

# Strategies to advance living kidney donation: a single center's experience

In Europe, living kidney donation rates differ considerably from country to country. These differences are related to deceased kidney donation rates: countries with higher deceased donation rates have lower living donation rates. Despite the differences, all countries have one thing in common, namely, the shortage of kidneys for transplantation. Living kidney donation is a good option to alleviate these shortages. In our center, 60% to 70% of all kidney transplants come from living donors. This article describes various strategies that may have contributed to these high living donation rates: team attitude, educational materials and meetings, and alternative donation programs (exchange donation, domino-paired donation, Good Samaritan donation). Also described are some less conventional strategies for increasing rate of living kidney donation that are not used in the Netherlands but may offer some good perspectives (eg, the "Norwegian approach" and home-based educational programs). (*Progress in Transplantation*. 2009;19:71-75)

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In Europe, living kidney donation rates differ considerably from country to country.<sup>1</sup> For countries where more than 100 kidney transplants are performed per year, living kidney donation rates range from 3% (Finland, Ireland, and Poland) to about 45% (Greece, the Netherlands, Sweden, Switzerland, and Ukraine). Romania has the highest percentage of living kidney donations (68%).<sup>1</sup> These differences in living kidney donation rates are related to deceased kidney donation rates: countries with higher deceased donation rates per million population have lower living donation rates. For example, Belgium, Portugal, and Spain all have deceased donation rates greater than 40 per million population, but living donation rates per million population in those countries are about one tenth as high, resulting in living kidney donations accounting for between 5% and 10% of all kidney transplants performed

annually.<sup>1</sup> These differences in the proportions of deceased and living kidney donations have multiple causes: cultural, historical, and legal factors are all intertwined and play a role. An exhaustive analysis of these factors for each European country is beyond the scope of this article, but we provide some illustrations to explicate each of these factors.

Regarding the legal factors, the type of donor-recipient relationship that is considered acceptable differs from country to country. For example, German transplantation law demands a close personal relationship between donor and recipient, which significantly limits the potential number of living donors.<sup>2</sup> Regarding historical factors, Norway offers a good illustration. Because of geographical characteristics, dialysis treatment was difficult to implement in Norway. Patients often lived too far from a dialysis center. This situation

has resulted in a strong policy in favor of living kidney donation for years, and nowadays living kidney donation is seen as the first option for each new patient.<sup>3</sup>

Finally, strong cultural differences exist. The differences between neighboring countries Belgium and the Netherlands are illustrative. Belgium has one of the highest deceased donation rates, whereas the Netherlands has one of the highest living donation rates. Three years ago, the Dutch parliament debated adopting a variant of the Belgian “opting out” system for deceased donation. The Belgian system assumes that everyone is an organ donor, unless this person has registered an objection toward organ donation during his or her life. The bereaved are not entitled to decide about the organs, but in clinical practice, their wishes are taken into account. In the end, the parliament did not adopt the Belgian system, because it was feared that this system would harm citizens’ autonomy.<sup>4</sup>

Despite the differences just described, all these countries have a shortage of kidneys for transplantation. Even in countries with good results for deceased donation, waiting lists are not zero and have grown in the past years. In the Netherlands, attempts to increase deceased donation rates have not been successful: the number of deceased kidney transplantations has remained stable for the past 20 years. Fortunately, we have performed better at increasing the living donation rates, as now nearly half of all kidney transplants come from living donors, and in our center, the proportion of living donors is even higher (60%-70%). Next, we describe various strategies that have contributed to these high percentages. After that, we describe some less conventional strategies that we do not use but that may offer some good perspectives.

### Strategies to Increase the Number of Living Kidney Donations

A first condition before taking up any strategy to increase the number of living kidney transplantations is a positive attitude among members of the transplantation team. All professionals involved in the procedure should feel comfortable with the practice of living kidney transplantation. Furthermore, it is important to realize that a positive attitude toward the practice of living kidney donation may not translate immediately into behavior actively promoting living kidney donation. One study<sup>5</sup> showed that although most Spanish hospitals do not have objections to living kidney donation, it was not systematically offered to patients. Obviously, it makes a difference whether the nephrologist starts discussing the option of living kidney donation with each new patient, or whether the nephrologist is merely willing to start procedures once the patient (or his family) asks for it. Patients are sensitive to physicians’ nonverbal and verbal behavior.<sup>6,7</sup> If the physician is not fully supportive of living kidney donation, a

satisfactory outcome is unlikely. If patients sense that the physician is not sure about this method, they are unlikely to trust the procedure and to proceed.

### Strategies Used in the Netherlands

*Patient Information Material.* The written information that we use in our center addresses issues related to both donors and recipients, and the same information is offered to donors and recipients. Written information should address the following topics: voluntarism, medical suitability, short- and long-term risks for donors, risk of graft loss, outcome with and without a living donor, postoperative course, and financial conditions.<sup>8</sup> In addition to this medical information, education that address recipients’ fears about transplantation, explains living donors’ donation experiences, and informs patients how to pursue living donation may increase recipients’ pursuit of living donation.<sup>9</sup>

In addition to written information, information can be offered in other forms, such as a DVD. In our center, we offer all patients and potential donors written information and an informational DVD on living kidney donation. This DVD consists of 2 parts: the first part includes general information on renal failure and transplantation provided by the members of our team, and the second part comprises several personal stories of donor-recipient pairs who underwent transplantation at our center. Most of these personal stories are positive about the procedure as a whole, but the DVD also includes one donor-recipient pair who had experienced failure of the transplanted organ. The story about the failed transplant is included because patients had commented that the previous version of the DVD (we now use the second version) was too positive about living donation. The new DVD provides a more balanced view of living donation.

*Patient and (Potential) Donor Information Meetings.* The transplant team at the regular outpatient consultations provides oral information about living kidney donation. In addition, information meetings, specifically targeted at living kidney donation/transplantation can be organized. Usually all patients eligible for transplantation are invited to attend these meetings and to bring anyone else who is interested. During these meetings, ample time is available for asking questions and discussion. Furthermore, various members of the transplant team talk about the procedure: the nephrologist, the surgeon, the transplant coordinator, and the social worker all inform the audience about their part in the procedure. In an effort to make it more comfortable and less intimidating for patients and possible donors to participate, meetings are often organized at locations other than the hospital. For this reason, one of our colleagues from the transplant center in Groningen has strikingly compared these meetings to a traveling circus.

*Offering the Opportunity to Consult Previous Donors.* The meetings with patients and (potential) donors just described usually include “expert presentations,” where transplant recipients and their donors tell their personal stories. In our experience, these presentations are always greatly appreciated by the audience, because audience members can easily identify with these experienced patients and donors. In addition to these presentations for larger audiences, we also offer the option for patients and potential donors who are thinking about whether or not to proceed with living kidney donation/transplantation to consult with a previous donor about his or her experiences with donation.

*Alternative Donation Programs.* A common problem for donor-recipient couples is an unfortunate blood type combination or a positive cross-match. Entering in a living kidney donation exchange procedure can help these couples. The first kidney exchange procedure in Europe took place between a Swiss and German couple, and nowadays living kidney exchange programs exist in Romania, in the United Kingdom, and especially in the Netherlands.<sup>10-12</sup> Other European countries, such as Belgium, have also attempted to initiate a kidney exchange donation program. The Dutch program started in 2004, and outcomes are good: nowadays, 10% of all living kidney donations are performed via a living kidney exchange procedure. In addition, psychological outcomes are comparable to the outcomes of regular “directed” kidney donation procedures, and participants in an exchange program have no need for additional psychological support.<sup>13</sup> Follow-up data from de Klerk et al<sup>14</sup> indicate that living kidney exchange donation is a feasible option for about half of the donor-recipient couples who register. The 50% who cannot be helped via an exchange procedure may profit from programs that aim at removing anti-donor HLA antibodies or the isoagglutinins of the ABO system.<sup>15,16</sup> In our center, we perform only the latter program.

Another alternative donation program is the Samaritan donation program. With this type of donation, a donor donates to someone he or she does not know.<sup>17</sup> Data from the United States have shown good results for these types of donors.<sup>18</sup> In Europe, this type of donation takes place in Sweden, the United Kingdom, and in the Netherlands.<sup>19,20</sup> In our center, some of the Samaritan donation procedures are performed as a “domino paired-kidney exchange,” wherein a Samaritan donor donates to the recipient of an incompatible exchange donation couple, on the condition that the donor of this couple donates to someone on the waiting list.<sup>21</sup> Our center is receiving an increasing number of telephone enquiries, reflecting a pool of donors that until recently was neglected.

## Strategies That May Offer a Good Perspective

*The Norwegian Approach.* In most European countries, it is up to the patient to find a living kidney donor. In Norway, physicians have taken on the role of the patient’s advocate.<sup>3</sup> This strategy has most likely contributed to an increase in the number of living donations, because many patients find it difficult to discuss the issue of living donation with their potential donors.<sup>20,21</sup> So, in Norway, physicians ask patients about the presence of potential donors. Afterwards, if the patient agrees, the physician telephones the potential donors to invite them for a consultation about living kidney donation and discusses with them whether they are willing to donate. Norwegian patients and donors generally consider this to be a common and nonthreatening approach. Norway is the only country in Europe, or probably in the world, that works this way. Research on whether this strategy might also be effective in other countries has yielded some, but not overwhelming, evidence that this approach could be effective in the Netherlands. In a study<sup>22</sup> of patients and their living donors, the majority of the living donors considered this approach too intrusive and feared adverse outcomes such as donor coercion.

*Home-based Educational Strategy: Subpopulations.* Rodrigue et al<sup>23</sup> have convincingly shown that a home-based educational program is effective in increasing the number of kidneys available for transplantation. In their study, health counselors visited patients and their potential donors in their private homes. In this way, various aspects of living kidney donation could be discussed in a confidential setting. Their program was especially effective in increasing living kidney donation rates in subpopulations, in their case African Americans. As far as we know, this home-based educational strategy has not been applied in Europe, and we are not aware of any center’s planning to do so.

Speaking for our own center, we may consider adopting such strategy for subpopulations, in our case mainly people from Morocco, Turkey, and Surinam. One of the reasons for doing so is that the patient and (potential) donor information meetings just described are seldom attended by patients from these subpopulations. An individual, home-based approach may suit their needs better. One of the drawbacks of initiating such program would be its time-consuming nature. An alternative, and already much of an improvement, would be offering patients and their families written information and a DVD in their own language, along with counseling by a transplant coordinator who speaks their language and has a better understanding of their culture.

*Early Intervention.* Another strategy to maximize the benefits from living kidney donation is preemptive

transplantation. With preemptive transplantation, patients avoid dialysis-induced morbidity, have a better quality of life (compared with dialysis), and better long-term outcomes.<sup>24,25</sup> In the Netherlands, 45% of living-donor transplants in 2007 were performed preemptively.<sup>26</sup> Nevertheless, the percentage of patients who had preemptive transplants among all 1850 patients who started renal replacement therapy was relatively low (8.7%). This percentage is accessible for improvement, especially as approximately 1000 patients are enrolled in transplant waiting lists each year. Strategies for improvement could be early education in the regional dialysis centers, referral to a transplant center at the time of creation of a vascular access, timely transplant evaluation, and early identification of living donors.<sup>27</sup> Some patients may need extra counseling at this stage, as they still are in the process of accepting their disease and do not feel ill yet. This situation may cause them to put off the decision about finding a living donor until preemptive transplantation is no longer feasible.

*Media.* Some patients try to find a living donor through Web sites such as [matchingdonors.com](http://matchingdonors.com). Although this practice is generally viewed as undesirable, there exists some cautious experience with accepting these pairings in the United States. In Europe, sites like [matchingdonors.com](http://matchingdonors.com) are less common. The “Big Donor Show,” broadcast last year on Dutch television, can be compared with this practice. The idea of the show was that a terminally ill woman, 36-year-old Lisa, would talk live in the studio with 3 preselected young patients, all in need of a kidney. Then she would choose which of them would receive her kidney before her death. Viewers would be able to advise her via text messages. This show was much criticized, but later turned out to be a hoax meant to raise awareness about the importance of organ donation.<sup>28</sup> This broadcast seems to have had a slight positive influence on the number of family consents in deceased organ donation. In addition, the program and accompanying media hype seems to have caused an increase in the number of Samaritan donation requests at our center, as we observed a slight decrease in these numbers in 2008.

*Incentives for Donation.* The idea of introducing incentives to increase the number of kidneys for transplantation has been debated in literature and at many international conferences.<sup>29</sup> Debates concern the moral acceptability and the type of incentive. In this respect, a recent report that came out in the Netherlands added fuel to the fire. This report from the Center of Ethics and the National Council of Public Health was offered to the Minister of Health on November 12, 2007.<sup>30</sup> The authors of the report concluded that under certain circumstances payment is morally justified, and that

payment and the voluntary nature of the act of donation are not mutually exclusive. According to the report, the most expedient way to arrange these payments is via life-long payment of health insurance reimbursements for living kidney donors. In the Netherlands, monthly costs for health insurance are approximately €90 per person. Still, at this moment, no plans have been made to implement such a system.

## Conclusion

Health care professionals and health care policy makers have good medical and ethical reasons to promote the many options of living kidney donation.<sup>31</sup> Some authors<sup>32</sup> even state that “Recruitment of the donor represents a medical and moral responsibility.” As we have shown, donors can be recruited in many ways. We have described several (educational) strategies that can be used to increase the number of living kidney transplantations. In conclusion, we hope that this article provides a useful overview for those wishing to expand their living kidney donation program.

## Addendum

The use, possibilities, and pitfalls of these strategies are among the topics to be discussed during the 2010 Congress of the European Platform on Ethical, Legal, and Psychosocial Aspects of Organ Transplantation that will be held in Rotterdam, The Netherlands, from April 18 to 21. For more information about this congress, go to [www.elpat.org](http://www.elpat.org).

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