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Evolution of a Living Donor Liver Transplantation Advocacy Program

Lisa Anderson-Shaw, Mary Lou Schmidt, Jeanine Elkin, William Chamberlin, Enrico Benedetti, and Giuliano Testa

Lisa Anderson-Shaw, DrPH, MA, MSN, is Director of the Clinical Ethics Consult Service and is an Assistant Clinical Professor at the University of Illinois Medical Center in Chicago, Illinois, *lkas@uic.edu.*
Mary Lou Schmidt, MD, is an Associate Professor in the Department of Pediatrics at the University of Illinois Medical Center, *Mls3@uic.edu.*
Jeanine Elkin, RN, is the Living Donor Liver Transplant Coordinator in the Division of Transplant Surgery at the University of Illinois Medical Center, *jelkin@uic.edu.*
William Chamberlin, MD, is Chief Medical Director at the University of Illinois Medical Center, *wchambe@uic.edu.*
Enrico Benedetti, MD, is Chief of the Division of Transplant Surgery and an Associate Professor at the University of Illinois Medical Center, *Enrico@uic.edu.*
Giuliano Testa, MD, is Director of the Living Donor Liver Transplant Program and an Associate Professor in the Division of Transplant Surgery at the University of Illinois Medical Center, *gtesta@uic.edu.*

INTRODUCTION

Living donor liver transplantation (LDLT), introduced as a standardized technique in Chicago in 1989, has proved successful in almost eliminating mortality on the pediatric waiting list for liver transplant. Rates of successful grafts and patients' survival in LDLT are equal and often superior to those of cadaveric liver transplantation. The same goal of reducing mortality on the waiting list that prompted worldwide acceptance of pediatric LDLT has been, in recent years, the main impetus promoting adult-to-adult LDLT.

It has been reported that 15 to 20 percent of patients waiting for a liver transplant will die without receiving one.[1] The newly introduced Model End-Stage Liver Disease score (MELD) system allows fast transplantation for very sick patients with a high MELD score, while forcing a longer wait for patients with a moderate score, despite encephalopathy, intractable ascites, and/or portal hypertension. In fact, MELD scores are calculated by a formula whose variables reflect only the laboratory values of patients, and do not take into account the clinical manifestations of their disease process. Consequently, patients who have great life limitations because of their liver disease, but who present with laboratory values that are not grossly abnormal, may face extremely long and painful waiting times. Moreover, in the MELD system, patients with hepatocellular carcinomas that are greater than five centimeters in diameter are, in essence, excluded from

the cadaveric waiting list. LDLT offers the unique chance of readily available treatment to many patients who are affected by end-stage liver disease.

The donor operation requires removal of either the right or the left side of the liver. In technical terms, the operation is called a hepatectomy. The donor will undergo either a right or a left hepatectomy. The decision of which side of the liver will be donated depends on the size of the donated liver and the size of the patient who will receive it. The University of Illinois Medical Center at Chicago (UIMCC) has an active LDLT program, where it is proposed as a possible therapeutic option to all candidates for liver transplantation. Patients who are thought to particularly benefit from a LDLT are those with life-limiting symptoms of liver decompensation that is not reflected by laboratory parameters such as intractable ascites and/or encephalopathy, or patients affected by hepatocellular carcinoma.

The donor evaluation is performed following a strict protocol, and only those potential donors who are found to have no medical conditions that may jeopardize a prompt recovery are accepted. Since the inception of our program, it was felt that all potential donors should be fully evaluated by a trained professional who was independent of the transplant team, to determine the willingness to donate and the absence of coercion. With time it became clear that the potential donors were also in need of in-depth counseling concerning insurance, power of attorney, and work-related and financial issues. It became evident that these issues were often ignored or underestimated by the potential donors. To manage these issues, UIMCC became the first hospital to implement a donor advocacy program. Within this program, informed consent is obtained by the transplant team and is reassessed by a member of the hospital's medical ethics consult service to check for the absence of coercion and guarantee the potential donor's right to refuse surgery until the last moment. In addition, the UIMCC ethics committee works closely with the medical ethics consult service to develop a program that guides donors through the donor advocacy process, which takes place early in the donor work-up phase.

ETHICAL QUESTIONS

Living organ donation has always raised difficult ethical questions. Such questions include: *How should autonomy and paternalism be balanced? When is it justified to expose a healthy person to harm primarily for the benefit of another?* and *Can truly informed consent ever be possible in this situation?* In addition to these questions, other considerations should be taken into account, including: *How should living donors be chosen? By whom? Should volunteers have any input in determinations of their own suitability? How should potential donors be evaluated for physical, emotional, and social suitability? What is our responsibility to living donors in protecting them from the potential harms that may result from donation?*

In using a living organ donor, we put an otherwise healthy person at risk primarily for the benefit of another. Consequently, there is a strong ethical responsibility to ensure that the process of selecting donors takes into account not just the physical suitability of the donor, but also evaluates other contextual issues, so that appropriate safeguards are in place to protect the interests of the living donor.

The ethics of living organ donation has continuing salience, largely because the need for cadaveric organs continues to exceed the supply.

The main ethical question concerning living organ donation is very well stated by Spital: "Throughout the history of living organ donation, concern about harming the donor has appropriately taken center stage in debates about the acceptability of this procedure. The most troubling ethical question has always been how can one justify exposing a healthy person to the risk of major surgery to benefit someone else?"[2]

How is it, then, that "we" choose living organ donors? Who decides whether a potential living donor has "what it takes," physically, psychologically, and socially? Is the autonomous consent of the potential donor sufficient? Although this article primarily describes our advocate process for living *liver* donors, we believe that living donor advocate programs would also be appropriate in living kidney, lung, pancreas, and small bowel transplantation. Our approach could be used as general guidelines for all such living donor advocate programs.

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A BRIEF HISTORY OF LDLT

First, we must look back, historically, to the living organ donor data. Although living kidney donation has been practiced for 50 years and has minimal morbidity/mortality issues, living liver donation is still very new, and the process of living liver donor assessment is not nearly as standardized. The timeline of LDLT is summarized in table 1.

The first adult-to-adult LDLT at UIMCC was performed in July 1999. Prior to the procedure, in October 1998, the transplant team came to the UIMCC Ethics Committee to review their new program and to seek assistance with the donor selection process. The transplant team reviewed the current donor and recipient criteria and discussed the overall ethics of the surgical procedure. The UIMCC medical director was supportive of the ethics committee's involvement with the LDLT program. The committee was very interested in participating in the donor selection process, and gave some general suggestions to the transplant team related to ethical issues such as coercion and informed consent. Three LDLT procedures took place between July 1999 and December 2000, before the formal donor advocacy process was initiated. Between January 2000 and January 2002, no LDLT procedures were performed at UIMCC.

BEGINNING OF THE FORMAL LDLT ADVOCATE PROCESS

In February 2002, a formal living liver donor interview process was established and a member of the UIMCC medical ethics consult service provided the first "donor advocate" interview. Since we began this service, 32 potential donors have been involved in our donor advocate interview process. Prior to January 2004, only adult-to-adult LDLTs were performed at UIMCC, but recently we have begun to perform adult-to-child LDLT procedures. The same advocacy approach is used for the living donor of a pediatric graft as is used for the living donor of an adult graft. Although the physical risks to living donors are different, based upon adult or pediatric recipients and various other health-related indicators, we strongly believe that the ethical issues related to either living donor are the same.

Why have a "donor advocate?" In the beginning, we wanted to make sure that potential donors were not feeling any coercion in their decision to make this type of donation. The interviews were informal—the first two took place in the cafeteria. The literature, although supportive of a donor advocate process, did not prove helpful in guiding this process or in offering any specific interview questions or tools to help us, so we simply started by discussing issues related to coercion and informed consent. As our process continues to evolve, we will surely clarify and define exactly what is meant by our use of the term "advocate." However, at the present, we would define our role of advocate as more of a donor "protector" and "educator," in that it is our job to assist in the process of informed consent as well as to highlight areas for the donor that might be potential problems in the donation process.

Through numerous discussions with the ethics committee's members and continuous reviews of the literature, our donor interview guidelines have taken shape (see appendix 1). One trained member of the Ethics Consult Service team, usually the director of the service acting as the donor advocate, interviews the potential living organ donor. It should be noted that, during this interview process, potential living donors are informed again, having been informed by the transplant team initially, that they are free to "back out" of this donation at any point in the work-up. All that is needed is a phone call or a discussion with the donor advocate, or any member of the transplant team. It has been the experience in our program that no potential living organ donor has made this call to back out of their donation. Potential living donors, have, however, been disqualified as a donor according to clinical or psychological criteria. Clinical decisions to withdraw a donor are made by the transplant team's physicians.

After each interview, the donor advocate prepares an interview summary using to the interview program outline, and sends a copy of this summary to the LDLT nurse coordinator. In addition, the advocate places a copy of this summary on the secured UIMCC intranet Ethics Consult Service web-board for review by the other members of the consult service/donor advocate team. This is very important, as it allows for almost instant peer feedback and eliminates the need for a team meeting, which can be very difficult to schedule.

This real-time feedback is important to the interviewer, who can then follow up with the transplant team as appropriate.[3] We do not ask for a vote among team members on whether to accept or reject the potential donor, but rather ask that team members express any concerns that need to be followed up, either with the potential donor or the transplant team. On at least two occasions, an "emergency" meeting has been called between the ethics consult service and the transplant team to discuss some issues of concern related to the interview outcomes. This indicates that our process has been a thoughtful and important one in dealing with donor advocacy.

"IMPARTIAL OTHER" INTERVIEW EVOLUTION

The consensus statement from the Live Organ Donor Consensus Group (2000) regarding live organ donors suggests, "an independent advocate for the donor should be identified whose only focus is the best interests of the donor . . . and that donor advocates should be empowered with full veto authority if they believe donation to be ill advised."[4] This veto power by an independent team of advisors (or donor advocate) was originally included in the New York State Health Department's proposed new rules for live liver transplants, but was stricken from the final proposal.[5] The issue of veto power by a donor advocate is a controversial one, and one that we currently do not endorse. The donor advocate, although he or she keeps the best interest of the donor at heart, is only one step, albeit an important step, in the potential living donor work-up. Discourse among the various providers involved in the living donor work-up process is essential to this process. The opinion of the donor advocate team is given very high consideration by the transplant team, and this must be an essential component to any donor advocacy program.

Our team believes that the best independent advocate for the donor must not be related in any way to the transplant team, as it is the only way to ensure the highest level of impartiality possible. Currently, our system calls for the ethics consultant/trained donor advocate to perform the confidential donor interview, to tell the donor that this information will be shared with a small donor advocate team (consisting of a registered nurse, a social worker, a medical doctor, and the pastoral care advisor), none of whom are employed by the transplant team. Ultimately, it is the surgical team who is responsible for the final decision on whether the donor goes ahead with surgery or not—but not without input from our donor advocate.

Our process typically begins with a monthly meeting between the LDLT nurse coordinator and the director of the ethics consult team. At this initial meeting, information on the potential living donor is reviewed so that we can discuss any major concerns prior to the interview process. After this meeting, the transplant nurse coordinator contacts the potential donor to set up an interview with the ethics consultant who acts as the donor advocate. We try very hard to conclude this interview process prior to the actual scheduling of the surgery, as we believe that having a date set for surgery may be somewhat coercive for the potential donor. The confidential donor advocate interview takes place in a private office between the potential donor and the advocate only. Should potential donors bring other family members with them, we ask the family to wait in the guest waiting area. The meeting lasts approximately 45 minutes. At the conclusion of the interview, potential donors are encouraged to write down any unresolved questions they have for the transplant team, and are given the ethics consultant's contact information in case they have any follow-up issues to discuss later. Typically, potential donors do not have contact with other members of the donor advocate team.

Although our surgeons have had experience, particularly in Germany, using paid donor advocates from the community rather than from the institution, we have not explored this option, nor have we been requested to do so by any of our potential living liver donors. This is an interesting concept, however, and one that needs further study. Although one could argue that simply being employed by the same institution as the transplant team is enough to create a conflict of interest within our donor advocate team, we strongly believe that this is not the case. Because the advocate team members are in no way dependent on the transplant department for monetary support, nor are we subject to any disciplinary sanctions related to the department, we truly do function independently. Our advocate team members are employed in various other departments within the institution and are not directly compensated for their advocate team role.

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LIVING DONOR LIVER TRANSPLANT INTERVIEW GUIDE

We have written a donor interview guide, which is in constant revision, that helps direct the process at UIMCC (see appendix 1). We assess the following information.

General information. We collect information on the donor's age, relationship to intended recipient, family members, financial/emotional responsibilities, circumstances under which the potential donor was approached about the possibility of donation, the reason(s) the potential donor wishes to donate, reasons why this person has chosen to go through the donation work-up, the possibility of other family/friends' willingness to be a donor.

Issues of coercion. Does this potential donor feel that he or she can "back out" of the donation process? Does this potential donor feel any pressure to go through with donation by family, friends, recipient, transplant team? Does the potential donor feel personal pressure/obligation to go through with this procedure?

Personal responsibility issues. Is the potential donor employed, and, if so, what arrangements have been made for time off? Has the potential donor made financial arrangements for self or others while off work? What would happen, financially, should the potential donor need to be off work for an extended time due to medical complications?

Advance directive issues. Does the potential donor have any form of advance directive and a will for his or her estate? If the potential donor has dependents, have legal arrangements been made for their care should the potential donor experience major health complications or death?

Two packets of advance directive forms and information are given to the potential donor—one for the donor and one for the intended recipient. Although these documents are not required, we encourage donors to fill out an advance directive, or, at the very least, to have a discussion related to advance directives with family members. We believe that by discussing advance directives, we can communicate the serious nature of this procedure, and this also allows the potential donor and recipient a way to bring up such serious but often uncomfortable issues with their family members prior to the surgery.

Informed consent issues. Can the potential donor describe the morbidity/mortality associated with the donation? Does the potential donor understand what will be done during surgery and the postoperative and recovery phase? Has the potential donor reviewed the consent form? Has the potential donor discussed mortality/morbidity with the transplant team? Does the potential donor have any questions for the transplant team?

During the interview, we ask that the potential donor write down any questions that he or she has for the transplant team on a piece of paper during our interview so the donor will not forget these questions.

Other issues. What if the transplant fails and the recipient's condition does not improve? How does the donor think he or she might react? What does the donor know about the chance of survival for the recipient with/without this surgery? In general, how does the donor feel about this procedure at this time?

Interview concerns. Are there any concerns that the interviewer wishes to highlight for the transplant team? Are there any items that the transplant team needs to follow up on? For example, we may ask the team to follow up on advance directives, or perhaps have a social worker follow up regarding financial concerns.

Interview summary. A typed summary of the donor advocate interview is sent to the transplant team.

OTHER AREAS TO BE ASSESSED BY THE DONOR ADVOCATE

In addition, we suggest that other issues be evaluated during the donor advocate assessment, including the donor's and his or her family's ability to cope with recovery and temporary change in the donor's role (that is, childcare and other duties typically assigned to the donor), donor's employer arrangements and financial hardships that may result if the donor is not able to return to work in a timely way, and potential future insurance difficulties (life, health) that are not known at this time. Our program and interview process expands on the clinical, social, and psychosocial evaluations done by the transplant team members, and includes ethical issues that transplant team/evaluators often do not emphasize.

THE IMPORTANCE OF THE DONOR ADVOCACY PROGRAM

A unique strength of our donor advocacy program is the attention we pay to contextual issues, such as family social dynamics, advance directives, and financial issues that the potential donor may not have thought through yet. We are currently working on a donor knowledge assessment tool that is related to general anatomy, mortality, and morbidity. Our consent process has been revised due to the experiences we have had with our donor advocate interviews. With the assistance of the UIMCC Ethics Committee, our living donor consent process has been revised to reflect the steps in the process, including separate consent forms for potential living donor evaluation and the living donor surgery consent form, each with educational information attached. Prior to our donor advocate program, there was a single consent form that encompassed both the evaluation and surgical aspects of the living organ donation.

We would like to see some national donor/recipient criteria (especially the acceptable threshold of benefit to recipient versus risk to donor) and a national registry for donor morbidity/mortality information to help us in our donor advocacy role. To be able to truly advocate for potential donors, it would seem appropriate that information on all living donors be available for review. It is interesting that there is currently no national registry to which living liver donor information is reported. So it is somewhat difficult to gather accurate data on all such procedures done in the U.S. or elsewhere.

THE NEED FOR A NATIONAL LDLT REGISTRY

The American Society of Transplant Surgeons (ASTS), in May of 2000, announced the creation of a National Registry that would track the number of LDLTs. At that time, the ASTS announced that there was not enough information on the procedure to accurately assign risk to the donor. Cronin and colleagues also support an organized registry, but with some reservations: "Realistically, however, specialty societies may not have enough clout to regulate the actions of surgeons and transplantation programs. In the absence of professional self-regulation, private health insurers and government agencies, such as the Health Care Financing Administration (HCFA), should provide oversight."[6] Broelsch and colleagues further point out the dangers of inadequate data: "Report of donor complications to these registries is not mandatory but is, in our opinion, an act of honesty and intelligence. Unfounded rumors or false reporting may lead to external peer control that will discredit the medical profession, limit its actions, and jeopardize the existence of living donor liver transplantation."[7] A more recent article by Hanto further highlights the lack of concise LDLT morbidity and mortality data because mandatory reporting, as such, has not been fully instituted. He notes that although the literature has reported two deaths among 706 living liver donors, discussions at professional meetings have revealed that the number of living donor deaths may be as high as six among the first 600 procedures. A mandatory registry that would record data on complications and death among living liver donors, he suggests, "could be used in efforts to minimize the risk" of this procedure.[8]

ISSUES OF OBLIGATION, RISK, DECISION MAKING, AND CONSENT

Ethically speaking, perhaps intimates and close relatives have a greater degree of obligation to donate organs and should be allowed to accept greater risks for donation than would a donor who is a stranger, because of their shared interests and moral obligations.[9] However, as Spital notes, even if an intimate or close relative wishes to accept this risk,

> there is no absolute right to donate an organ, because . . . physicians are moral agents who are responsible for their actions and for the welfare of their patients. Therefore, while the values and goals of the potential donor should be given great weight during the decision-making process, physicians may justifiably refuse to participate in living organ donation when they believe that the risks for the donor outweigh the benefits.[10]

To this end, Spital describes an ethic of care that is "designed to guide and explain behavior in personal relationships" that may transcend being informed to the fullest when making a consent decision.[11]

Perhaps it is not possible to ever obtain fully informed consent, but we believe that there is a burden to obtain consent that is as informed as possible, providing each potential living organ donor with all of the available data we have. Although there is currently no database that provides accurate morbidity and mortality data to potential living liver donors, the transplant community has been proactive in developing some guidelines to assist potential donors with the decision to donate. On 25 April 2002, the ASTS published a position statement on adult-to-adult living liver donation:

> The person who gives consent to be a live organ donor should be competent, willing to donate, free from coercion, medically and psychosocially suitable, fully informed of the risks and benefits as a donor, and fully informed of the risks, benefits, and alternative treatment available to the recipient. The benefits to both donor and recipient must outweigh the risks associated with the donation and transplantation of the living donor organ.[12]

Other contextual donor criteria concerns that we review include potential donors who have multiple dependents, who may be unemployed, who are single parents, or who may be vulnerable in other social contexts. The principle of autonomy, when decisions about living organ donors are made, cannot be the only factor that is examined. Other relevant contextual information must also be taken into account.[13] Donors have to be chosen carefully to avoid not just medically, but also morally, questionable outcomes.[14]

These risks to donors must be reviewed in the context of the benefits to the recipient. This concept is one of equipoise. Broadly defined, the term *equipoise* describes the balance between the risks and the benefits attributed to the two arms of a research study group. To achieve equipoise, the risks and benefits to subjects in research study groups must be equal. Cronin, Mills, and Siegler note, with regard to LDLT, that there is a "double equipoise, . . . which reflects a balance between potential benefits and risks for both the recipients and the donors. In certain situations, the use of a graft from a living donor cannot be justified ethically."[15] The Live Organ Donor Consensus Group writes, "The benefits to both donor and recipient must outweigh the risks associated with the donation and transplantation of the living donor organ."[16] According to the ASTS, "While it may not be possible to firmly state that adult-to-adult living donor liver transplantation should not be done in situations in which the recipient has a poor chance of overall survival, the added risk to the donor must be balanced with a realistic estimate of the chances of success."[17] UIMCC transplant surgeons do not have a specifically stated threshold whereby double equipoise would be met for living liver donors, but, rather, we evaluate the risk to each potential donor to the survival of the recipient on a case-by-case basis. However, a significant mortality rate, such as a rate of 20 percent for a recipient's survival at one year, would not be justified to accept the risks of mortality and morbidity for the living donor. For clinical indications that are accepted in a cadaveric liver transplant, the accepted success rate should be the same for a living donor transplant. The donor advocates do look at double equipoise issues and have maintained that the mortality risk to the potential donor must be less than the expected survival of the recipient.

It is extremely important that the donor advocate assess potential living donors' understanding of the morbidity and mortality that is associated with the procedure that they wish to undergo. A recent study that examined three years of data from 1,000 living liver donors reports that the mortality rate for LDLT was 0.5 percent and the complication (morbidity) rate was between 10 and 40 percent (most complications were mild, although some donors required further surgery for bile leak, bleeding, or hernia repair).[18] Broelsch and colleagues state, "There are no minor or major complications only complications that may alter the recovery of the donor."[19] In another recent study, Brown and colleagues report on 449 adult-to-adult LDLTs between 1997 and 2000 with a mortality rate of 0.2 percent and morbidity of 14 percent, stating that complications in donors are relatively common.[20] Again, we must emphasize that without proper reporting mechanisms, the figures related to morbidity and mortality are incomplete, as suggested elsewhere in this article.

Despite, perhaps, the overall lack of understanding related to the aspects of informed consent, morbidity, and mortality, it appears that living organ donors are generally satisfied after the donation. A recent study reports,

> . . . for most donors the decision to donate was easy or not very difficult and was made spontaneously. The amount of information about the risks of LRLT [living-related liver transplantation] was limited at

> the time of decision but increased remarkably immediately before the operation. In 28 percent, family conflicts occurred. Retrospectively, all but two donors (91 percent) would donate again. On average, donors started working after nine weeks and felt fully recovered after 13 weeks. Adverse financial affects were experienced by 41 percent of the donors because of the donation, and four of those received compensation. Importantly, quality of life did not differ between donors and nondonors.[21]

Goldman reports similar results in 1993; of the 20 donors surveyed, the donors were usually extremely committed to donation and "seemed almost unswayable in their convictions about the procedure. The decision to donate was made very quickly; further information had little impact."[22] These donors exhibited considerable denial or minimization about the potential risks to donors and were annoyed or surprised when reminded about them. Almost all of the donors described their willingness to proceed as "simply part of doing whatever you can for your child."[23] A major benefit gained by the donors was an increase in self-esteem.

The experiences of the donor advocates at UIMCC are very similar to these research findings related to the spontaneity of LDLT decisions; we also find that subsequent information related to morbidity and mortality does little to change donors' minds on going through with donation.

PSYCHOLOGICAL EVALUATION OF POTENTIAL LIVING DONORS

In addition to the independent donor advocate assessment, a trained psychologist should do a psychological evaluation. The Live Organ Donor Consensus Group writes,

> Factors that need to be taken into consideration in the psychosocial evaluation of the potential donor include, but are not limited to, ambivalence, guilt, depression, substance abuse, and vulnerability to coercion; the extent to which the decision to donate is consistent with the potential donor's values, including religious beliefs and sense of charity and community; the nature of the relationship between the donor and the recipient; the potential benefits to the donor; the potential medical risks and urgency of the donation; and the potential economic risks associated with donation.[24]

In addition, the group states, "Psychological evaluation offers an opportunity not merely to veto donation, but to intervene proactively to enhance both the donor's decision to donate and the actual donation experience of all involved parties."[25]

At UIMCC, a trained psychologist who is employed by the department of transplantation performs a psychological evaluation on all potential living organ donors. It might be the case that the psychological evaluation reveals just cause for withdrawal of the potential donor from the transplant work-up. For example, severe depression or suicidal ideation by the potential living organ donor would result in withdrawal until appropriate therapy was initiated, at which time the individual may be re-evaluated as a potential living organ donor.

The results of the psychological evaluations are often not available for review by the donor advocate prior to his or her interview, due to scheduling issues. The donor advocate team would, in any case, prefer not to review the psychological evaluation prior to their interview so as not to unduly bias the donor advocate interview process. Once all the clinical, social, psychological, and donor advocate assessments are complete, the transplant team meets to review and make final recommendations regarding the potential living donor. The donor advocate has not been involved in this final process until recently, but now routinely provides input at this meeting.

CONCLUSION

There is no question that living organ donation decreases the wait time for those who need organ transplantation. The answers to the questions that are related to living organ donation are not as easily answered. Since we began to map out our living organ donor advocate program in 1998, with the first LDLT procedure

in 1999, our process and our program have evolved greatly based upon our experiences. Our donor advocate team, along with the UIMCC Ethics Committee and transplant team, have worked closely to develop interview guidelines, consent forms, and educational materials for our potential living organ donors. We discuss our process and program each month at our ethics committee meeting, when we receive a postoperative report on our living organ donors from the transplant team. Our advocate process and program is reviewed and revised based on experience, the literature, and the expertise of our members. Currently, the donor advocate team does not conduct post-transplant follow-up interviews with our living organ donors, but we plan to institute a formal evaluation process for our donor advocacy program in the near future. More research and discussion in this area would be welcomed.

Rejection of a potential living organ donor for various contextual reasons, as opposed to various clinical reasons, may be viewed as exercising medical paternalism. Paternalism of most kinds, especially in medicine, is not popular, at least in the U.S., as it implies that someone other than the individual decides what is in the individual's best interest. Even in a best-case scenario, when the steps of informed consent have been adequately addressed, it may well be the responsibility of the independent donor advocate "system" to act to protect potential living donors from what it is they wish to do. This protection may possibly even extend beyond the personal autonomy of the potential donor.

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NOTES

1. C. Broelsch et al., "Living Related Liver Transplantation: Medical and Social Aspects of a Controversial Therapy," *Gut* 50, no. 2 (2002): 143-5.

2. A. Spital, "Justification of Living-Organ Donation Requires Benefit for the Donor that Balances the Risk: Commentary on Ross et al.," *Transplantation* 74, no. 3 (2002): 423-4.

3. L. Anderson-Shaw, "The Use of E-Mail in Clinical Ethics Case Consultation," *The Journal of Clinical Ethics* 12, no. 1 (Spring 2001): 39-42.

4. Live Organ Donor Consensus Group, "Consensus Statement on the Live Organ Donor," *Journal of the American Medical Association* 284, no. 22 (2000): 2919-26.

5. L. Polgreen, "State to Give Liver Donors Safeguards in Transplants," *New York Times,* 26 September 2003.

6. D. Cronin, M. Millis, and M. Siegler, "Transplantation of Liver Grafts from Living Donors into Adults—Too Much, Too Soon," *New England Journal of Medicine* 344, no. 21 (2001): 1633-37.

7. See note 1 above.

8. D. Hanto, "A 50-Year-Old Man with Hepatitis C and Cirrhosis Needing Liver Transplantation," *Journal of the American Medical Association* 290, no. 24 (2003): 3238-46.

9. L. Ross et al., "Should All Living Donors be Treated Equally?" *Transplantation* 74, no. 3 (2002): 3238-46.

10. A. Spital, "Ethical Issues in Living Organ Donation: Donor Autonomy and Beyond," *American Journal of Kidney Disease* 38, no. 1 (2001): 189-95.

11. Ibid.

12. American Society of Transplant Surgeons, press release, 25 April 2002, *www.asts. org/livingliverdonorupdated.cfm.*

13. N. Biller-Andorno et al., "Who Shall be Allowed to Give? Living Organ Donors and the Concept of Autonomy," *Theoretical Medicine & Bioethics* 22, no. 4 (2001): 351-68.

14. N. Biller-Andorno and H. Schauenburg, "It's Only Love? Some Pitfalls in Emotionally Related Organ Donation," *Journal of Medical Ethics* 27 (2001): 162-4.

15. See note 6 above.
16. See note 5 above.
17. See note 13 above.
18. See note 8 above.
19. Ibid.
20. R. Brown et al., "A Survey of Liver Transplantation From Living Adult Donors in the United States," *New England Journal of Medicine* 348, no. 9 (2003): 818-25.
21. M. Karliova et al., "Living-Related Liver Transplantation from the View of a Donor: a 1-Year Follow-Up Survey," *Transplantation* 73, no. 11 (2002): 1799-1804.
22. L. Goldman, "Liver Transplantation Using Living Donors," *Psychosomatics* 34, no. 3 (1993): 235-40.
23. Ibid.
24. See note 5 above.
25. Ibid.