

# **HEALTH RELATED PHILANTHROPY: THE DONATION OF THE BODY (AND PARTS THEREOF)**

Volume I  
*Final Report of the  
Health Related Philanthropy Study Group*

December 2004

## Summary

The academic study of philanthropy has focused on private action for the public good. Included in this broad definition has been the study of the public good of improving health, but most work has been on the philanthropic contributions of time and money to health institutions such as hospitals and medical schools.

Another area of philanthropic research has been on various determinants of giving. Yet one very obvious act of giving in the health field has been largely neglected in philanthropic studies; the literal donation of self: blood, tissue, DNA, organs and bodies. There is a long tradition in bioethics research involving the ethical, legal and policy issues associated with donation, including factors involving the donation of bodies and their parts whether for transplantation, treatment, research, or education.

In August 2003, we were awarded a grant from the Indiana University Center on Philanthropy, entitled "Health Related Philanthropy: The Donation of the Body (and Parts Thereof)." The primary goal of the project was to bring together the methodology and results of these two fields of study—philanthropy and bioethics—to shed light on this most personal act of donation, what we have called "health-related philanthropy." This grant enabled the IU Center for Bioethics to establish a Health Related Philanthropy Study Group.

This report describes the main outcomes of the Study Group, specifically the results of a national telephone survey conducted on our behalf by the IUPUI Public Opinion Lab; and the publications, scholarly presentations, and related outreach efforts in the media and elsewhere. We also want to highlight and pay particular attention to an outcome that may have been just as valuable as the more traditional ones of grants and publications: namely, the opportunity that this grant provided to bring together a very diverse group of faculty and students from the IUPUI and Bloomington campuses, and interested members

from the community. It is not common -- even on today's enlightened university campuses that emphasize the importance of interdisciplinary studies -- for faculty and students from different departments and schools to come together for a sustained period of time to discuss critically important issues of social policy. More than this, we attracted interested and regular participation from individuals and groups in the Indianapolis community. The Study Group succeeded in this regard beyond our original expectations. Indeed, the synergistic effect of bringing together diverse perspectives and expertise stimulated a number of unexpected additional activities, including several spin-off projects. We will describe these as well.

We would like to express our gratitude to the IU Center on Philanthropy Research Fund, and for the ongoing support of our work by the Director of Research Patrick Rooney, and Executive Director Eugene Tempel. We also want to thank the Lilly Endowment, Inc., whose funds support both the IU Center on Philanthropy and the IU Center for Bioethics (the latter Center is supported by a grant to the IU School of Medicine to establish the Indiana Genomics Initiative), and to the academic and non-academic organizations that provided additional support to extend the national telephone survey: in particular the IU School of Medicine, the IUPUI School of Liberal Arts, the Indiana Organ Procurement Organization, and the Indiana Blood Center.

Finally, we'd like to thank our two graduate research assistants, Elizabeth Garman and Ujjal Basu Roy for their assistance in all aspects of the Study Group. They took responsibility for running the listserv, organizing the meetings, and assisting in the analysis of the survey of public opinion. We also thank Karen Salmon and Jeff Bartenbach for assistance in the preparation of this report.

•Eric M. Meslin, Ph.D.  
Kimberly A. Quaid, Ph.D.  
(Co-Investigators)  
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## **Project Goal**

The overall goal of this project was to bring together the methodology and results of philanthropy and bioethics to shed light on the combined thematic topic of “health-related philanthropy.” We identified three approaches to accomplishing this goal: a year-long university based Study Group, a survey of public opinion, and the preparation of a proposal for external funding to continue the work. These approaches were successful, as the summary below will demonstrate.

## **The Health Related Philanthropy Study Group (HRPSG)**

The use of study groups has been shown to be an effective approach for engaging diverse participation in the discussion of topical problems in bioethics and health care. Our past success in 2001-2002, in which the IU Center for Bioethics convened a study group to discuss ethical issues in human stem cell research led us to conclude that a similar approach would work for this topic as well. (The 2001-2002 study group report is available at [www.bioethics.iu.edu/products.html](http://www.bioethics.iu.edu/products.html))

The Health Related Philanthropy Study Group (HRPSG) was convened on the campus of Indiana University-Purdue University Indianapolis. The HRPSG met 18 times from September 2003 to June 2004. An electronic listserv was used to facilitate meeting scheduling, distribute materials, and provide updates on news and research in the field. The listserv had approximately 50 members. On average, 15 faculty and students attended the HRPSG meetings, with some meetings including as many as 30 participants. The central feature of the HRPSG was the regular lecture and seminar series, open to the university community and the public. This series (see Table A) allowed experts in different fields, with different approaches and disciplinary perspectives to examine specific topics in health related philanthropy, especially at the intersection of philanthropic studies and bioethics.

We organized the seminars to ensure that there would be different perspectives at each session--sometimes two different academic perspectives, other times coupling an academic presentation with one from an external organization. We were also able to host several distinguished experts from afar. H. Tristram Engelhardt, Jr., M.D., Ph.D., (Rice University) spoke on “Giving, Selling, and Having Taken: Conflicting Views of Organ Transfer” as part of the HRPSG and The McDonald-Merrill-Ketcham Award Lecture; Jon Merz, J.D., Ph.D., (University of Pennsylvania) spoke on informed consent and human biological materials; Susan Lederer, Ph.D., (Yale) spoke on “Donation of Blood and Organs: Comparative Historical Perspectives” and Burleigh Trevor-Deutsch, L.L.B., Chair of the Bayer International Bioethics Advisory Council (Ottawa, Canada) spoke on “Non-therapeutic Immunization for the Production of Rare and Novel Antibodies: Ethical and Policy Issues.”

One of the most gratifying aspects of the Study Group was the diversity of faculty and expertise that it attracted from across the IUPUI campus, as well as the Bloomington campus and the broader community. For example, faculty participation included those from the following departments, centers, institutes and schools: School of Liberal Arts (IUPUI): Economics, History, Philosophy, Philanthropic Studies, Political Science, Religious Studies, Sociology; School of Medicine: Anatomy, Hematology, Medicine, Medical and Molecular Genetics, Oncology, Pathology, Pediatrics, and Surgery; School of Law; School of Nursing; Institutes and Centers: The Regenstrief Institute, the IU Center for Bioethics, the IU Center on Philanthropy, the Center on Law and Health, the IUPUI Public Opinion Laboratory, and the Poynter Center (IU Bloomington).

Other active HRPSG participants included representatives from Clarian Health Partners, Inc., the Indiana Organ Procurement Organization, and the Indiana Blood Center.

**Table A: 2004-2005 Health Related Philanthropy Seminar Schedule**

- September 10** **Donation of Self: History of Organ Transplantation and Philanthropy of Giving**  
Dwight Burlingame, Ph.D., Indiana University Center on Philanthropy  
William H. Schneider, Ph.D., School of Liberal Arts, IU Center for Bioethics
- September 24** **Transplantation of Organs**  
Mark D. Pescovitz, M.D., Indiana University Transplantation  
Tom Buersmeyer, C.O.O., Indiana Organ Procurement Organization
- October 8** **Economic Factors of Donation**  
Mark Wilhelm, Ph.D., Richard Steinberg, Ph.D.  
Gwendolyn Morrison, Ph.D., IUPUI Department of Economics
- October 22** **Philosophical, Theological, Social Issues**  
Craig Dykstra, Ph.D., Lilly Endowment  
Steven Ivy, M.Div., Ph.D., Clarian Health Partners  
Ann Mongoven, Ph.D., Religious Studies, IU Bloomington
- November 5** **Organ Transplantation and the Law: Do We Own Our Bodies?**  
David Orentlicher, M.D., J.D., IU Law School, IU Center for Bioethics  
Sam Davis, Indiana Organ Procurement Organization
- November 12** **Special Lecture**  
H. Tristram Engelhardt, Jr., M.D., Ph.D., Rice University “Giving, Selling, and Having Taken: Conflicting Views of Organ Transfer” (The McDonald-Merrill-Ketcham Award Lecture)
- December 3** **Issues in Blood Donation**  
William H. Schneider, Ph.D., School of Liberal Arts, IU Center for Bioethics  
Byron Buhner, Director, Indiana Blood Center  
Leo McCarthy, M.D., Former Director, Indiana University Hospital Blood Bank  
Dan Waxman, M.D., Medical Director, Indiana Blood Center
- December 17** **DNA and Tissues: Consent and Privacy Concerns**  
Kimberly Quaid, Ph.D., Medical and Molecular Genetics, Psychiatry, IU Center for Bioethics  
Munro Peacock, Ch.MB., Director, General Clinical Research Center, Indiana University Hospital  
Special Guest: Jon Merz, J.D., Ph.D., University of Pennsylvania, Center for Bioethics
- January 7** **Review and Planning of HRP meetings**  
Eric Meslin, Ph.D., IU Center for Bioethics  
Kimberly Quaid, Ph.D., Medical and Molecular Genetics, Psychiatry, IU Center for Bioethics
- January 21** **Review of Draft HRP Telephone Survey**  
James Wolf, M.A., Director, IUPUI Public Opinion Laboratory
- February 4** **The Anatomical Education Program: Bequeathal of Human Bodies after Death**  
David Burr, M.D., Director, Anatomical Education Program; Chair, Department of Anatomy, IU School of Medicine

**Table A (cont'd)**

- February 18**     **Final Review of HRP Survey**  
James Wolf, M.A., Director, IUPUI Public Opinion Laboratory
- March 3**         **Donation and Human Excellence**  
Richard Gunderman, M.D., Ph.D., Department of Philosophy, IUPUI, and Department of Radiology, IU School of Medicine
- March 24**       **Philanthropy and Health Donation in Holland and France: Work in Progress**  
William H. Schneider, Ph.D., School of Liberal Arts, IU Center for Bioethics  
Mark Wilhelm, Ph.D., IUPUI School of Economics
- April 21**        **Issues of Cost and Allocation in Transplantation**  
Jennifer Girod, R.N., Ph.D., IU Religious Studies, Poynter Center  
John Ellis, M.D., FAAP
- May 3**           **Donation of Blood and Organs: Comparative Historical Perspectives**  
Susan Lederer, Ph.D., History of Medicine, Yale Medical School
- May 19**         **Review of National Telephone Survey Results**
- June 2**          **Special Lecture**  
Burleigh Trevor-Deutsch, L.L.B., Chair of Bayer International Bioethics Advisory Council, Ottawa, Canada, “Non-therapeutic Immunization for the Production of Rare and Novel Antibodies: Ethical and Policy Issues.”

## Survey of Public Opinion

While many studies have been conducted of the public opinion on the individual topics of organ transplantation, blood donation, and volunteering, no systematic effort had been attempted to study attitudes between and among these activities. Several meetings of the HRPSG were devoted to designing an instrument that would be used to capture public opinion. The IUPUI Public Opinion Laboratory, led by James Wolf, conducted a national telephone survey, the full report of which is found in Volume II of this report, and available at <http://www.bioethics.iu.edu/HRPsurvey.pdf>. Below we summarize the methods and some of the main findings from that survey.

*Methods.* Since no surveys of public opinion on the broad topic of health related philanthropy had been conducted, our original intention was to conduct a modest study – a telephone survey of 400 Indiana households involving 10-minute interviews – large enough to begin to understand the perceptions that motivate or constrain people in their willingness to donate blood, tissue, DNA, organs or their entire body, but small enough to be conducted efficiently during the grant period. These views are contrasted with those relating to the donation of money and time (the traditional giving behaviors in philanthropy). But during the course of the HRPSG it became obvious, largely due to the expert input by Jim Wolf and his colleagues at the IUPOL, that a larger national sample would be more valuable and possible. A survey committee was formed to develop the interview instrument (which was expanded to 15 minutes), and various drafts were distributed to the HRPSG via email and later discussed at the study group meetings. Additional funding for the expanded survey was obtained from four sources: the Indiana Organ Procurement Organization, the Indiana Blood Center, the IU School of Medicine, and the IUPUI School of Liberal Arts.

The final instrument was a questionnaire to survey 1,055 adults by telephone. (A copy of the

instrument is found in Volume II of this report). The sample was made up of randomly selected households from across the continental United States with phone numbers drawn from the four major U.S. Census regions (West, Midwest, South and Northeast) with probability proportional to the size of the population. The study was determined to be exempt from review by the Indiana University Institutional Review Board. Telephone interviews began on February 29 and ran through March 24, 2004.

*Findings.* The response rate was 22 percent, a number considerably smaller than we would have liked, but nevertheless sufficient to draw some general conclusions. About 40 percent of the sample was male although 48 percent of the U.S. population is male. Only about 16 percent of the sample was under 30 years old although over 20 percent of the U.S. population is that age. The margin of error for all aggregate statistics is less than plus or minus three percent.

- Of those who give to religious charities, older married adults are most likely to give; race and household income also play an important role.
- Of those who give to non-religious charities, income plays the most significant role, with age and education level also having strong positive effects.
- Those who volunteer the most are also of high income levels and are mostly middle-aged and white, but when all factors are held constant it is the person's education level that is the most important determinant of whether or not people volunteer.
- People who donated blood in the past year are more likely to be young, but those who are male with higher income are more likely to report that they have given blood at some point in their lives.
- Women are much more likely to have signed an organ donation statement, as are middle-aged persons and those with higher incomes.
- Younger people are much more willing to donate a kidney right now, particularly to

- a family member.
- Fewer than 10% of the adult population have made arrangements to have their entire bodies donated to science.
- Knowing what the blood, organ or body donation is to be used for (medical procedure, research or education) has a strong impact on a person's willingness to donate.
- Public opinion about the use of public policy to encourage organ donation is divided.
- Young, lower income individuals support tax breaks and payments to donors.

Given that our primary goal of this project was to bring together the methodology and results of philanthropy and bioethics to shed light on the combined thematic topic of "health-related philanthropy," we looked at the simple correlation between our measures of giving of money or time and our measures of HRP, and came to the following conclusions:

- People who have given money to religious charities are no more or no less likely to have given blood in the previous year than other people, but they are much less likely to be willing to donate organs or their whole body to science.
- Conversely, those who gave to non-religious organizations in the previous year are much more likely than average to have also given blood last year or to be willing to donate their organs.

## Study Group Products

This grant was intended to stimulate further discussion and research. Five types of products arose from the HRPSG: external grants/contracts; publications and related resources; presentations; media coverage; and a category of new research developments.

### 1. External Grants/Contracts

Several grants were either informed by or directly resulted from the HRPSG:

*Center for Excellence in Medical Informatics.* Clement McDonald, M.D., Director of the Regenstrief Institute, was awarded a \$2 million grant by the Indiana 21st Century Fund to "develop an advanced infrastructure for medical research in Indiana." Eric M. Meslin, Ph.D., is a participant researcher on Dr. McDonald's grant, with responsibility for addressing the ethical issues associated with consent and privacy issues associated with collection of materials.

*Establishing a Community-Based Bio-Repository to Support the Life Sciences.* The Indiana Organ Procurement Organization submitted a grant application to the Indiana 21st Century Fund to establish a Center for Excellence that would create and manage a self-sustaining bio-repository to support academic and commercial research associated with the expanding life science initiatives occurring in Indiana. Both Eric M. Meslin, Ph.D., and Kimberly Quaid, Ph.D., were involved in preparing the grant. Although the grant was not funded, contacts with IOPO and its regional members were established, and have served to increase visibility of the Center's work at IOPO, and more recently at Biocrossroads.

*Indiana Center for Excellence in Bioethics and Biobanks (INCEBB).* The IU Center for Bioethics submitted a grant application to the NIH, the purpose of which was to establish on the IUPUI campus a Center for Excellence that would enhance the capacity of investigators, regulators, policy makers and scholars to participate in research that leads to better practices in the collection, storage and use of human biological materials. Both Eric M. Meslin, Ph.D., and Kimberly Quaid, Ph.D., were involved in preparing the grant. Other members of the HRP Study Group included William H. Schneider, Ph.D., David Orentlicher, M.D., J.D., and James Wolf, M.A. Although the grant was not funded, an intellectual infrastructure was developed that continues to stimulate ongoing projects.

*Organ Transplant Education.* Rose Fife, M.D., Director of the Indiana University National Center of Excellence in Women's Health, a program



within the Indiana University School of Medicine was awarded a contract (\$15,000) from the U.S. Department of Health and Human Services to support an education program on Organ and Tissue Donation (OTD) targeting the women and minority populations around the state. Dr. Fife will be collaborating with Eric M. Meslin, Ph.D., and Mark Pescovitz, M.D. of the Indiana University Transplant Program, and with the Indiana Organ Procurement Organization.

Further grants are being developed including:

*Biobanks and GIS.* The IU Center for Bioethics, the Polis Center, the Geographic Information System Program in the Ruth Lilly Medical Library, and the RAND Corporation are jointly developing a grant to fund the first ever GIS-based tracking system for the collection and storage of donated human biological materials. This is a proof of concept grant intended to demonstrate the value of simplifying the task of identifying the location of human biological materials—anywhere in the U.S.—with the additional feature of linking those samples with established and accepted protocols (e.g., best practices, informed consent).

*Informed Consent involving human biological materials.* The Center for Bioethics is developing a grant application the purpose of which will be to compare barriers to public willingness to donate tissues in genetics research. Existing U.S. regulations provide little uniform guidance to IRBs and institutions regarding the review of protocols involving human biological materials. In addition, common approaches by U.S. medical schools have not been developed either at the level of policy or in terms of practice guidance. Moreover, existing international guidance is not yet harmonized, leaving individual countries to develop their own guidelines or to adapt their procedures from existing guidance. As more developed countries seek to collaborate with developing countries in genetics research, common approaches, procedures and policies will be needed that jointly satisfy their respective countries and institutions.

## 2. Publications

Katz RA. Too Much of a Good Thing: When Charitable Gifts Augment Victim Compensation. DePaul Law Review. 2004; 53: 547.

Katz RA. [Review of the book On being non-profit: a conceptual and policy primer]. VOLUNTAS: International Journal of Voluntary and Nonprofit Organizations. 2004; 15(2): 208-210.

Katz RA. Donor Intent. In: D.F. Burlingame (Ed.) Philanthropy in America: A Comprehensive Historical Encyclopedia. 2004.

Malet J, Bazin C, Subran S, Wolf J, Schneider WH. “Etablissement Francais du Sang.” Cer-Phi French National Study on Blood Donation, 2004.

Meslin EM, Quaid KA. Ethical Issues in the Storage, Collection and Research Use of Human Biological Materials. Journal of Clinical Laboratory Medicine. November, 2004; 144: 229-234.

Quaid KA, Jessup N, Meslin EM. “Disclosure of Genetic Information Obtained Through Genetic Testing.” Genetic Testing. 2004; 9: 347-355.

Quaid KA, Kinon A, Meslin EM. “The Use of Neonatal Blood Spots for Research: A Review of State Policies.” (in process).

## 3. Presentations

William H. Schneider, James Wolf, Eric M. Meslin, Kimberly Quaid. “Health Related Philanthropy.” Panel presentation, American Society for Bioethics and Humanities. Philadelphia, PA: October 29, 2004.

Eric M. Meslin. “Entitlement to Transplantation by Undocumented Foreign Nationals: The Relationship between Citizenship, Justice and Philanthropy as Policy Criteria.” Rutgers University: June 11-12, 2004.



Robert A. Katz. "Sticker Shock: The Controversy Over Hospital Discounts, Collections, and Charity Care for the Uninsured." Indianapolis, IN: May 20, 2004.

Jason Eberl. "Ethical Principles and Charity Care." Indianapolis, IN: June 7, 2004.

#### 4. Media Coverage

Results of the HRP Project were discussed in the print and radio media on two occasions.

"Health Related Philanthropy." Sound Medicine/Sound Ethics, WFYI 90.1. [July 3, 2004] A one-hour interview with Sam Davis, Director of Professional Services and Public Affairs, IOPO, and Bill Reed of the Indiana Blood Center. Eric M. Meslin was the co-host of Sound Ethics with Barbara Lewis. <http://www.soundmedicine.iu.edu/segment.php4?seg=136>.

"Organ and Tissue Donation." Indianapolis Star [August 26, 2004].

#### 5. Additional Research Areas

*Biocrossroads*. Eric M. Meslin and Kimberly Quaid have participated in discussions with Biocrossroads on state-wide efforts to develop a biorepository of donated human tissue and materials for use in genetics research.

*Charity Care*. An unexpected but fortuitous consequence of the HRP Study Group was the stimulation of additional areas of study and collaboration. One particular topic, developed by Jason Eberl, Ph.D., Department of Philosophy, Robert Katz, J.D., IU School of Law, and Steve Ivy, M.Div., Ph.D., Senior Vice President, Clarian Health Partners, focused on the intersection between law, philanthropy and hospital management. A small group of HRP members (Eberl, Ivy, Katz, and Meslin) began to examine more closely issues that arose from the legal requirement for hospitals to provide a certain amount of care free of charge. Their findings were presented to academic and clinical persons at two

forums sponsored by the Department of Values and Ethics of Clarian Health Partners. (see above).

*International Collaborations*. William H. Schneider, Ph.D., has developed a number of important relationships with colleagues in other countries. Two projects he is actively pursuing are:

- Health Related Giving: Giving Blood in the U.S. and Wider World

The most pressing concerns about the blood supply are naturally its safety and adequacy. A slightly longer-term perspective, however, raises the question of who gives blood and why. These concerns have existed since blood transfusion became practical at the beginning of the twentieth century. Attempts to find answers have varied from country to country, but the decentralized system of collection in the U.S. has posed particular problems. The immediate plans for further research require coordination of existing work and planning of specific new studies to be done. To accomplish this, Dr. Schneider is planning to host a one-day planning meeting in Indianapolis with some key people in the field.

- An International Conference on Humanitarian Medicine

Fifteen years ago there was a conference and publication, which helped give theoretical definition and practical guidance for those eager to work in humanitarian medicine. The timing was appropriate, with the end of the Cold War and the recognition of AIDS as a global crisis. In response, a number of scholars and practitioners met under the sponsorship of several existing humanitarian organizations, under the leadership of Jacques Lebas who held a chair in Health and Humanitarian Action at Ste. Antoine Hospital in Paris. After assembling three dozen practitioners and scholars, they authored and collected documents (philosophical, historical, legal and practical) to serve above all as a guide "for all volunteers who have the fortune and the privilege, for the first

time or not, to embark on a humanitarian mission.” Professor Schneider has begun planning to hold a similar conference and produce another volume to assist those working in humanitarian medicine.

### **Additional Resources**

All materials referred to in this report are available on the IU Center for Bioethics website at [www.bioethics.iu.edu](http://www.bioethics.iu.edu). Included are PowerPoint slide presentations and related notes of seminar speakers, links to organizations and their policies, as well as several annotated bibliographies which are also available in Volume III.