Diogenes' Lamp: Performatives, Stem-Cell Politics, and Ethics in the Public Representation of Science

Kirk C. Allison, Ph.D., M.S

Program in Human Rights & Health

School of Public Health, University of Minnesota

alli0001@umn.edu

APHA 2007: Politics, Policy & Public Health

4131.0 Public Health Science, ethics, Policy, and Politics

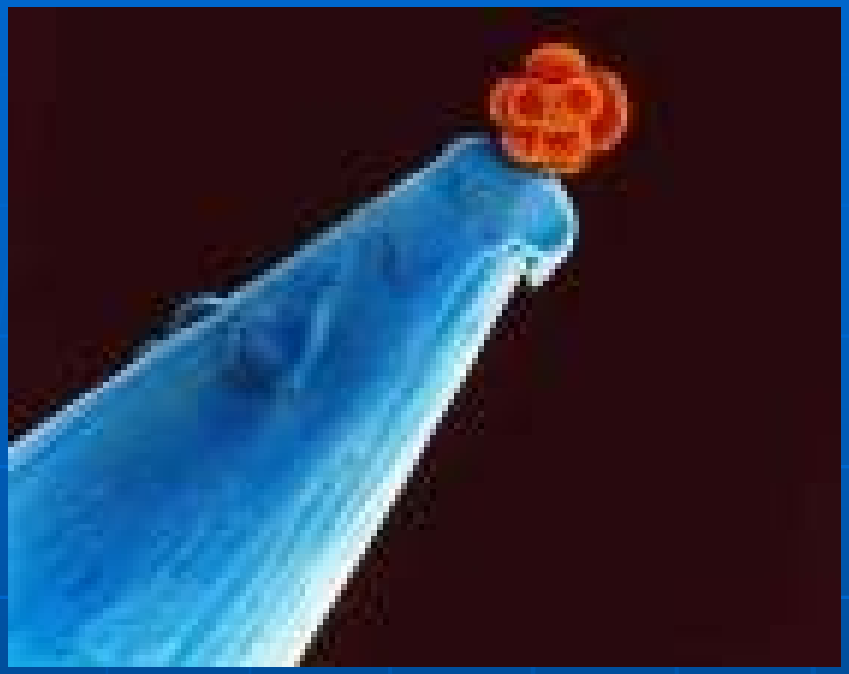
12:30 p.m., Tuesday, 6 November 2007

Διογένης ὁ Σινωπεύς

Diogenes of Sinope, 4th C BC(E)

(After a long day on Capitol Hill)

***Diogenes* by John William Waterhouse, 1905**



What does this image convey
in the scientific-political discourse of . . .

- Developmental biology ?
- Regenerative medicine ?
- Stem cell science ?
- Nanotechnology ?

Credit: Dr. Yorgas Nikas / Photo Researchers, Inc.

In policy, politics & public health - Information is a Public Good

- Accurate information is a public good in a democratic society and a *public health good*.
  - In market theory, imperfect information leads to economic inefficiencies.
  - In the political realm, imperfect (or mis-) information leads to policy inefficiencies.
  - For public health either leads to resource inefficiencies and poorer outcomes.

Information as a Public Good

- Imperfect information in part is a function of uncertainty (the falsification horizon of a new scientific subdisciplines is distant)
  - Claims:

    Accurate & Justified | Accurate & Unjustified

    Inaccurate & Justified | Inaccurate & Unjustified
- Accurate information is an ethical good.
  - Misinformation is ethically (and politically) pernicious because it deprives one's ethical (and political) freedom.

Asymmetries of Knowledge

- A characteristic of stem cell ethics / policy debates in public discourse has been that lines of dispute involve not only judgments of value, but also operational definitions of technical terminology.

Hypothesis: the duration of information asymmetries between scientists and public is partially an ethical artifact: greater translation is possible, but not always a perceived interest where asymmetry increases authority or autonomy.

Overview

- Information as a Public Good
- Polling and framing
- Performatives and stem cell politics
- The promise of miracles? California Proposition 71
- Repairatives

Following August 9, 2001 stem cell announcement – Gallup poll re 'ban'

Overall, do you approve or disapprove of Bush's decision on stem cell research? Do you disapprove because the ban is -- [ROTATED: too strict (or) not strict enough]?

Gallup Poll

(COMBINED RESPONSES)

		2001 Aug 10-12	2001 Aug 9 ^
		%	%
Approve		60	50
Disapprove		34	25
	Too strict	*(12)*	*(7)*
	Not strict enough	*(19)*	*(13)*
	Don't know	*(3)*	*(5)*
No opinion		6	25

^ Based on one night poll of 581 national adults conducted directly after President Bush's speech on stem cell research. Polls conducted entirely in one day, such as this one, are subject to additional error or bias not found in polls conducted over several days.

How important is the issue of stem cell research to you -- very important, somewhat important, not too important, or not at all important?

Polling and Question Framing

- Negative or positive framing can have a significant effect on stated preferences.

  Tversky A and Kahneman D. The framing of decisions and psychology of choice. *Science* 1981; 211: 453-8.

- Nisbet (2003) identifies wording effects in the stem cell context ...

  Public Opinion Quarterly 2004;68(1):131-154.

Polling and Question Framing

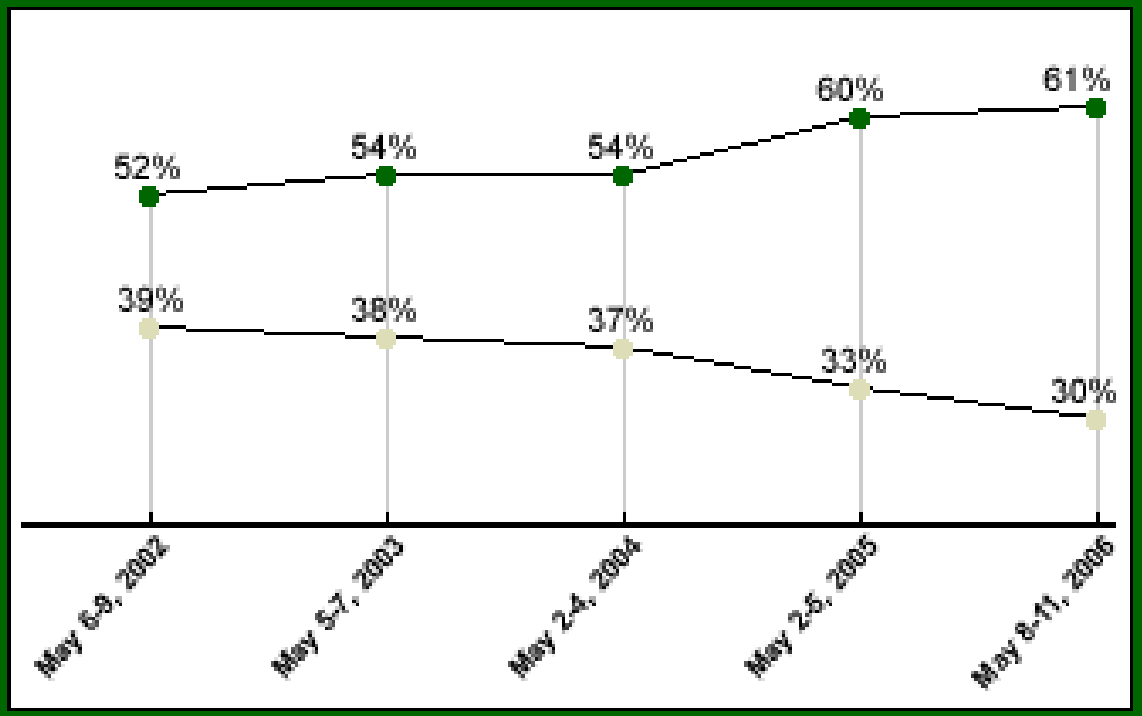
- Juvenile Diabetes Research Foundation
  - Embryos donated to research
  - 8 high profile diseases ‘possible cures’
- National Conference of Catholic Bishops
  - “live embryos would be destroyed”

JDRF results (1/01): 65+, 25-, 9?

NCCOB results (6/01): 24+, 70-, 5?

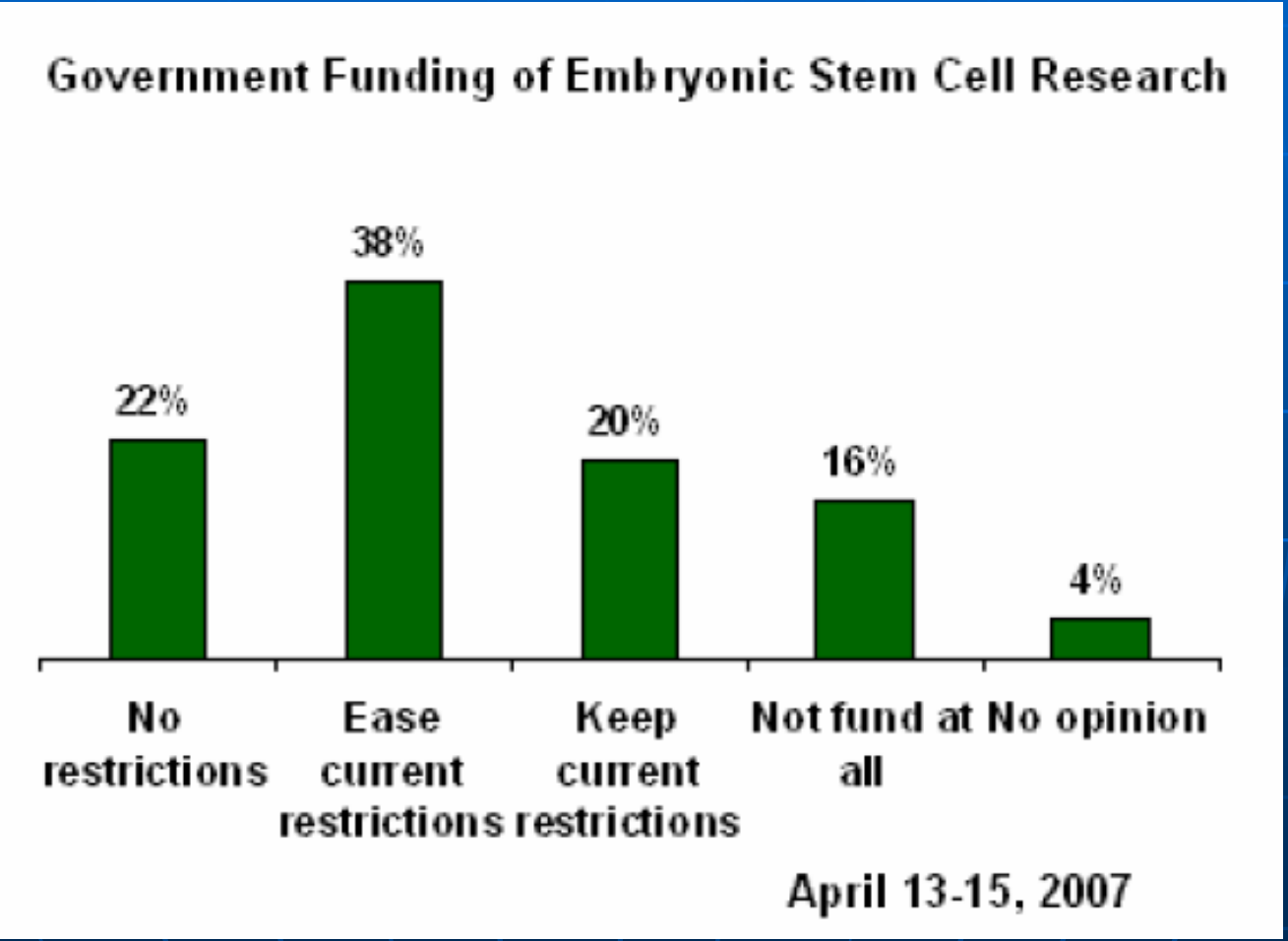
Moral acceptability – "medical research using stem cell obtained from human embryos" 2002-2006

Next, I'm going to read you a list of issues. Regardless of whether or not you think it should be legal, for each one, please tell me whether you personally believe that in general it is morally acceptable or morally wrong. How about -- medical research using stem cells obtained from human embryos?



Gallup Poll, 2007

Embryonic Stem Cell Research, Opinion, April 13-15, 2007



Gallup Poll, 2007

Performatives, Politics and the Public Representation of Science

Performatives

How to do things with words

J.L. Austin (1955/1962)

- Examples: promising, betting, naming, ...
- Performatives as expressions are neither true nor false – they *do*.
- Rather than describing a state of affairs, they create a state of affairs as a speech act.

Performatives – a short primer on 'doing things with words'

- Still, performatives can *fail* due to the formal procedure or intent.
- Austin calls such failure an infelicity.
  - The case of insincerity, dissimulation.

    (e.g. convicting while knowing innocent)
- A failed performative is hollow, but not without consequence.

Performatives
"How to do things with words"

- Definitions in legislation have this *performative* characteristic.

> "§ 301. Definitions
>
> "In this chapter:
>
> "(1) HUMAN CLONING.—The term 'human cloning' means human asexual reproduction, accom-

- "Of all people, jurists should be best aware of the true state of affairs. Perhaps some now are. Yet they will succumb to their own timerous fiction that a statement of 'the law' is a statement of fact." (Austin)

Doing things with words, or: when is a clone a clone?

Stem Cell Information

The **National Institutes of Health** resource for stem cell research

Home › Info Center › Glossary

http://stemcells.nih.gov/info/glossary.asp

NIH Glossary baseline

Clone—Generate identical copies of a molecule, cell, or organism.

1. When it is used to refer to cells grown in a tissue culture dish, a clone is a line of cells that is genetically identical to the originating cell. This cloned line is produced by cell division (mitosis) of the originating cell.
2. The term clone may also be used to refer to an animal produced by somatic cell nuclear transfer (SCNT).

Cloning—See Somatic cell nuclear transfer (SCNT).

Stem Cell Information

The **National Institutes of Health** resource for stem cell research

Home › Info Center › Glossary

http://stemcells.nih.gov/info/glossary.asp

Somatic cell nuclear transfer (SCNT)—A technique that combines an enucleated egg (nucleus removed) and the nucleus of a somatic cell to make an embryo. SCNT is the scientific term for cloning. SCNT can be used for therapeutic or reproductive purposes, but the initial stage that combines an enucleated egg and a somatic cell nucleus is the same. See also therapeutic cloning and reproductive cloning.

Stem Cell Information

The **National Institutes of Health** resource for stem cell research

Home › Info Center › Glossary

http://stemcells.nih.gov/info/glossary.asp

Therapeutic cloning—The goal of therapeutic cloning is to create cells that exactly match a patient. By combining a patient's somatic cell nucleus and an enucleated egg, a scientist may harvest embryonic stem cells from the resulting embryo that can be used to generate tissues that match a patient's body. This means the tissues created are unlikely to be rejected by the patient's immune system. See also Somatic cell nuclear transfer (SCNT).

Reproductive cloning—The goal of reproductive cloning is to create an animal being identical to the animal that donated the somatic cell nucleus. The embryo is implanted in a uterus and develops into a live being. The first animal to be created by reproductive cloning was Dolly the sheep, born at the Roslin Institute in Scotland in 1996. See also Somatic cell nuclear transfer (SCNT).

ETHICS

Issues in Oocyte Donation for Stem Cell Research

David Magnus and Mildred K. Cho*

Therapeutic Cloning Caveat

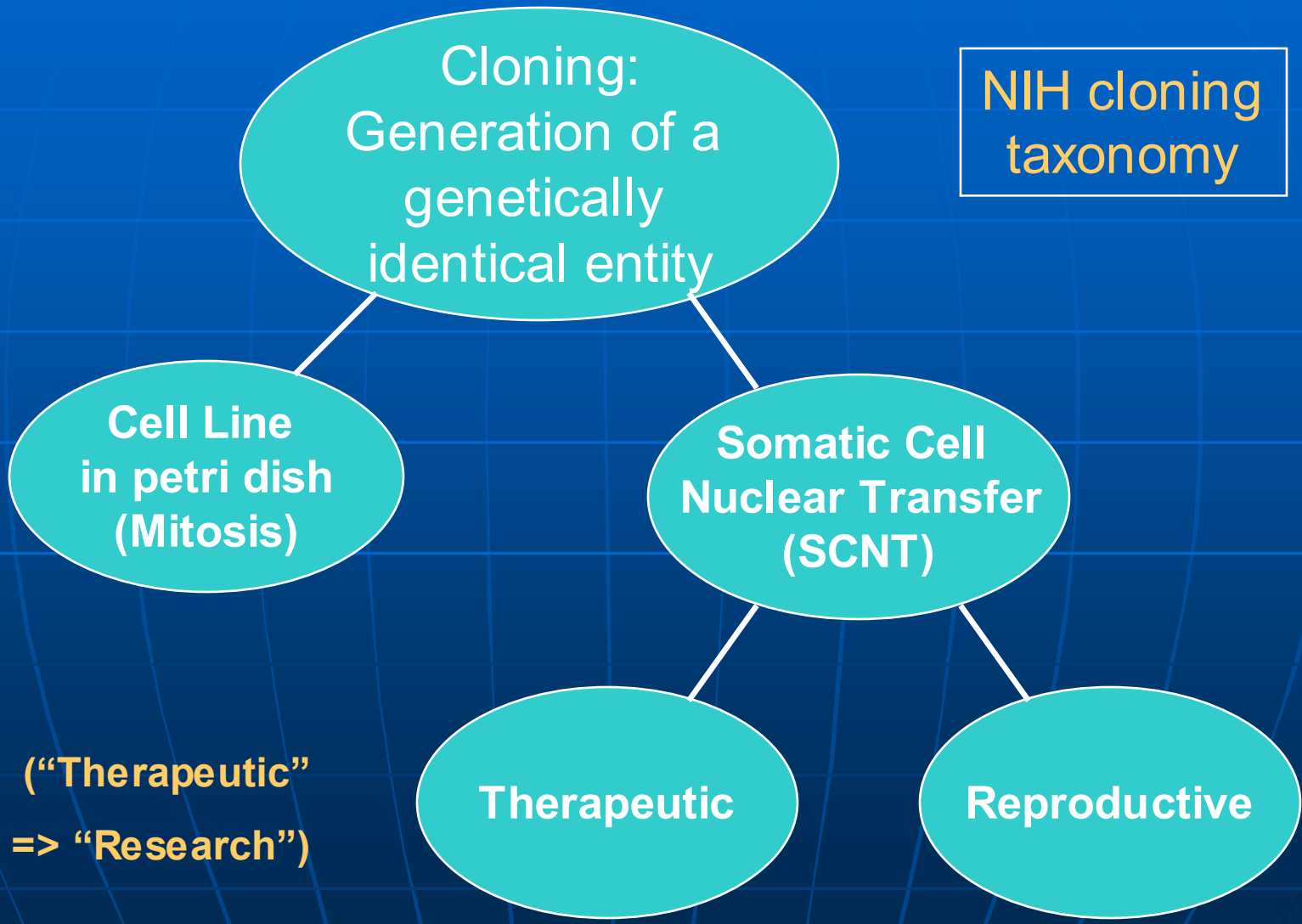
transfer research." Similarly, it is important not to use the term "therapy" when what is meant is "research" and not to refer to hESC research as "therapeutic cloning." There is currently no such thing as "therapeutic cloning" and this is not "therapeutic cloning research," nor can we say with any certainty that "cell therapy" is in the near future.

17 JUNE 2005 VOL 308 SCIENCE

Stem Cell Information

The National Institutes of Health resource for stem cell research

Home › Info Center › Glossary



Cloning: Legislative / Referenda Performative Definitions

- “Cloning”
- “Human Cloning”
- “Cloning a Human Being”

means . . .

California: Proposition 71
(November 2, 2004)

PROPOSED LAW

CALIFORNIA STEM CELL RESEARCH AND CURES INITIATIVE

(k) "Human reproductive cloning" means the practice of creating or attempting to create a human being by transferring the nucleus from a human cell into an egg cell from which the nucleus has been removed for the purpose of implanting the resulting product in a uterus to initiate a pregnancy.

NIH-consistent definition of reproductive cloning

Missouri

2006 Ballot Measure
Constitutional Amendment 2

Stem Cell Initiative

Submitted October 11, 2005

6. As used in this section, the following terms have the following meanings:

(2) "Clone or attempt to clone a human being" means to implant in a uterus or attempt to implant in a uterus anything other than the product of fertilization of an egg of a human female by a sperm of a human male for the purpose of initiating a pregnancy that could result in the creation of a human fetus, or the birth of a human being.

"Clone or attempt to clone a human being" =

Implantation or attempting to implant in a uterus

≠ SCNT – Not NIH-consistent

New Jersey
(NJS 2C:11A-1)

"As used in this section, 'cloning of a human being' means the replication of a human individual by cultivating a cell with genetic material through the egg, embryo, fetal and newborn stages into a new human individual."

Not NIH-consistent:

(SCNT + Implantation + Gestation for 9 months ≠ Cloning)

Minnesota

S.F. No. 100, 3rd Engrossment - 85th Legislative Session (2007-2008)

Sec. 2. **[145.427] STATE POLICY FOR STEM CELL RESEARCH.**

Subdivision 1. **Research use permitted.** The policy of the state of Minnesota is that research involving the derivation and use of human embryonic stem cells, human embryonic germ cells, and human adult stem cells from any source, including somatic cell nuclear transplantation, shall be permitted and that full consideration of the ethical and medical implications of this research be given. Research permitted under this section must not include cloning. Research involving the derivation and use of human embryonic stem cells, human embryonic germ cells, and human adult stem cells, including somatic cell nuclear transplantation, shall be reviewed by an approved institutional review board.

Minnesota

S.F. No. 100, 3rd Engrossment - 85th Legislative Session (2007-2008)

- **"Research permitted under this section must not include cloning. Research involving the derivation and use of human embryonic stem cells, human embryonic germ cells, and human adult stem cells, including somatic cell nuclear transplantation, shall be reviewed by an approved institutional review board."**

Not NIH-consistent

(not even self-consistent)

Federal Examples
A higher standard?

110TH CONGRESS
1ST SESSION

S. 812

To prohibit human cloning and protect stem cell research.

IN THE SENATE OF THE UNITED STATES

MARCH 8, 2007

Mr. HATCH (for himself, Mrs. FEINSTEIN, Mr. SPECTER, Mr. KENNEDY, and Mr. HARKIN) introduced the following bill; which was read twice and referred to the Committee on the Judiciary

SECTION 1. SHORT TITLE.

This Act may be cited as the "Human Cloning Ban and Stem Cell Research Protection Act of 2007".

Hatch et al.

110TH CONGRESS
1ST SESSION

S. 812

To prohibit human cloning and protect stem cell research.

"§ 301. Prohibition on human cloning

"(a) DEFINITIONS.—In this section:

"(1) HUMAN CLONING.—The term 'human cloning' means implanting or attempting to implant the product of nuclear transplantation into a uterus or the functional equivalent of a uterus.

Back to Missouri - Not NIH-consistent:

Cloning = SCNT + Implantation into uterus or equivalent

110TH CONGRESS
1ST SESSION

S. 1036

To amend the Public Health Service Act to prohibit human cloning.

Brownback

IN THE SENATE OF THE UNITED STATES

MARCH 29, 2007

Mr. BROWNBACK (for himself, Ms. LANDRIEU, Mr. ALLARD, Mr. BUNNING, Mr. BURR, Mr. CHAMBLISS, Mr. COBURN, Mr. CORKER, Mr. CORNYN, Mr. CRAPO, Mr. DEMINT, Mrs. DOLE, Mr. DOMENICI, Mr. ENSIGN, Mr. ENZI, Mr. GRAHAM, Mr. GRASSLEY, Mr. HAGEL, Mr. INHOFE, Mr. KYL, Mr. LOTT, Mr. MCCAIN, Mr. MARTINEZ, Mr. SESSIONS, Mr. THOMAS, Mr. THUNE, Mr. VITTER, and Mr. VOINOVICH) introduced the following bill; which was read twice and referred to the Committee on Health, Education, Labor, and Pensions

SECTION 1. SHORT TITLE.

This Act may be cited as the "Human Cloning Prohibition Act of 2007".

110TH CONGRESS
1ST SESSION

S. 1036

To amend the Public Health Service Act to prohibit human cloning.

"(a) DEFINITIONS.—In this section:

"(1) HUMAN CLONING.—The term 'human cloning' means human asexual reproduction, accomplished by introducing nuclear material from one or more human somatic cells into a fertilized or unfertilized oocyte whose nuclear material has been removed or inactivated so as to produce a living organism (at any stage of development) that is genetically virtually identical to an existing or previously existing human organism.

NIH-consistent definition of cloning = SCNT

110th Congress – 22 Bills with "cloning" in Thomas.loc.gov search

- 22 hits 13 unique bills (5 HR, 7 Sen.)
- Check for NIH definition consistency x ES $ attitude
- Consistent: 10 of 13
- ES $ Neutral & Non-expansive were all consistent 8/8
- $ Expansive 2, 2, 1

	NIH Cons	NIH NonC	Indef
ES$ +	2	2	1
ES$ Neut	2	0	0
Not ES$ +	6	0	0

Chi-Square = 9.530, df=4, p=.05

Implications

- Legislative definitions are a particularly potent site of public (mis)education in the public representation of science. *Lex docet* at the nexus of Politics, Policy, & Public Health.
- NIH-consistent definitions are found on pro- and contra-ESC measures – doable.
- Intentionally imprecise or misleading (performative) language may have short political utility but long-term policy, public educational and public health disutility.

. . . a statement of ‘the law’ should at least attempt to be a statement of fact

Human Reproduction Vol.22, No.4 pp. 905–911, 2007
Advance Access publication December 18, 2006
doi:10.1093/humrep/del467

NEW DEBATE

Human embryo: a biological definition

J.K.Findlay[1,2], M.L.Gear[1], P.J.Illingworth[3], S.M.Junk[1,4], G.Kay[5], A.H.Mackerras[1], A.Pope[6], H.S.Rothenfluh[1,8] and L.Wilton[7]

This paper defines a human embryo from a biological standpoint that takes into account emerging technologies in reproductive science. The paper does not consider legal, moral, religious or social views. As the definition of a human embryo must reflect the multifactorial processes of development, an approach has been adopted which combines recognition of observed events with potential for further development. This acknowledges that fertilization and development are not static processes, and as such embryo status can only be defined by observation of specific markers. The following biological definition of 'human embryo' is proposed.

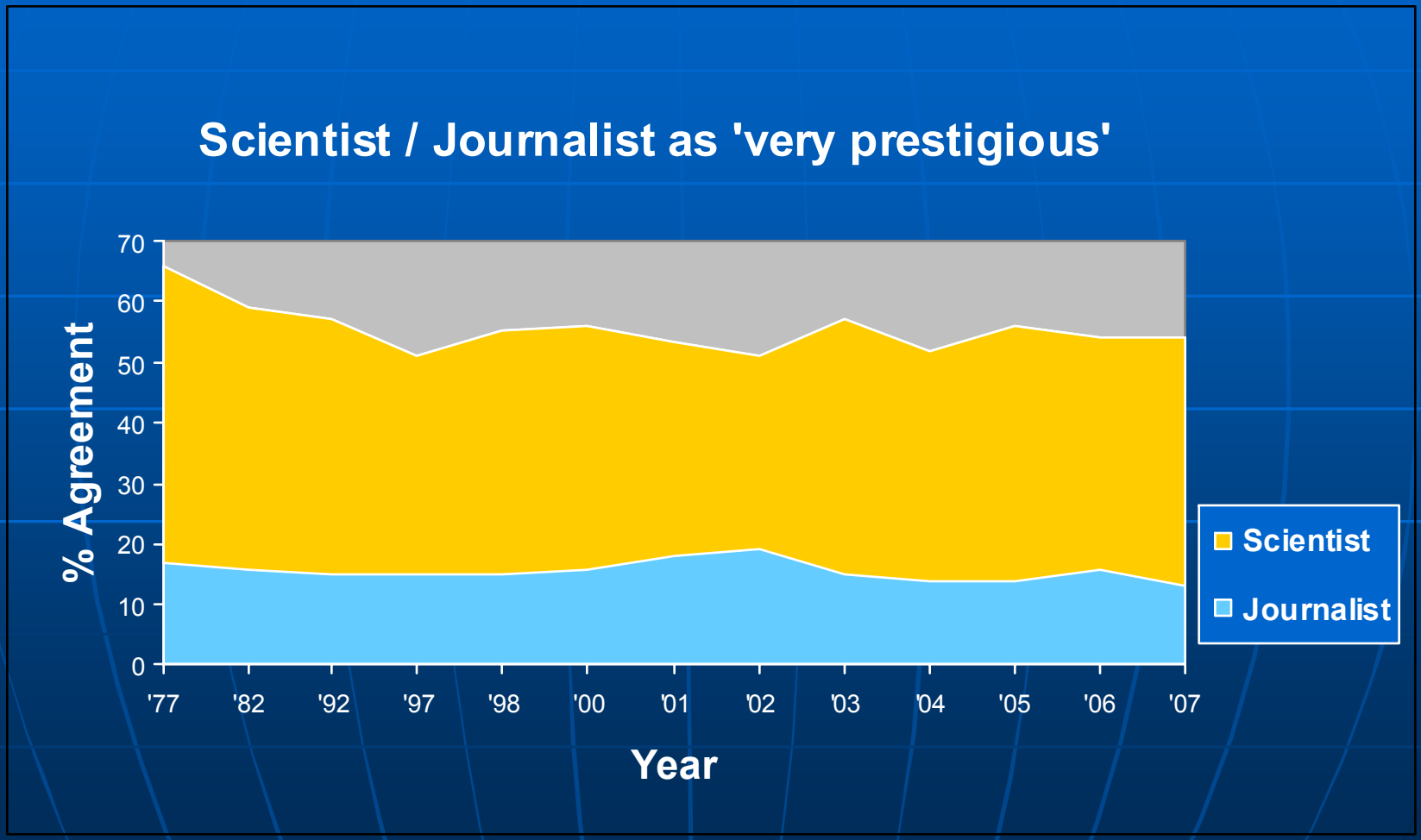
A human embryo is a discrete entity that has arisen from either:

(i) *the first mitotic division when fertilization of a human oocyte by a human sperm is complete or*
(ii) *any other process that initiates organized development of a biological entity with a human nuclear genome or altered human nuclear genome that has the potential to develop up to, or beyond, the stage at which the primitive streak appears,*

and has not yet reached 8 weeks of development since the first mitotic division.

"The paper does not consider legal, moral, religious or social views."

U.S. Scientist as ‘very prestigeous’ 1977-2007 (-12%)



Source: Harris Poll #77, 29-Year Trend
August 1, 2007

Altman L. Promises of miracles: news releases go where journals fear to tread; a double standard in reports to the public and the experts. New York Times. 1995;10 Jan:B6.

and lower standard: "Scientists rarely make exaggerated claims when reporting their results in the scientific literature because it is poor etiquette and likely to provoke the scorn of their peers . . . [but] news releases are a different matter."[5] Responsibility for distorted reporting in

Expert to Public Horizon Problem

- "To start with, people need a fairy tale," said Ronald D.G. McKay, a stem cell researcher at the National Institute of Neurological Disorders and Stroke. "Maybe that's unfair, but they need a story line that's relatively simple to understand."

Rick Weiss, Stem cells an unlikely therapy for Alzheimers. Washington Post, Thursday, June 10, 2004; Page A03

Bubela (2006) - 'Cycle of Hype'

Clin Genet 2006: 70: 445–450
Printed in Singapore. All rights reserved

CLINICAL GENETICS
doi: 10.1111/j.1399-0004.2006.00693.x

Genetic Diversity and Science Communication

Science communication in transition: genomics hype, public engagement, education and commercialization pressures

Bubela T. Science communication in transition: genomics hype, public engagement, education and commercialization pressures. Clin Genet 2006: 70: 445–450. © Blackwell Munksgaard, 2006

T Bubela

School of Business, University of Alberta, Edmonton, Alberta, Canada

Timelines / Result Expectations

Bubela (2006)

"Cycle of Hype" (Caulfield)

Actors:

- Primary: Scientists –> Media –> Public
  - Demand Curves: Funding, Stories, Cures
- Secondary: *SS, Industry, Politicians
  - Demand Curves: $/Acad, $, Votes

* Social Sci. Currency: Ethical and Social Risk

Do the print media "hype" genetic research? A comparison of newspaper stories and peer-reviewed research papers

CMAJ 2004;170(9):1399-407

Tania M. Bubela, Timothy A. Caulfield

ß See related article page 1415

627 news articles re 111 sci. papers

- 63% News reports - no exaggeration
- 26% Slight
- 11% Moderate to high exaggeration

- Benefit likelihood: 98% News, 99% Papers
- Risk/Cost: 15% News, 5% sci. papers

California Proposition 71 (2004)

"CALIFORNIA STEM CELLS RESEARCH AND CURES INITIATIVE"

- Constitutional referendum
- 10 years, $3B funding (state bonds)
- Patient advocacy groups called "integral" and "essential" to the effort from the beginning

The promise of miracles? Proposition 71

California Stem Cell Research and Cures Initiative

"Medical researchers believe.stem cell research could lead to "treatments and cures for many diseases and injuries including:

Cancer, heart disease, Alzheimers, Parkinson's, HIV / AIDS, multiple sclerosis, lung disease and spinal injuries.

Alan D. Cherrington, Ph.D.
Professor of Molecular Physiology & Biophysics
Charles H. Best Professor of Diabetes Research
Department Chair
Professor of Medicine
Vanderbilt University

OFFICIAL VOTER INFORMATION GUIDE

CALIFORNIA GENERAL ELECTION — NOVEMBER 2, 2004

PROP 71 — STEM CELL RESEARCH. FUNDING. BONDS. INITIATIVE CONSTITUTIONAL AMENDMENT AND STATUTE.

ARGUMENT in Favor of Proposition 71

PROPOSITION 71 IS ABOUT CURING DISEASES AND SAVING LIVES.

Stem cells are unique cells that generate healthy new cells, tissues, and organs. Medical researchers believe stem cell research could lead to treatments and cures for many diseases and injuries, including:

Cancer, heart disease, diabetes, Alzheimer's, Parkinson's, HIV/AIDS, multiple sclerosis, lung diseases, and spinal injuries.

Prop. 71 also prohibits any funding for cloning to create babies, reinforcing existing state law banning human reproductive cloning. It's totally focused on finding medical cures.

Vote YES on 71—IT COULD SAVE THE LIFE OF SOMEONE YOU LOVE.

ALAN D. CHERRINGTON, Ph.D., *President*
American Diabetes Association
CAROLYN ALDIGE, *President*
National Coalition for Cancer Research (NCCR)
JOAN SAMUELSON, *President*
Parkinson's Action Network

(k) "Human reproductive cloning" means the practice of creating or attempting to create a human being by transferring the nucleus from a human cell into an egg cell from which the nucleus has been removed for the purpose of implanting the resulting product in a uterus to initiate a pregnancy.

Arguments printed on this page are the opinions of the authors and have not been checked for accuracy by any official agency.

Proposition 71 passes 59% to 41%

CIRM CALIFORNIA INSTITUTE FOR REGENERATIVE MEDICINE

About CIRM

The **California Institute for Regenerative Medicine** ("**The Institute**" or "**CIRM**") was established in early 2005 with the passage of Proposition 71, the California Stem Cell Research and Cures Initiative. The statewide ballot measure, which provided $3 billion in funding for stem cell research at California universities and research institutions, was approved by California voters on November 2, 2004, and called for the establishment of a new state agency to make grants and provide loans for stem cell research, research facilities and other vital research opportunities.

The **Independent Citizens Oversight Committee** ("**ICOC**") is the 29-member governing board for the Institute. The ICOC members are public officials, appointed on the basis of their experience earned in California's leading public universities, non-profit academic and research institutions, patient advocacy groups and the biotechnology industry.

California Institute of Regenerative Medicine

CIRM - Independent Citizens Oversight Committee (N=29)

- Incl. 10 disease group advocacy reps.

- Spinal cord injury
- Alzheimers
- MS or ALS
- Type I Diabetes
- Type II Diabetes

- Heart
- Cancer
- Parkinsons
- Mental Health
- HIV/AIDS

Source: Official Voter Information Guide. California General Election 2004. Text of Proposed Laws, Proposition 71, p. 148.

CIRM Scientific and Medical Research Funding Group (N=23)

- 1 Chair (CIRM Chair)
- 15 Scientists
- 7 of 10 disease advocacy representatives

Source: Official Voter Information Guide. California General Election 2004. Text of Proposed Laws, Proposition 71, p. 151.

CIRM 10-year Strategic Goal

1 Phase II clinical trial for 1 embryonic stem cell derived therapy by the end of 10 years.

Zach Hall, PhD, founding president of CIRM, “Stem Cell Research: At the Intersection of Science, Politics, Law, and Culture” (University of Minnesota, October 9, 2007)

Response to CIRM Strategic Goal

Some patient advocacy representatives on CIRM committees “felt betrayed” stating “you are taking away our hope.”

Zach Hall, PhD, founding president of CIRM, “Stem Cell Research: At the Intersection of Science, Politics, Law, and Culture” (University of Minnesota, October 9, 2007)

Why or how ‘betrayed’?

- Patient advocacy groups were described as“integral” from the beginning and “essential” to Proposition 71 success
- => Did the research timeline become apparent (to scientists) only after Prop 71 passed?

Current disease treatments or trials with stem cells [...?]

- **Adult Stem Cells** **Embryonic SC**

Cancers:

Do No Harm: The Coalition of Americans for Research Ethics

http://www.stemcellresearch.org/facts/treatments.htm

- Brain Cancer
- Retinoblastoma
- Ovarian Cancer
- Skin Cancer: Merkel Cell Carcinoma
- Testicular Cancer
- Tumors abdominal organs Lymphoma
- Non-Hodgkin's lymphoma
- Hodgkin's Lymphoma
- Acute Lymphoblastic Leukemia
- Acute Myelogenous Leukemia
- Chronic Myelogenous Leukemia
- Juvenile Myelomonocytic Leukemia

"The ethical and political controversy surrounding embryonic stem cell research makes scientific claims especially **prone to exaggeration or distortion.** All such claims should receive careful scrutiny…."

—Prentice and Tarne

19 JANUARY 2007 VOL 315 **SCIENCE** www.sciencemag.org

"By promoting the falsehood that adult stem cell treatments are already in general use for 65 diseases and injuries, Prentice and those who repeat **his claims mislead laypeople and cruelly deceive patients"**

—Smith *et al.*

SHANE SMITH,[1] WILLIAM NEAVES,[2]* STEVEN TEITELBAUM[3] Publishe

www.sciencemag.org **SCIENCE** VOL 313 28 JULY 2006

Science 8 June 2007:
Vol. 316. no. 5830, pp. 1422 - 1423
DOI: 10.1126/science.316.5830.1422b

LETTERS

Adult Versus Embryonic Stem Cells: Treatments

D. A. Prentice and G. Tarne used their letter "Treating diseases with adult stem cells" (19 Jan., p. 328) to try to defend Prentice's previous claim that "over 65 human diseases" have been "effectively treated through adult stem cells" (1). Now Prentice and Tarne say that what he really meant was that adult stem cell treatments for 65 diseases are being tested for possible efficacy.

Response

In none of these studies do the authors state merely that they are about to "test" whether adult stem cells may benefit patients or that they have begun "enrollment" in clinical trials. Rather, all these studies (including those on breast cancer and heart damage) are reports of completed trials in which patients with these conditions benefited.

Et tu, 70 & Alzheimers

A partial reparative

A taxonomy of commitments incumbent upon scientists and other professionals articulating public representations of science.

Commitments

- Ethic of Probity
  - Sober estimation of future prospects, uncertainties
- Ethic of Transparency
  - Gradient between what is admitted to ‘over a beer’ vs. before the camera
  - Expert obligation to correct misinformation - also when misinformation (e.g. hype) serves outcome interest

Commitments

- Ethic of Translation
  - Commitment to decrease the asymmetry of knowledge between expert and lay public (and thereby the power differential).

"Diogenes, Having Failed in his Search for an Honest Man, Finds Some Stoic Dogs“ - Jean-Léon Gérôme, 1860

Framing Science: The Stem Cell Controversy in an Age of Press/Politics

Matthew C. Nisbet, Dominique Brossard and Adrianne Kroepsch

The Harvard International Journal of Press/Politics 2003; 8; 36

- **Agenda-building activity ~ stem cell research stages**
- **Media attention variation ~ agenda building activity**
- **Media attention variation ~ policy arena**

Research Question 1: What was the level of agenda-building activity related to stem cell research across its stages of development?

Research Question 2: How did media attention to stem cell research vary in relation to this underlying agenda-building process?

Research Question 3: How did media attention to stem cell research vary in relation to the policy arena in which debate took place?

Nisbet, Brossard, Kroepsch (2003), cont'd

Bone Marrow 1975	Embryo Ban 1995	Discovery 1998	Controversy 2001

- Science Articles
- Press Releases
- Capitol Hill Testimony
- News Articles

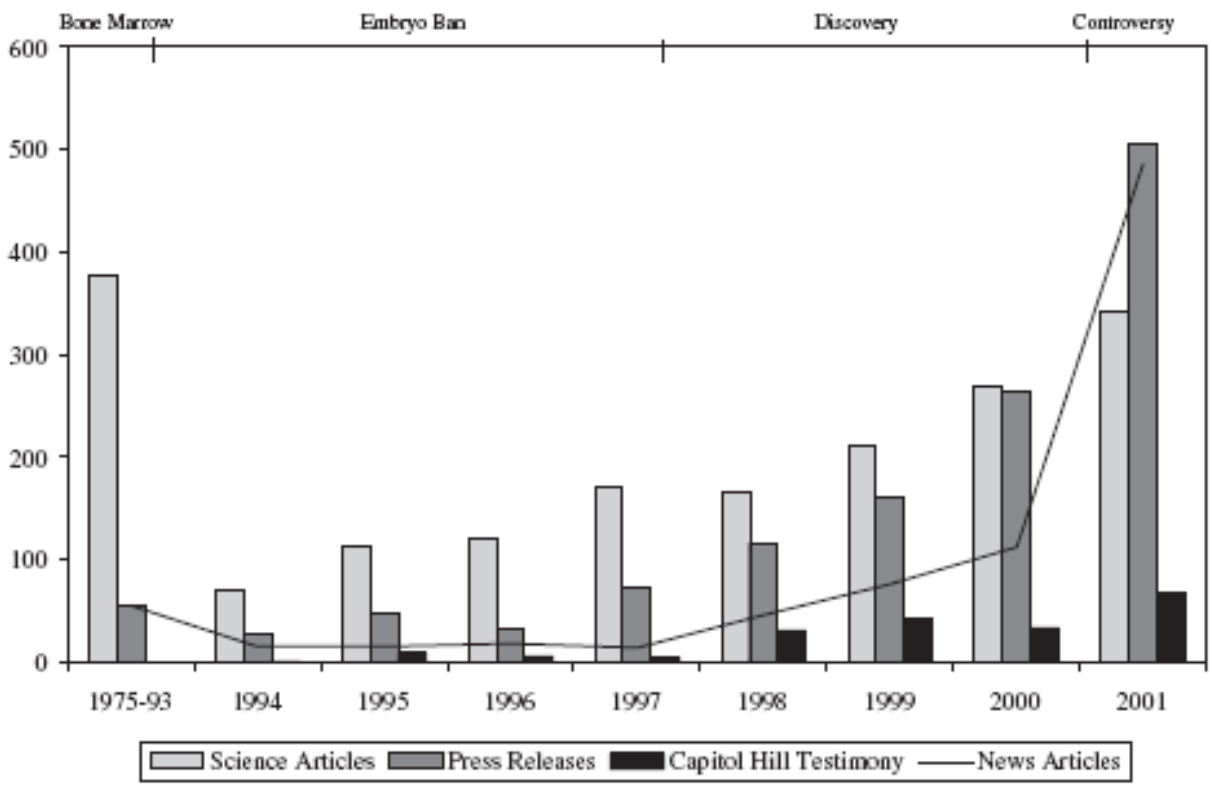


Figure 1
Agenda-Building Indicators and Media Attention across Stages of Development

Cont'd Bone Marrow Embryo Ban Discovery Controversy

Stem Cell Source	1975-93 n=55	1994-97 n=62	1998-01 n=234	2001 n=486
None	12.1	13.2	19.2	18.2
Embryo, Cloned E	1.4	11.8	52.8	74.7
Adult SC	10.3	14.2	9.4	12.9
Bone Mar, Blood	58.6	47.1	21.9	8.3
Fetal	6.9	4.4	4.5	3.6
Neural	1.4	4.4	7.5	3.4
Umbilical Cord Bl	8.6	17.6	4.5	2.4
Animal	17.2	23.5	10.2	6.1

Cryopreserved embryos in the United States and their availability for research

2003 **Fertil Steril. 2003 May;79(5):1063-9.**

David I. Hoffman, M.D.,[a] Gail L. Zellman, Ph.D.,[b] C. Christine Fair, M.A.,[b] Jacob F. Mayer, Ph.D.,[c] Joyce G. Zeitz, B.Sc.,[d] William E. Gibbons, M.D.,[c] and Thomas G. Turner, Jr., M.S.[e]

In association with The Society for Assisted Reproductive Technology (SART) and RAND

Objective: To determine the number of embryos stored at assisted reproductive technology (ART) clinics in the United States and their current disposition.

Design: A targeted survey instrument sent by the SART–RAND team to all medical practices providing in vitro fertilization services in the United States.

Result(s): The SART–RAND team surveyed all 430 ART practices in the United States. Of these practices, 340 returned surveys for analysis. The data from these surveys were merged with data taken from the 1999 SART dataset, which contains information about practice size and success rates. Responding clinics reported a total of 396,526 embryos in storage as of April 11, 2002. The vast majority of the embryos (88.2%) were targeted for patient use. Small numbers of embryos were available for research, donation, destruction, quality assurance, or other uses.

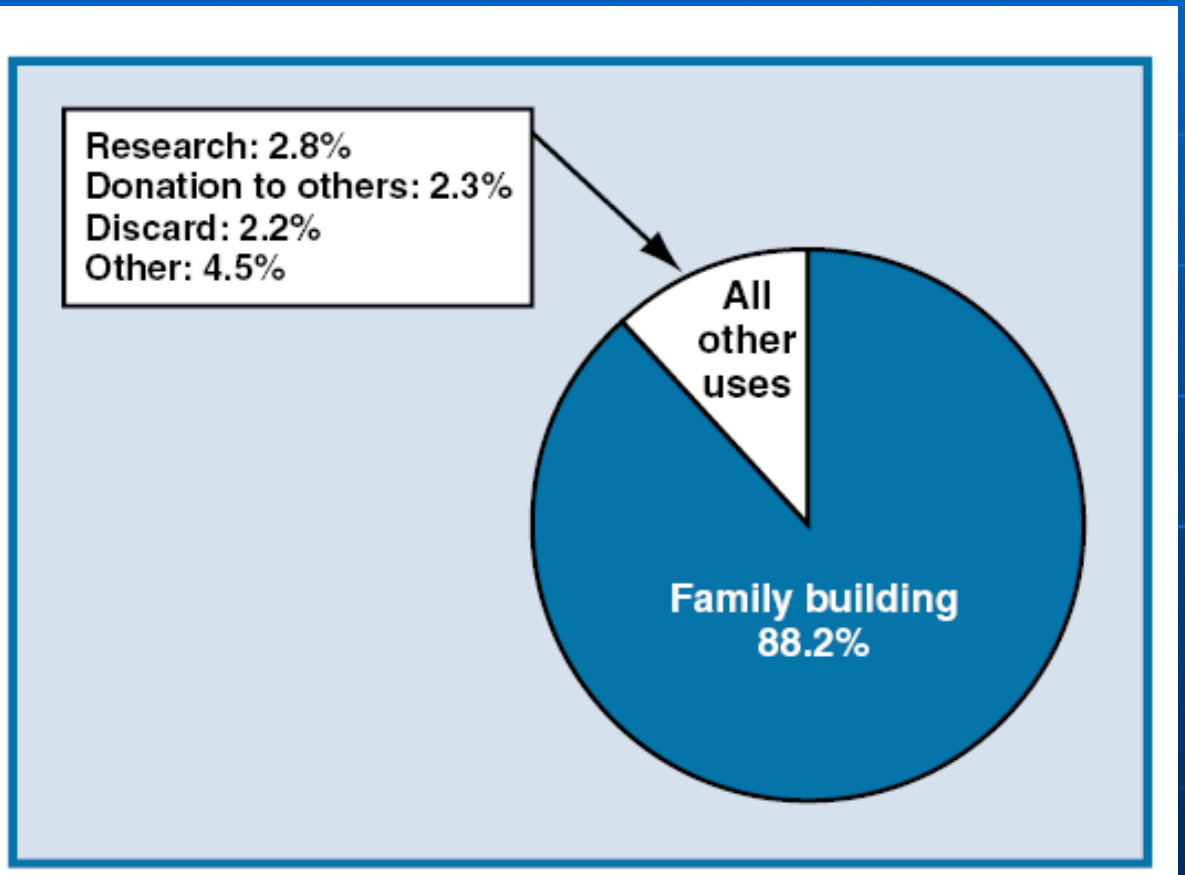
Conclusion(s): Nearly 400,000 embryos are stored in the United States, the majority of which (88.2%) are targeted for patient use. Few are available for research (2.8%), limiting possible conversion into embryonic stem cell lines. (Fertil Steril® 2003;79:1063–9. ©2003 by American Society for Reproductive Medicine.)

Key Words: IVF, ART, cryopreserved embryos, cryopreservation, stem cells

LAW & RAND HEALTH *Research Brief*

The Law & Health Initiative is a collaboration of the RAND Institute for Civil Justice and RAND Health

How Many Frozen Human Embryos Are Available for Research?



Designated Use of Frozen Embryos in the United States as of April 2002

Media Check on Reporting re Hoffman

- Nexus/Lexus Search Terms:

  Embryo, RAND, 400,000 -News All
  (English Full Text, last 5 years)

- 82 hits (5/8/03–7/30/07)

- 58 unique

Reporting re Hoffman (2003-07) Fairly Consistent Years 1-3

Year	**2.8% Resrch**	2.3% Adopt.	2.2% Disc.	1% QC	SCL% 275
All	77	30	30	9	25
(11) 1	82	55	73	27	18
(6) 2	100	17	17	0	50
(21) 3	95	40	30	10	20
(15) 4	53	7	7	0	27
(4) 5	25	0	0	0	25

% reflects citation attempts – lower accurate citation; +/- no sig. differences

Originally published in *Science* Express on 21 June 2007
Science 6 July 2007:
Vol. 317. no. 5834, pp. 46 - 47
DOI: 10.1126/science.1145067

Lyerly, Faden (2007)

POLICY FORUM

EMBRYONIC STEM CELLS:

Willingness to Donate Frozen Embryos for Stem Cell Research

Anne Drapkin Lyerly[1*] and Ruth R. Faden[2]

- Query patient (not clinic) attitude
- CA, CO, DC, MY, MO, NJ, NC, OR, VA
- N=2210, R=1244 (1025 w/ embryos)

Originally published in *Science* Express on 21 June 2007
Science 6 July 2007:
Vol. 317. no. 5834, pp. 46 - 47
DOI: 10.1126/science.1145067

POLICY FORUM

Lyerly, Faden (2007)

EMBRYONIC STEM CELLS:
Willingness to Donate Frozen Embryos for Stem Cell Research

Anne Drapkin Lyerly[1*] and Ruth R. Faden[2]

- "Somewhat or Very Likely" to donate to
  - 22% Adoptive Couple / ~ Discard
  - 28% Nonreproductive Cloning
  - 49% Medical Science
  - 60% Stem Cell Research
- Upper potential of 2000-3000 US stem cell lines vs. Hoffman 275