


## Personal Viewpoint

# The Living Donor Collective: A Scientific Registry for Living Donors

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**In the setting of an overall decline in living organ donation and new questions about long-term safety, a better understanding of outcomes after living donation has become imperative. Adequate information on outcomes important to donors may take many years to ascertain and may be evident only by comparing large numbers of donors with suitable controls. Previous studies have been unable to fully answer critical questions, primarily due to lack of appropriate controls, inadequate sample size, and/or follow-up duration that is too short to allow detection of important risks attributable to donation. The Organ Procurement and Transplantation Network**

does not follow donors long term and has no prospective control group with which to compare postdonation outcomes. There is a need to establish a national living donor registry and to prospectively follow donors over their lifetimes. In addition, there is a need to better understand the reasons many potential donors who volunteer to donate do not donate and whether the reasons are justified. Therefore, the US Health Resources and Services Administration asked the Scientific Registry of Transplant Recipients to establish a national registry to address these important questions. Here, we discuss the efforts, challenges, and opportunities inherent in establishing the Living Donor Collective.

**Abbreviations:** CI, confidence interval; CMS, Centers for Medicare & Medicaid; CV, cardiovascular; ESRD, end-stage renal disease; HR, hazard ratio; HRS, Health and Retirement Study; HRSA, Health Resources and Services Administration; HUNT, Health Study of Nord-Trøndela; MACE, major adverse cardiac event; NA, not available; NDI, National Death Index; NHANES, National Health and Nutrition Examination Survey; OPTN, Organ Procurement and Transplantation Network; PCD, Pharmaceutical Claims Data Clearinghouse; SAC, Standard Acquisition Costs; SRTR, Scientific Registry of Transplant Recipients

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## Introduction

The first successful human organ transplant took place in 1954, when 23-year-old Ronald Herrick donated a kidney to his identical twin brother Richard. Ronald eventually developed end-stage renal disease (ESRD) requiring hemodialysis and died at age 79 of cardiovascular disease complications. As reported in local news sources (Data S1), he had no regrets about his decision to donate, but his donation raised many questions that remain unanswered today. Did donating a kidney cause or contribute to ESRD? Did donating a kidney cause or contribute to his cardiovascular disease or other complications known to be associated with chronic kidney disease (1)? Donors should know how donation may affect their health and whether they can take steps to prevent complications. Candidates for donation and their families,

intended recipients, transplant programs, and the general public also need to know what risks donors are taking and how their risk varies according to demographic and clinical profiles.

## What Have We Learned From Donor Studies?

There will never be randomized controlled trials of living organ donation. Retrospective observational studies, including large cohorts of all living donors, maximize duration of follow-up while avoiding the inevitable attrition of participants in prospective studies. Five large retrospective studies of living kidney donors matched to controls have been performed using methods designed to identify persons whose baseline health was similar to the donors' health (Table 1) (2–6). These studies produced conflicting results. Choosing appropriate controls in retrospective studies of donors is difficult, at best. Donors undergo extensive evaluation, including radiographic imaging studies to ensure that they are healthy. Controls from population health surveys have not undergone such extensive evaluations and may not be as healthy as donors. In addition, studies to date have used relatively short-term follow-up and cannot reliably ascertain the lifetime risk of donation (Table 1).

Few studies have addressed long-term outcomes after living liver donation. Muzaale et al reported that cumulative mortality for living liver donors was similar to that for living kidney donors and healthy community residents at 2 years (7). In the Adult to Adult Living Donor Liver Transplantation Cohort Study (A2ALL), with up to 10 years of follow-up, 6% of donors first experienced complications > 1 year after donation (8). Two of three deaths in the cohort occurred > 1 year after donation (one drug overdose and one suicide). Despite the importance of the A2ALL findings, these data have limitations, including follow-up of < 6 years for most A2ALL donors.

Ideal controls for comparing outcomes of actual donors would be candidates for kidney and liver donation who completed their evaluations and were found to be suitable but ultimately did not donate due to factors unrelated to their physical or mental health. However, to our knowledge, no long-term follow-up studies of donor candidates have been carried out. Likewise, we do not know how many potential donors are evaluated and found to have risk factors for conditions that preclude them from donating. Nor do we know how many might have been suitable donors despite these risks, or how often the outcomes of perceived risks became reality. For example, many donors are rejected because they are perceived to be at high risk for type 2 diabetes, but we do not know what proportion of these potential donors actually develop diabetes or develop chronic kidney disease as a result. The uncertainty in predicting outcomes potentially affected by organ

donation has no doubt contributed to the substantial variability in living donor acceptance criteria adopted by transplant programs across the United States.

## Is Our Knowledge Gap a Barrier to Living Organ Donations?

The number of living donor kidney transplant procedures in the United States *decreased* 14.3%, from its peak of 6,572 in 2005 to 5,629 in 2016 (Figure 1A) (9). During the same period, the number of deceased donor kidney transplant procedures *increased* 35.5%, from 9,913 in 2005 to 13,431 in 2016. The reasons for the decline in living kidney donation are impossible to know with certainty. The economic well-being of the US population has been tenuous, and many potential donors may feel less secure in the decision to donate an organ if faced with prospects of job loss, health or life insurance loss, and uncertain household income. Further, studies reporting previously unrecognized attributable risks of living kidney donation have appeared in the medical literature and could have played a role in dissuading potential donors from donating (Table 1). In particular, outcomes for African American donors have been a source of concern (10) and may have implications for access to living donor transplantation among African American transplant candidates.

Living liver donations peaked at 524 in 2001. A highly publicized report of a living donor death likely led to a precipitous decline in the number of living donor liver transplants performed in the ensuing years in the United States (11). Only 219 living donor liver transplants were performed in 2009, but this number increased to 345 in 2016 (Figure 1B) (9). Although the focus of living liver donors has understandably been on short-term outcomes, interest and uncertainty have been growing among donors and caregivers regarding long-term effects (12). Also uncertain is the potential impact of lack of information on donor outcomes on living liver donation rates.

Few living donor transplants of organs other than kidney or liver are performed. Between 2005 and 2016, 20 living donor intestine transplants were performed (9), likely reflecting relatively limited demand. Twelve living donor lung transplants were performed: four in 2006, three in 2007, and one each in 2005, 2009, 2011, 2012, and 2013. Only five living donor pancreas transplants have been performed: two in 2005 and one each in 2006, 2008, and 2013.

## Why We Need a Scientific Registry for Living Donors

Maximizing the benefits of living organ donation can best be achieved if we first fully understand the risks.

**Table 1:** Retrospective studies of mortality and end-stage renal disease in kidney donors compared with healthy controls

First author, publication year	Donors			Controls			Outcome (95% CI)	
	Source	n	Years	Follow-up	Source	n		Years
Segev, 2010 (2)	US, OPTN	80 347	1994–2009	6.3 <sup>1</sup>	NHANES <sup>2</sup>	9364	1988–1994	Mortality p > 0.05
Garg, 2012 (3)	Administrative <sup>3</sup>	2028	1992–2009	6.8 <sup>1</sup>	Administrative <sup>2,3</sup>	20 280	1992–2009	Death or MACE HR 0.66 (0.48–0.90)
Mjøen, 2013 (4)	Norway	1901	1963–2007	15.1 <sup>1</sup>	HUNT <sup>2</sup>	32 621 <sup>4</sup>	NA	MACE HR 0.85 (0.57–1.27) All-cause death HR 1.3 (1.11–1.52) CV death HR 1.40 (1.03–1.91)
Muzaale, 2014 (5)	US, OPTN	96 217	1994–2011	7.6 <sup>1</sup>	NHANES <sup>2</sup>	9364	1988–1994	ESRD in donors HR 30.8 (24.3–38.5) <sup>5</sup>
Reese, 2014 (6)	US, OPTN	3368 <sup>6</sup>	1996–2006	7.4 <sup>1</sup>	HRS <sup>2</sup>	3368 <sup>6</sup>	1996–2006	ESRD in controls HR 3.9 (0.8–8.9) <sup>5</sup> All-cause death HR 0.90 (0.71–1.15)

CI, confidence interval; CV, cardiovascular; ESRD, end-stage renal disease; HR, hazard ratio; HRS, Health and Retirement Study; HUNT, Health Study of Nord-Trøndela; MACE, major adverse cardiac event; NA, not available; NHANES, National Health and Nutrition Examination Survey; OPTN, Organ Procurement and Transplantation Network.

<sup>1</sup>Median follow-up in years.

<sup>2</sup>Excluding individuals with contraindications to kidney donation.

<sup>3</sup>Four provincial healthcare databases, Ontario, Canada.

<sup>4</sup>32 621 of 74 991 participants considered fit for kidney donation.

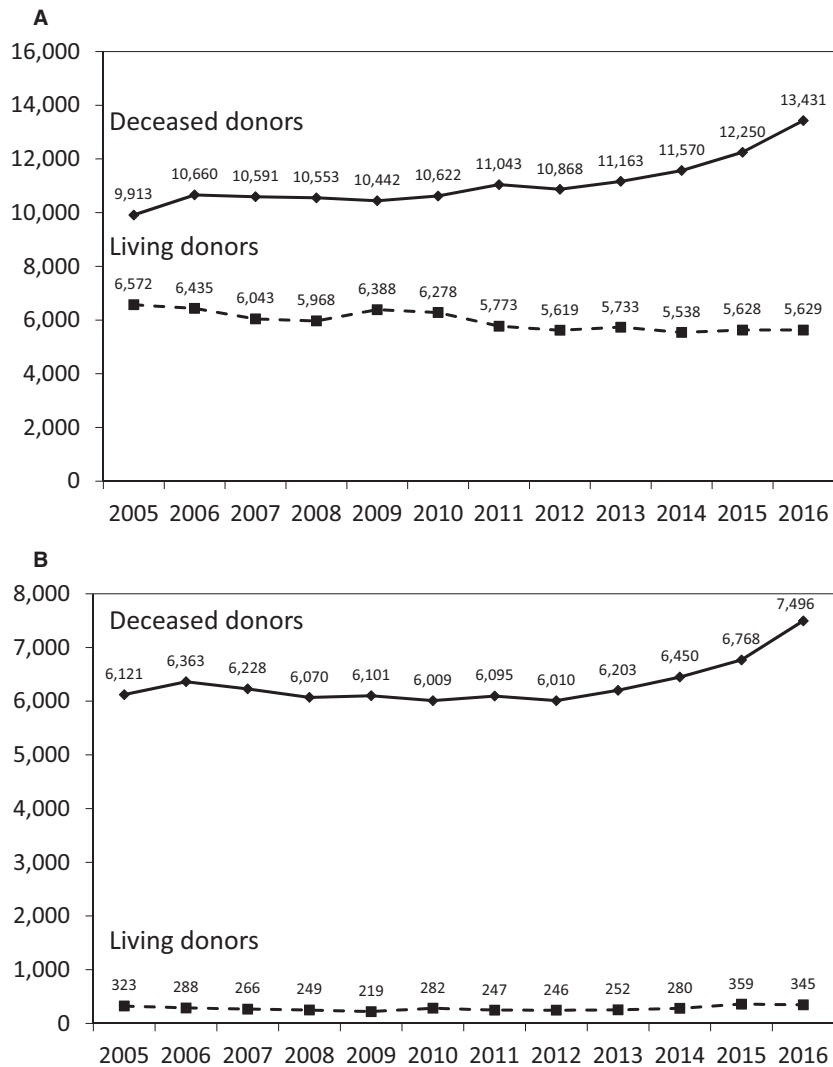
<sup>5</sup>Cumulative incidence at 15 years per 10 000 (95% CI).

<sup>6</sup>Aged at least 55 years matched to similar-risk individuals in the HRS.

Outcomes such as death, ESRD, or liver failure are expected to be infrequent among donors screened to be healthy, and therefore large numbers of donors must be followed for long periods of time to measure donation-attributable risks for outcomes important to donors. Results from the registry will not be completely realized for years, but the time to start is now. There are also good reasons to collect follow-up information on donor candidates who do not donate. First, the best individuals with whom to compare outcomes of donors are fully evaluated donor candidates who do not donate for reasons unrelated to the risk of donation per se, such as when other preferred donors are available or the proposed recipient does not undergo transplant. We do not know how many such donor candidates there are, but it is likely that only a national registry can provide sufficient numbers to compare their outcomes with those of actual donors. Second, it is equally important to understand whether medical reasons donor candidates do not donate are justifiable. Only by following donor candidates who are turned down or decide not to donate due to concerns that donation would adversely affect their health can we determine whether those concerns are justified. Finally, criteria used to select donors are likely to continue to evolve in the future, and therefore studying the outcomes of candidates and donors once is not sufficient. The need to understand the effects of changes in our evaluation and selection process will be ongoing, and monitoring outcomes of future candidates and donors will always be important. As long as living donation is practiced, comprehensive follow-up will be necessary.

### Establishing the Scientific Registry for Living Donors

The US Health Resources and Services Administration (HRSA) asked the Scientific Registry of Transplant Recipients (SRTR) to establish a national Scientific Registry for Living Donors (Figure 2). We recruited 10 transplant centers to initiate a vanguard, pilot study to establish the logistics of data collection, with the ultimate goal of including all living donor transplant programs in the United States (Table 2). We held our first investigators meeting at SRTR in Minneapolis, Minnesota, on April 4–5, 2017. We propose to register all living liver and kidney donor candidates who come to a transplant program for evaluation and undergo a history and physical examination. We understand that many potential donors are screened before they come to the transplant program, but it would be virtually impossible to define a “potential donor” based on information that is variously and often incompletely collected at the time of initial contact. In addition, there would be far too many potential donors to allow SRTR to maintain contact and follow-up. Therefore, for the pilot period we adopted a practical definition that will allow data



**Figure 1:** Trends in the numbers of kidney transplants (A) and liver transplants (B) in the United States, 2005–2016.

collection for what we believe will be a manageable number of donor candidates who have undergone at least some prior screening.

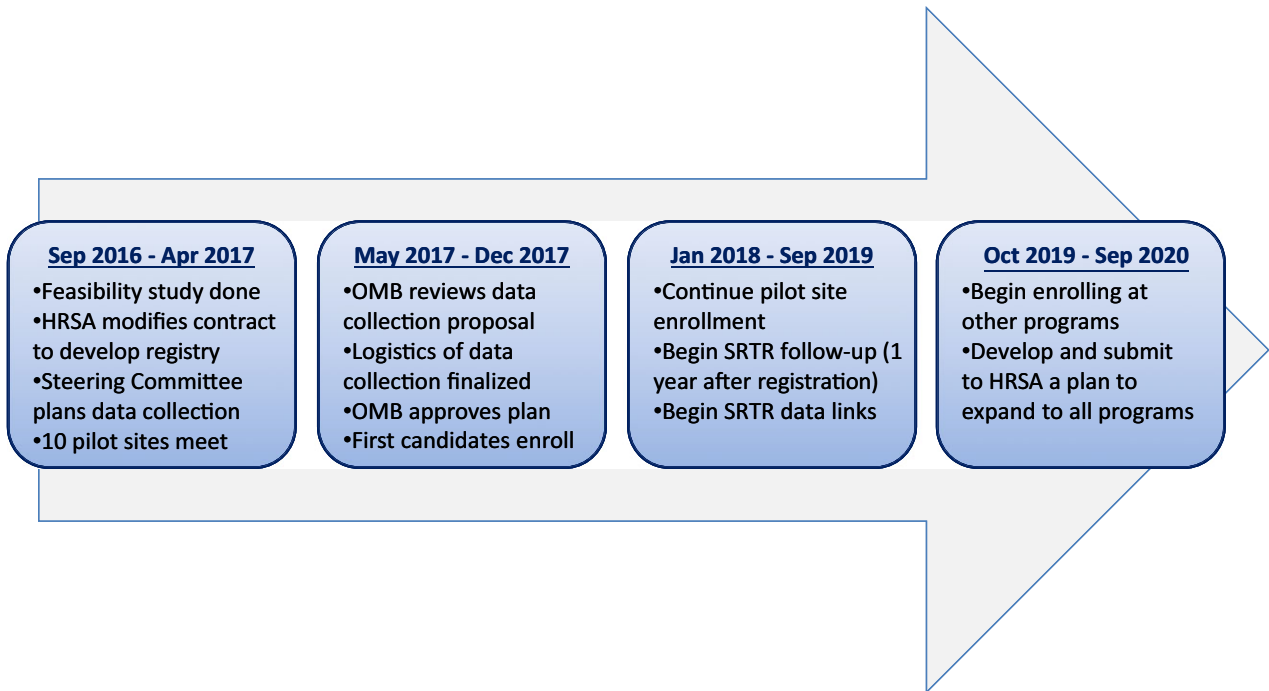
**Initial Registration Information**

Candidates will be registered through a secure online data collection system provided by SRTR. Transplant programs will be asked to collect data that are currently collected as part of the Organ Procurement and Transplantation Network (OPTN) Living Donor Registration (Table S1). Ultimately, we anticipate that the information collected will be electronically transferable to OPTN to avoid duplicate data collection. In addition, these data may eventually be collected using other platforms and then electronically transmitted to SRTR. However, during the vanguard phase SRTR will develop

an independent, web-based data entry system. Programs will also be asked to supply the reasons a donor candidate did not donate. Proposed reasons have been derived from the medical literature for kidney donors (Table S2) and for liver donors (Table S3). These lists of reasons may be modified in the course of the vanguard phase. Transplant programs will be asked to provide the reasons for not donating when it becomes clear that a donor candidate will not donate or no more than 2 years after registration if the potential donor has not donated (Figure 3).

**Follow-Up Information From Surveys**

Follow-up information will be collected by SRTR, not by the transplant programs. SRTR will establish procedures for maintaining contact with participants by using a brief



**Figure 2: Four-year timeline for establishing the Living Donor Collective.** HRSA, Health Resources and Services Administration; OMB, Office of Management and Budget; SRTR, Scientific Registry of Transplant Recipients.

**Table 2:** Living donor transplants in 2016 at 10 centers participating in the pilot living donor collective

	Kidney	Liver	Total
Kidney and liver centers: 7			
MNMC, Rochester Methodist Hospital, Mayo Clinic	149	22	171
CAUC, UCLA Medical Center	142	0	142
NYMS, Mount Sinai Medical Center	102	21	123
MNUM, University of Minnesota Medical Center	92	4	96
MDJH, Johns Hopkins Hospital	53	7	60
TXTX, Baylor University Medical Center	35	17	52
PAPT, University of Pittsburgh Med Center	13	28	41
Kidney-only centers: 3			
GAEM, Emory University Hospital	88	0	88
MNHC, Hennepin County Medical Center	19	0	19
MOSL, Saint Louis University Hospital	6	0	6
<b>Total participating centers: 10</b>	<b>699</b>	<b>99</b>	<b>798</b>

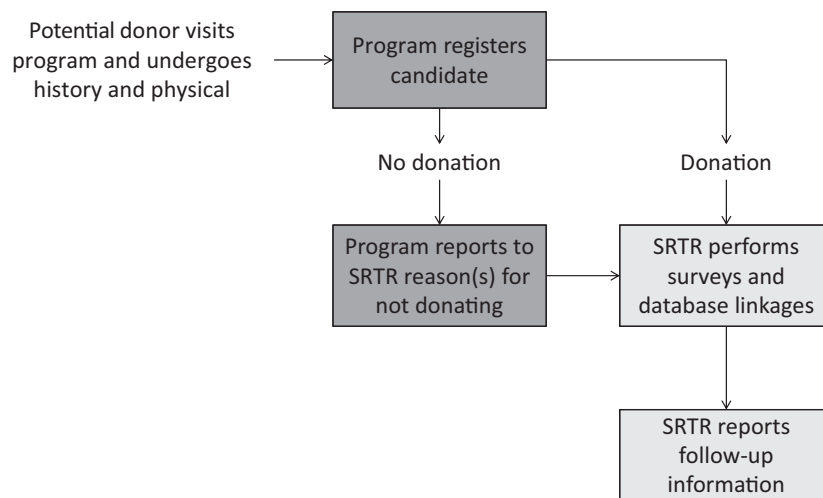
Four-letter abbreviations are Organ Procurement and Transplantation Network unique identifiers.

survey instrument (Table S4). SRTR will contact participants via mail, email, social media, or phone approximately 1 year after donation or 1 year after determination of nondonation, and approximately every 1–2 years, thereafter. The exact intervals will be determined by feedback from participants and by cost restraints. In addition, we will work with the 10 participating vanguard sites to

develop a separate, comprehensive survey instrument for participants that will include both medical and psychosocial issues important to candidates and donors. This comprehensive survey will be administered to a random sample of participants at times to be determined to maximize the amount of accrued follow-up information on potential complications of donation.

We will also develop and administer surveys addressing specific complications of interest and importance to donors. For example, three studies have reported that preeclampsia is more common in kidney donors than in the general population, including women selected as controls by baseline good health similar to donors (13–15). Therefore, we will place a high priority on establishing the risk of kidney donation with regard to pregnancy. We will work with the participating sites to develop a survey instrument for pregnancy complications for all women aged 45 years or younger.

However, we cannot address all potentially important issues with follow-up surveys. Therefore, an important feature of the collective is our ability to provide the means for other investigators to conduct their own investigations. As a public entity under contract to HRSA, SRTR can help investigators gain access to information to conduct studies that will improve our understanding of living donation outcomes. The only restriction is the guarantee to protect privacy of individual health information.



**Figure 3: Flow of information.** Dark gray indicates the responsibility of the transplant program and light gray the responsibility of SRTR. From top to bottom and left to right: (1) a potential donor does not become a candidate requiring registration until he or she visits a program and undergoes history and physical examination; (2) the program registers the candidate with SRTR; (3) if donation does not occur, the program reports the reasons for not donating to SRTR; (4) SRTR maintains contact with candidates and donors with follow-up surveys and database linkages; (5) SRTR reports follow-up information on each program's secure site and summary follow-up information to the general public. SRTR, Scientific Registry of Transplant Recipients.

### Follow-Up Information From Linking Registry Data to Other Databases

Because transplant programs cannot provide comprehensive long-term follow-up information on all of their donor candidates, we will link our registration data to Centers for Medicare & Medicaid Services (CMS) data to determine which participants develop ESRD. Data on end-stage liver disease among donor candidates will be obtained by linking to the OPTN transplant registry and CMS data. In addition, we will link donor candidate registry data to the Centers for Disease Control and Prevention, the National Center for Health Statistics, and the National Death Index to obtain data on deaths and causes of death among donors. For other complications, we will link registry data to a pharmaceutical claims data (PCD) clearinghouse. The PCD collects prescription drug fill records reimbursed by private payers, public payers, and self-paid fills and has been explored in pilot form to describe several exposures and outcomes of interest to donors, such as pharmaceutical treatments for depression (16), hypertension (17), diabetes (18), gout (19), and pain (20,21). Other public and private data sources will also be used as available to obtain long-term follow-up information on donors and potential donor controls.

### Maintaining Relevancy for Participants

To better understand what potential and actual donors want to know, we established an advisory committee comprising previous donors and individuals who have studied issues related to organ donation. This committee

will help determine what questionnaires and follow-up information are most important to donors and which items the registry should prioritize. In addition, the registry will maintain a website to provide the latest information of importance to donors, focusing not only on outcomes but also on other issues and information that may be helpful, such as information on kidney paired-donation programs, the National Living Donor Assistance Center, and other resources and links.

### Goals, Challenges, and Solutions

Our overarching goal is to optimize living organ donation in the United States. To achieve this goal, we face a number of challenges (Table 3). Although donor candidates are typically screened before undergoing detailed evaluation, it is difficult to define when someone becomes a donor candidate, and the number of candidates registered will no doubt vary from program to program. These numbers and the time and effort required to register candidates will be determined as part of the pilot study.

Another challenge is determining reasons for not donating. This, too, will be addressed as part of the pilot study. The list of potential reasons for not donating and how these are defined and determined will be optimized.

The methods that SRTR should use to best maintain contact with participants must also be determined. Some combination of mail, phone, email, and social media will no doubt be required to suit the needs of all individuals. Information of interest to participants and programs and

**Table 3:** Living donor collective goals, challenges, and solutions

Goals	Challenges	Solutions
Vanguard study to determine		
1) Which living donor candidates should be registered.	Heterogeneity in practices at programs	Optimize definitions and collection
2) Possible reasons for not donating.	Difficult to define and collect	Optimize definitions and collection
3) Best methods for follow-up.	Difficult to maintain contact	<ul style="list-style-type: none"> <li>Establish database linkages that ensure nearly 100% follow-up</li> <li>Establish optimal survey methods</li> </ul>
4) What candidates, donors, and programs want to know.	Learning what candidates/donors want to know	Survey candidates, donors and programs
5) How to provide candidates, donors and programs with what they want to know.	Informing candidates, donors, and programs	<ul style="list-style-type: none"> <li>Web-based information</li> <li>Newsletters</li> <li>Social media</li> </ul>
Comprehensive registry to		
6) Achieve willing participation of every living donor program in the US.	Benefits need to outweigh burdens	Provide useful information for candidates, donors, and programs
7) Minimize data collection burdens.	Time and effort of initial registration	<ul style="list-style-type: none"> <li>Public Health Authority eliminates need for program IRB approvals</li> <li>CMS coverage as a SAC</li> <li>SRTR provides follow-up</li> </ul>
8) Remove barriers of over-estimated risk to encourage living donation.	Determine outcomes of candidates who do not donate due to perceived risk of diabetes, kidney stones, CVD, and CKD, etc.	SRTR surveys and data linkages to assess outcomes of donor candidates who do not donate to determine if decisions predict outcomes
9) Achieve 100% follow-up of critical outcomes, e.g., death, cause of death, and ESRD.	<ul style="list-style-type: none"> <li>Registration of all donor candidates</li> <li>Defining controls declining for reasons not related to health</li> </ul>	Link to NDI and CMS for deaths, causes of death, and ESRD
10) Achieve adequate follow-up of key outcomes, e.g., preeclampsia, gout, and access to care.	<ul style="list-style-type: none"> <li>Adequate participation</li> <li>Adequate resources to collect follow-up information</li> </ul>	SRTR surveys and data linkages

CKD, chronic kidney disease; CMS, Centers for Medicare & Medicaid Services; CVD, cardiovascular disease; ESRD, end-stage renal disease; IRB, institutional review board; NDI, National Death Index; SAC, standard acquisition costs; SRTR, Scientific Registry of Transplant Recipients.

how to provide this information must likewise be determined by obtaining appropriate feedback.

Key to the success of a comprehensive universal registry of living donor candidates ultimately will be the willing participation of transplant programs nationwide. This cooperation will be possible only if the time and effort required to register candidates is minimal. We will strive to achieve this goal. In addition, by SRTR assuming the burden of collecting long-term follow-up information, we hope to provide a return on the initial investment required to register donor candidates by providing useful information for programs and their donor candidates.

### Summary

There is a critical lack of information on long-term outcomes of living organ donors. Understanding outcomes of importance to donors, such as end-stage organ failure (ESRD, liver failure) and mortality, require large numbers of donors, long-term follow-up, and adequate controls. These conditions are likely to be met only by establishing a national registry of living donors. SRTR is establishing a registry whereby transplant programs will register all potential kidney and liver donors who come to the program for evaluation. SRTR will provide long-term follow-up of donors and donor candidates who do not donate

through regular surveys and by linking data to other health care registries. The resulting information will be made available to all stakeholders to help fill the current gaps in our understanding of outcomes after living organ donation.

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## Disclosure

The authors of this manuscript have no conflicts of interest to disclose as described by the *American Journal of Transplantation*.

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## Appendix Additional Living Donor Collective Participants

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## Supporting Information

Additional Supporting Information may be found in the online version of this article.

**Data S1.** Supplementary material.

**Table S1.** Living donor and potential living donor initial registration worksheet (kidney and liver).

**Table S2.** Reasons potential living kidney donors do not donate.

**Table S3.** Reasons potential living liver donors do not donate.

**Table S4.** Brief survey instrument used to maintain contact with all participants at approximately 1 year after registration has been completed.