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FATAL FLAWS: NEW ZEALAND'S HUMAN TISSUE ACT FAILS TO PROVIDE AN AVENUE FOR INDIVIDUALS TO GIVE LEGALLY BINDING INFORMED CONSENT

Jennifer J. Howard[†]

Abstract. Improving the worldwide organ transplantation rate is an important goal for the world health community. Thousands of people die each year waiting for organs that would save their lives. New Zealand has one of the poorest rates of transplantation in the Western world. In 2008, New Zealand passed the Human Tissue Act in an attempt to improve the number of donors and ultimately increase the number of transplants performed. To promote the autonomy of individuals, the new law prioritized who can give informed consent for organ donation upon death, with individuals' actions and intentions being paramount. The law allows individuals to provide informed consent to donate their organs upon death or to designate another individual to make the decision for them. The family's permission is requested only if the donor or nominee failed to give informed consent. This framework is necessary to address one of the biggest obstacles to organ donation: the family's refusal to donate. Because of ethical and publicity concerns, doctors and organ procurement specialists will not take an organ over an objection by the family, although trends suggest this might be changing. This comment argues that key parts of the law prevent it from increasing the number of donors. The law fails to establish a national registry where New Zealanders can register their informed consent. While the law allows for the database to be created in the future if the need arises, not instituting it immediately leaves those individuals who would otherwise donate few options: a will or advance directive. These options are costly, and very few people will take the initiative to execute them. Failure to create another option leaves the status quo in place; a donor designation on a driver's license will not be considered by medical professionals, and the family will decide whether or not to donate their loved one's organs. This comment argues further that New Zealand can strengthen its legislation and the autonomy of the individual by establishing a national registry and pairing it with a required response system. Required response would mandate that all New Zealanders choose during life what they would like to have done with their body upon death. When New Zealanders register their informed consent in the national registry, physicians and organ procurement specialists can have reliable, accurate information about the wishes of the deceased. Through these two systems, New Zealand can move toward implementing a system of first person consent. In conjunction with these recommendations, an advertising and education campaign should be instituted to positively influence the family and help promote a culture in New Zealand where donation is the norm.

I. INTRODUCTION

"One person has the potential to save seven lives and enhance the quality of living for more than fifty others through organ and tissue donation."¹

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With the impressive advances in medical technology over the last sixty years and the many miraculous ways that organs and tissues can change the lives of human beings, one might expect that individuals would be galvanized to sign up to donate organs, tissue, and blood.² Unfortunately for the thousands of people on organ transplant waitlists across the globe, this is not the case.³ While fresh ideas and new legislation have increased transplantation rates for many developed countries around the globe, others have lagged behind.⁴ New Zealand's current donor rate is 8.6 per million in the population.⁵ This is one of the worst rates in the developed world, where the average rate among leading nations is 21.4 donors per million people. Some countries, such as Spain and Croatia, have rates above thirty donors per million people.⁶ This is also lower than New Zealand's rate ten years ago, which peaked at ten donors per million.⁷ In 2008, New Zealand passed the Human Tissue Act ("2008 Act") in an attempt to improve its donation rates. The 2008 Act lays out a definition of informed consent, provides a clear hierarchy of interested parties, and outlines how physicians and organ procurement specialists can obtain informed consent.⁸ Passing this

¹ Abena Richards, *Don't Take Your Organs to Heaven . . . Heaven Knows We Need Them Here: Another Look at the Required Response System*, 26 N. ILL. U. L. REV. 365, 368 (2006).

² For an interesting summary of the progression of medical technology in the area of transplantation, see *History of Transplantation -Timeline*, THE GIFT OF A LIFETIME, <http://www.organtransplants.org/understanding/history/index.html> (last visited Oct. 23, 2012).

³ See, e.g., NATIONAL HEALTH SERVICES BLOOD AND TRANSPLANT ACTIVITY REPORT 2010-11, TRANSPLANT ACTIVITY IN THE UK 3 (2011) (reporting that on March 31, 2011 there were 10,583 patients on the United Kingdom waiting list); UNITED NETWORK FOR ORGAN SHARING, <http://www.unos.org/index.php> (reporting that on January 15, 2012, there were 112,649 people on the United States wait list); Alex He Jingwei et. al., *Living Organ Transplantation Policy Transition in Asia: Towards Adaptive Policy Changes*, GLOBAL HEALTH GOVERNANCE 4 (2010) (Vol. III, No. 2) (reporting that China's wait list holds 1.5 million people).

⁴ See, e.g., Steve P. Calandrillo, *Cash for Kidneys? Utilizing Incentives to End America's Organ Shortage*, 13 GEO. MASON L. REV. 69 (2004) (discussing a variety of ways to use incentives to increase donation rates); J. Andrew Hughes, *You Get What You Pay For?: Rethinking U.S. Organ Procurement Policy in Light of Foreign Models*, 42 VAND. J. TRANSNAT'L L. 351 (2009) (surveying countries who have instituted presumed consent models); Christopher Tarver Robertson, *From Free Riders to Fairness: A Cooperative System for Organ Transplantation*, 48 JURIMETRICS J. 1 (2007) (proposing a system where those people who are "free riders" or unwilling to donate their organs are precluded from receiving the organs available).

⁵ This number is based on the 2011 data compiled in ANZOD REGISTRY REPORT 2012, AUSTRALIA AND NEW ZEALAND ORGAN DONATION REGISTRY 1 (2012), available at <http://www.anzdata.org.au/anzod/ANZODReport/2011/ANZOD2011.pdf>. This registry is not a way of recording consenting donors but a joint venture by the two countries to record and report statistics and data.

⁶ *Id.* at 3 (listing Spain with a rate of 35.9 donors per million, and Croatia with a rate of 33.5 donors per million).

⁷ AUSTRALIA AND NEW ZEALAND ORGAN DONATION (ANZOD) REGISTRY, available at <http://www.anzdata.org.au/anzod/v1/indexanzod.html> (Annual Reports 1997 through 2012).

⁸ Human Tissue Act 2008 (N.Z.).

legislation also served to address a major obstacle in obtaining informed consent—the objections of the family—by promoting individual autonomy.⁹

This comment argues that New Zealand's recent organ donor legislation will fail to meaningfully improve donor rates because it does not create an accessible means by which a citizen can declare his or her intention to donate their organs upon death. This comment further argues that to improve donor rates, the legislature should implement the part of the proposed law it contemplated but failed to pass: a national registry. While the immediate implementation of the registry was removed from the bill, it included a provision allowing for the creation of a registry in the future. The legislature's rationale for not requiring the registry at the time of the bill's passage was the high costs of implementation, as well as concerns that it would be underused.¹⁰ The legislature, however, should implement this provision and amend the law to include a required response element. When these two social structures are paired, they provide reciprocal support and help address the criticisms directed at each system when viewed in isolation.¹¹ A required response system would dictate that all New Zealanders decide how they wish their organs to be treated upon their death. This would eliminate the legislature's anxiety about underutilization of a costly registry and maximize the resources spent creating the database.¹²

The 2008 Act focuses on informed consent and, as written, requires that informed consent be given "in the light of all information that a reasonable person . . . need[s] in order to give informed consent."¹³ Thus, to make the registered consent "informed" and subsequently binding, individuals must be educated about their decision. Moreover, required response systems are often considered a limited solution unless they involve an aggressive advertising and education campaign.¹⁴ Advertising and education are necessary to implement the registry as New Zealanders are informed about the new way to register consent and are provided enough information to make the consent firmly "informed" and binding.

⁹ See Laura A. Siminoff et al., *Factors Influencing Families' Consent for Donation of Solid Organs for Transplantation*, 286 JAMA 71 (2001) (discussing that the low rate of consent by families is a major limiting factor in the success of organ donation).

¹⁰ [2008] 646 NZPD 15428 (N.Z.) (parliamentary debate).

¹¹ See *infra* Part VI.B.

¹² For an explanation and analysis of required response systems, see Richards, *supra* note 1.

¹³ Human Tissue Act 2008, § 9(1)(c) (N.Z.).

¹⁴ Denise Spellman, *Encouragement is Not Enough: The Benefits of Instituting a Mandated Choice Organ Procurement System*, 56 SYRACUSE L. REV. 353, 362 (2006) (note).

Implementing these provisions highlights the two important themes of the 2008 Act: informed consent and individual autonomy.¹⁵ Under this framework, New Zealanders should have more control over their bodies and be able to make an informed decision during life that will be respected. This should ease existing pressure on families who are often left to make an arduous decision about their loved one at a stressful and traumatic time.

Part II of this comment discusses New Zealand's transplant challenges and some important changes that the Human Tissue Act of 2008 required. It outlines the most important aspects of the law, explains the underpinnings of informed consent, and explains the prioritization of the people surrounding a donation decision. Part III discusses how the new legislation fails to provide a way for individuals to exercise their newly emphasized autonomy. It also outlines the practical implications of this failure, mainly that families will continue to decide on behalf of deceased persons and why donation rates will not improve. Finally, Part IV posits that the creation of a national registry paired with a required response system will provide an effective avenue for obtaining legally binding consent while promoting the autonomy of individuals and strengthening their statutory right to be fully informed.

II. THE HUMAN TISSUE ACT PRIORITIZES THE INDIVIDUAL'S DECISION TO DONATE ORGANS

New Zealand must make significant changes to the organ procurement system to increase the number of organs transplanted in the country and bring its rates closer to global standards. The country's organ donation rate is very low when compared with other developed nations.¹⁶ In an effort to address the stagnant organ donor rate, New Zealand updated its 1964 Human Tissue Act in 2008.¹⁷ The overhaul of the Act provided an improved legal framework that increased the focus on individual autonomy and the importance of informed consent, but failed to implement a provision whereby individuals might register consent in a way that is legally binding and would be respected upon death.¹⁸

¹⁵ See generally Human Tissue Act 2008 (N.Z.) (informed consent and individual autonomy are discussed in the purpose and overview sections of the Act and are underpinnings of the structure of the law).

¹⁶ See generally ANZOD REGISTRY REPORT 2012, *supra* note 5, at 2 (comparing international donors per million in the population in 2011 by country).

¹⁷ Human Tissue Act 2008 (N.Z.).

¹⁸ See generally Human Tissue Act 2008 (N.Z.).

While legislators generally agreed that New Zealand needed to improve its rate of donation, they disagreed substantially on how to achieve this goal.¹⁹ The first draft of the new legislation included a provision that would have created a national registry where all New Zealand citizens could register their informed consent or informed objection.²⁰ Unfortunately, this provision was the subject of much debate and was ultimately taken out of the final version.²¹ However, the final bill did include a provision allowing for the creation of a national registry in the future if donation rates continued to lag and substantial evidence was gathered to prove that the registry was the most efficient way to use the necessary funds.²²

A. *The State of Transplantation in New Zealand*

Statistics demonstrate the dire prospects for those awaiting a life-saving transplant in New Zealand. As of January 1, 2012, 512 New Zealanders were on the organ transplant waitlist.²³ Between January 1, 2011 and December 31, 2012, only 186 organs were transplanted.²⁴ Of those, the majority—118—were kidneys.²⁵ Of the kidneys, 48%, or fifty-seven organs, came from live donors, and of the thirty-six livers transplanted, eight came from live donors.²⁶ Live donors are usually obtained from a relative of the recipient, obtained through a paired organ exchange program,²⁷ or achieved through a “domino transplant” triggered by an altruistic donor who agrees to donate a kidney to a total stranger.²⁸ The remaining 121 organs were recovered from deceased donors.²⁹ Deceased donors are donors who have suffered a severe brain injury, such as bleeding or trauma, and are declared brain dead while their body and vital organs are supported by artificial

¹⁹ [2008] 646 NZPD 15428 (N.Z.).

²⁰ *Id.*

²¹ Human Tissue Act 2008 (N.Z.).

²² Human Tissue Act 2008, § 78(N.Z.).

²³ ANZOD REGISTRY REPORT 2012, *supra* note 5 (This is not an average, but the total number of patients who are currently on the list as of the date January 1, 2011).

²⁴ *Id.*

²⁵ *Id.*

²⁶ *Id.*

²⁷ For a general overview of paired organ exchanges and its benefits to organ donation rates, see Michael T. Morley, *Increasing the Supply of Organs for Transplantation Through Paired Organ Exchanges*, 21 YALE L. & POL'Y REV. 221 (2003); J. Andrew Hughes, *supra* note 4, at 369.

²⁸ For a news report on the first “domino” transplant in New Zealand and an explanation of the difference between “domino” and paired organ exchanges, see Fiona Barber, *Giving and Living*, AUSTRALIAN WOMEN'S WEEKLY, Sept. 2011, at 53-58, *available at* http://www.adhb.govt.nz/documents/kidney_exchange.pdf.

²⁹ ANZOD REGISTRY REPORT 2012, *supra* note 5.

means.³⁰ All 121 organs recovered from deceased donors were retrieved from only thirty-eight individuals.³¹ These statistics indicate that New Zealand's demand for organs has outpaced its need.³²

While the waitlist provides a snapshot of the need for donors in New Zealand, it does not reflect the true number of patients who need organs.³³ Many people whose bodies have deteriorated past the point of being healthy enough to receive an organ are removed from the waitlist.³⁴ In an effort to utilize such a scarce resource, the organ transplantation protocols for achieving a spot on the list are rigid and exclude many who could otherwise be viable candidates in a scheme where more organs are available.³⁵ New Zealand must innovate and introduce more powerful legislative reforms to improve its rate of organ donation.

B. *The Human Tissue Act of 1964*

The Human Tissue Act of 1964 ("1964 Act") contained only basic guidelines for donating organs.³⁶ It allowed donation to occur if individuals expressed their intention to donate "either in writing at any time or orally in the presence of two or more witnesses during [one's] last illness."³⁷ It also allowed persons lawfully in possession of a body to authorize the donation if they, after a reasonable inquiry, had no reason to believe the deceased person had objected to organ donation, and that the deceased person's spouse did not object.³⁸ In practice, The 1964 Act left much to interpretation and relied heavily on the input of the family, as this was the only real avenue for a medical professional who sought donation to ascertain whether the deceased person had ever objected to organ donation during life.³⁹ It further

³⁰ THE TRANSPLANTATION SOCIETY OF AUSTRALIA AND NEW ZEALAND, ORGAN TRANSPLANTATION FROM DECEASED DONORS: CONSENSUS STATEMENT ON ELIGIBILITY GUIDELINES AND ALLOCATION PROTOCOLS vii (2010) [hereinafter TRANSPLANTATION SOCIETY].

³¹ ANZOD REGISTRY REPORT 2012, *supra* note 5.

³² *Id.*

³³ *See* TRANSPLANTATION SOCIETY, *supra* note 30.

³⁴ *Id.*

³⁵ *Id.* at 2.

³⁶ Human Tissue Act 1964, § 3(1) (N.Z.), *repealed by* Human Tissue Act 2008, § 4(1)(e)(i) (N.Z.).

³⁷ Human Tissue Act 1964, § 3(2) (N.Z.), *repealed by* Human Tissue Act 2008, §§ 3(1), 4(1)(e)(i) (N.Z.).

³⁸ Human Tissue Act 1964, § 3(2) (N.Z.), *repealed by* Human Tissue Act of 2008 (N.Z.).

³⁹ *See generally* Human Tissue Act 1964, § 3(1)-(2) (N.Z.), *repealed by* Human Tissue Act of 2008, § 4(1)(e)(i) (N.Z.); *see also* [2007] 643 NZPD 12838 (N.Z.) (discussing the ambiguity created by the 1964 Act and the need for interpretation).

allowed a spouse to overrule the deceased person's wishes, thus allowing the will of the family to trump a lack of objection or assent to donation.⁴⁰

C. *The Human Tissue Act of 2008*

The Human Tissue Act of 2008 ("2008 Act") replaced the 1964 Act, overhauling a consent model over forty years old.⁴¹ The 2008 Act model focuses on "informed consent."⁴² While consent has been a part of the global legal community from the beginning of the twentieth century, informed consent only became accepted as a widespread concept essential to the physician-patient relationship in the last thirty years.⁴³ As a basic concept, informed consent refers to:

Legal rules that prescribe behaviors for physicians and other healthcare professionals in their interactions with patients and provide for penalties, under given circumstances, if physicians deviate from those expectations; to an ethical doctrine, rooted in . . . society's cherished value of autonomy, that promotes patients' right of self determination regarding medical treatment, and to an interpersonal process whereby these parties interact with each other to select an appropriate course of medical care.⁴⁴

The 2008 Act is not the first adoption of this concept in New Zealand. "[Informed consent] is the basis to the Code of Health and Disability Consumers' Rights . . . specifically, the code [outlines] the individual's right to be fully informed or the right to make an informed choice and give informed consent."⁴⁵ Informed consent focuses on individuals and their need for information to make a knowledgeable decision about their own

⁴⁰ Human Tissue Act 1964, § 3(2)(b) (N.Z.), *repealed by* Human Tissue Act of 2008, § 4(1)(e)(i) (N.Z.).

⁴¹ Human Tissue Act 2008, § 4(1)(e)(i) (N.Z.).

⁴² *See id.* § 4(1)(a)-(b). For an overview of informed consent, *see* RUTH R. FADEN & TOM L. BEAUCHAMP, A HISTORY AND THEORY OF INFORMED CONSENT 125 (1986).

⁴³ FADEN & BEAUCHAMP, *supra* note 42.

⁴⁴ JESSICA W. BERG ET AL., INFORMED CONSENT: LEGAL THEORY AND CLINICAL PRACTICE 3 (2d ed. 2001).

⁴⁵ [2007] 643 NZPD 12838 (N.Z.). *See also* Health and Disability Commissioner Act, (Code of Health and Disability Services Consumers' Rights) Regulations 1996, SR 1996/78, reg. 1-2 (N.Z.).

care.⁴⁶ Under The 2008 Act, informed consent must be obtained in order to retrieve organs from an individual.⁴⁷

The 2008 Act defines both “informed consent” and “informed objection.”⁴⁸ The consent or objection must specifically allow for the type of collection being sought, for example, for transplantation, research purposes, or to determine a cause of death.⁴⁹ The consent or objection must be given by a person or group entitled to provide it, must be given freely after receiving information a reasonable person would expect to receive, must meet certain formal requirements, and must not have been subsequently revoked.⁵⁰ The formal requirements for a valid informed consent or informed objection mandate that it be in writing, or be made orally in the presence of two or more witnesses present at the same time.⁵¹ The 2008 Act specifically indicates this may be done by last will.⁵²

In addition to defining and requiring informed consent, The 2008 Act specifies who may give informed consent and in what order it may be sought from those individuals in the event potential donors fail to state their wishes while living.⁵³ The law creates the following order of priority: the individual, the individual’s nominee, the individual’s immediate family members, then a close relative of the individual.⁵⁴ As indicated in the diagram below, at each level, the individual or group has an opportunity to give informed consent or raise an informed objection.⁵⁵ Should the person or group at that level fail to do either, the opportunity falls to the next level.⁵⁶

⁴⁶ Health and Disability Commissioner Act, (Code of Health and Disability Services Consumers’ Rights) Regulations 1996, SR 1996/78, reg. 1-2 (N.Z.).

⁴⁷ *Id.* § 19.

⁴⁸ *Id.* § 9(1)-(2).

⁴⁹ *Id.* § 9(1)(a).

⁵⁰ *Id.* § 9(1-2).

⁵¹ *Id.* § 43(1).

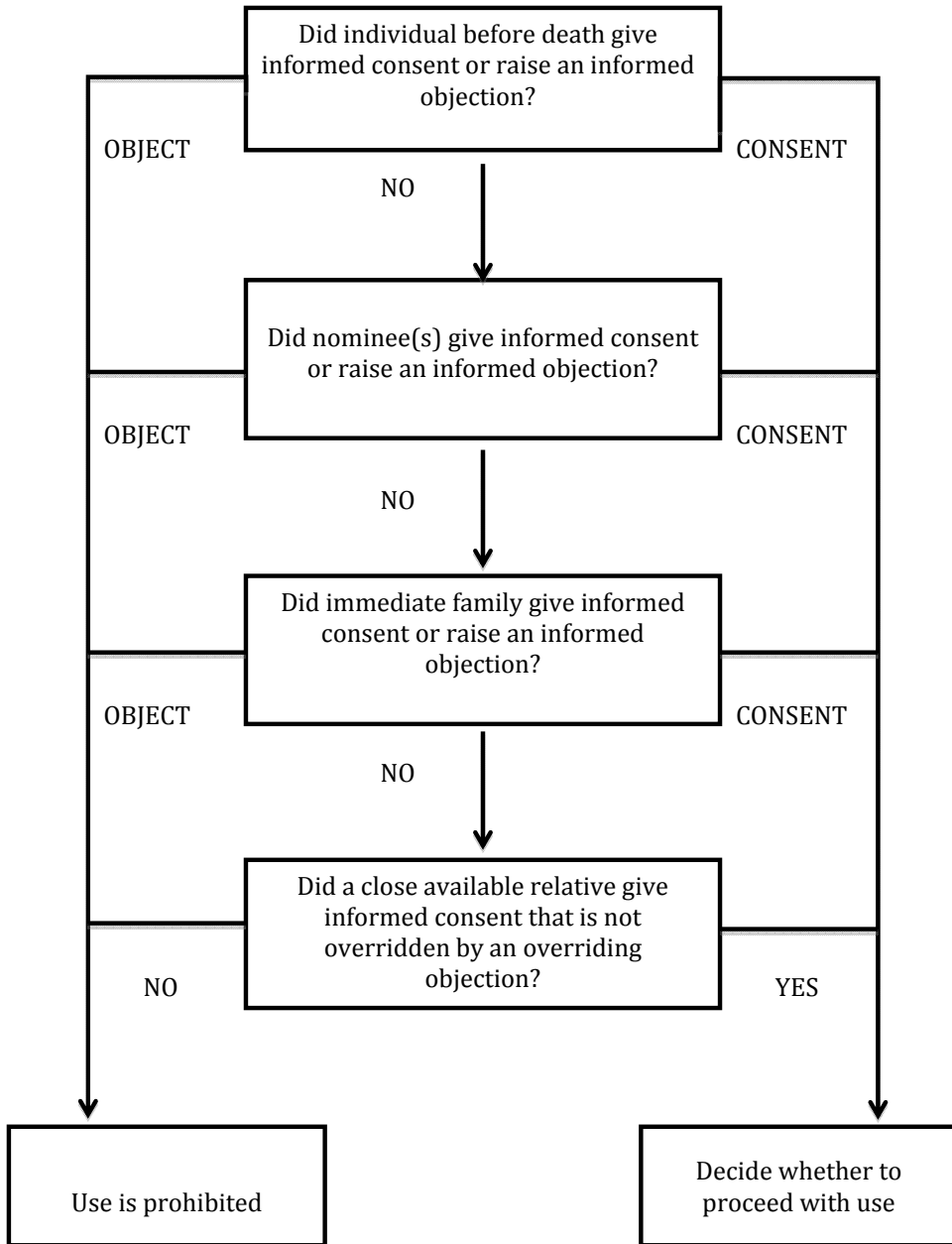
⁵² *Id.* § 43(2).

⁵³ *Id.* § 31(2)(a-d).

⁵⁴ *Id.*

⁵⁵ *Id.*; Human Tissue Act 2008, § 9(1)-(2) (N.Z.) (informed objection and informed consent defined).

⁵⁶ Human Tissue Act 2008, § 31(2)(a)-(d) (N.Z.).



This framework provides detail and structure that did not exist in the 1964 Act. The 2008 Act attempts to eliminate ambiguities in the law's application to the donation process and provides a clear way for procurement specialists to proceed in any situation that might arise.⁵⁸

D. *New Zealand's Driver License Donor Choice and the Paradox Between Intentions to Donate and Actual Donation*

The 2008 Act aimed to address an apparent disconnect between public support of organ donation and very low donation rates. Currently, New Zealand's Transport Agency requires New Zealanders to choose whether they would like to be listed as an organ donor when obtaining a driver license.⁵⁹ Although many New Zealanders mistakenly believe this decision to be binding,⁶⁰ in reality it is only recording a person's general willingness to donate and does not provide the necessary informed consent or informed objection required by law.⁶¹ Indicating "yes" on the form merely results in the term "donor" being added to one's license.⁶² Choosing either "yes" or "no" means that a driver will be entered into the database indicating his or her choice.⁶³ Over one million people, or roughly 25% of New Zealand's population, have registered their willingness to become donors through this system.⁶⁴ Although 25% may seem low, it is likely the number of New Zealanders who support donation is much higher. While there are no studies targeting New Zealand specifically, surveys in developed nations indicate that 80-90% of the public generally approve of organ donation.⁶⁵

This data suggests that there is a problem converting general approval for organ donation or a wish to become a donor into concerted action

⁵⁷ This image is adapted from the flowchart in the HUMAN TISSUE BILL AS REPORTED FROM THE HEALTH COMMITTEE 11 (2007), available at http://www.parliament.nz/NR/rdonlyres/2087DD0D-4B93-4839-B915-ECAEB8DD56C4/80121/DBSCH_SCR_3890_53996.pdf.

⁵⁸ [2007] 643 NZPD 12838 (N.Z.).

⁵⁹ NEW ZEALAND TRANSPORT AGENCY, ORGAN AND TISSUE DONATION, <http://www.nzta.govt.nz/licence/photo/organ-and-tissue-donation.html> (last visited Oct. 23, 2012).

⁶⁰ [2006] 635 NZPD 6467 (N.Z.).

⁶¹ NEW ZEALAND TRANSPORT AGENCY, *supra* note 59.

⁶² *Id.*

⁶³ *Id.*

⁶⁴ [2006] 630 NZPD 2748 (N.Z.).

⁶⁵ See, e.g., Felix Oberender, *Organ Donation in Australia*, J. OF PEDIATRICS AND CHILD HEALTH 47, 637-41 (2011) (stating that Australia's public support for organ donation is 80%); Pew Research Center for the People & the Press, *Bradley Boxes Out Political Center* (May 20, 1999), <http://www.people-press.org/1999/05/20/bradley-boxes-out-political-center/> (stating that 81% of Americans support organ donation).

resulting in binding legal decisions. This paradox continually frustrates organ donor advocates and has been the subject of significant global research.⁶⁶ While a number of factors contribute to the problem, one that continually surfaces as a paramount concern is a family's ability to participate in the decision regarding its loved one's organ donation.⁶⁷ This occurs either when a family refuses to donate a relative's organs even when the relative has given consent to donate, or by a family's refusal to donate when there is no decision from the deceased during life.⁶⁸ The importance of the family's role in the organ donation process cannot be overstated.

Despite the many factors that contribute to a family's refusal, research has found that refusal is often driven by common misconceptions or psychological barriers present at the time a family is approached for donation.⁶⁹ Such misconceptions include a family's fear of inadequate healthcare provided to donors, mistaken conclusions about the views of various religions, fear of increased financial cost, and a general avoidance of thinking about death.⁷⁰ Paramount among these concerns is how the traumatic experience of losing a loved one can prevent the family from making an informed, rational decision regarding their family member's organs. While there are no exact numbers for New Zealand's refusal rate by family members, parallels can be drawn from studies in other countries, where the rate of refusal when a family is left with the decision is generally around 50%.⁷¹ The 2008 Act recognized this concern and structured its

⁶⁶ See Sheldon F. Kurtz & Michael J. Saks, *The Transplant Paradox: Overwhelming Public Support for Organ Donation vs. Under-Supply of Organs: The Iowa Organ Procurement Study*, 21 IOWA J. CORP. L. 767 (1996).

⁶⁷ Laura A. Siminoff et al., *Factors Influencing Families' Consent for Donation of Solid Organs for Transplantation*, 286 JAMA 71 (2001); Beatriz Dominguez-Gil et al., *Decrease in Refusals to Donate in Spain Despite No Substantial Change in the Population's Attitude Towards Donation*, 13 ORGAN, TISSUES & CELLS 17 (2010).

⁶⁸ Siminoff et al., *supra* note 67; Dominguez-Gil et al., *supra* note 67.

⁶⁹ See Spellman, *supra* note 14, at 373-77 (discussing the many misconceptions that are a barrier to donation); see also Charles C. Dunham, "Body Property: Challenging the Ethical Barriers in Organ Transplantation to Protect Individual Autonomy," 17 ANNALS HEALTH L. 39 (2008) (specifically discussing cultural and religious views, lack of motivation, distrust of the medical community, perceived inequities in organ distribution, and reluctance to face death as barriers to organ donation).

⁷⁰ See Spellman, *supra* note 14, at 373-77.

⁷¹ Carlos V. R. Brown et al., *Barriers to Obtaining Family Consent for Potential Organ Donors*, J. OF TRAUMA: INJURY, INFECTION, AND CRITICAL CARE 68, 447-51 (2010); NATIONAL ORGAN AND TISSUE DONATION INITIATIVE, U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES (May 19, 1999) available at <http://archive.hhs.gov/news/press/1999pres/990519.html>. See also Jennifer L. Mesich-Brant and Lawrence J. Grossback, *Assisting Altruism: Evaluating Legally Binding Consent in Organ Donation Policy*, 30 J. HEALTH POL'Y & L. 687, 695 (2005). The studies referenced here are not specific to New Zealand. The number of refusals in New Zealand is unascertainable. Australia and New Zealand's Organ Donation Registry does not record a refusal in any of the organ transplantation data. See AUSTRALIA AND NEW ZEALAND ORGAN DONATION REGISTRY, ANZOD REGISTRY REPORT 2011, 23 (2011) available at

informed consent hierarchy to attempt to address this problem and put the decision to donate back into the hands of the individual.⁷² Unfortunately, the efforts of the legislature fell short of doing so.

III. THE 2008 HUMAN TISSUE ACT GIVES GREATER AUTONOMY TO INDIVIDUALS, BUT DOES NOT PROVIDE A WAY FOR THEM TO EXERCISE THEIR AUTONOMY

The 2008 Act creates a strong framework for physicians and organ procurement specialists to obtain informed consent, but it fails to create a way to provide this consent in a way that can be easily used.⁷³ The 2008 Act requires oral or written consent, which can only be achieved through a will or advance directive.⁷⁴ Many New Zealanders support organ donation and would likely grant binding legal consent were it practicable. However, the law fails to provide a reasonable way for them to be included in the group of potential donors.

The 2008 Act fails to consider the quandary created for organ procurement specialists as they attempt to apply the prioritization framework practically. Without an easy way for someone to create binding informed consent or select a nominee, the law leaves organ procurement staff to sort through complicated family structures to discover whether someone capable has provided the proper consent.⁷⁵ The 2008 Act, in reality, provides no fundamental change to the status quo.

A. *The 2008 Act Provides Only Two Options to Procure Informed Consent Which Alone Will Not Increase Transplantation Rates*

The 2008 Act provides that an individual may give informed consent during life through written or oral mechanisms if they do so in the presence of two witnesses simultaneously.⁷⁶ To achieve oral informed consent, individuals must have a formal conversation with two people discussing their will to donate.⁷⁷ These witnesses must also be subsequently called to the deceased's bedside to confirm this will to donate in time for the organs

<http://www.anzdata.org.au/anzod/ANZODReport/2011/ANZOD2011.pdf>.

⁷² Human Tissue Act 2008 (N.Z.).

⁷³ *Id.*

⁷⁴ *Id.*

⁷⁵ *Id.*

⁷⁶ *Id.* § 43(1).

⁷⁷ *Id.*

to be viable for transplant.⁷⁸ Even if this is achieved and conveyed to the organ procurement specialist in time, an objection by other family members would likely curtail donation.⁷⁹ Therefore, oral consent is unlikely to overcome these barriers and lead to increased donation. The more feasible route to attain informed consent would be through writing in the form of a will or an advance directive.⁸⁰

It is costly to draft a will or create an advanced directive.⁸¹ Some of this cost can be ameliorated in New Zealand because of the Public Trust.⁸² The Public Trust is a government agency whose role is to “develop, promote, conduct, or otherwise participate in the business of providing comprehensive estate management and administration services, including associated legal, financial, and other services.”⁸³ The Public Trust has an online application where New Zealanders can make a will at no cost.⁸⁴ However, it is mandatory that the Public Trust is appointed as the executor and the trustee of an individual's estate, or a fee is imposed.⁸⁵ The overall fee depends on the complexity of the estate.⁸⁶ It is unlikely that New Zealanders would undertake this endeavor solely to make known their wishes to donate. Even if New Zealanders intend to create a will expressly for donation, the online platform requires other important decisions to be included, such as dispositions of property and appointing guardians for

⁷⁸ *Id.* § 14. This section outlines the duties of the person collecting the tissue. It requires that the person take all reasonably practicable steps to ascertain whether or not informed consent has been given. This would likely mean that they would have to hear from both witnesses attesting to oral consent in person, or over the phone. In their absence, the person collecting would be unable to ascertain whether or not oral informed consent was given, and would be forced to move to the next step in the process, ascertain whether or not there was a nominee, which presents the same problem.

⁷⁹ [2008] 646 NZPD 15484 (N.Z.) (discussing that in practice, a doctor will not take an organ if the family has raised an objection).

⁸⁰ Human Tissue Act 2008, § 43 (N.Z.). This section specifically contemplates the use of wills to accomplish the informed consent writing requirement. It requires that a will follow the requirements of the Wills Act of 2007, but need not be valid to be used in the context of informed consent to donate organs.

⁸¹ For a consumer report that surveyed four trust companies, see ADMINISTRATION COSTS – WILLS, available at <http://www.consumer.org.nz/reports/wills/administration-costs> (showing a will for a single person costs an average of \$170-\$180).

⁸² *Personal Services – Wills, New Zealand Public Trust, NEW ZEALAND PUBLIC TRUST*, available at <http://www.publictrust.co.nz/life-events/becoming-a-family/wills/what-is-a-will.html>.

⁸³ Public Trust Act 2001, § 8(1)(a) (N.Z.).

⁸⁴ See *Fees and Charges–Wills, NEW ZEALAND PUBLIC TRUST*, available at http://www.publictrust.co.nz/_data/assets/pdf_file/0017/17621/PTEL12_P-FC-Wills-and-EPAs-FA-10-10.pdf. Due to privacy reasons, the Public Trust does not provide statistics on how many of those New Zealand residents choose to be organ donors in their wills.

⁸⁵ *Id.*

⁸⁶ *Id.*

children.⁸⁷ This will discourage individuals from taking this step if they are unsure about how to proceed on other important decisions.

Even if individuals complete a will or advance directive, there is currently no way for individuals to register this document so it will be available to any physician attending them at the end of life.⁸⁸ While they can submit these documents to their family physician or home medical facility, this is yet another step they must take. It is also problematic to assume that people would be receiving end of life care after an accident at their local medical facilities. They can tell their families their decisions and make the documents known to them, but if the families object to the donation or are too bereaved to enforce it, their objection will override the donation.⁸⁹

This is also true if the individual wishes to object to donating. Individuals have the same issues registering their objections and, should they feel differently about organ donation than their families, they could end up becoming a donor over their own express wishes to the contrary. The current system leaves physicians and organ procurement specialists blind to the wishes of patients and subject to the will of patients' family's.

If there is no action taken by the individuals to make either informed consent or an informed objection, the next in line to determine donation is a nominee selected by individuals to make the decision for them.⁹⁰ Under the 2008 Act, the selection of the nominee must meet the same formal requirements required for individuals to make the decision themselves.⁹¹ It must be in writing or have been orally declared to two people.⁹² Because the same obstacles exist for selecting the nominee as exist for individuals giving consent themselves, this is equally unlikely to be used.

The current system of "registering" one's wish to become an organ donor on a driver's license further hinders the two options provided in the 2008 Act.⁹³ An individual can register his or her preference to become an organ donor when obtaining a driver license, and the word "donor" will appear on his or her card.⁹⁴ New Zealanders could falsely believe this notation on the driver's license creates binding consent and that no further

⁸⁷ NEW ZEALAND PUBLIC TRUST, PERSONAL SERVICES – WILLS, *supra* note 82.

⁸⁸ [2008] 646 NZPD 15484 (N.Z.).

⁸⁹ *Id.* (discussing that in practice, a doctor will not take an organ if the family has raised an objection).

⁹⁰ Human Tissue Act 2008, § 31(2)(b) (N.Z.).

⁹¹ *Id.* § 43.

⁹² *Id.*

⁹³ NEW ZEALAND TRANSPORT AGENCY, *supra* note 59.

⁹⁴ *Id.*

action is needed to secure their intent to donate. This false perception may mean they will exclude this information in a will. Medical facilities have access to the driver license database and to the responses of New Zealand drivers, but the database is not even consulted unless the family asks for the information.⁹⁵ As Congressman Steve Chadwick said:

[i]ntensivists⁹⁶ told me . . . they would never look at the motor vehicle license and whether the person had ticked the donor box. Just because someone has signed the motor vehicle license to say that he or she would like to be a human tissue donor, . . . [it] is not going to cloud their decisions on diving in to retrieve organs.⁹⁷

The punishments and affirmative defenses provided at law for physicians and organ procurement specialists further exacerbate the problem. A physician or organ procurement specialist who collects tissue without the appropriate informed consent may face fines or imprisonment.⁹⁸ Should physicians refuse to take organs “for any reason,” even if informed consent has been given, the law protects them to the fullest.⁹⁹ This heavily tips the scale against taking organs if the doctor believes there could be a claim that informed consent was not properly obtained or that a valid objection had been raised.

B. Next-of-Kin Will Determine Whether Organs Are Retrieved Without Reforming the Status Quo

If individuals fail to indicate their wishes or appoint a nominee to make the decision for them, the next level in the hierarchy to give informed consent is the immediate family.¹⁰⁰ “Immediate family” is defined as someone in a close relationship with the deceased or someone responsible for the deceased’s welfare, and who fits into one of the thirteen relationships specifically listed in the 2008 Act.¹⁰¹ All who fall within the “immediate

⁹⁵ [2008] 646 NZPD 15484 (N.Z.).

⁹⁶ A physician who specializes in the care of critically ill patients. See Ed Marchan, et. al., *The Intensivist*, 5 JHN J. art. 4 (2010).

⁹⁷ [2008] 646 NZPD 15484 (N.Z.).

⁹⁸ Human Tissue Act 2008, § 22(1) (N.Z.).

⁹⁹ *Id.* § 17.

¹⁰⁰ *Id.* § 31(2)(c).

¹⁰¹ *Id.* § 6(a)-(b) (specifically listed are spouse, civil union partner, *de facto* partner, child, parent, guardian, grandparent, brother, sister, stepchild, step-parent, stepbrother, or stepsister).

family” category must then make a unanimous decision to give informed consent for donation or make an objection.¹⁰² According to the statute, if there is no general agreement, then consent may be obtained by a close available relative.¹⁰³ The definition of a “close available relative” includes spouses, children, parents, and siblings, in that order of priority.¹⁰⁴ Under the close available relative category, each of the four relation levels will have the chance to step apart from the “immediate family” and provide informed consent so long as no one exists in a category with a higher priority.¹⁰⁵ However, consent by a close relative is subject to an overriding objection by another close available relative.¹⁰⁶ This means that if another person who qualifies as a “close available relative” objects, this relative’s objection will control.¹⁰⁷

This complicated structure could overwhelm even the most knowledgeable and experienced physician. The problem is summed up well by Andy Tookey,¹⁰⁸ an advocate for organ donation in New Zealand, who said, “[i]f any in the family object, [doctors] won’t go ahead with it. Doctors aren’t going to sit there and sort through who’s who and who has got higher ranking and demand to see birth certificates to prove it.”¹⁰⁹ The 2008 Act has unreasonable and impractical expectations for doctors and organ procurement specialists who are already in a time sensitive situation regarding retrieving organs. If they follow the statute, they are expected to research the presence of a will or advance directive, ascertain if there has been oral informed consent or a nomination, explore the possibility of unanimous consent or objection from the immediate family, organize the family tree to determine whether a close available relative can provide consent, and finally, check once more that there is no overriding objection.¹¹⁰ It is unreasonable to expect that a physician will go to great

¹⁰² *Id.* § 40.

¹⁰³ *Id.* § 31(2)(d) (the statute also provides for a slightly different prioritization for persons under the age of sixteen).

¹⁰⁴ *Id.* § 10.

¹⁰⁵ *Id.* § 31(2)(d).

¹⁰⁶ *Id.* § 41.

¹⁰⁷ *Id.*

¹⁰⁸ Andy Tookey became involved in organ donation advocacy after his daughter Katie was diagnosed with a rare liver disease. He has been instrumental in passing the new law but was disappointed with the shortcomings. He continues to advocate for legislative change and runs a website supporting the efforts. See GIVELIFE, <http://www.givelife.org.nz> (last visited Oct. 24, 2012).

¹⁰⁹ Claire Trevett, *Organ Donor Change Falls Short, Say Critics*, N.Z. HERALD, Apr. 9 2008, http://www.nzherald.co.nz/organ-donation/news/article.cfm?c_id=1501077&objectid=10502878.

¹¹⁰ Human Tissue Act 2008 (N.Z.).

lengths to step through this process if the family has indicated any discomfort with transplantation.

It is apparent from both The 2008 Act and the likely outcome of its application that the family will continue to play a significant role in the organ donation process. This raises the question: why do organ donation advocates fear decisions being left up to the immediate family? Studies show that when immediate families are left to decide whether to donate a loved one's organs, they fail to give consent about half of the time.¹¹¹ Other studies cite the family's refusal as a predominant factor for failure of progressive organ donation systems such as presumed consent.¹¹² Family members are generally under an enormous amount of stress at the time they are approached for informed consent, as the average time for contacting the family is around six hours¹¹³ after the declaration of a person's brain death.¹¹⁴ There are very few deaths that occur in a way that physically preserves a person's organs and allows them to donate, with most studies placing the number at less than 1%.¹¹⁵ The fact that family members eliminate half of this small pool of donors illustrates the importance of creating an effective pathway for individuals to establish binding legal consent.

Furthermore, even if the family is not being asked directly for its consent, its objection can override the individual's decision.¹¹⁶ Historically, even in countries with other systems such as presumed consent, a family's objection would override an individual's informed consent and prevent

¹¹¹ See Brown et al., *supra* note 71; NATIONAL ORGAN AND TISSUE DONATION INITIATIVE, *supra* note 71; Mesich-Brant & Grossback, *supra* note 71.

¹¹² David Orentlicher, *Presumed Consent to Organ Donation: Its Rise and Fall in the United States*, 61 RUTGERS L. REV. 295, 309-10 (2009).

¹¹³ Orly Hazon, *Increasing the Supply of Cadaver Organs for Transplantation: Recognizing that the Real Problem is Psychological, Not Legal*, 3 HEALTH MATRIX 219, 238 (1993).

¹¹⁴ AUSTRALIAN AND NEW ZEALAND INTENSIVE CARE SOCIETY, *The ANZICS Statement on Death and Organ Donation* (3.1 ed. 2010). The two ways an individual becomes capable of donating results from a declaration of either an irreversible cessation of circulatory system, called donation after cardiac death ("DCD") or irreversible cessation of all functions of the entire brain, called brain death ("BD"). While brain death is much more common, cardiac arrest has become more widely used.

¹¹⁵ See, e.g., Matthew Thomas & Michael Klapdor, *The Future of Organ Donation in Australia: Moving Beyond the 'Gift of Life'*, Research Paper for the Social Policy Section, PARLIAMENT OF AUSTRALIA, DEPARTMENT OF PARLIAMENTARY SERVICES 4 (Oct. 3, 2008), available at <http://www.aph.gov.au/library/pubs/rp/2008-09/09rp11.htm#statistics> (stating less than one percent of all deaths in a hospital result in brain death and are capable of donating); *Understanding Death Before Donation*, THE GIFT OF A LIFETIME, <http://www.organtransplants.org/understanding/death/> (last visited Oct. 4, 2012) (estimating less than 1%).

¹¹⁶ [2008] 646 NZPD 15484 (N.Z.) (third reading) (discussing that in practice, a doctor will not take an organ if the family has raised an objection).

donation.¹¹⁷ There are important reasons that doctors in most systems will not take organs over the objections of the family despite obtaining a potential donor's informed consent.¹¹⁸ Chief among them is the fear of a media backlash that sensationalizes a family's grief and negatively impacts the public trust of the organ donation system and ultimately its willingness to become donors.¹¹⁹ This means that a doctor or organ procurement specialist looks for signs of objection to donation that may become a problem for the transplantation community and doctors personally, and will err on the side of not harvesting the organs.¹²⁰

IV. NEW ZEALAND SHOULD INSTITUTE THE 2008 ACT'S NATIONAL REGISTRY PROVISION WITH A REQUIRED RESPONSE FRAMEWORK

Pairing a national registry with a required response system will increase the rate of organ donation in New Zealand. The systems will work concurrently to address the limitations that exist were either system to be instituted in isolation. Proponents of required response are concerned that the program will not work unless there is a major push to simultaneously educate the public about the organ shortage and encourage the public to donate.¹²¹ To institute the registry, New Zealand will need to engage in a national awareness campaign to educate the public on the new registry, the options they will face when selecting whether to donate, and prepare them to make an ultimate decision. It is only through this education that unequivocal "informed" consent will be achieved. Furthermore, required response can address a major limitation of instituting the registry alone—underutilization. Combined, the systems lead to a cost-benefit ratio that is more acceptable to taxpayers. Both of these systems highlight the fundamental ideals New Zealand emphasized when writing its new law: informed consent and individual autonomy.¹²²

A national organ donor registry requiring every New Zealander to participate would increase the pool of donors and increase transplantation

¹¹⁷ Kieran Healy, *Do Presumed-Consent Laws Raise Organ Procurement Rates?*, 55 DEPAUL L. REV. 1017 (2006).

¹¹⁸ Hazony, *supra* note 113, at 237.

¹¹⁹ Healy, *supra* note 117, at 1029.

¹²⁰ *Id.*

¹²¹ Symposium, *The United States System of Organ Donation, The International Solution, and the Cadaveric Organ Donor Act: "And the Winner Is. . ."*, 20 J. CORP. L. 5, 41 (1995).

¹²² Hayley Cotter, *Increasing Consent for Organ Donation: Mandated Choice, Individual Autonomy, and Informed Consent*, 21 HEALTH MATRIX 599 (2011) (arguing that mandatory choice supports individual autonomy and informed consent).

rates while respecting individual autonomy and the cultural and spiritual needs of the family unit. The national registry would provide an easy way for New Zealanders to register their informed consent or informed objection. Hospitals and medical professionals could determine easily whether the individual provided informed consent or an informed objection, whether he or she selected a nominee, the nominee's contact information, and whether the individual deferred the decision to immediate family. The concerns about underuse and the high cost of instituting the registry could be addressed by simultaneously passing a required response provision. On their income tax form, New Zealanders would be required to make a choice about how they want their organs treated upon death and who is in charge if they prefer not to make the decision themselves.

A. A Registry Will Create a Link Between Donor Intention and Binding Legal Consent

Creating the registry is an important step to increase organ donations.¹²³ The legislature closely examined how it might implement the registry and what the expected benefits would be.¹²⁴ The legislature decided it was an inopportune time to create the registry because it was unable to conclude, based on research performed by the committee, that there was evidence a registry would improve numbers at a rate that would warrant the high cost of implementation.¹²⁵ While the committee is correct that a registry is expensive, these costs would be front-loaded and would diminish when the system was in place and public understanding of the structure improved.¹²⁶ Aside from the fact that pairing it with a required response system would help maximize its efficiency, a registry alone can provide benefits to a languishing donor rate.¹²⁷

A registry allows more people to make a legally binding informed decision about their bodies upon death.¹²⁸ A registry provides information to a hospital or physician quickly, so providers can assess a situation immediately. If a person has nominated someone or deferred to the family,

¹²³ See WORLD MEDICAL ASSOCIATION, STATEMENT ON HUMAN ORGAN AND TISSUE DONATION AND TRANSPLANTATION 2-3 (adopted Oct. 2000 and revised Oct. 2006).

¹²⁴ [2008] 646 NZPD 15484 (N.Z.).

¹²⁵ *Id.*

¹²⁶ Cotter, *supra* note 122, at 614-15 (discussing how Utah spent more money initially).

¹²⁷ See Phyllis Coleman, *Brother, Can You Spare a Liver?, Five Ways to Increase Organ Donation*, 31 VAL. U. L. REV. 1, 39-40 (1996).

¹²⁸ See Human Tissue Act 2008, § 78 (N.Z.) (outlining the implementation of a registry in the future).

the needed contact information can be easily obtained. Approaching a family armed with information that the individual has already made a decision can mean the difference between an organ donation going forward and one that fails to materialize.¹²⁹ The media attention provided by implementing and educating the public about the registry is a useful way to improve the sharing of information among the family, as well as promoting an overall atmosphere where donation is the norm, an important characteristic of high donor rate nations.¹³⁰

1. A Registry Would Allow for Easy Registration of Informed Consent or Objection and Provide an Efficient Way for Organ Procurement Specialists to Ascertain Whether Consent Has Been Given

The implementation of a registry would provide a missing link between an individual's intention to donate and completing a donation. A national registry would essentially be a database that logged each New Zealander's decision to donate or objection to donating, the decision to appoint a nominee to decide for the individual, or the individual's decision to defer to the family. The database would provide the same rigorous privacy protections that any New Zealand health care system would require under existing law.¹³¹ The registry would allow New Zealanders to provide legally binding informed consent that complies with the formal requirements of the statute.¹³² The national education effort should include a national advertising campaign, as well as targeted education focusing on dispelling common myths, providing details about the donation process, and providing information about organ scarcity and the need for increased donations. By creating a free registry, New Zealand would not require individuals to make any additional decisions about their health or property, and would thus provide a straightforward way for New Zealanders to register.¹³³

¹²⁹ Mesich-Brant & Grossback, *supra* note 71, at 707.

¹³⁰ *Id.*

¹³¹ Privacy Act 1993 (N.Z.); Health Information Privacy Code 1994 (N.Z.). For details of privacy law as it relates to healthcare, see *Privacy Act and Codes*, PRIVACY COMMISSIONER, <http://privacy.org.nz/the-privacy-act-and-codes/>.

¹³² Human Tissue Act 2008, § 78 (N.Z.).

¹³³ An advance directive generally includes information regarding end of life care and decisions regarding life support. A will generally requires testators to make decisions about their property on death, which could hold up the process. The Public Trust, which offers a free will service for New Zealanders which allows them to act as executors and trustees, requires that you make decisions regarding property, naming guardians for children, and funeral directions, among others. This is typical of decisions that New Zealanders would have to make and could inhibit them from simply making their decision to be an organ donor. See *Personal Services – Wills, New Zealand Public Trust*, *supra* note 82.

The potential benefits of such a system for physicians and organ procurement staff would be tremendous. A hospital, even one far from a person's residence, would have access to the database twenty-four hours a day, and could easily ascertain whether a person has given informed consent or lodged an informed objection. This is particularly important during a time-sensitive situation. To match a donor to a recipient is a long process that takes precise coordination and timing.¹³⁴ Before an organ can be retrieved, the organ is matched properly with the appropriate waitlist patient through a series of tests and procedures.¹³⁵ Because of this, every second that a team has to organize and facilitate this process can determine the success of transplantation. Rather than having to wait for a doctor to go through the process of sifting through the statutory hierarchy, a doctor can immediately access the database, ascertain the individual's intentions, and move forward with preparing the family and deceased for transplantation.¹³⁶

2. *Despite Penalties, the Structure of the Current Law Supports Procuring Organs Over a Family's Objection*

The 2008 Act provides the legal framework to allow doctors and organ procurement specialists to take organs over the objection of family members.¹³⁷ If the consent is given at the "close available relative" level, another person in this same category can lodge an overriding objection.¹³⁸ An overriding objection for informed consent obtained by the individual is not provided in the statute. While doctors must be vigilant because of the potential punishments for taking an organ without informed consent,¹³⁹ the physician's verification of a donor's consent in the database should satisfy the affirmative defense to an informed consent offense as provided in The 2008 Act.¹⁴⁰ Under section 25 of the 2008 Act, the defendant must show "on the balance of probabilities, that he . . . believed on reasonable grounds that . . . informed consent was required . . . and was given and was not overridden by an overriding objection."¹⁴¹ The inquiry would stop after

¹³⁴ TRANSPLANTATION SOCIETY, *supra* note 30.

¹³⁵ *Id.*

¹³⁶ [2006] 630 NZPD 2748 (N.Z.) (first reading).

¹³⁷ Human Tissue Act 2008 (N.Z.).

¹³⁸ *Id.* § 9(3).

¹³⁹ *Id.* § 22(1)-(2).

¹⁴⁰ *Id.* § 25.

¹⁴¹ *Id.* § 25(1)(b).

ascertaining the individual's informed consent because no party could legally override it.

The structure of the 2008 Act is similar to the Uniform Anatomical Gift Act in the United States. The United States act also provides that familial consent is not necessary when the decedent is a registered donor,¹⁴² although in practice in the United States this is not widely used.¹⁴³ Historically, it was completely ignored and families were continually approached for consent to donate.¹⁴⁴ However, more recently there is a move toward recognizing "first person" consent, meaning that if the individual gave a valid consent during life that was not revoked, procurement specialists would not look to the family for approval.¹⁴⁵ This could be implemented in New Zealand when community perceptions regarding donation evolve.¹⁴⁶ Support for physicians is mounting in this area. One author suggests that not taking organs after obtaining valid informed consent amounts to a breach of contract.¹⁴⁷ Under this theory, a physician sued on a claim that he or she took organs without valid consent could counter-sue the family for tortious interference with a contract.¹⁴⁸ While this idea pushes the progressive bounds, it reflects a trend toward disregarding family objections when valid consent has been ascertained. Another proposal suggests that deciding what to do with a loved one's organs under those circumstances creates additional anxiety for the family at an already turbulent time.¹⁴⁹ Taking the decision out of their hands and following the wishes of the deceased can become a benefit for families under first person consent.

¹⁴² Uniform Anatomical Gift Act, § 2(h) (1987).

¹⁴³ Kristin Cook, *Familial Consent for Registered Organ Donors: A Legally Rejected Concept*, 17 HEALTH MATRIX 117 (2007).

¹⁴⁴ See Phyllis Coleman, *supra* note 127, at 34-35.

¹⁴⁵ Cook, *supra* note 143. For a more general discussion of the subject and gathering support, see also, *Position Statement, Adherence to First Person Consent*, THE NATIONAL ORGANIZATION OF TRANSPLANT PROFESSIONALS, available at http://www.natco1.org/public_policy/documents/FirstPersonConsent.pdf; Karen Sokohl, *First Person Consent: OPOs Across the Country are Adapting to the Change*, UNOS UPDATE (2002).

¹⁴⁶ Cotter, *supra* note 122, at 619 (2011) (discussing first person consent legislation in the United States, and improved sign-up).

¹⁴⁷ Cook, *supra* note 143.

¹⁴⁸ *Id.*

¹⁴⁹ Thomas May, et al., *Patients, Families, and Organ Donation: Who Should Decide?*, 78 MILBANK Q. 232-36 (2000).

3. *The Registry Would Help Foster a Culture Where Donation Is the Norm and Ease the Pressure on Families to Make Donation Decisions*

The transplant community in New Zealand may not immediately embrace taking the organs over the family's objection. Regardless, the registry's implementation and success does not hinge on its acceptance, as family involvement can be ameliorated in other ways. Studies suggest that a family's awareness of the deceased's decision to donate will increase its willingness to allow donation should it be left with the decision.¹⁵⁰ It could also decrease overriding objections if valid informed consent exists.¹⁵¹ A family is more likely to be aware of its loved one's decision to donate, independent of finding out at the individual's death bed, if the registry's implementation is connected with an advertising and education campaign that facilitates discussions among family members.¹⁵² Studies show that an important aspect of many high-donor countries is a culture where donation is the "norm" and expectations that someone will donate are high throughout the community.¹⁵³ Some scholars suggest that this is even more important than the presumed consent model, which is also connected to high donor countries but suffers from ethical concerns.¹⁵⁴ The World Health Organization discusses programs that are more likely to succeed in procuring organs without consent of the family when public understanding is "deep-seated and unambiguous."¹⁵⁵ A population that is more educated about the need for donors will have higher overall donation rates.¹⁵⁶

Education and increasing awareness are essential tools to the overall success of these policies. The 2008 Act requires that binding consent be obtained after a person receives all information reasonably expected. Therefore, the education campaign surrounding the registry and the required

¹⁵⁰ Laura A. Siminoff & Renee H. Lawrence, *Knowing Patients' Preferences About Organ Donation: Does It Make a Difference?*, 53 J. TRAUMA 754, 756 (2002) (study showed that only 10% of families overrode consent when they knew the deceased had chosen to donate); Carmen M. Radecki & James Jaccard, *Psychological Aspects of Organ Donation: A Critical Review and Synthesis of Individual and Next-of-Kin Donation Decisions*, 16(2) HEALTH PSYCHOLOGY 183 (1997).

¹⁵¹ Siminoff, *supra* note 150; Radecki & Jaccard, *supra* note 150.

¹⁵² [2006] 630 NZPD 2748 (N.Z.).

¹⁵³ See Healy, *supra* note 117, at 1028-29 (where the author suggests that presumed consent laws are not increasing rates directly, but rather indirectly increasing rates by creating a culture where donation is normal).

¹⁵⁴ *Id.*

¹⁵⁵ WORLD HEALTH ORGANIZATION, GUIDING PRINCIPLES ON HUMAN CELL, TISSUE AND ORGAN TRANSPLANTATION 2 (2010).

¹⁵⁶ Mesich-Brant & Grossback, *supra* note 71, at 707. See also Felix Cantarovich et. al., *An International Opinion Poll of Well-Educated People Regarding Awareness and Feelings About Organ Donation for Transplantation*, 20:6 TRANSPLANT INT'L 512, 512-18 (2007).

response system must be robust, and materials should be developed with the informed consent philosophy in mind. The campaign will increase the likelihood that individuals will register consent rather than an objection if focused on the misconceptions driving down consent and capitalizes on general community acceptance of donation. Some proposals suggest targeting young people in schools and educating them at an earlier age.¹⁵⁷

B. The Required Response System Will Compliment the Registry and Increase the Number of New Zealanders Who Have Recorded Binding Informed Consent

Pairing the donor registry with a required response system would maximize the utility of the registry. The Health Committee raised one concern about the registry: underutilization.¹⁵⁸ The committee feared that with the high cost of instituting the registry, it was unlikely to be widely used and would thus not affect the donation rate.¹⁵⁹ This concern can be eliminated by instituting a required response element that calls for all New Zealanders to make a decision about the allocation of their organs upon death.¹⁶⁰ By forcing everyone to make a decision, the required response system furthers one of the main purposes of the 2008 Act: respecting “the autonomy and dignity of the individual whose tissue is before or after his or her death, collected or used.”¹⁶¹

1. The Required Response System Can Be Implemented Through Tax Returns

New Zealand can maximize the use of the registry if it mandates that all New Zealanders decide how to handle their organs upon death when they file an income tax return. The system outlined here is drawn from the work of a United Network for Organ Sharing (“UNOS”) subcommittee on required response as well as the “Cadaveric Organ Donation Act” written and proposed by a group of students drawing on the suggestions of

¹⁵⁷ Vanessa Chandis, *Addressing a Dire Situation: A Multi-Faceted Approach to the Kidney Shortage*, 27 U. PA. J. INT’L ECON. L. 205, 257-59 (2006).

¹⁵⁸ [2008] 646 NZPD 15484 (N.Z.).

¹⁵⁹ [2007] 645 NZPD 14809 (N.Z.).

¹⁶⁰ INDIVIDUAL INCOME TAX, INLAND REVENUE (July 20, 2011), <http://www.ird.govt.nz/income-tax-individual/>. New Zealand requires individuals and businesses to pay an income tax filed annually.

¹⁶¹ Human Tissue Act 2008, § 3(a)(1) (N.Z.).

UNOS.¹⁶² Each year, New Zealanders would be required to fill out a section of their income tax form addressing their choice to either 1) give informed consent to donate their organs, 2) give an informed objection to donating their organs, 3) nominate a person whom they wish to make the decision for them upon death, or 4) defer the decision to their family members should the need arise.¹⁶³ The tax form would not be complete and considered “filed” until the form was complete.¹⁶⁴ Parents could register their children, and anyone who was not earning income and thus not filing taxes could file a decision directly with the registry. For a variety of reasons, most donors are young people¹⁶⁵ and the probability that a young person files no income is likely very low;¹⁶⁶ thus it is reasonable to conclude that high donor likelihood correlates with the income tax target population.

After New Zealanders make a selection regarding organ donation, the information would be entered into the national donor registry and would be immediately available to hospitals and organ procurement staff. At any point, an individual could change his or her choice by contacting the registry directly. The person could also update this choice on his or her income tax at the next opportunity and the most recent decision will be valid for donation purposes. The form the individual files with their taxes selecting the donation method must provide enough information required for informed consent or “all information that a reasonable person . . . needed in order to give informed consent.”¹⁶⁷ This could include initialing the form next to all pertinent information to ensure the individual is acknowledging the facts of transplantation and understands how informed consent will be applied. Should the individual choose to register his or her informed objection, it will be upheld even if the family chooses otherwise, putting individual autonomy at the forefront. If the person selects a nominee, the nominee’s contact information can be listed to improve a hospital’s response time in informing the nominee and facilitating a possible donation. Finally, the individual can

¹⁶² Sheldon F. Kurtz & Michael J. Saks, *Cadaveric Organ Donation Act, Foreword*, 18 J. CORP. L. 523 (1993). See also Richards, *supra* note 1, at 411 (this comment discusses the parameters of a required response system and is based on the model from the UNOS subcommittee’s work and recommendations on how to implement a required response system by the “Cadaveric Organ Donation Act”).

¹⁶³ Richards, *supra* note 1, at 411. See also J. Michael Dennis et al., *AN EVALUATION OF THE ETHICS OF PRESUMED CONSENT AND A PROPOSAL BASED ON REQUIRED RESPONSE*, REPORT OF THE PRESUMED CONSENT SUBCOMMITTEE, OPTN/UNOS ETHICS COMMITTEE (1993).

¹⁶⁴ Richards, *supra* note 1, at 411.

¹⁶⁵ ANZOD REGISTRY REPORT 2011, *supra* note 71, at 1.

¹⁶⁶ STATISTICS NEW ZEALAND, *YOUNG PEOPLE 1986-2006: STUDY, WORK AND INCOME*, available at http://www.stats.govt.nz/browse_for_stats/income-and-work/employment_and_unemployment/young-people-1986-2006-study-work-income/source-of-personal-income.aspx.

¹⁶⁷ Human Tissue Act 2008, § 9(1)(c) (N.Z.).

still choose to leave the decision to the immediate family, which would apply stage three on the priority schedule in the 2008 Act.¹⁶⁸

2. *Required Response Would Increase Donation Rates*

Implementing the required response system will call for the government to institute a public education campaign to ensure that New Zealanders comprehend the mandatory nature of the program and understand how to comply to ensure that their taxes are filed in a timely manner. If thoughtfully implemented, the required response system can overcome a drawback that many donation advocates fear would result from required response systems; that is, people using the system to register their informed objection, resulting in a loss of transplantable organs rather than an increase.¹⁶⁹ In a survey conducted in the United States, where a similar voluntary registration system is used, 52% of respondents who had failed to register cited failure to ask as the primary reason for their lack of registration.¹⁷⁰ This highlights a major advantage of required response and a reason why it can increase rates—many people are simply waiting for someone to pose the question, and be provided an uncomplicated way to join the list of those giving informed consent.

3. *The High Cost of Dialysis Coupled with New Zealand's Unusually High Rate of Kidney Problems Increase New Zealand's Financial Incentive to Boost Transplants*

New Zealand should consider the cost savings of transplantation versus the medical costs of a population whose health continues to decline on the waitlist. In a relevant study in the United States, dialysis cost \$55,000 per year for those patients awaiting a kidney.¹⁷¹ This is particularly

¹⁶⁸ *Id.* § 31(2)(c).

¹⁶⁹ Richards, *supra* note 1, at 411.

¹⁷⁰ See Dennis et al., *supra* note 163.

¹⁷¹ *Transplant Roundtable on the Organ Donation and Recovery Improvement Act*, 109th Cong. 3 (2005) (written statement of Ginny Bumgardner and Trent Tipple), available at http://www.natco1.org/public_policy/pdfs/RoundtableL-HHS-EduWrittenTestimony41105_D0040522_.pdf. See also Arthur Matas & Mark Schnitzler, *Payment for Living Donor (Vendor) Kidneys: A Cost-Effective Analysis*, 4 AM. J. TRANSPLANTATION 216 (2003) (showing a savings of \$94,000 per patient if transplanted rather than continued lifetime kidney dialysis). The United States provides health coverage for its elderly population in a program known as Medicare and covers medical care for segments of the population that qualify because of low income. Because these programs cover many of the costs of end stage renal disease, they are particularly concerned with increasing transplantations overall and lowering the wait times where patients need dialysis.

applicable in New Zealand where 89% of the waitlist for all organs is made up of people awaiting kidney transplants.¹⁷² In fact, since the 1960s, there has been a dramatic increase in the number of patients starting renal replacement therapy dialysis due largely to diabetes.¹⁷³ As explained by Dr. Jackie Blue, a National Party member and member of the Health Committee that reviewed the proposed legislation, New Zealand's future medical situation can be described as "hav[ing] a tidal wave of renal failure coming our way."¹⁷⁴ Dialysis is very expensive, and at the end stages of kidney failure can be required up to three times a week.¹⁷⁵ Because waiting for a kidney takes about two to five years,¹⁷⁶ this imposes dramatic health care costs onto New Zealand, which insures most of its population through public health benefits.¹⁷⁷ Therefore, New Zealand has a separate monetary incentive to improve transplantation rates.

V. CONCLUSION

Countries around the world continue to innovate to increase the number of available organs for transplantation. Through programs like presumed consent, first person consent, various incentives, and education campaigns, scholarship is advancing quickly as results of these efforts are analyzed and improved. While no country is currently keeping pace with demand, some have made clear strides toward the goal of having a transplantable organ for each individual on the waitlist before they succumb to their disease. Every additional donor these programs secure changes the lives of the citizens in those nations, from the patients whose lives are saved, to the families who suffer tremendously when losing a loved one. It is unfortunate that anyone's life must depend on the death of another person. However, when death is inevitable, deciding to offer a chance at life to another can be an easier choice to make when the choice is removed from the bedside of the deceased. New Zealand has an opportunity to join these

¹⁷² See ANZOD REGISTRY REPORT 2012, *supra* note 5, at 3 (showing 89% of all wait are comprised of kidney recipients, compared with Australia's at 75%).

¹⁷³ AUSTRALIA AND NEW ZEALAND DIALYSIS AND TRANSPLANT REGISTRY, ANZDATA REGISTRY 2007 REPORT 26 (2007).

¹⁷⁴ [2007] 645 NZPD 14809 (N.Z.) (committee).

¹⁷⁵ Justin Roake, *Gifts of Life in Short Supply*, 115 N.Z. MED. J. 1159 (2002). See also Spellman, *supra* note 14 (stating that long-term dialysis is more expensive than transplantation).

¹⁷⁶ ANZOD REGISTRY REPORT 2011, AUSTRALIA *supra* note 71, at 34 (showing median wait time in Australia is 3.8 years for DBD and 4.9 for DCD recipients; there is no similar chart with New Zealand's numbers, 2012 numbers in this area were unavailable).

¹⁷⁷ NEW ZEALAND MINISTRY OF HEALTH, <http://www.health.govt.nz> (last visited Oct. 24, 2012).

nations by creating a national registry with a required response system and moving toward recognizing donor designations after death, despite family objections. Such a system will fulfill the goals of the New Zealand legislature by promoting individual autonomy, enabling informed consent, and increasing public awareness of all aspects of organ scarcity. While New Zealand has shown it is determined to tackle this issue through passage of the Human Tissue Act of 2008, the law needs to be amended to become a tool capable of meeting the nation's goals. New Zealand should address the deficiencies in the law now, before more people pay for this shortcoming with their lives.