

John S. Gill, Professor of Medicine University of British Columbia, Canada

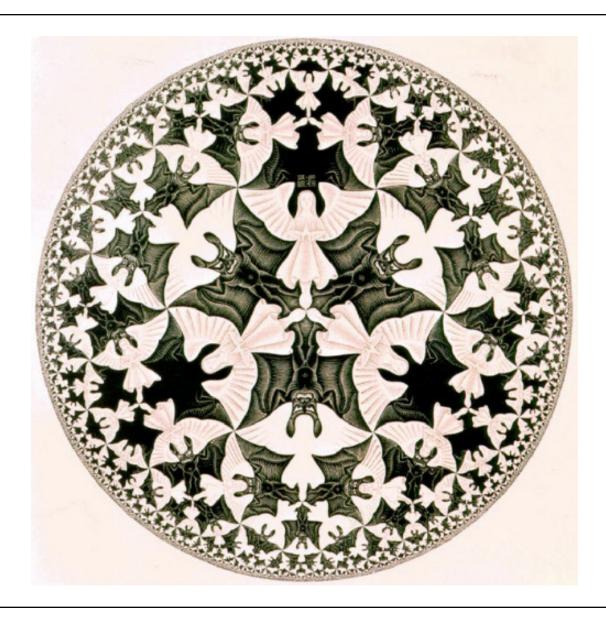


FEBRUARY 25-27, 2016 • PHOENIX, ARIZONA

Conflict of Interest Disclosure

- I have no relevant financial relationships to disclose.
- I will not discuss any off-label use of drugs or devices
- I am a member of the AST Board of Directors
- I am a member of the Declaration of Istanbul Custodial Group





Overview

- Definitions
- International Perspective
- Incentives in the United States (Past to Present)
- Public Opinion

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Incentive - A Broad Definition

 All forms of material gain or comparable advantage offered in exchange for consent to living donation or authorization of deceased donations of organs

IOM Definition

- A <u>financial incentive</u> is the provision of something of material value to motivate consent for organ removal
 - Direct payments
 - Indirect (i.e. tax deductions/ contributions to charities)
- <u>Non-financial</u> incentives
 - Community recognition
 - Preferential access to donated organs

What constitutes an incentive may vary

• Between countries/regions

What constitutes an incentive may vary

- Between countries/regions
- Between individuals

Behavioural Agency and Utility Theory

What factors motivate individuals to take a course of action?

- Utility Theory: individuals seek to maximize health, wealth
- Subcategories of utility
 - Extrinsic: material rewards, money
 - Intrinsic: pleasure from task, satisfaction, health (altruism)
 - Signalling motivation: how perceived by others

Behavioural Agency & Utility Theory Construct for Donor Decision Making

Intrinsic

Altruism "selfless concern for the well-being of others" derive benefit (internal & external)

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- modified by relationship to recipient
- Donor Health
 - short and long term surgical and medical consequences

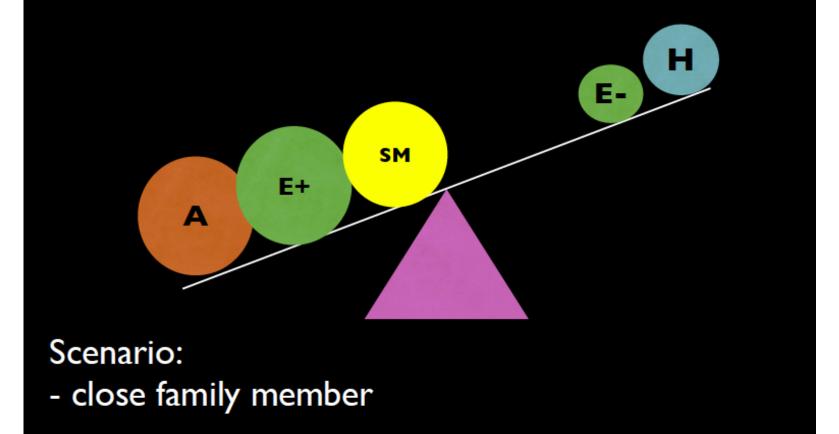
Extrinsic

- Economic (+ve)
 - close relative with transplant (potential wage earner, caregiver burden, socioeconomic impact of chronic disease)
- Economic (-ve)
 - financial impact of being a living donor

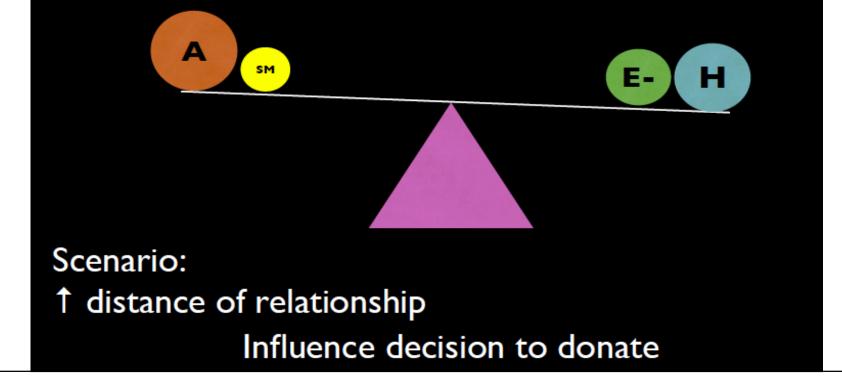
Signalling Motivation

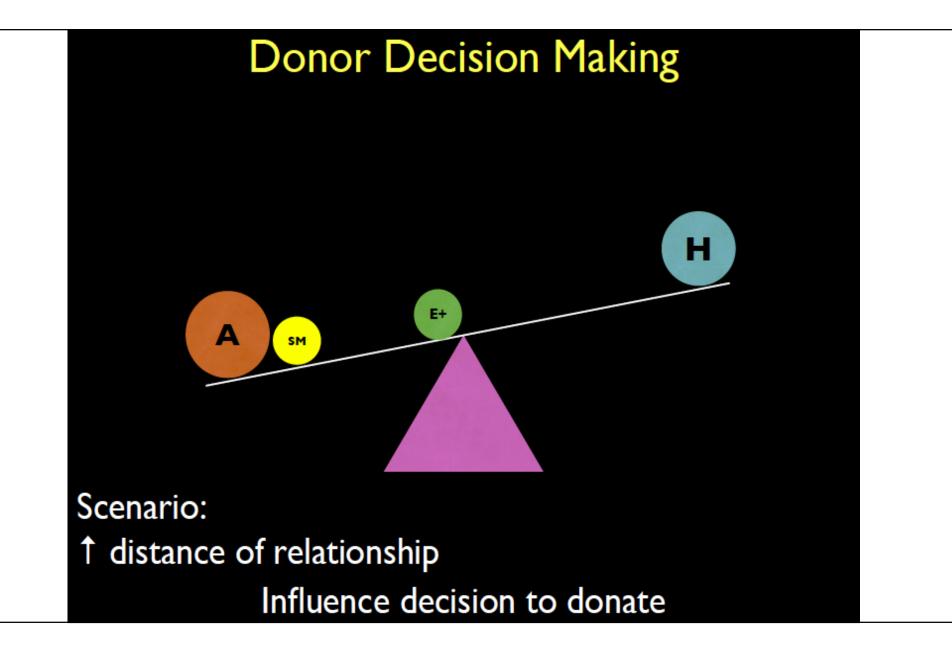
- How perceived by others: family, friends, peers, society
- Likely modified by relationship to recipient











Definition of Disincentive

- A factor, especially a financial disadvantage, that tends to discourage people from doing something
- Also may vary between
 - Countries/Regions
 - Individuals

Potential Disincentives for Living Donors

Indirect costs

Lost wages for donor and supports

Use of employer-sponsored paid time off

Effect on insurability

Effect on employment stability

Direct costs

Transportation to transplant center for testing, surgery, and follow-up care Food, lodging, and incidentals for donation-related

visits for donor and supports

Dependent care

Uncovered medical expenses

Clin J Am Soc Nephrol 10: 1696–1702, 2015

Total Estimated Costs for Living Donors

- Range \$0 20,000
- Average of approximately \$5000
- Approximately 1 month's household wages
- ¼ U.S. donors experience financial strain

Clin J Am Soc Nephrol 10: 1696–1702, 2015 Am J Transplant 14: 916–922, 2014

Country			Non-medical	ovpopsos	covered		Reimbursem is dependant		Out-of- province/ state/		
	Province/ territory/state/ region/(program)	Travel	Accommodation	Meals	Lost	Childcare	Donor income	Recipient income	Availability from other programs ¹	Program in pilot phase	country donors eligible
Australia	Western Australia	Yes	Yes	Yes	No	No	No	No	Yes	No	No
Belgium		No	No	No	Yes	No	No	No	Yes	No	No
Bolivia ²		Yes	Yes	Yes	No	No	Yes	Yes	N/A	No	N/A
Canada	British Columbia	Yes	Yes	Yes	Yes	Yes	No	No	Yes	Yes	Yes
	Manitoba	Yes	Yes	Yes	Yes	Yes	TBD	No	TBD	No	No
	New Brunswick	Yes	Yes	Yes	Yes	Yes	N/A	N/A	N/A	No	Yes
	Newfoundland and Labrador	Yes	Yes	Yes	No	No	No	No	Yes	No	No
	Northwest Territories	Yes	Yes	Yes	No	No	No	No	Yes	No	No
	Nova Scotia	Yes	N/A	N/A	N/A	N/A	Yes	N/A	Yes	N/A	N/A
	Ontario	Yes	Yes	Yes	Yes	Yes	No	No	Yes	No	Yes
	Prince Edward Island	Yes	No	No	No	No	N/A	No	N/A	No	Yes
	Quebec	Yes	No	No	No	No	Yes	No	N/A	N/A	N/A
	Saskatchewan	Yes	Yes	Yes	Yes	Yes	Yes	No	Yes	No	No
Chile		No	No	No	Yes	No	No	No	No	No	No
Czech Republic		Yes	No	No	Yes	No	No	No	Yes	No	No
Denmark		Yes	Yes	Yes	Yes	Yes	Yes	No	No	No	Yes
France		Yes	Yes	Yes	Yes	Yes	No	No	N/A	No	Yes
Germany		Yes	Yes	No	Yes	No	N/A	N/A	Yes	No	N/A
Israel		Yes	Yes	Yes	Yes	Yes	Yes	No	No	No	No
Netherlands		Yes	Yes	Yes	Yes	Yes	No	No	Yes	No	Yes
New Zealand	(Live Organ Donors Welfare Program)	No	No	No	Yes	Yes	No	No	No	No	No
	(National Travel Assistance Program)	Yes	Yes	No	No	No	No	No	Yes	No	No
Norway		Yes	Yes	Yes	Yes	Yes	No	No	No	No	Yes
Philippines		Yes	Yes	Yes	Yes	Yes	No	No	No	No	No
Saudi Arabia		Yes	Yes	Yes	Yes	Yes	Yes	No	No	No	Yes
Singapore		Yes	Yes	Yes	Yes	Yes	No	No	TBD	No	Yes
Sweden		Yes	Yes	Yes	Yes	Yes	Yes	No	N/A	No	Yes
Switzerland		Yes	Yes	Yes	Yes	No	No	No	No	No	Yes
Turkey		Yes	No	No	No	No	No	No	N/A	No	No
United Kingdom		Yes	Yes	No	Yes	Yes	No	No	Yes	No	Yes
United States		Yes	Yes	Yes	No	No	Yes	Yes	Yes	Yes	No

Reimbursement Non-Medical Expenses of Living Donors. Sickand AJT 2009; 9: 2825-36

Table 2: Global non-medical expense reimbursement programs: coverage and program details

Overview

- Definitions
- International Perspective
 - Asia/Gulf States (Saudi Arabia, Qatar)
 - Israel
 - Singapore
 - Chile
 - China
 - Iran
 - Canada
- Incentives in the United States
- Public Opinion

Asia Gulf State Countries

- Key Considerations
 - High rates of end organ failure
 - Large income disparities
 - Islam
 - Most scholars endorse organ donation, many individuals are still reluctant, particularly regarding deceased donation
 - High number of transplant tourists
 - Large expatriate populations (migrant workers)

Saudi Arabia Incentives-Live Donors

- 2007 reward 50,000 riyals (US \$13,300) and other benefits including life-time medical care for unrelated donors in a system regulated at the national level
- 2008 unrelated donors
 - King Abdul Aziz Third Degree Medal
 - discount airfares on Saudi Airlines
 - 50,000 riyals (provided third party through a charitable organization)
 - no lifetime medical coverage
- 2011-
 - Government will pay 50K rivals to donor dependents in the event of death
 - Saudi Airlines 50% discount

Qatar

The Doha Donation Accord Aligned With the Declaration of Istanbul: Implementations to Develop Deceased Organ Donation and Combat Commercialism

Hanan Alkuwari,¹ Riadh Fadhil,^{1,2} Yousef Almaslamani,¹ Abdalla Alansari,¹ Hassan Almalki,¹ Hatem Khalaf,¹ and Omar Ali¹

Keywords: Doha accord, Donation, Commercialism.

(Transplantation 2014;97: 3-4)

DDA Provisions for Live Donors

A comprehensive health insurance for life while residing in Qatar is provided for the live related donor following donation and irrespective of the medical condition requiring care, regardless of their nationality or employment status.

A medical condition identified before donation that renders a potential donor medically unsuitable will be cared for without cost to the potential donor.

HMC covers expenses incurred during evaluation for donation and surrounding the donation procedure until discharge from hospital.

Disability insurance is provided in accordance with national norms if a disability occurs as a complication of the donation process, inclusive of the evaluation and postoperative periods.

If the live donor develops end-stage organ failure, they receive an allocation priority for transplantation.

Provisions of the DDA are accessible only by related live donors and recipients residing in Qatar (Qatari and expatriates), and not by visitors.

DDA Provisions for Families of Deceased Donors

Counseling and travel support for families of the deceased organ donor will be provided as necessary at the time of donation. Transfer of the coffin of the deceased to the homeland of an expatriate worker is assured by Qatari regulation. No money is provided directly to the family of the deceased. In the course of their engagement with potential donor families, donor coordinators may also facilitate referral to social support services where needed, irrespective of whether consent is provided for donation. Of note, access to financial and other supports through the hospital social work program and Qatar charities is available to all families of deceased patients at HMC.

Israel – Living donors

- (a) Earning loss reimbursement of 40 days based on the donor's average income during the three months prior to donation. An unemployed donor will be reimbursed based upon the minimum salary in the market at the time of donation.
- (b) A fixed sum transportation refund to cover all commuting to and from the hospital for the donor and his relatives for the entire hospitalization and follow-up period.
- (c) Reimbursement for seven days of recovery in a recuperation facility within three months after donation.
- (d) Five years reimbursement of medical, work capability loss and life insurances, all to be refunded upon submission of appropriate insurance policies and payment receipts.
- (e) Reimbursement of five psychological consultations and treatments upon submission of appropriate receipts.

Israeli donors also receive non-monetary compensation

- Exemption from national health tax (time limited)
- Certificate of recognition
- Free Admission to National Parks

A new law for allocation of donor organs in Israel

Jacob Lavee, Tamar Ashkenazi, Gabriel Gurman, David Steinberg

Lancet 2010; 375: 1131-33

Panel: Organ transplantation law⁸

"The steering committee of Israel's National Transplant Center will establish rules for organ allocation that take into account the following considerations:

- Consent given by a person during his life to donate an organ following his death, accords both the person and his first degree relatives priority in organ allocation.
- An organ donated by a person following his death accords his first degree relatives priority in organ allocation.
- An organ donated by a person during his life not for a designated recipient accords him or his first degree relatives priority in organ allocation."

Although Israelis can register as organ donors, the next of kin make the ultimate decision about whether to donate the organs of a deceased individual, so the policy provides an incentive for the very person(s) deciding about organ donation

Preliminary increase in deceased donation in Israel

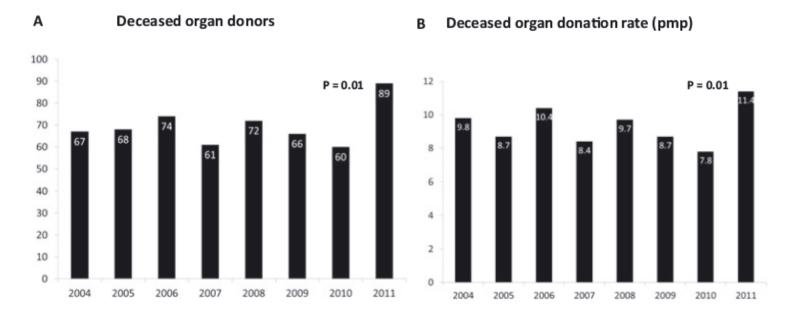


Figure 1: (A) Annual number of deceased organ donors. (B) Annual deceased organ donation rate (pmp-per million population).

American Journal of Transplantation 2013; 13: 780-785

Singapore

- Presumed consent for deceased donation
 - Individuals who do not opt out given priority for transplantation
 - Unlike Israel no priority for next of kin
 - Immediate family members receive a 50% subsidy in medical expenses for 5 years following donation
- Living Donors in <u>need</u> supported by 3rd party (NKF)
 - Cost of annual health screening and medical follow-ups
 - Reimbursement of Hospitalization & Surgical insurance premiums until age 85
 - One time reimbursement for loss of income up to \$5,000
 - Life Insurance coverage sum \$200,000 until the age of 69
- Recipients can provide direct compensation to live donors
 - Expenses; transportation, wages, life insurance and anticipated costs of longterm medical care
 - No direct government support
 - If recipients cannot afford to reimburse they can seek support from welfare organizations

Chile - 2013

- Opt-out policy
- Priority given to candidates for transplant who have not opted out

Financial compensation for deceased organ donation in China

Xiaoliang Wu and Qiang Fang

J Med Ethics 2013 39: 378-379 originally published online January 15, 2013

- Red Cross
 - Basic funeral expenses
 - \$1600 USD for purchase of grave plot
 - \$3200 USD gratitude
 - Eligible for addition \$4800 USD hardship
 - Average yearly family income \$2100 USD

Iran

- 1988 Payment for unrelated living kidney donors
- Government gift -approximatel \$400 USD
- Supplementary payment negotiated directly between the recipient and living donor (\$10,000 USD)
- Putative oversight by non for profit organization –maintains a buyer's market by providing a back- up donor in the event that a recipient and donor cannot agree price
- Government pays for transplant related expenses
- Medical coverage for 1 year post donation

Paid Donation: A Global View

Nasrollah Ghahramani, S. Adibul Hasan Rizvi, and Benita Padilla Advances in Chronic Kidney Disease, Vol 19, No 4 (July), 2012: pp 262-268

Critique of Iranian System

- Directed donation and lack of safeguards against exploitation
- Commercialism compromised recipient and donor selection
- Heavy reliance on indigent living donors
 - Poor donor satisfaction and regret
 - Poor donor follow up
- Lack of transparency

Iranian System – has NOT eliminated the waiting list – 2011 Data

Organ	Waitlisted Patients	Transplants				
Kidney	17910	2273				
Liver	1280	395				
Heart	351	82				
Lung	220	18				
Pancreas	200	24				

Iranian Journal of Kidney Diseases | Volume 8 | Number 3 | May 2014





SELECT A YEAR 2013 2012 2011 2010 2009 2008 2007 2006 2005 2004 2003 2002 2001 2000 1999 1998 1997 1996 1995 1994 1993

ORGAN DONATIONS	2013	ACTUAL DECEASED DONORS		NORS	UTILIZED DECEASED DONORS		ACTUAL DCD DONORS		s	UTILIZED DCD DONORS		LIVING DONORS		
		NUM		PMP	NUM		PMP	NUM	Р	MP	NUM	PMP	NUM	PMP
		670		8.70	670		8.70	0		0	-		1540	20
ORGAN TRANSPLANTS	2013	KID	NEY	LIV	ER	PANC	REAS	HEA	ART	LU	NG	HEART	LUNG	
		NUM	PMP	NUM	PMP	NUM	PMP	NUM	PMP	NUM	PMP	NUM	РМР	
D	ECEASED	1169	15.10	553	7.20	24	0.3	91	1.20	14	0.2	-	(°	9.9% G:
	VING	1501	19.5	39	0.5		22	1.2				1.2	N	



AJKD World Kidney Forum

Financial Incentives to Increase Canadian Organ Donation: Quick Fix or Fallacy?

John S. Gill, MD, MS,¹ Scott Klarenbach, MD,² Lianne Barnieh, PhD,³ Timothy Caulfield, LLM, FRSC,⁴ Greg Knoll, MD,⁵ Adeera Levin, MD,⁶ and Edward H. Cole, MD⁷

January 2014 Volume 63, Issue 1, Pages 133–140

Canada Legal Considerations

- Each Canadian province has its own legislation that effectively bans the sale of organs and tissues
 - Broad language prohibiting any benefit from donation of tissues or organs

Canada - Legal Considerations There is some Wiggle Room

 Incentives that recognize the gift of donation, or perhaps even for time, and pain or suffering related to the donor surgery might be permissible without changes to legislation

Caulfield T and Klarenbach S. Can J Kidney Health Dis. 2014; 1:7.

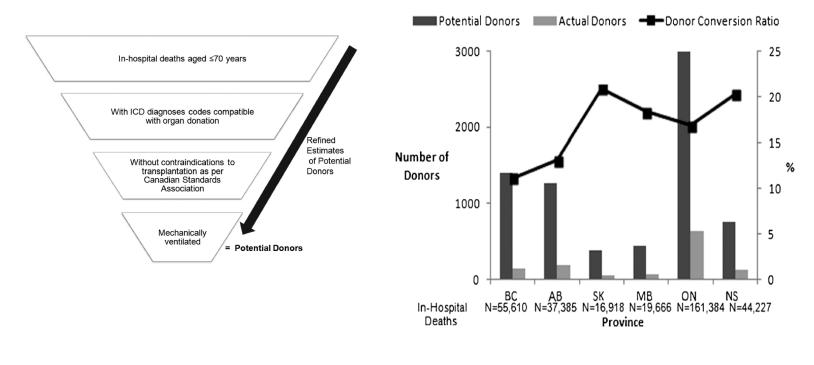
What Priority Should FI be Given?

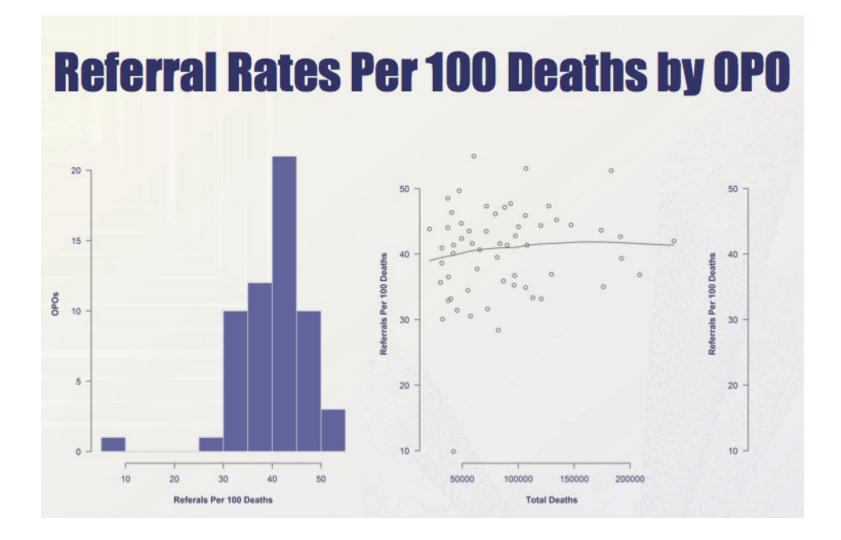
- Fls are unproven
- Will take a time to implement
- Empiric evidence needed but maintain the gift model of donation and/or reciprocity based
- Should not be prioritized over distract from efforts to maximize established mechanisms of donation



Estimation of Potential Deceased Organ Donors in Canada

Caren Rose, PhD,¹ Peter Nickerson,² Francis Delmonico,³ Gurch Randhawa,⁴ Jagbir Gill,^{1,5} and John S. Gill, MD, MS^{1,5}

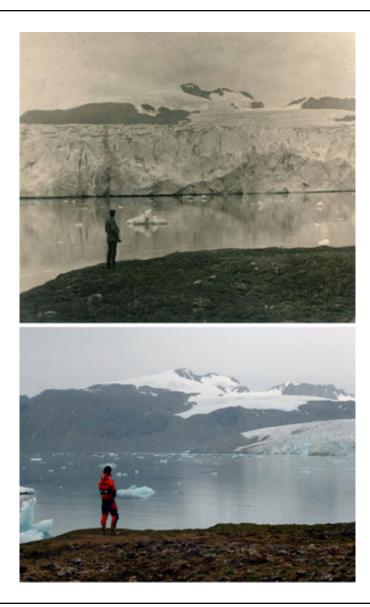




SRTR

Overview

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1968 – Uniform Anatomical Gift Act

- Did not expressly prohibit organ sales but the use of the word "GIFT" in the the title was interpreted to inhibit sales
- E.B Stason suggested the matter of compensation "should be left to the decency of human beings"
 - The drafters did not expect this to be a major problem and because crafting a prohibition on compensation would "not be easy"
- By 1973 all 50 states had adopted UAGA

 1984 Dr. Barry H Jacobs, a physician with a revoked medical license, testified before Congress regarding his International Kidney Exchange Ltd that planned to "commission kidney from persons living in Third World countries or in disadvantaged circumstances in the United States for whatever price would induce them to sell their organs" International Kidney Exchange, Ltd. 11345 Sunset Hills Road Reston, Virginia 22090 U.S.A.



ATTN HEMODIALYSIS DIR./ADMIN PRESBYTERIAN HOSPITAL IN NY 622 WEST 168TH STREET NEW YORK NY 10032

70,000 AMERICANS SUFFER FROM CHRONIC KIDNEY FAILURE AND NEED A KIDNEY TRANSPLANTATION OPERATION ... PLEASE HELP THEM.

Courtesy David Cohen

H. BARRY JACOBS; M.D. Diplomate of the American Board of Surgery Diplomate of the National Board of Medical Examiners Medical Director TOLL FREE 800-336-0332 DC and VA. (703) 435-9400

International Kidney Exchange, Ltd. 11345 Sunset Hills Road Reston, Virginia 22090 U.S.A.

Dear Hospital Administrator:

We are involved in national and international kidney transplantation programs.

We would like to utilize the services of your hospital for these programs. The donor patients will require elective uni-lateral nephrectomies. The recipient patients will require the transplantation operation.

For either or both of these services, please give us a firm price, which should include all hospitalization services, operating room costs, and anesthesia costs. Furthermore, we need to know the fee which will be charged by the operating surgeon as well as by any treating consultants. If you cannot quote the doctors' professional fees, please have them contact us directly or supply us with their names and addresses so that we may obtain that information from them.

The nephrectomy operation can be performed at any hospital with major operating room facilities. The removed kidney is irrigated free of all blood, placed in a sterile container, packed in ice, and immediately shipped to the recipient's hospital for transplantation.

Any Medicare approved hospital can perform the nephrectomy operation and be reimbursed by Medicare for the surgery and hospitalization. Your hospital invoices those services to the transplantation hospital which, in turn, submits the unified bill to Medicare. However, advance payment will be made for privately funded operations.

Medicare has approved payment to approximately 25 hospitals to do transplantation operations. If your hospital is also interested in performing transplantation operations which will be paid for on a cash basis, please let us know. All fees will be held in escrow prior to the operation and immediately disbursed subsequent to the operation, independent of the success of the procedure.

Unlike the nephrectomy surgery, transplantation surgery will need a fully equipped hospital, including arteriography x-ray facilities, radiation therapy (to treat acute rejection), and the services of a urologist, vascular surgeon, and internist with chemotherapy experience. Since the availability of Cyclosporin, the success of transplantation surgery has significantly improved, while complications from chemotherapy have substantially diminished.

You may limit your participation to only the nephrectomy operation. The patients will arrive from various locations (both from the United States and worldwide), may require additional out-patient studies, and then will be admitted for additional tests and for the nephrectomy operation. If the recipient will have the transplantation operation done at a different institution, a coordinating supervisor will work with you to arrange for the transportation of the kidney.

Member of the Better Business Bureau

Please advise me as soon as possible of your interest as we shall limit participating hospitals to only one per geographic area.

Sincerely yours A. Barry Jacobamp. H. Barry Jacobs, M.D.

Medical Director

HBJ/plg

1984- National Organ Transplant Act (NOTA)

- NOTA rendered it unlawful "for any person to knowingly acquire, receive or otherwise transfer any human organ for valuable consideration for use in human transplantation if the transfer affects interstate commerce"
- NOTA defined human organs (including fetal) as kidney, liver, heart, lung, pancreas, bone marrow, corne, a eye, bone and skin or any subpart thereof specified by the Secretary of Health and Human services by regulation"

Excludes blood, ova, sperm

1984- National Organ Transplant Act

• Does not define "valuable consideration" but made it clear the term does not include

"reasonable payments associated with the removal, transportation, implantation, processing, preservation, quality control and storage of a human organ or the expenses of travel, housing, and lost wages incurred by the donor of a human organ in connection with the donation of the organ"

A broad term – anything that confers a benefit Thought to prohibit paired exchanges

*2007—Public Law 110-144, Charlie W. Norwood Living Organ Donation Act, December 21, 2007—Clarified that paired donation, as defined in the act, is not considered valuable consideration for purposes of Section 301 of NOTA; requires annual report that details the progress towards understanding the long-term health impacts of living donation. [GPO: <u>Text</u>, <u>PDF</u>]

Features of NOTA

- NOTA is a CRIMINAL statute
 - Enforcement solely through criminal PROSECUTION.
 - Enforcement solely through DOJ, which typically does not issue interpretive rules.
 - Only rulemaking authority provided to HHS is to define what constitutes an "organ" for NOTA purposes.

NOTA has been interpreted broadly

In 1994, Pennsylvania developed "a pilot program for reimbursement of funeral expenses to donor families [that] was not implemented because the state's attorney general was cautioned by government officials that such a program would be a violation of NOTA."

'Robert Arnold et al., *Financial Incentives for Cadaver Organ Donation: An Ethical Reappraisal*, 73 **TRANSPLANTATION** 1361, 1363 (2002).

Is it possible to interpret NOTA more narrowly?

 The kidney purchasing schemes that initially motivated NOTA were envisioned as businesslike enterprises. For this reason, it would not be entirely inconceivable for a court to read the language merely to ban third parties from profiting from organ procurement on a per-transaction basis, especially if public sentiment were to shift dramatically in favor of allowing some sales.

Diane Millman: ASTS Legal Counsel, Powers, Pyles, Sutter & Verville

Transplantation[®]

Transplantation. 2002 Apr 27;73(8):1361-7.

FORUM

FINANCIAL INCENTIVES FOR CADAVER ORGAN DONATION: AN ETHICAL REAPPRAISAL¹

ROBERT ARNOLD, STEVEN BARTLETT, JAMES BERNAT, JOHN COLONNA, DONALD DAFOE, NANCY DUBLER, SCOTT GRUBER, JEFFREY KAHN, RICHARD LUSKIN, HOWARD NATHAN, SUSAN ORLOFF, JEFFREY PROTTAS, ROBYN SHAPIRO, CAMILLO RICORDI, STUART YOUNGNER, AND FRANCIS L. DELMONICO²

Ethics Committee of the American Society of Transplant Surgeons

Agreed on criteria for an ethically acceptable incentive

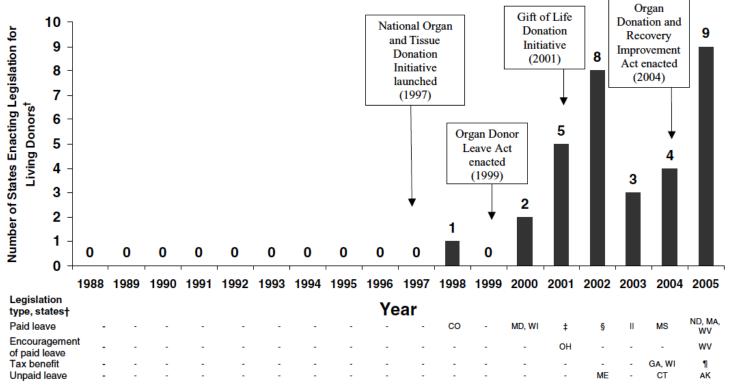
Recommended a pilot study to determine public acceptance and impact of reimbursement of funeral expenses or a charitable contribution for deceased donors

Surgeons Back Study Of Payment for Organs; Plan Aimed at Boosting Donor Rates

The Washington Post The Washington Post April 30, 2002 | Susan Okie | Copyright

Facing a severe and worsening shortage of **organs** for transplantation, the ethics committee of the American Society of Transplant **Surgeons** has endorsed a pilot program under which the family of someone who dies could be offered a small sum of money to thank them for agreeing to donate their relative's **organs**.

The committee "was unanimously opposed to the exchange of money for cadaver **donor organs**," said Francis Delmonico, a Massachusetts transplant surgeon and committee member who addressed the American Transplant Congress yesterday at its annual meeting here. However, Delmonico said, a majority of the panel members supported reimbursement "for funeral expenses or a charitable contribution as an ethical approach. ...



Legislation and Living Kidney Donation

* Some states enacted more than one type of legislation during a single year

American Journal of Transplantation 2008; 8: 1451–1470

IOM - 2006 Financial Incentives within a Donation Framework

- Important to preserve the idea that organs are donated rather than sold
- "Under the right circumstances donated organs might continue to be perceived as gifts, despite the presence of financial incentives."

IOM - 2006

- Did not explicitly state that financial incentives were ethically wrong
- Pointed to lack of empiric evidence
- Pilot program might be undertaken if other less controversial strategies to increase organ donation have been tried and proven unsuccessful

Resources available to living donors in the United States

National Living Donor Assistance Center

Grants for travel and lodging expenses Means testing based on both donor and recipient household income

Nonprofit foundations and emergency grants

Report variable levels and types of assistance including travel, housing, uncovered medical expenses, lost wages

Paid leave for living donation recovery

Federal employees

Postal employees

Employees of some local municipalities

Tax deductions/credits to offset losses associated with living kidney donation

15 states offer tax deductions (requires itemization of taxes)

1 state offers credits

Clin J Am Soc Nephrol 10: 1696–1702, 2015

American Journal of Transplantation 2015; 15: 1173–1179 Wiley Periodicals Inc. © Copyright 2015 The American Society of Transplantation and the American Society of Transplant Surgeons

Meeting Report

doi: 10.1111/ajt.13233

AST/ASTS Workshop on Increasing Organ Donation in the United States: Creating an "Arc of Change" From Removing Disincentives to Testing Incentives

American Journal of Transplantation 2015; 15: 1187–1191 Wiley Periodicals Inc. © Copyright 2015 The American Society of Transplantation and the American Society of Transplant Surgeons

Personal Viewpoint

doi: 10.1111/ajt.13232

Living and Deceased Organ Donation Should Be Financially Neutral Acts

F. L. Delmonico^{1,*}, D. Martin², B. Domínguez-Gil³, E. Muller⁴, V. Jha⁵, A. Levin⁶, G. M. Danovitch⁷ and A. M. Capron⁸ American Journal of Transplantation 2016; 16: 29–32 Wiley Periodicals Inc. © Copyright 2015 The American Society of Transplantation and the American Society of Transplant Surgeons

Personal Viewpoint

doi: 10.1111/ajt.13524

Engaging Living Kidney Donors in a New Paradigm of Postdonation Care

AMERICAN SOCIETY OF TRANSPLANTATION

Living Donor Protection Act to be Introduced

AST members:

Our government relations team has informed us that the Living Donor Protection Act of 2016 is scheduled to be introduced Thursday by Rep. Jerrold Nadler (D-NY) and Rep. Michael Burgess, MD (R-TX) in the House, and by Sen. Mark Kirk (R-IL) and Sen. Kirsten Gillibrand (D-NY) in the Senate.

This is exciting news, especially because the new Senate bill in addition to the reintroduction of last year's House bill means that we will now have two legislative vehicles advocating for living donor protections.

The legislation seeks to:

- Prohibit denial of coverage or increase in premiums of life or disability insurance for living organ donors;
- 2. Clarify organ donation surgery as qualifying as a serious health condition under FMLA; and
- Update educational materials on the benefits of live donor transplantation and the process/outcomes of live donation.

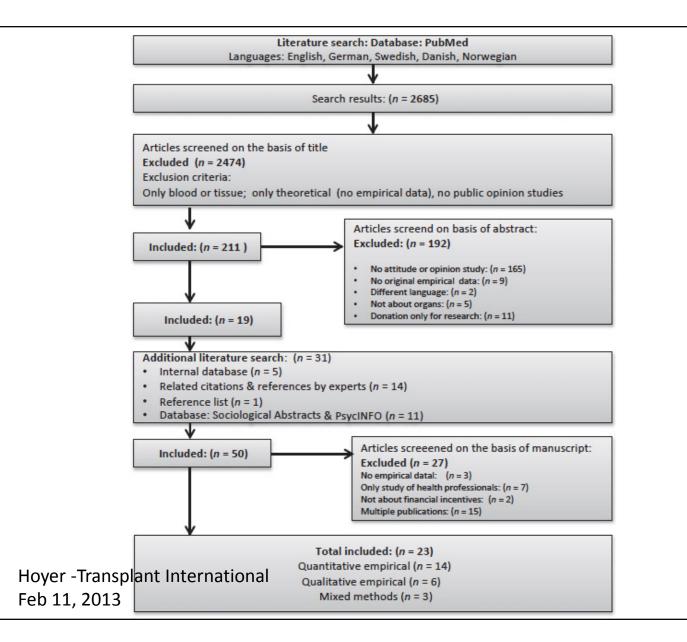
We are already working with additional stakeholder organizations to support this legislation, and we want to acknowledge the efforts of the AST's Live Donor Community of Practice for their contributions in helping to shape this legislation.

We will continue to keep you updated as this bill progresses.

Visit the AST website to learn more

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- Definitions
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Public Opinion - Themes

- Review did not find broad based support for FI
 - More support for removal of disincentives and reciprocity models
- Geographic Differences
 - American Studies slightly higher support for FIs
 - European Studies-less supportive of direct payments, more support indirect FI
 - Great Britain –somewhat higher support for FI than other European countries

Penny Wise, Pound Foolish? Coverage Limits on Immunosuppression after Kidney Transplantation

John S. Gill, M.D., and Marcello Tonelli, M.D.

Kidney-Transplant Survival and Immunosuppressive Coverage Policies for Selected Countries (for Recipients of a First Kidney-Only Transplant from a Deceased Donor).*			
Country	5-Yr Survival	10-Yr Survival	Government-Funded Immunosuppressive Coverage
percent			
Australia	81	59	Lifetime for all recipients
Canada	80	58	Lifetime for all recipients
United Kingdom	78	56	Lifetime for all recipients
United States	69	43	Lifetime for recipients >65 yr of age or with work- related disability; 3 yr for all other recipients

N ENGLJ MED 366;7 NEJM.ORG FEBRUARY 16, 2012

Summary

- The definition of an incentive may vary between countries / individuals
- Incentives are used to directly / indirectly increase donations
- Policy/Law/ Practice
 - Should reflect societal values and current realities
 - There has been considerable change in the U.S.
 - -Other developed countries do more than U.S.
- Because of Pragmatic Considerations
 - Current focus should be on removing disincentives and financial neutrality, health insurance for living donors
- Need for ongoing respectful academic discourse/ engagement





Acknowledgements

- Scott Klarenbach Nephrologist/ Health Economist University of Alberta
- Tim Caulfield Professor of Law- University of Alberta

Overview

- Declaration of Istanbul
- International Perspective
- History of Incentives in the United States
- Legal landscape
- Public Opinion
- The elephant(s) in the room

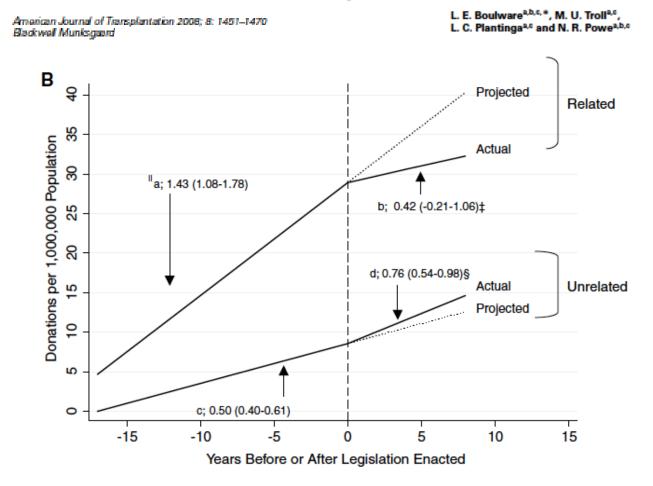
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Is it possible to interpret NOTA more narrowly?

- The most radical change that one could imagine occurring within the current statutory language would involve reinterpreting NOTA to ban only the involvement of "middlemen" in organ sales
- The kidney purchasing schemes that initially motivated NOTA were envisioned as businesslike enterprises. For this reason, it would not be entirely inconceivable for a court to read the language merely to ban third parties from profiting from organ procurement on a per-transaction basis, especially if public sentiment were to shift dramatically in favor of allowing some sales.

The Association of State and National Legislation with Living Kidney Donation Rates in the United States: A National Study



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...you know what I'm craving? A little perspective. That's it. I'd like some fresh, clear, well-seasoned perspective. Can you suggest a good wine to go with that? -Anton Ego (Ratatouille)