

May 11-14, 2010 • Portland Art Museum • Portland, Oregon, USA www.ethics2010.org

Abstract Submission Form - Panels

Please contact	John Tuohe	v at	ethics@providenc	e.org	with any	questions.

Name: Lisa Anderson-Shaw, DrPH, MA, MSN

Title/Degree: <u>Director, Ethics Consult Service</u>, <u>Assistant Clinical Professor</u>, <u>University of Illinois Medical</u>

Center, Chicago, Illinois

Institution: University of Illinois, Chicago

Country: <u>United States of America</u>

Email: <u>LKAS@uic.edu</u>

Phone including country code (http://www.countrycallingcodes.com): 312-636-8762

Primary contact: <u>Lisa Anderson-shaw</u>

Additional panelists, if any (up to three):

Name: <u>David Cronin, MD, PhD</u>

Title/Degree: <u>Director, Liver Transplant Surgery</u>

Institution: Medical College of Wisconsin, Milwaukee

Country: United States of America

Name: Nanette Elster, JD, MPH

Title/Degree: <u>Director, Health Law Institute</u>

Institution: <u>Depaul Univesity Law School</u>

Country: United States of America

Name:	
Title/Degree:	
nstitution:	
Country:	

Proposed Session Title: <u>Disclosure of Misattributed Paternity in Living Kidney Transplant: Point,</u> Counterpoint.

Describe topic or case to be discussed up to 300 words:

Living kidney donation for transplantation is very common and can contribute significantly to the quality of life for the recipient. It is often the case that a family member is the living kidney donor for a loved one and this is seen in particular in cases of adult children donating to their parent.

Living organ donation is a viable option for many individuals waiting for organ transplantation. Often, the living donor is related to the intended recipient, as in a adult child donating a kidney to their mother or father. Living organ donors are evaluated on many levels and the evaluation process includes a psycho-social evaluation as well as an assessment by a donor advocate, as required by the CMS program. In addition, histocompatablity (HLA) testing is done routinely on donor and recipient, and although this testing is not done to establish paternity it can reveal that the donor is not genitically related to the recipient, a fact that may not be known to either.

Once this misattributed paternity is discovered, what, if any, obligation is there on the part of the transplant team to disclose this information to the recipient and/or the living donor? Are there legal, ethical, or clinical reasons that such information be disclosed and if so, what is the best way to disclose this information?

This panel will discuss this issue and argue the different considerations that must be examined with such cases. How does this affect the clinical case for the recipient? If there is no alteration in risk of rejection from the un-related kidney, is there a reason or obligation to disclose paternity information to the recipient?

If the surgical risk is not affected for the donor, should disclosure of misattributed paternity be disclosed to the donor as it may have some impact on the informed consent process?

Are there social, moral, and/or legal reasons that may prohibit disclosure of this information to either the donor or recipient? Should there be policy or standards by institutions or even the transplant community that address the issue of potential misattributed paternity?

Finally, we will provide some potential solutions to this issue for discussion.

Describe briefly each proposed panelist's position to be offered (up to 300 words):

<u>Lisa Anderson-Shaw, as a clinical ethicist who provides assessment of potential living organ donors, will stress the need for disclosure of all information that can affect the informed consent. It might be necessary to disclose genetic information to the potential donor should that be a factor in their decision to donate their kidney or not.</u>

Nanette Elster, JD, MPH as an attorney will discuss the legal implications and requirements for infomed consent as well as the privacy considerations that must be evaluated for each of the participants as well as the parent who may have been aware of the paternity but had chosen not to disclose it.

David Cronin, MD, PhD, as a practicing transplant surgeon involved in live donor transplants will review the practical implications of finding misattributed paternity. The potential finding of misattributed paternity should be anticipated by programs involved in live donor kidney transplantation. As such, the consent process should include a discussion about how such information will be handled and transmitted. Because identification of misattributed paternity is derived from private information from two individuals (donor and recipient), the obligations of protecting privacy, providing disclosure and truthfulness require a different decision analysis than is traditionally applied to individual, patient-specific information.

Are you pl	anning to or will you be willing to submit a poster along with your panel?
Yes	⊠No