

## **NATCO, THE ORGANIZATION FOR TRANSPLANT PROFESSIONALS**

### ***Living Donor Health Care Coverage, Insurability and Follow-up Position Statement***

**NATCO**, *The Organization for Transplant Professionals*, represents approximately 2,500 devoted individuals who follow the patient from the evaluation phase and the waiting list period through transplantation event and long-term post-transplant. NATCO's members can be found in procurement organizations and in hospital settings, offering counseling and medical management, serving as a daily resource for patients and families.

Everyday, transplant coordinators and organ procurement personnel work together to match organs with patients awaiting transplants. Despite these efforts, the number of patients awaiting organs for transplantation far exceeds those available.

This discrepancy has resulted in growing numbers of live donor transplants for kidney and liver recipients with some cases reported for lung, and less commonly for pancreas, and intestine transplantation. It is important to note that recipient outcomes have been excellent in kidney transplant with good outcomes now reported in liver transplant as well. Donor outcomes have been good although there has been mortality and morbidity associated with live donation, particularly in liver.

Recently, the transplant community has worked collaboratively to develop guidelines and protocols to protect the well-being of all potential live organ donors. Much of the transplant community's foci has been on the medical and surgical outcomes of living donors with some focus on quality of life issues. Despite these positive steps, there has been little or no concerted effort by the transplant community to address issues related to the financial impact of donation, health insurance and life insurance eligibility for live donors.

Currently, donor evaluation, donation and post-operative recovery medical expenses are covered by the donor recipient's health insurance. There is significant variability in the length of post-donation insurance coverage. For example, Medicare will allow reimbursement under the recipient's coverage for any donor complication directly related to the donation. However, there are anecdotal experiences reported by transplant centers of difficulty in securing long-term insurance after donation, particularly in circumstances where the recipient may have since died or no longer has Medicare coverage. In some circumstances, the process of obtaining living donation expense reimbursement can be cumbersome, with some recipients' health insurance carriers requiring the donor insurance be issued a bill for services and in response, issue a denial of payment before the recipients' carriers will reimburse.

A particular problem for transplant centers occurs when potential living donors lack current health insurance coverage. There is security in knowing that the evaluation, donation and post-operative care will likely be covered by the recipient's coverage; however, the long-term care of the donor presents a dilemma.

The greatest area of concern for donors is the complications that require health resource utilization after hospital discharge. In these cases, it is not clear who has primary responsibility for payment of services: the recipient's insurance, the donor's insurance, the donor, or the transplant center. Most recipient insurance carriers will have specific policies for coverage of the donor, which are generally restricted to coverage of the hospitalization itself and possibly 90 days of peri-operative coverage of treatment for

transplant-related complications, though even this cannot be assumed, and generally, there are no provisions for prescription medications.

Donors with limited economic means may find it impossible to pay for prescriptions for basic pain medication or acid suppression therapy upon discharge. Transplant centers are generally unwilling to ask the donor or the donor insurance to be responsible for care related to the donation in the immediate post-operative period. Therefore, most centers will provide post-operative services without charge for a specified period of time.

It is not clear at this point whether the act of donation will influence the donor's future insurability, especially if there is a complication. This is a greater issue in the United States, where there is no guarantee of universal health coverage, as compared to nations like Canada, where donors currently have access to care irrespective of economic status. A recently published survey of several insurance carriers in the United States suggested that there may well be a negative impact of live donation on access and/or cost of future insurance for the donor.<sup>1</sup>

Practices around the country vary with regard to which programs will allow uninsured donors to proceed with donation and how non-covered medical expenses are paid. There have been instances where potential donors have chosen not to donate due to fear of non-covered medical expenses following donation and lack of protection from future health and life insurance discrimination.

Most donors will underestimate the potential financial impact of donation. For donors of modest means, out-of-pocket expenses such as travel costs to the transplant center, hotel stay if travel is from a long distance, parking, prescription drug cost, and unpaid leave from work are all significant potential factors in post-operative financial stress. A September 2005 international consensus conference on living donation held in Vancouver, Canada identified duration of and type of living donor follow-up is affected by presence of health insurance and described it as an international problem.<sup>2</sup>

NATCO surveyed the transplant community regarding current practice<sup>3</sup> and received the following responses:

- 4% of centers require living donors to have their own health insurance to be eligible to donate;
- 39% of centers had eligible donors decline donation due to fear of future insurance problems;
- 9% of centers report that absence of health insurance affects post-donation care;
- Up to 55% of centers are paying for donor-related follow up care;
- 2% of centers report that living donors were denied health insurance after donation;
- 40% of centers report that they believe more living donors would come forward if they were protected by law from health care discrimination; *and*
- 82% of centers believe the federal government should provide living donor catastrophic health care coverage.

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<sup>1</sup> Nissing MH, Hayashi PH. Right Hepatic Lobe Donation Adversely Affects Donor Life Insurability Up to One Year After Donation. *Liver Transplantation* 11(7): 843-847, 2005.

<sup>2</sup> Vancouver meeting.

<sup>3</sup> Online NATCO survey, February 2006.

**Recommendation:**

NATCO believes that potential living donors should not be denied the opportunity to donate due to absence of health or life insurance. Furthermore, living donors should not pay higher insurance premiums or be denied health or life insurance because they donated an organ. A living donor should not use portions of their lifetime maximum for donor-related charges and should not have out-of-pocket medical expenses related to donation.

Currently, there are no federal or state laws protecting a donor from future insurance discrimination. NATCO believes the government should protect donors from insurance discrimination. Additionally, NATCO believes it is important to create legislation that removes financial disincentives to living donation, including:

- Establishing coverage obligations for recipient insurers, requiring them to provide life-long coverage for donation-related complications and follow-up;
- Clarifying transplant center obligations for the donor, including guarantee of follow-up care and management of complications;
- Permitting lifetime Medicare eligibility for donor-related complications for those donors denied coverage due to impairment resulting from donation; *and*
- Improving reimbursement for donation-related expenses.

Adopted May 2006