. Typically, the evaluation to determine if the potential donor is a good candidate for living donation, the donation surgery, and the post-operative care is covered by the recipient's Medicare or private health insurance. However, travel costs, certain follow-up expenses, and lost wages are not compensated..²⁹⁸ Moreover, pre-operation procedures, the transplantation, and recovery time often require the donor to miss several days of work..²⁹⁹ Often, the donor takes a few of days off from work before the surgery for any required travel and pre-surgery testing and preparations..³⁰⁰ Then, the donor spends three to seven days in the hospital post operation, and requires an additional four to six weeks for full recovery..³⁰¹ The average recovery time for donations is two to six weeks before

²⁹⁶ Mary Olbrisch, Sharon M. Benedict, Deborah L. Haller, James L. Levenson, "Psychosocial Assessment of Living Organ Donors: Clinical and Ethical Considerations" *Progress in Transplantation* 11 no. 1 (2001): 40-49.

²⁹⁷ Ibid.

²⁹⁸ "What to Consider Before Donating," *American Transplant Foundation*, accessed August 27, 2017, https://www.americantransplantfoundation.org/about-transplant/living-donation/becoming-a-living-donor/five-questions-to-ask-yourself/.

²⁹⁹ Ibid.

³⁰⁰ Ibid.

³⁰¹ Ibid.

a donor may return to normal activity, but the recovery time could potentially be longer. Thus, a donor with an average earning of approximately \$35,000 per year will experience a monetary loss of about \$2,700 if he or she takes four weeks off from work to recover.

Finally, a kidney transfer exposes the donor to certain life risks that might place him or her in a life-threatening position should the remaining kidney later malfunction. Some studies confirm that a healthy individual who donates one kidney can lead a relatively normal life. However, other studies report individuals who donate a kidney may have a greater chance of later developing high blood pressure.³⁰² Moreover, athletes and individuals who typically engage in activities with physical contact must make lifestyle changes to reduce the likelihood of damaging their remaining kidney. Because a disproportionate number of kidney donors derive from a highly-selected group of healthy individuals and not the general population, the post-operation reduction in certain physical activities do require many to make lifestyle adjustments and give up certain hobbies.³⁰³

³⁰² Neil Boudville et al, "Meta-Analysis: Risk for Hypertension in Living Kidney Donors," *Annals of Internal Medicine* 145 no.3 (2006): 185-196, http://annals.org/aim/article/726717.

³⁰³ Gaston, Kumar, and Matas, "Reassessing Medical Risk in Living Kidney Donors," 1017.

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