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Giving Life: Increasing Organ Donation and Creating an Altruistic Organ Donation Registry

Rebekah Morrissey

Code Sections Affected

Health & Safety Code §§ 7152, 7152.1, 7152.2 (new); Vehicle Code § 12811 (amended).

SB 1395 (Alquist); 2010 STAT. Ch. 217

I. INTRODUCTION

On June 9, 2008, at Apple's Worldwide Developers Conference, Steve Jobs, co-founder and CEO of Apple, took the stage to unveil the newest version of the iPhone.¹ However, the majority of the media coverage did not focus on the iPhone's new features; rather, it focused on Jobs' gaunt appearance.² In 2008 and 2009, Jobs cancelled several public appearances, which caused the press to speculate about his health.³ In truth, Jobs' liver was failing and he needed a transplant.⁴ In 2009, 3,400 Californians waited for liver transplants, "671 got one[,] 400 died," and the rest continued to wait.⁵ Fortunately for Jobs, he had the resources and knowledge to secure a liver from a donor in Tennessee.⁶ He found his donor liver through a process called "multiple listing," which involves traveling the country, receiving evaluations, and gaining a place on the organ donor list at multiple hospitals.⁷ However, the majority of people waiting for organs cannot afford multiple listings, even though this increases the chances of finding a viable tissue match.⁸ "Insurance companies only cover one listing" due to the expense of testing at multiple hospitals.⁹

After his transplant, Jobs got involved in raising awareness about organ donation in order to convince more people to become organ donors.¹⁰ At a dinner

1. Nicholas Carlson, *How Steve Jobs Got Sick, Got Better, and Decided to Save Some Lives*, BUSINESS INSIDER (Apr. 20, 2010, 6:00AM), <http://www.businessinsider.com/how-steve-jobs-got-sick-2010-04> (on file with the *McGeorge Law Review*); Arnold Kim, Posting to *Apple Announces WWDC 2008*, MACRUMORS.COM (Mar. 13, 2008, 16:27 EST) <http://www.macrumors.com/2008/03/13/apple-announces-wwdc-2008-june-9-13-2008/> (on file with the *McGeorge Law Review*).

2. Mathew Wingram, *Is Steve Jobs Sick Again, or Just Thin?*, MATHEW WINGRAM BLOG (June 9, 2008), <http://www.mathewwingram.com/work/2008/06/09/is-steve-jobs-sick-again-or-just-thin/> (on file with the *McGeorge Law Review*) (noting that one blogger thought Jobs looked "emaciated").

3. Carlson, *supra* note 1.

4. *Id.*

5. *Id.*

6. *See id.* (noting that many wealthy Americans, like Jobs, attempt to get on various donor lists throughout the United States).

7. *Id.*

8. *Id.*

9. *Id.* ("[G]etting listed is very expensive.").

10. *See id.* ("And so, in a departure from a largely apolitical career, Steve decided to do something about it.").

in December of 2009, Jobs spoke to Maria Shriver, wife of Governor Schwarzenegger, about increasing the number of donors in California.¹¹ She in turn spoke to the Governor.¹² Believing this idea had merit, the Governor contacted State Senator Alquist “a long time advocate for organ donation.”¹³ After sitting on Senator Alquist’s desk for several years, Alquist introduced SB 1395, “[a]ll thanks to Steve Jobs—and his now-departed liver.”¹⁴

II. LEGAL BACKGROUND

Existing law prohibits the sale or purchase of organs for transplant.¹⁵ Any person who needs an organ transplant must receive the organ as a gift, and the hospital can only charge a reasonable fee for the organ’s procurement and transplantation.¹⁶ Californians may donate at death or during their lifetime.¹⁷ To donate at death, a donor must do one of the following: indicate a wish to donate on his or her driver’s license and register with a donor database; directly register as a donor with a donor database; specify a wish to donate in a will; or have an authorized agent give consent at the donor’s death.¹⁸ To donate during their lifetime, donors must sign a donor card or other record indicating a wish to donate, and “at least two adults [must witness the signature], at least one of whom is a disinterested witness.”¹⁹

Federally-approved Organ Procurement Organizations (OPOs) maintain California’s organ donation registry.²⁰ The OPOs established a non-profit organization called Donate Life California, whose primary function is the maintenance of the California Organ and Tissue Donation Registry, which compiles the names of people willing to donate organs upon their death.²¹ Under existing law, there is no registry that maintains a list of donors willing to donate during their lifetime.²²

Prior to 2005, the Department of Motor Vehicles (DMV) asked applicants if they wished to join the registry and provided forms for applicants to mail directly

11. *Id.*

12. *Id.*

13. *Id.*

14. *Id.*

15. CAL. HEALTH & SAFETY CODE § 7150.75 (West Supp. 2010).

16. *See id.* (“A person [or hospital] may only charge a reasonable amount for the removal, processing, preservation, quality control, storage, transportation, implantation, or disposal of a part.”).

17. *Id.* § 7150.20.

18. *Id.*

19. *Id.* § 7150.20(a)(4).

20. *Id.* § 7150.9.

21. SENATE FLOOR, COMMITTEE ANALYSIS OF SB 1395, at 4 (May 12, 2010).

22. Press Release, Office of the Governor of the State of California, Gov. Schwarzenegger Announces Legislation to Increase Organ Donation Opportunities (Mar. 19, 2010) [hereinafter Governor’s Press Release] (on file with the *McGeorge Law Review*) (noting that SB 1395 would create the “nation’s first living donor registry”).

to Donate Life California in order to enroll.²³ A pink “donor” sticker attached to the front of a driver’s license signaled an intention to donate.²⁴ The donor registry added the applicant to the registry only when Donate Life California received the mailed form.²⁵ In 2005, the DMV began electronically submitting the names of those who elected to become organ donors directly to Donate Life California.²⁶

The existing application for a driver’s license provides a space where the applicant may consent to become an organ donor.²⁷ If the applicant indicates a wish to donate, the DMV will print “DONOR” in a pink dot on the front of the license.²⁸ An employee of the DMV will direct the applicant to the back of the application, which contains information on how the program works and how to cancel enrollment.²⁹ Drivers under the age of eighteen may become donors, but the final decision regarding donation belongs to a parent or legal guardian.³⁰

III. CHAPTER 217

Chapter 217 creates a non-profit organization called the Altruistic Living Donor Registrar (ALDR).³¹ The ALDR will compile and maintain a list of people in California willing to donate kidneys during their lifetime.³² The registry will share the information of willing donors with “federally designated organ procurement organizations[] and transplant centers in California.”³³ The ALDR may receive donations from private sources and will make information available to the public regarding the “number of donors on the registry,” “changes in the number of donors on the registry,” and “general characteristics of donors.”³⁴

Chapter 217 also provides that after July 1, 2011, any application or renewal of a driver’s license in California will include a yes or no check box asking applicants if they wish their organs to be donated when they die.³⁵ An employee

23. See SENATE FLOOR, COMMITTEE ANALYSIS OF SB 1395, at 4 (May 12, 2010) (explaining that prior to 2005, the DMV provided forms to enroll in the registry to applicants that included instructions to mail the forms to Donate Life and Donate Life found this procedure an ineffective way to sign up donors).

24. *Id.* at 2.

25. *Id.* at 4.

26. CAL. VEH. CODE § 12811(b)(5) (West 2010).

27. *Id.* § 12811(b)(1).

28. *Id.* § 12811(b)(4).

29. *Id.* § 12811(b)(1).

30. *Id.*

31. CAL. HEALTH & SAFETY CODE § 7152.2(a) (enacted by Chapter 217).

32. *Id.* The ADLR may add those who are willing to donate other tissues and organs during their lifetimes to the registry if the Federal Centers for Medicare and Medicaid Services and the United Network for Organ Sharing regard those types of transplants as “safe and without a significant risk of complications, and would not adversely affect the health of the donor.” *Id.* § 7152.2(e) (enacted by Chapter 217).

33. *Id.* § 7152.2(b) (enacted by Chapter 217).

34. *Id.* § 7152.2(d)(1)–(3) (enacted by Chapter 217).

35. CAL. VEH. CODE § 12811(b)(1) (amended by Chapter 217).

of the DMV must verbally ask the applicant if he or she would like to register, and provide information about the program and how to cancel enrollment.³⁶

IV. ANALYSIS

The ADLR allows live donors to join the registry and avoid questioning of their motives because the fear of selling organs for profit.³⁷ The small changes to driver's license forms aim to encourage more people to donate their organs.³⁸

A. *The Need for an Altruistic Donor Registry*

Chapter 217 creates the first state registry of kidney donors willing to give an organ to a stranger during their lifetime.³⁹ With more than 100,000 people in the United States today on an organ transplant list, and approximately 21,000 of them Californians, proponents of the ALDR argue that creating this registry will allow doctors to match willing donors with those in need of transplants.⁴⁰ The current system of registration for donation necessitates the ALDR.⁴¹ The number of patients needing kidneys is around 16,000 and counting, and the current system cannot provide enough kidneys for those in need of transplants.⁴² President of Donate Life, Bryan Stewart, highlighted the inadequacy of the current registry to address donation needs in a speech announcing this bill.⁴³ Mr. Stewart noted that "even if every actual deceased organ donation opportunity was authorized by a registered donor or the donor's family, we could not keep up with the growing need."⁴⁴ Altruistic donation, facilitated by the creation of the ALDR, helps to bridge the gap between deceased donors and the growing number of people needing kidney transplants.⁴⁵

With such a pressing demand for organs, it would likely surprise many Californians to realize that donating a kidney to a stranger is often a long and difficult process.⁴⁶ The process of organ donation itself provides another reason the ALDR is needed: altruistic donors who elect to donate to a complete stranger

36. *Id.* § 12811(b)(2)-(3) (amended by Chapter 217).

37. See Erin Allday, *Living Donor Registry Would Be 1st in Nation*, S.F. CHRON., Apr. 19, 2010, at A1 ("[I]t's not easy for Good Samaritan organ donors to give up a kidney or other tissues they don't necessarily need, despite the fact there are tens of thousands of people waiting for transplants.").

38. Governor's Remarks, Governor Arnold Schwarzenegger, Gov. Schwarzenegger Announces Legislation to Increase Opportunities for Organ Donation, Create First-In-Nation Living Donor Registry (Mar. 19, 2010) [hereinafter Governor's Remarks] (on file with the *McGeorge Law Review*).

39. Governor's Press Release, *supra* note 22.

40. *Id.*

41. See Governor's Remarks, *supra* note 38 (quoting Bryan Stewart).

42. *Id.*

43. *Id.*

44. *Id.*

45. *Id.*

46. Allday, *supra* note 37.

are often met with skepticism by medical professionals who fear that the donors may have been coerced or paid for their organs.⁴⁷ Questioning the motives of donors attempting to engage in a selfless and generous act allows the fear of selling organs, an illegal act in the United States, to slow down the transplant process.⁴⁸

Doctors and medical ethicists often struggle to determine why an otherwise healthy individual would undergo the risks of surgery to donate a kidney to a complete stranger.⁴⁹ The skepticism of physicians is due largely to the rareness of altruistic donation, which accounts for less than one percent of live donations in the United States.⁵⁰ For example, a physician in Boston began researching the motivations behind organ donation from strangers after encountering a patient who asked if he could go out and find his own kidney donor.⁵¹ The physician met with a transplant board to determine whether it would even be “morally appropriate” to approve such a transplant.⁵² Under the ALDR, healthy people wishing to donate kidneys will not meet the skepticism and questioning common under existing law, and those who need transplants will receive them more quickly.⁵³

B. Increasing Donor Registration

The other component of Chapter 217 makes a relatively small change to the DMV protocol for registering donors who wish to donate organs upon death.⁵⁴ Instead of allowing drivers to opt-in to the donor registry, Chapter 217 mandates a yes-or-no answer to the question of organ donation.⁵⁵ Although the DMV cannot deny a driver’s license to anyone who does not answer the question, it is likely that the number of organ donors will increase given that “only about half of people who would donate actually bother to sign up.”⁵⁶ By making the choice

47. *Id.*

48. *See id.* (citing the case of a kidney transplant recipient whose doctors suspected coercion or payment because the donation was to a friend’s nanny).

49. David Steinberg, *Kidneys and the Kindness of Strangers*, 22 HEALTH AFFAIRS 184, 184-87 (2003), available at <http://content.healthaffairs.org/content/22/4/184.short> (on file with the *McGeorge Law Review*); Allday, *supra* note 37.

50. Steinberg, *supra* note 49. While donation of a kidney to a stranger is very rare in the United States, it is actually illegal in other countries. *Id.* The United Kingdom, Germany, and India all prohibit kidney donation to a stranger. *Id.* The United Kingdom requires living donors to provide proof of a relationship to the donee, such as a marriage certificate or photos documenting a blood relationship or close friendship. *Id.*

51. *Id.*

52. *Id.*

53. *See id.* (examining the problems faced by altruistic donors).

54. *California Bill to Create Living Donor Registry Clears Senate*, REAL NUMERACY BLOG (June 3, 2010, 12:51 PM), <http://realnumeracy.spaces.live.com/blog/cns!21AFBB7E5EC91E49!625.entry> [hereinafter REAL NUMERACY] (on file with the *McGeorge Law Review*).

55. *Id.*

56. *Id.*

to join the registry more explicit, supporters hope more people who are willing to donate organs will finally take the step to join the registry.⁵⁷ A North Carolina study found that nearly twenty percent of families ignored the wishes of the deceased when it came to organ donation, and only thirty-seven percent of families agreed to donate when DMV records did not indicate consent.⁵⁸ However, in North Carolina, the DMV cannot automatically enroll those who list a preference to be an organ donor on their DMV application.⁵⁹

While North Carolina's system differs from California's, the basic principle translates: without enrollment, many people willing to donate will not have their wishes carried out.⁶⁰ Supporters of Chapter 217 contend that simply asking one additional question of applicants—"Do you want to be an organ donor?"—may double the number of donors on the registry.⁶¹

V. CONCLUSION

Chapter 217 aims to increase the number of registered organ donors in California and help save the lives of the thousands of Californians waiting for organs.⁶² By creating the ALDR, Chapter 217 hopes to fill the void between the growing need for organs and the current donor shortfall.⁶³ Shepherded into existence by Steve Jobs, one of the wealthiest Americans, Chapter 217 helps to ensure that money is no longer as important a factor in determining who will receive a kidney transplant.⁶⁴ As the need for organs grows, the small change to the driver's license application ensures that Californians willing to donate can do so.⁶⁵ "Organ donation is one of the kindest and the simplest and the most generous and the most powerful actions that each and every one of us can take."⁶⁶ What started as a simple idea, became a powerful piece of legislation, and will hopefully lead to many kind and generous acts that give the gift of life to many Californians.⁶⁷

57. *Id.*

58. See Martha Kerr, *Organ Donor Designation on Driver's License Frequently Ignored by Family*, MEDSCAPE MEDICAL NEWS, Feb. 23, 2007, <http://www.medscape.com/viewarticle/552691> (on file with the *McGeorge Law Review*) (noting that out of fifty-nine possible donors, the family only authorized donation in twenty-two cases).

59. *Id.* (noting that DMV designations are not "legally binding").

60. REAL NUMERACY, *supra* note 54.

61. Governor's Remarks, *supra* note 38 (quoting Steve Jobs).

62. *Id.* (citing Governor Schwarzenegger)

63. *Id.*

64. Carlson, *supra* note 1.

65. REAL NUMERACY, *supra* note 54.

66. Governor's Remarks, *supra* note 38.

67. *Id.*