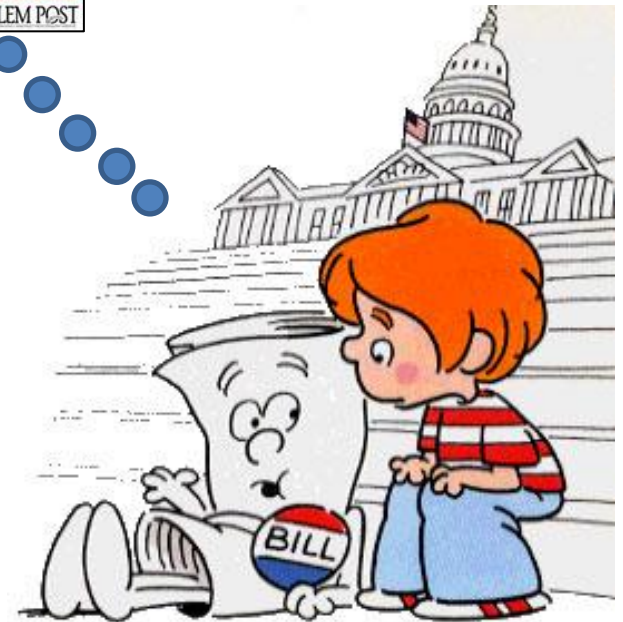
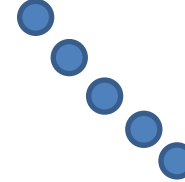
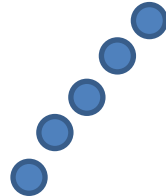
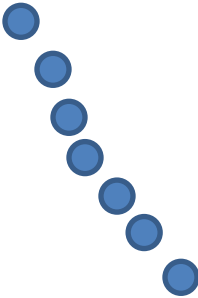


Research Advocacy

Dorry Segev, MD, PhD
Professor of Surgery and Epidemiology
Associate Vice Chair
Dept of Surgery
Johns Hopkins Univ



Motivating HOPE

- Poor outcomes of HIV+ patients on kidney and liver waiting lists
- Encouraging outcomes with NIH HIV trial
- Encouraging outcomes with HIV-to-HIV in South Africa



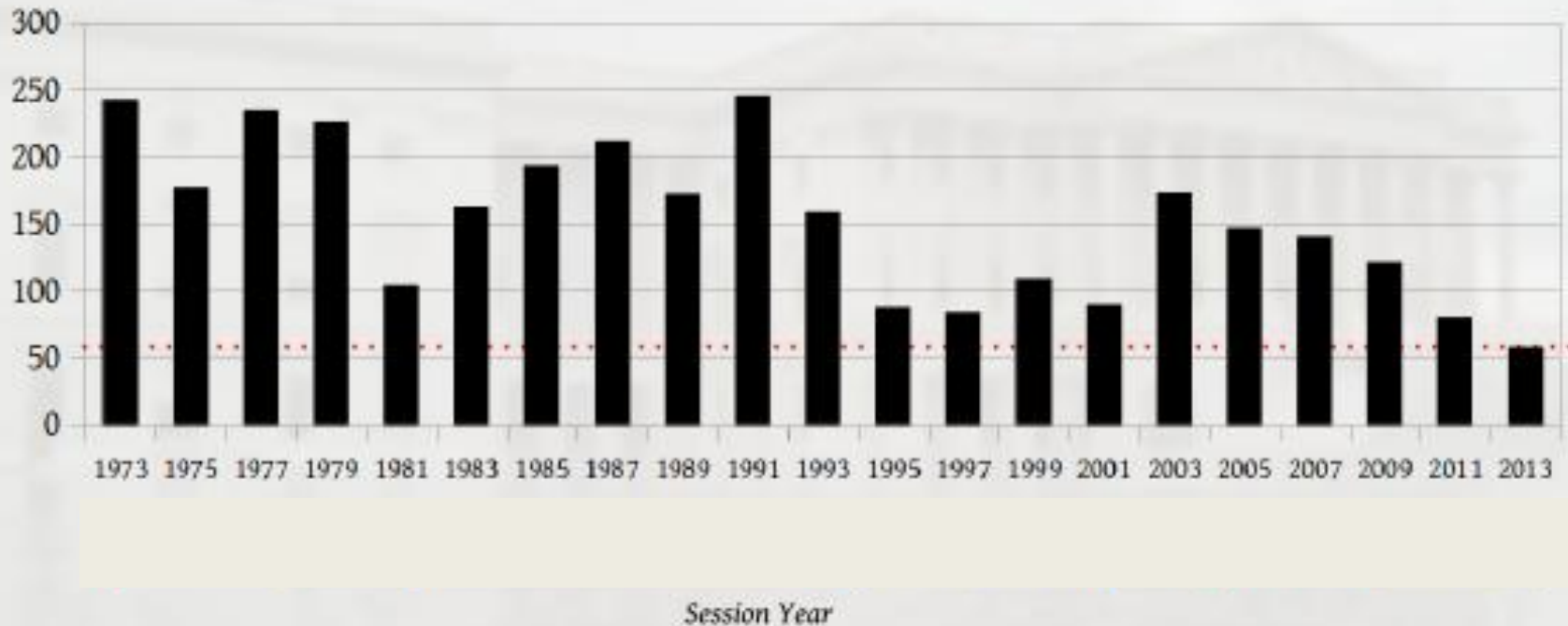
42 U.S.C. 274(b) Section 372(b)

"...including standards for preventing the acquisition of organs that are infected with the etiologic agent for acquired immune deficiency syndrome"

(National Organ Transplant Act, 1984/88)

Bills Enacted

First Session of Each Congress Since 1973



- >7,000 bills before Congress
- < 5% become law

From Bench to Bill: How a Transplant Nuance Became One of Only 57 Laws Passed in 2013

Brian J. Boyarsky, BA, and Dorry L. Segev, MD, PhD*†*

(Ann Surg 2015;xx:xxx–xxx)

“I’m just a bill, yes I’m only a bill, and I’m sitting here on Capitol Hill.

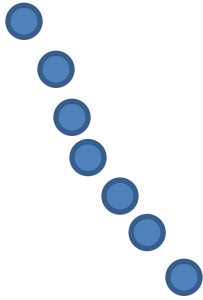
Well, it’s a long, long journey to the capital city,
It’s a long, long wait while I’m sitting in committee,
But I know I’ll be a law someday. . .

At least I hope and pray that I will, but today I am still just a bill.”

(Schoolhouse Rock)

Getting Congress to Do Something

- How many people are we talking about?
- What will be the benefit if we do this?
 - How many lives will be saved
 - How much money will it cost (or save)
- What is the political benefit/risk?
 - Will our constituents benefit?
 - Will our constituents be harmed?



Estimating the Potential Pool of HIV-Infected Deceased Organ Donors in the United States

**B. J. Boyarsky^a, E. C. Hall^{a,b}, A. L. Singer^a,
R. A. Montgomery^a, K. A. Gebo^{c,d,e}
and D. L. Segev^{a,d,*}**

^a*Department of Surgery, Johns Hopkins School of
Medicine, Baltimore, MD*

^b*Department of Surgery, Georgetown University School
of Medicine, Washington, DC*

^c*Department of Medicine, Johns Hopkins University
School of Medicine, Baltimore, MD*

^d*Department of Epidemiology, Johns Hopkins School of
Public Health, Baltimore, MD*

^e*HIV Research Network, Baltimore, MD*

**Corresponding author: Dorry L. Segev, dorry@jhmi.edu*

**Received 03 December 2010, revised 24 January 2011
and accepted for publication 09 February 2011**

2011
February.
March.
April.
July.
August.
November.

AJT study published
HIVMA & major AIDS groups position established
NYT coverage of study
ASTS, AST, UNOS, AOPO position established
First meeting on Capitol Hill
AMA endorsement

2012
March.

June.

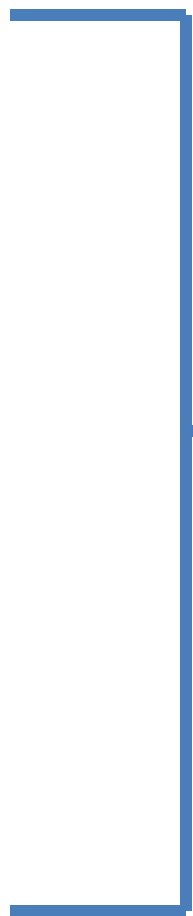
Lead sponsors established
Draft legislative language
Meet with HHS/ONAP
Congressional briefing

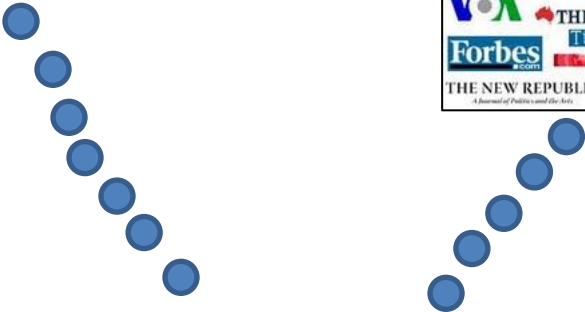
Meetings on the Hill

2013
February.
March.

June.
November.

HOPE Act introduced
CBO scoring
Senate HELP passes HOPE Act
Senate passes HOPE Act
House E & C passes HOPE Act
House passes HOPE Act
Obama signs HOPE Act





"All the News
That's Fit to Print"

The New York Times

Washington Edition

Today, summerlike, clouds then sun, breezy, high 85. Tonight, mostly cloudy, showers, a thunderstorm late, low 59. Tomorrow, more rain, high 65. Weather map, Page D8.

VOL. CLX . . . No. 55,372

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MONDAY, APRIL 11, 2011

\$2.00

A Push to Let H.I.V. Patients Accept Organs That Are Infected

By PAM BELLUCK

David Aldridge of Los Angeles had a kidney transplant in 2006, but he will soon need another. Like many people living with H.I.V., he suffers from kidney damage, either from the virus or from the life-saving medications that keep it at bay.

Until recently, such patients did not receive transplants at all because doctors worried that their health was too compromised. Now they can get transplants, but organ-donor waiting lists are long. And for Mr. Aldridge, 45, and other H.I.V. patients, a potential source of kidneys and livers is off limits, because it is illegal to transplant organs from donors who test posi-

other experts are calling for repeal of the provision that bans such transplants, a 23-year-old amendment to the National Organ Transplant Act.

"The clock is ticking more quickly for those who are H.I.V.-positive," said Dr. Dorry Segev, transplant surgery director of clinical research at Johns Hopkins and a co-author of a new study indicating that 500 to 600 H.I.V.-infected livers and kidneys would become available each year if the law were changed. "We have a huge organ shortage. Every H.I.V.-infected one we use is a new organ that takes one more person off the list."

The ban on transplanting or-

Quotation of the Day

"The clock is ticking more quickly for those who are H.I.V.-positive."
DR. DORRY SEGEV, a co-author of a study indicating that 500 to 600 H.I.V.-infected livers and kidneys would become available each year if the law were changed to allow their use in some patients.

2011

February.

AJT study published

March.

HIVMA & major AIDS groups position established

April.

NYT coverage of study

July.

ASTS, AST, UNOS, AOPO position established

August.

First meeting on Capitol Hill

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Meet with HHS/ONAP

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Meetings on the Hill

2013

February.

HOPE Act introduced

March.

CBO scoring

Senate HELP passes HOPE Act

June.

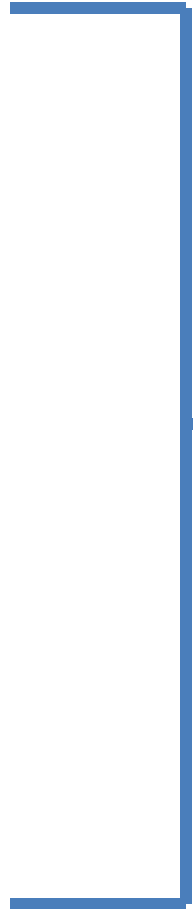
Senate passes HOPE Act

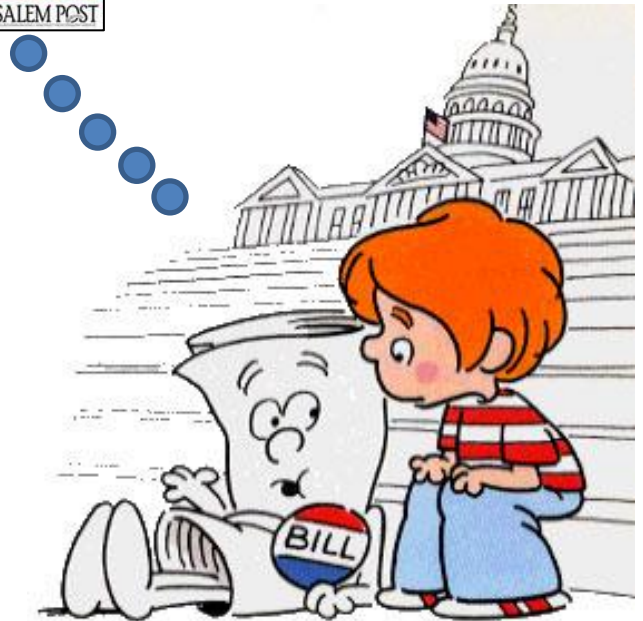
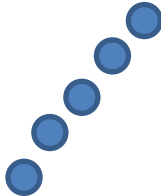
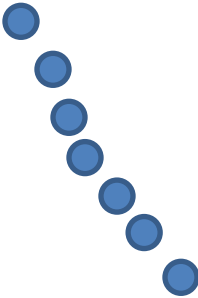
November.

House E & C passes HOPE Act

House passes HOPE Act

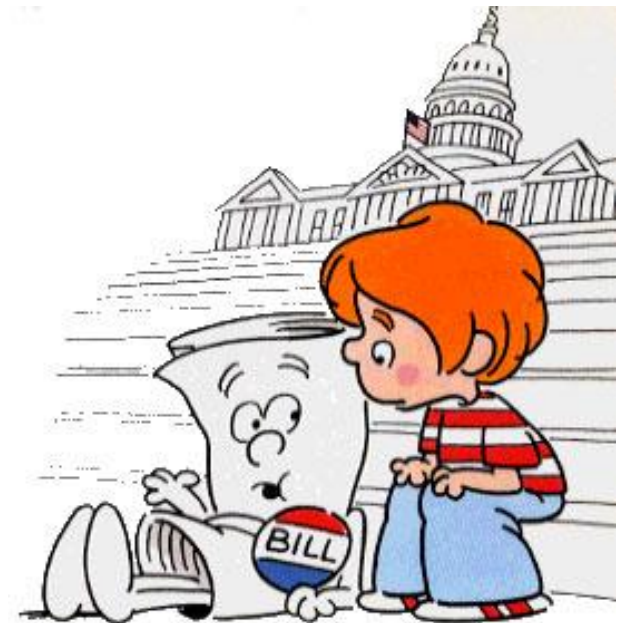
Obama signs HOPE Act





Our Effort Inside the Beltway

- **Congress**
 - US Senate
 - US House of Representatives
- **The Obama Administration**
 - National AIDS Strategy
 - HHS/HRSA
- **Professional group endorsements**
 - Transplantation
 - HIV/AIDS
 - General medical
 - Patient advocacy



Official Endorsements

AIDS Community Research Initiative
AIDS Foundation of Chicago
AIDS Law Project of Pennsylvania
AIDS Project Los Angeles
AIDS Treatment News
AIDS United
American Academy of HIV Medicine
American Association of Kidney Patients
American Medical Association
American Sexual Health Association
American Society of Nephrology
AST
ASTS
American Transplant Foundation
amfAR, The Foundation for AIDS Research
Association of Nurses in AIDS Care
AOPO
Birmingham AIDS Outreach
Cascade AIDS Project
Center for HIV Law and Policy
Community Access National Ntwk
Dialysis Patient Citizens
Eye Bank Association of America
Fenway Health/Fenway Institute
Gay & Lesbian Medical Association

Gay Men's Health Crisis
HealthHIV
HIV Dental Alliance
HIV Medicine Association
Human Rights Campaign
Infectious Diseases Society of America
Lambda Legal
Latino Commission on AIDS
Mendocino County AIDS/Viral Hepatitis Network
Moveable Feast
NATCO
National Minority AIDS Council
Okaloosa AIDS Support
RAIN Oklahoma
Renal Physicians Association
San Francisco AIDS Foundation
Sisterhood Mobilized for Research & Treatment
Texas Transplant Society
The AIDS Institute
Transplant Recipients International
Treatment Action Group
UNOS
US Positive Women's Network
VillageCare
Warren Clinic for Pediatric Infectious Diseases

Congressional Briefing



Increasing Organ Donation

Repeal of the 1980s federal ban on transplanting organs from
HIV+ donors to benefit HIV+ recipients

HIV Medicine Association • amfAR, The Foundation for AIDS Research
Human Rights Campaign • AIDS United • Treatment Action Group

Invite you to a Congressional Briefing held in collaboration with the offices of



Wednesday, June 27, 2012

12:00 - 1:00 pm

Room SVC 201-00

*** Lunch will be provided ***

Joel Newman

Professor of Medicine
Johns Hopkins School of Medicine
Assistant Director, Communications
United Network for Organ Sharing (UNOS)

Thomas Lane

Kidney Transplant Recipient

Kindly **RSVP** by June 25 to bjb@jhmi.edu



Congressional Briefing in June 2012

- Moderated by ABC journalist
- > 100 legislative aides
 - Standing room only
 - Facts and emotions
- Very positive write up in CQ & feedback from staff
- BEFORE we had a bill introduced

Senate Co-Sponsors

*Boxer, Barbara [D-CA]

*Baldwin, Tammy [D-WI]

Warren, Elizabeth [D-MA]

Feinstein, Dianne [D-CA]

Blumenthal, Richard [D-CT]

Landrieu, Mary [D-LA]

Schatz, Brian [D-HI]

Levin, Carl [D-MI]

Pryor, Mark [D-AR]

*Coburn, Thomas [R-OK]

*Paul, Rand [R-KY]

Enzi, Michael [R-WY]

Burr, Richard [R-NC]

Kirk, Mark [R-IL]

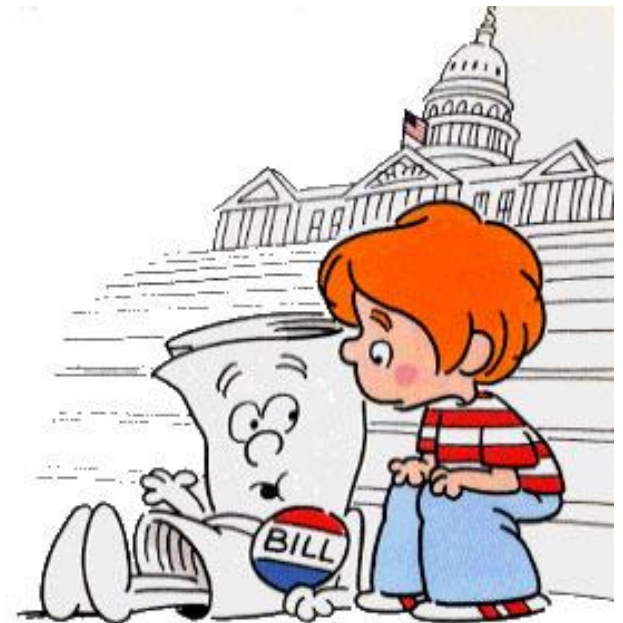
Blunt, Roy [R-MO]

House Co-Sponsors

*Capps, Lois [D-CA24]	Rush, Bobby [D-IL1]	Harris, Andy [R-MD1]
Cummings, Elijah [D-MD7]	Takano, Mark [D-CA41]	Burgess, Michael [R-TX26]
Grijalva, Raúl [D-AZ3]	Pingree, Chellie [D-ME1]	Griffin, Tim [R-AR2]
Lee, Barbara [D-CA13]	Brady, Robert [D-PA1]	Wittman, Robert [R-VA1]
Wilson, Frederica [D-FL24]	Hastings, Alcee [D-FL20]	Radel, Trey [R-FL19]
Moore, Gwen [D-WI4]	Shea-Porter, Carol [D-NH1]	Miller, Candice [R-MI10]
Payne, Donald [D-NJ10]	Speier, Jackie [D-CA14]	Petri, Thomas "Tom" [R-WI6]
Clay, Lacy [D-MO1]	Cartwright, Matthew [D-PA17]	Young, W. Bill [R-FL13]
Rangel, Charles [D-NY13]	Jackson Lee, Sheila [D-TX18]	Benishek, Dan [R-MI1]
Schiff, Adam [D-CA28]	Maloney, Sean [D-NY18]	McKinley, David [R-WV1]
Braley, Bruce [D-IA1]	McDermott, Jim [D-WA7]	Ros-Lehtinen, Ileana [R-FL27]
Huffman, Jared [D-CA2]	Titus, Dina [D-NV1]	Harper, Gregg [R-MS3]
Loeb sack, David [D-IA2]	Carson, André [D-IN7]	
Polis, Jared [D-CO2]	Levin, Sander [D-MI9]	
Norton, Eleanor [D-DC0]	Cohen, Steve [D-TN9]	
Costa, Jim [D-CA16]	Pocan, Mark [D-WI2]	
Michaud, Michael [D-ME2]	Christensen, Donna [D-VI0]	
Ruiz, Raul [D-CA36]	Schwartz, Allyson [D-PA13]	
Cicilline, David [D-RI1]	Chu, Judy [D-CA27]	
Maloney, Carolyn [D-NY12]	Himes, James [D-CT4]	
Schakowsky, Janice "Jan" [D-IL9]	Lipinski, Daniel [D-IL3]	

S330/HR698: Progress

- Introduced **Feb 14**, 2013
- Senate:
 - HELP Committee: 3/20/13
 - Floor Vote: Unanimous 6/17/13
- House:
 - E&C Committee: 7/17/13
 - Suspension: 11/12/13
- **Obama: 11/21/13**







ABC News @ABC · Mar 31
 1st liver **transplant** between **HIV**-positive donor and recipient is milestone for **HIV** patients. abcn.ws/25yxvv3



The New York Times

HEALTH

Hopkins Begins Nation's First HIV-Positive Organ Transplants



NPR Health News @NPRHealth · Mar 31
 New Source Of **Transplant** Organs For Patients With **HIV**:
 Others With **HIV** n.pr/1RLIzxl

27 18

[View summary](#)



TIME.com @TIME · Mar 31
 First ever **HIV-to-HIV** liver transplant performed in U.S.
ti.me/1pMuWVe

THE BALTIMORE SUN

BREAKING SPORTS MARYLAND POLITICS OPINION OBITS ENEWSPAPER ADVERTISING

Johns Hopkins performs first transplants between donors, recipients infected with HIV

PHOTO GALLERY



Dorry Segev, M.D., Ph.D.



In a medical first, HIV-infected organs are transplanted into HIV-positive patients

There used to be a longstanding ban on the use of HIV-infected organs in transplantation.

LATIMES.COM | BY LOS ANGELES TIMES



People Magazine @people · Mar 31
 Johns Hopkins performs first successful **HIV**-positive organ **transplant**
peoplem.ag/YvMn3vR

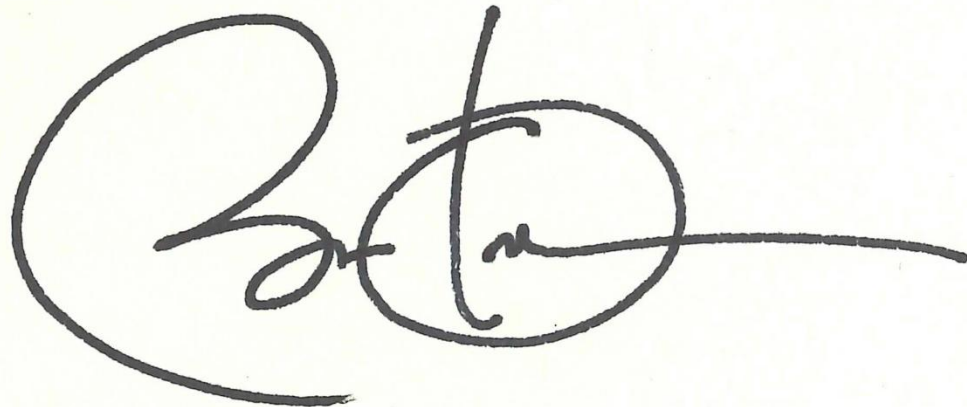
Dear Dr. Segev:

I wanted to take a moment to extend my congratulations on all you've done to successfully increase access to life-saving organ transplants.

I was proud to sign the HOPE Act into law in 2013 as part of the effort to expand the national supply of organs for all those in need. Through your team's actions—including performing the first-ever transplants between HIV-positive donors and recipients in the United States—the intent of this legislation has been realized and will continue to be for generations to come.

Again, congratulations. You and your colleagues have my very best.

Sincerely,

A handwritten signature in black ink, appearing to be Barack Obama's signature, consisting of a large 'B' followed by 'arack' and a long horizontal line.

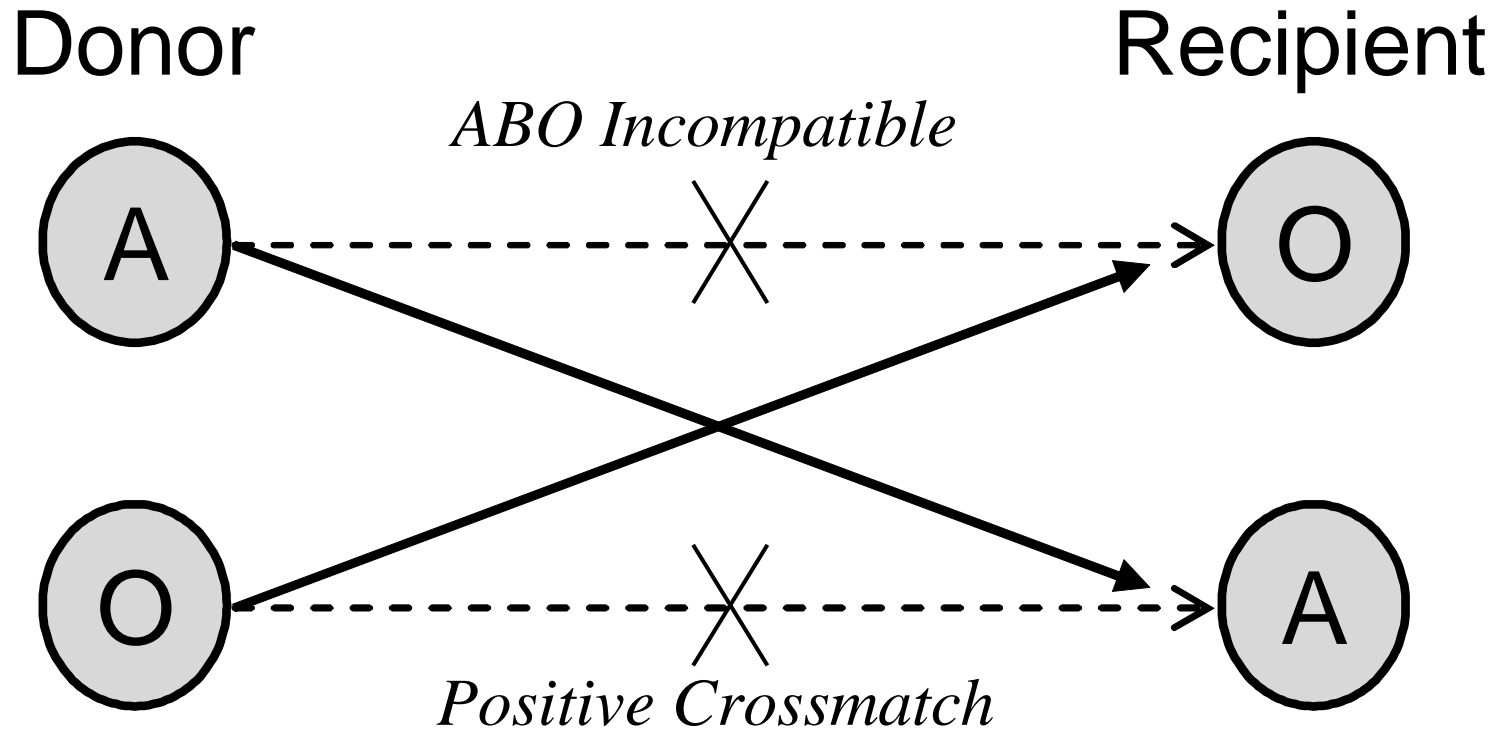


National Institutes of Health

Turning Discovery Into Health

- R01AI120938: Unlocking the potential of HIV-infected deceased donors for organ transplantation
- R34AI123023: HOPE in Action: HIV-to-HIV solid organ transplantation in the US
- U01AI134591: HOPE in Action: A clinical trial of HIV-to-HIV kidney transplantation
- U01AI138897: HOPE in Action: A clinical trial of HIV-to-HIV liver transplantation

Kidney Exchange: Paradigm



42 U.S.C. 274(e)

"It shall be unlawful for any person to knowingly acquire, receive, or otherwise transfer any human organ for valuable consideration for use in human transplantation..."

(National Organ Transplant Act, 1984/88)

Kidney Paired Donation and Optimizing the Use of Live Donor Organs

Dorry L. Segev, MD

Sommer E. Gentry, MS

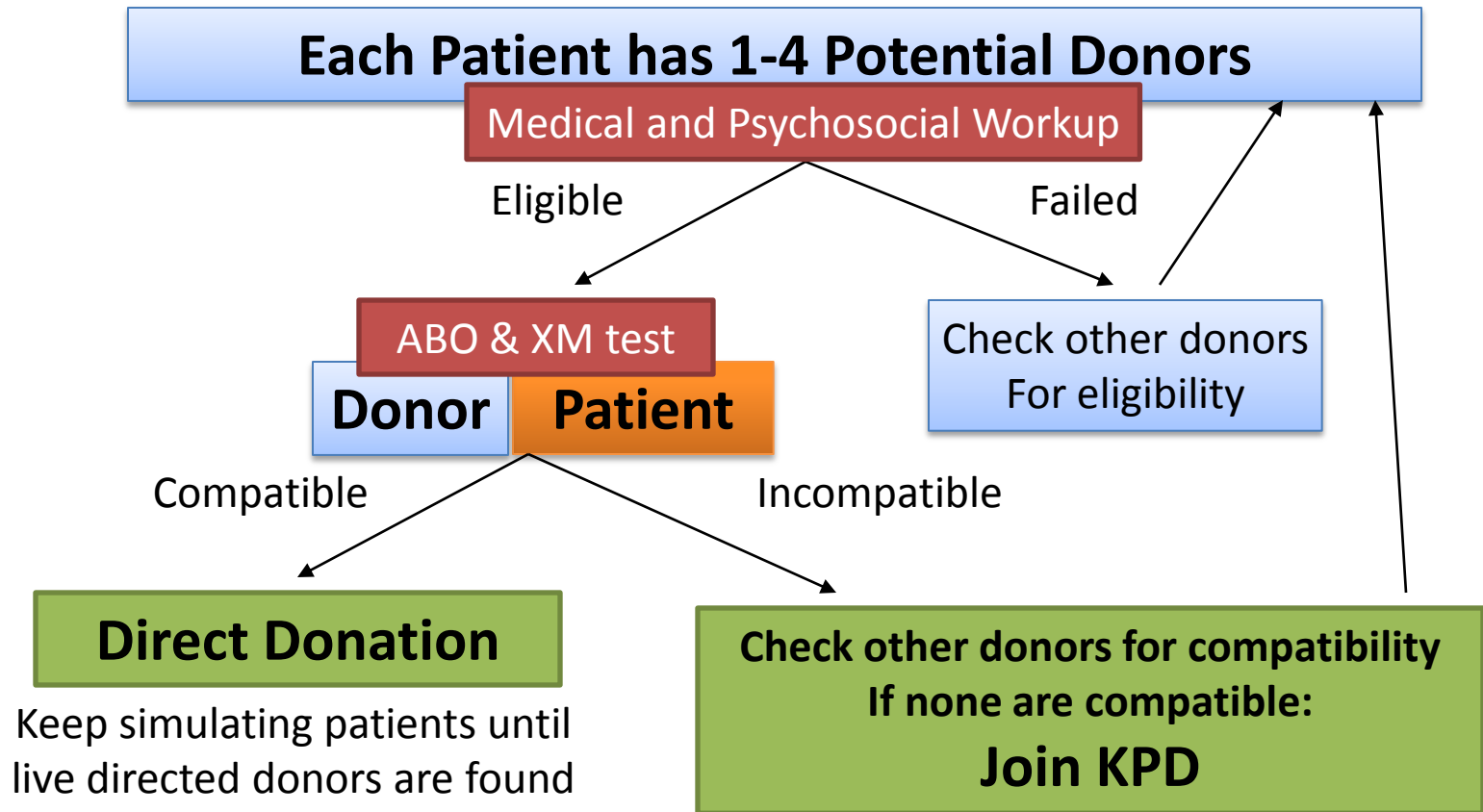
Daniel S. Warren, PhD

Brigitte Reeb, MFA

Robert A. Montgomery, MD, DPhil

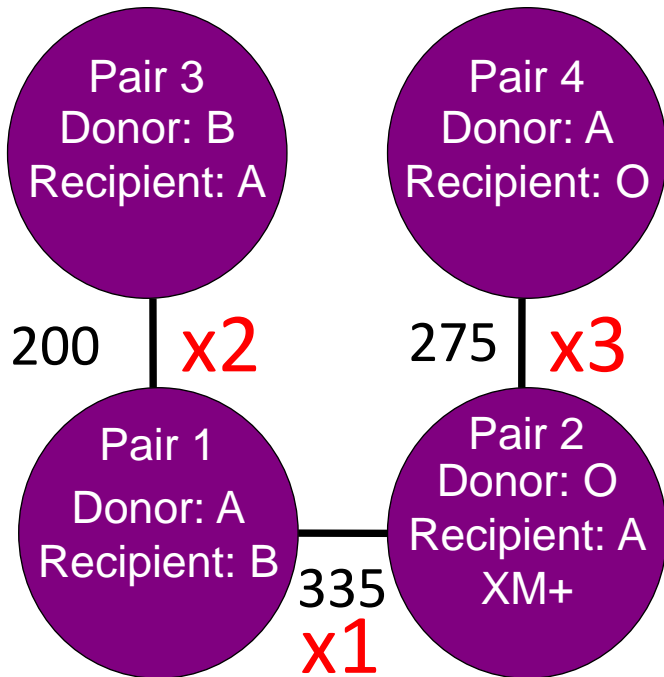
- How many pairs?
- How best to match them?
- How many lives would be saved?
- How much money would Medicare save?

Mathematical Modeling: Monte Carlo Simulation



(Segev, JAMA, 2005)

Kidney Exchange: IP Optimization



x_1 = pair 1 and 2 match

x_2 = pair 1 and 3 match

x_3 = pair 2 and 4 match

objective:

$$\max(335 * x_1 + 200 * x_2 + 275 * x_3)$$

subject to constraints:

$$x_1, x_2, x_3 \in \{0, 1\}$$

$$x_1 + x_2 \leq 1$$

$$x_1 + x_3 \leq 1$$

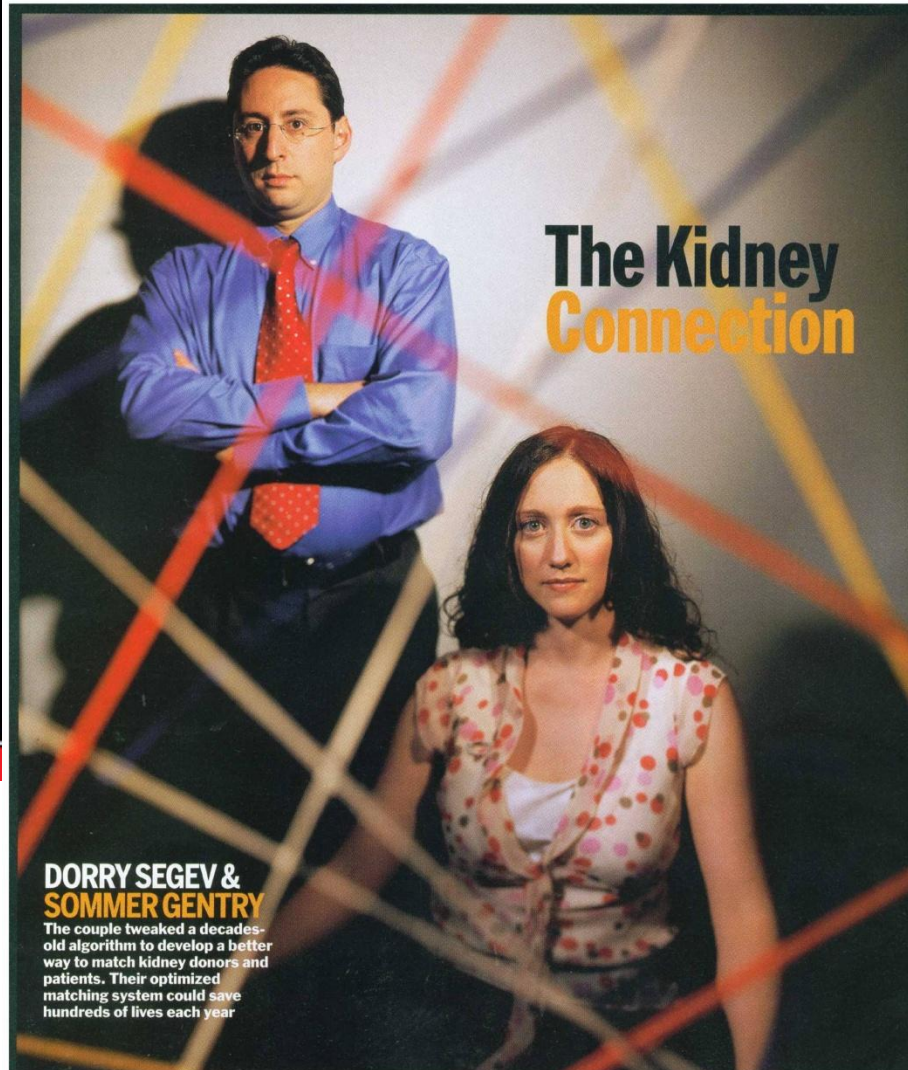
(Segev, JAMA, 2005)

SEPTEMBER 12, 2005

www.time.com AOL Keyword: TIME

TIME

New Orleans,
September 2, 2005



The Kidney Connection

DORRY SEGEV & SOMMER GENTRY

The couple tweaked a decades-old algorithm to develop a better way to match kidney donors and patients. Their optimized matching system could save hundreds of lives each year

A BILL

To amend the National Organ Transplant Act to clarify that kidney paired donations shall not be considered to involve the transfer of a human organ for valuable consideration.

1 *Be it enacted by the Senate and House of Representa-*
2 *tives of the United States of America in Congress assembled,*

3 **SECTION 1. SHORT TITLE.**

4 This Act may be cited as the “Living Kidney Organ
5 Donation Clarification Act of 2007”.

1 **SEC. 2. AMENDMENT TO THE NATIONAL ORGAN TRANS-**
2 **PLANT ACT.**

3 Section 301(a) of the National Organ Transplant Act
4 (42 U.S.C. 274e(a)) is amended by adding at the end the
5 following: “For purposes of this section, kidney paired do-
6 nations shall not be considered to involve the transfer of
7 a human organ for valuable consideration.”.

S.487

Title: A bill to amend the National Organ Transplant Act to clarify that kidney paired donations shall not be considered to involve the transfer of a human organ for valuable consideration.

Sponsor: [Sen Levin, Carl](#) [MI] (introduced 2/1/2007) [Cosponsors](#) (10)

Related Bills: [H.R.710](#)

Latest Major Action: 2/16/2007 Referred to House committee. Status: Referred to the House Committee on Energy and Commerce.

COSPONSORS(10), BY DATE [order is left to right]: (Sort: [alphabetical order](#))

Sen Bond, Christopher S. [MO] - 2/1/2007	Sen Dorgan, Byron L. [ND] - 2/1/2007
Sen Graham, Lindsey [SC] - 2/1/2007	Sen Durbin, Richard [IL] - 2/1/2007
Sen Mikulski, Barbara A. [MD] - 2/1/2007	Sen Pryor, Mark L. [AR] - 2/1/2007
Sen Cardin, Benjamin L. [MD] - 2/1/2007	Sen Brown, Sherrod [OH] - 2/13/2007
Sen Isakson, Johnny [GA] - 2/13/2007	Sen Chambliss, Saxby [GA] - 2/16/2007

H.R.710

Title: To amend the National Organ Transplant Act to clarify that kidney paired donation does not involve the transfer of a human organ for valuable consideration.

Sponsor: [Rep Norwood, Charles W.](#) [GA-10] (introduced 1/29/2007) [Cosponsors](#) (29)

Related Bills: [S.487](#)

Latest Major Action: 1/29/2007 Referred to House committee. Status: Referred to the House Committee on Energy and Commerce.

COSPONSORS(29), ALPHABETICAL [followed by Cosponsors withdrawn]: (Sort: [by date](#))

[Rep Allen, Thomas H.](#) [ME-1] - 2/12/2007

[Rep Brown-Waite, Ginny](#) [FL-5] - 2/13/2007

[Rep Capps, Lois](#) [CA-23] - 2/7/2007

[Rep DeGette, Diana](#) [CO-1] - 2/7/2007

[Rep Gingrey, Phil](#) [GA-11] - 2/12/2007

[Rep Johnson, Henry C. "Hank," Jr.](#) [GA-4] - 2/12/2007

[Rep Markey, Edward J.](#) [MA-7] - 2/13/2007

[Rep Payne, Donald M.](#) [NJ-10] - 2/12/2007

[Rep Pitts, Joseph R.](#) [PA-16] - 2/12/2007

[Rep Ruppersberger, C. A. Dutch](#) [MD-2] - 2/7/2007

[Rep Shimkus, John](#) [IL-19] - 2/12/2007

[Rep Upton, Fred](#) [MI-6] - 2/12/2007

[Rep Westmoreland, Lynn A.](#) [GA-3] - 2/7/2007

[Rep Whitfield, Ed](#) [KY-1] - 2/12/2007

[Rep Wynn, Albert Russell](#) [MD-4] - 2/7/2007

[Rep Boozman, John](#) [AR-3] - 2/13/2007

[Rep Burgess, Michael C.](#) [TX-26] - 2/7/2007

[Rep Cubin, Barbara](#) [WY] - 2/12/2007

[Rep Ferguson, Mike](#) [NJ-7] - 2/12/2007

[Rep Inslee, Jay](#) [WA-1] - 1/29/2007

[Rep Kilpatrick, Carolyn C.](#) [MI-13] - 2/13/2007

[Rep Myrick, Sue Wilkins](#) [NC-9] - 2/12/2007

[Rep Pickering, Charles W. "Chip"](#) [MS-3] - 2/12/2007

[Rep Price, Tom](#) [GA-6] - 2/13/2007

[Rep Sessions, Pete](#) [TX-32] - 2/12/2007

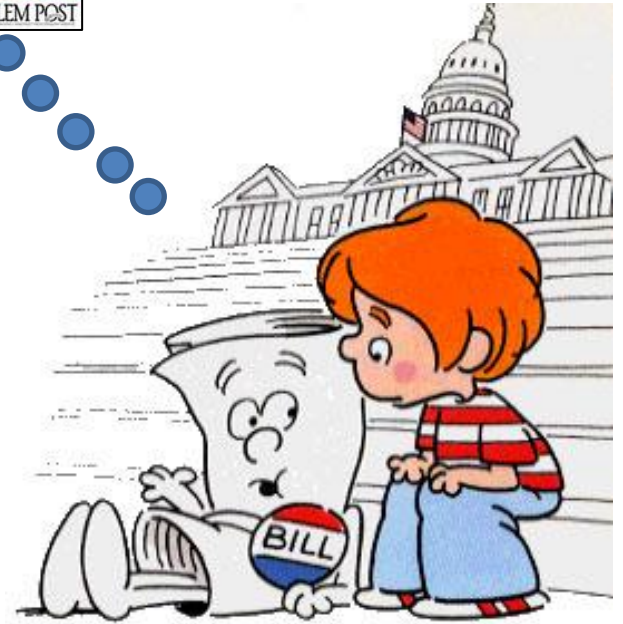
[Rep Simpson, Michael K.](#) [ID-2] - 2/12/2007

[Rep Walden, Greg](#) [OR-2] - 2/13/2007

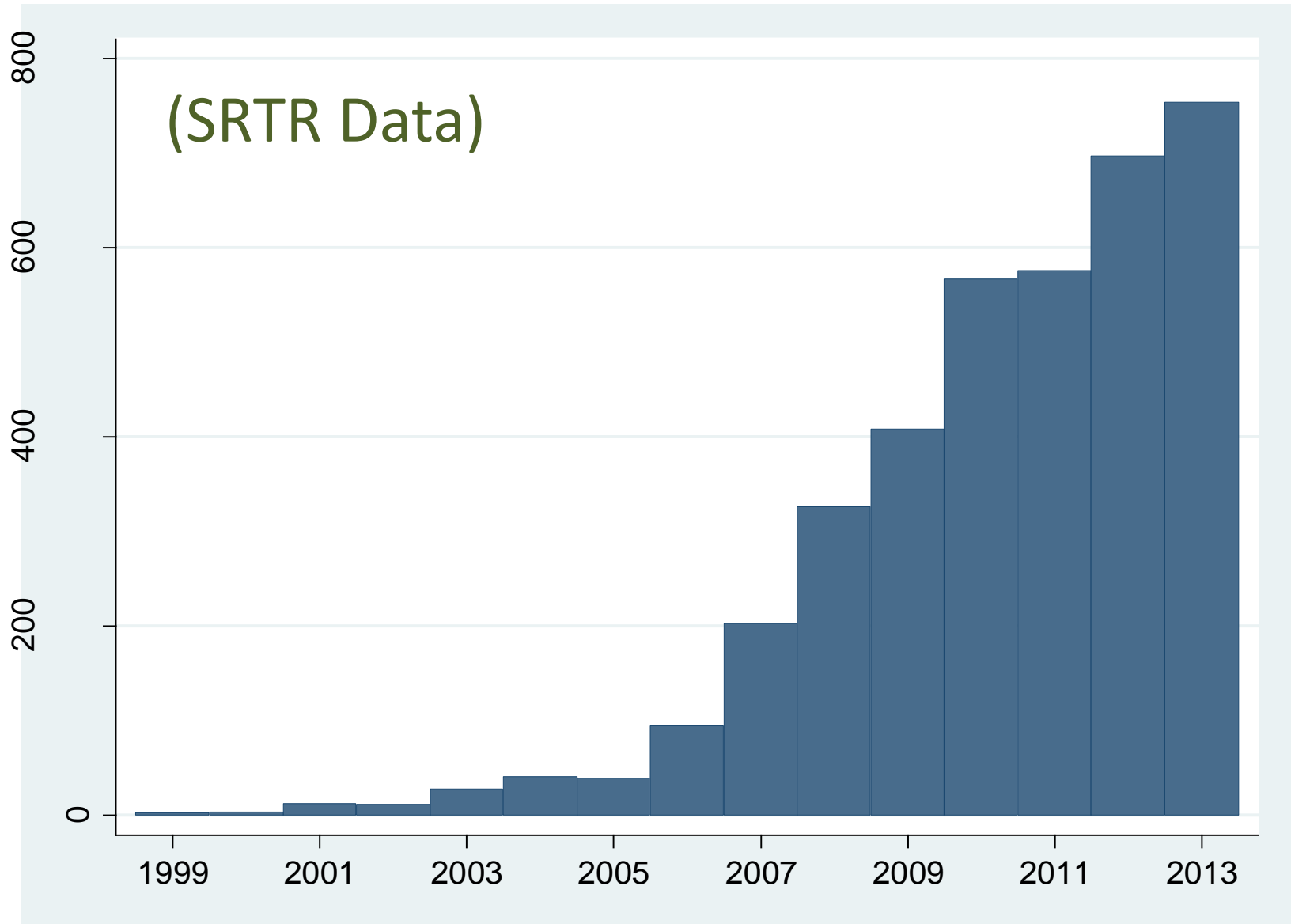
[Rep Wexler, Robert](#) [FL-19] - 2/7/2007

[Rep Wilson, Joe](#) [SC-2] - 2/12/2007

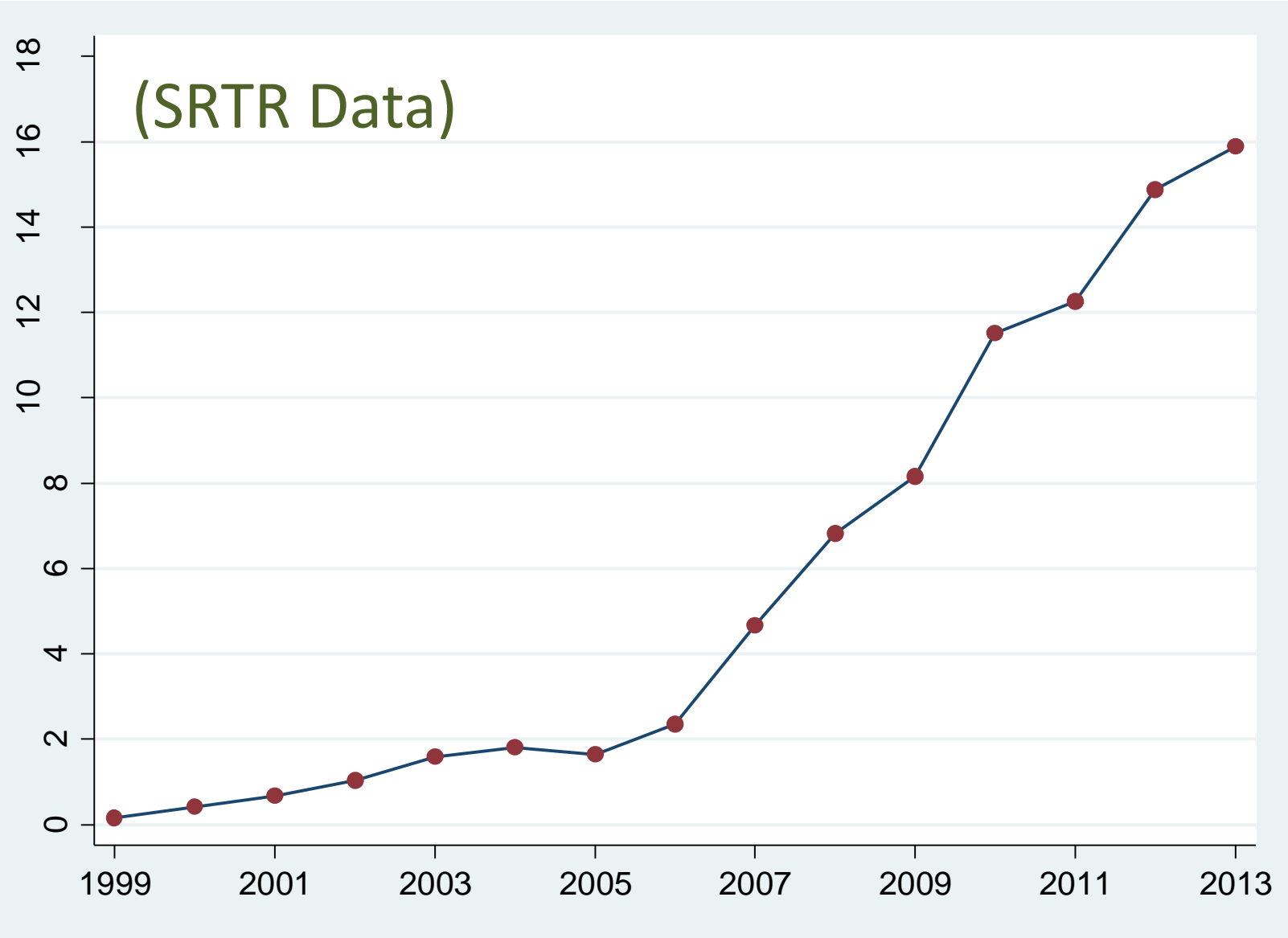




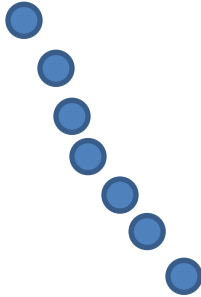
Kidney Exchange in the US: >5000



16% of Live Donor Transplants

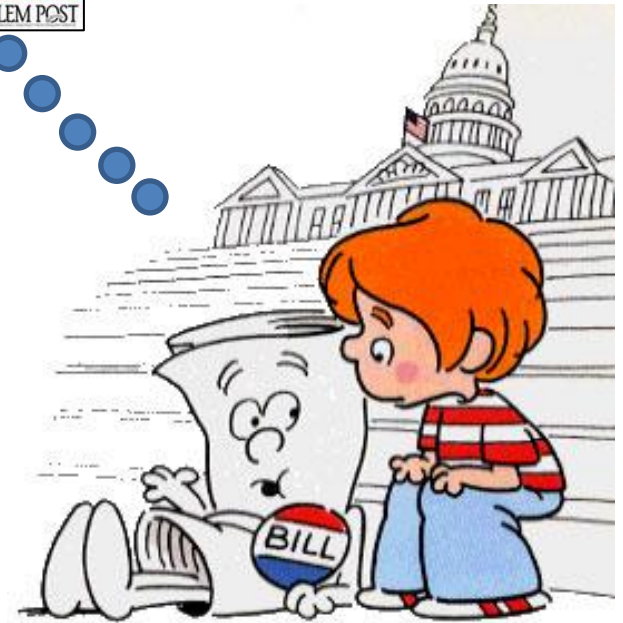


*Learn the policy
Think from the trenches*



*Learn the science
Publish for the policymakers*

*Make media connections
Learn how to talk to media*



*Learn how congress works (Fellowship?)
Work with advocacy groups, societies, LAs*