Approved: February 20, 2006
Date

MINUTES OF THE HOUSE HEALTH AND HUMAN SERVICES COMMITTEE

The meeting was called to order by Chairman Jim Morrison at 1:30 P.M. on February 16, 2006, in Room 526-S of the Capitol, a Joint Meeting with the Senate Public Health and Welfare Committee.

All members were present except Representative Kelley, who was excused.

Committee staff present:
Melissa Calderwood, Kansas Legislative Research Department
Mary Galligan, Kansas Legislative Research Department
Renae Jefferies, Revisor of Statutes' Office
Gary Deeter, Committee Secretary

Conferees appearing before the committee:
Dr. David Prentice, Family Research Council, Washington, D.C.
Kevin Siek, Disabilities Rights Advocate, Topeka Independent Living Resource Center
Alyce Brown, AARP
Steve Jeffers, Director, Institute for Spirituality in Health

Others attending:
See attached list.

David Prentice, Ph.D., Family Research Council, Washington, D.C., presented information on adult stem cell cures. (Attachment 1) He outlined the basic concepts regarding stem cell research, stating that each stem cell has two characteristics, first in its native form, and then in differentiation. He noted the difficulty of controlling differentiation of any cell, adult or embryonic. Regarding the present stem cell lines, he said contaminants in stem cell lines can be washed to remove them. He reviewed the issue of cloning (somatic cell nuclear transfer), commenting on therapeutic cloning and reproductive cloning, noting the difficulty of achieving a match. He said that a New Jersey law now allows a gestating clone to be eligible for harvest any time before birth. He then listed therapeutic or regenerative benefits using a patient's own adult stem cells.

Answering questions, Dr. Prentice said it is harder to harvest some types of adult stem cells than it is embryonic stem cells, but adult stem cells will transfer from, say, bone marrow to heart readily. He acknowledged that research is moving toward using chemical transfers that will obviate the need for anything but nutrients for stem cells. He replied that embryonic stem cells are more vulnerable to creating tumors because their "job description" is to grow rapidly; taken out of its controlled environment, embryonic stem cells become more random. He acknowledged that adult stem cells deteriorate slightly as an individual ages, but a person's own stem cells would less likely be rejected. Regarding umbilical cord blood, he said those stem cells are more versatile. He replied that the danger of a woman donating eggs for research is that daily high-dose hormone shots for a week sometimes over-stimulate the ovaries to cause serious

swelling.

The Chair opened the hearing on **HCR 5011**. (Last year's testimony on the resolution is found at http://www.kslegislature.org/hhhs/05-06/.)

Kevin Siek, Disabilities Rights Advocate, Topeka Independent Living Resource Center, spoke as a proponent, stating that 80% of all long-term home health care in America is provided by family members and that over 250,000 Kansans give 275 million hours annually. (Attachment 2) He said the resolution is one way to say thank you. He provided Attachment 3 for additional documentation.

Alyce Brown, AARP, also testified in support of the resolution. (Attachment 4) She said unpaid caregivers deserve our thanks and our support.

Deanne Bacco, Executive Director, Kansas Advocates for Better Care, submitted written testimony in support of the resolution. (Attachment 5)

The Chair closed the hearing on **HCR 5011** and opened the hearing on **HCR 5031.**

Steve Jeffers, Director, Institute for Spirituality in Health, testified as a proponent. (Attachment 6) He commented on the importance of clear definitions (advanced directive, health-care directive, medical durable power of attorney, and living will), noting the benefits of these resources and how few Kansans avail themselves of them. He submitted a PointPoint presentation to illustrate his comments. (Attachment 7)

The Chair closed the hearing.

Staff Melissa Calderwood briefed the committee on **HB 2734**. She said the bill creates new law allowing a person to take a licensure examination even if some or all credits were obtained online, so long as the credits were obtained from an accredited institution. A fiscal note was provided. (Attachment 8)

Staff Mary Galligan gave a briefing on **HB 2739**, explaining that the bill expands current law to prohibit not only smoking, but use of tobacco products—and not only in hospital facilities, but also on hospital property. The bill mandates hospital administrative officers to develop policies implementing the requirements of the bill. She noted that long-term-care facilities are exempt if tobacco use in conducted in a well-ventilated area.

The Chair suggested members consider **HCR 5011** for passage. A motion was made and seconded to amend the resolution to include Social and Rehabilitative Services family care-givers and to correct the wording for the Kansas Department *on* (not *of*) Aging. The motion passed.

A motion was made, seconded, and passed to recommend the resolution as favorable for passage as amended. The meeting was adjourned at 3:15 p.m.

JOINT COMMITTEE MEETING: HOUSE HEALTH AND HUMAN SERVICES AND SENATE PUBLIC HEALTH AND WELFARE
GUEST LIST

DATE: February 16, 2006

NAME	REPRESENTING
Blake Smith	Smith-3 Academy
Kevin Hoppock MD	Medical Society of Sg County
Beth Innes	Hutfles Govt Relations
BRAD KEMP	KCLC
Lisa Benton	American Cancer Society
Jace Smith	American Cancer Society
Kevin Siek	TILRC
Sharon Joseph	KS ADAPT
Alex Kotoyantz	P.I.A.
Chad Austin	KS Hosp Assoc
L. Therese Bangert	Ks. Cath Conf
Beatrice Swoopes	K.S. Cath. Conference
Janice Ann Fowler	KAHP
John C. Peterson	Ks Assn for Professional Fowers
Lindsey Douglas	Heim Law Firm
Kevin J Bacon	KCDC
Nikki Reeder	Civic Council of Greater KC
[illegible]	AARP
Alyce Brown	AARP

JOINT COMMITTEE MEETING: HOUSE HEALTH AND HUMAN SERVICES AND SENATE PUBLIC HEALTH AND WELFARE
GUEST LIST

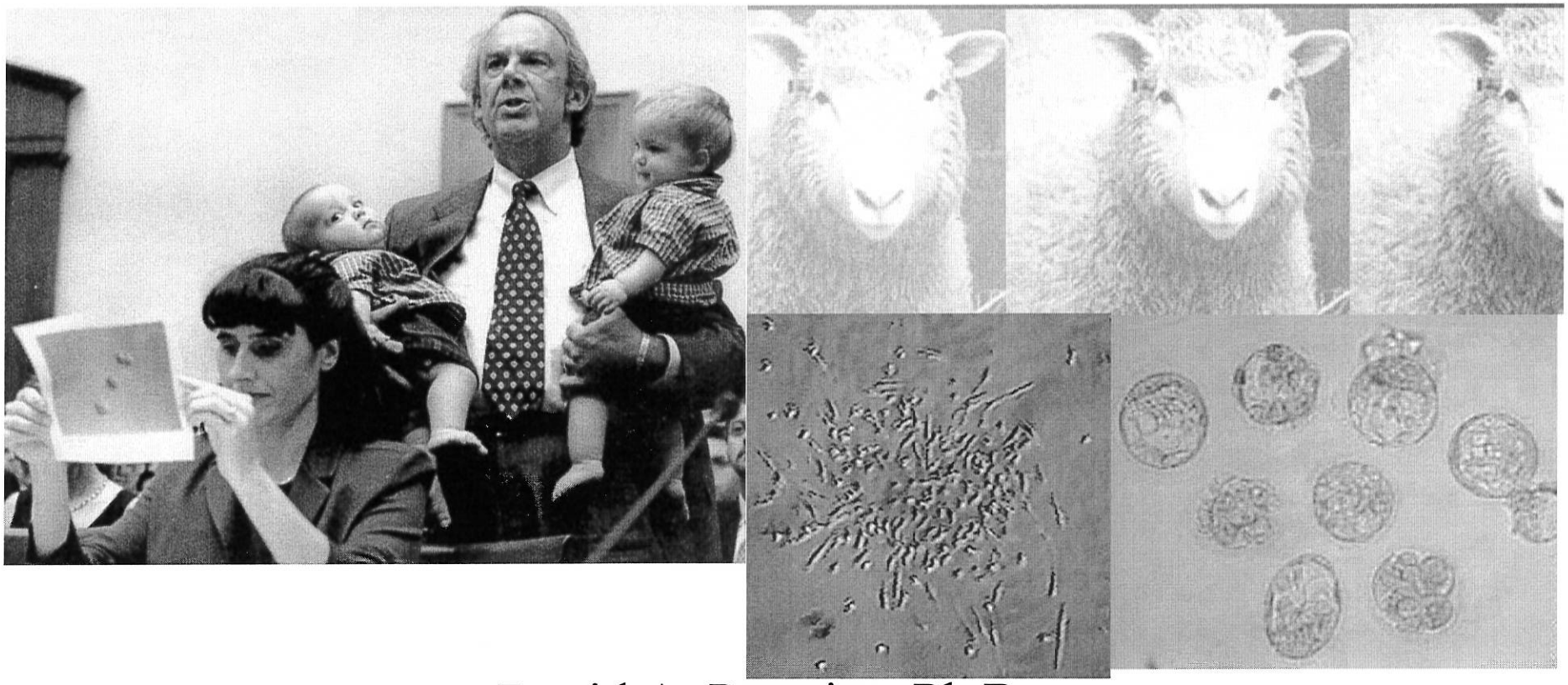
Page Two

DATE: February 16, 2006

NAME	REPRESENTING
Johnna Lickteig	public

Attachment 1
HHS 2-16-06

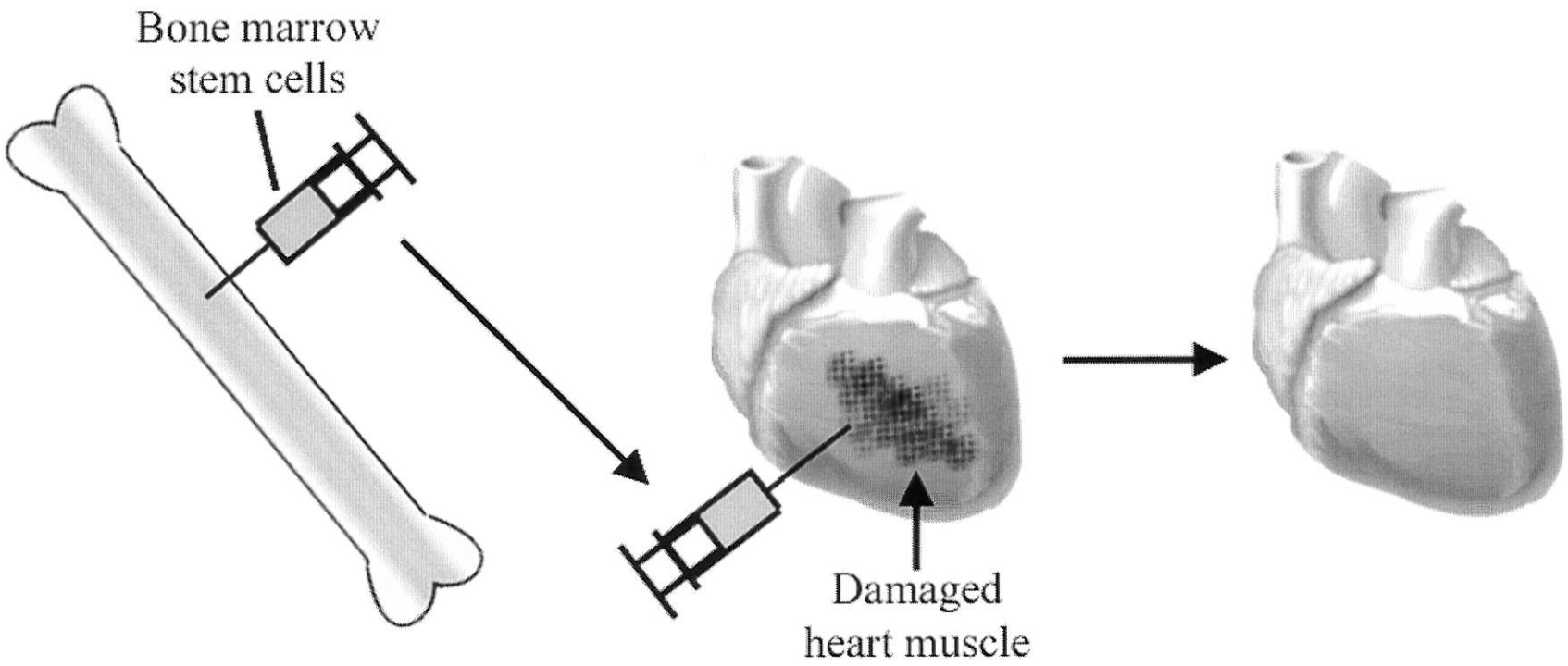
Stem Cells

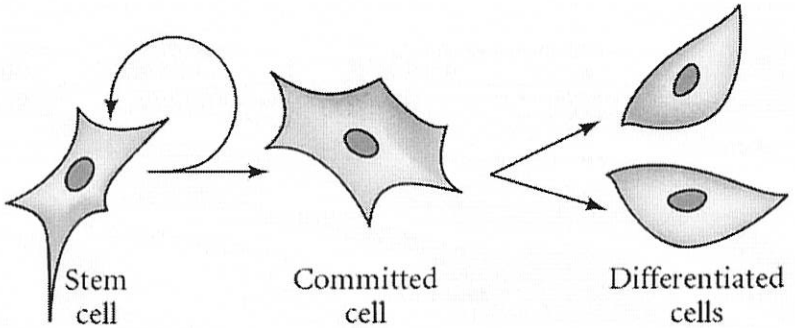


David A. Prentice, Ph.D.
Family Research Council and Georgetown University Medical School
Washington, D.C., USA

STEM CELL DEPOT

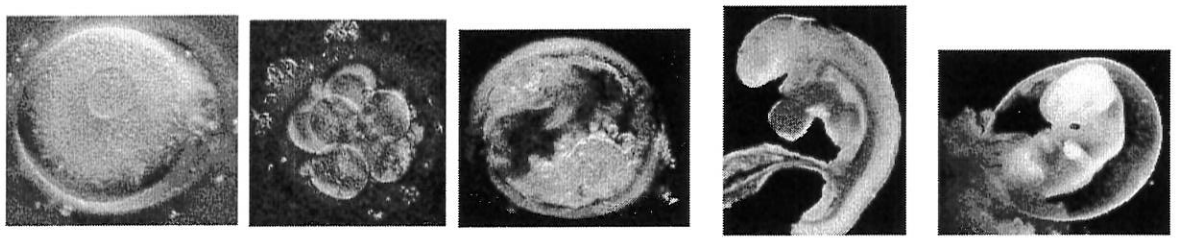
Regenerative Medicine with Stem Cells



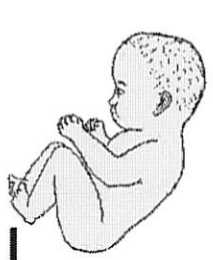


Stem Cells

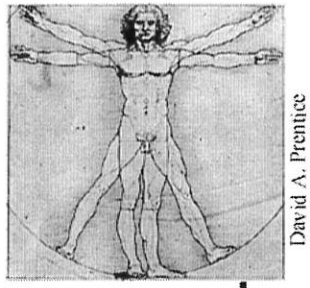
Human Developmental Continuum ⟶



Single-cell Embryo | 3-day Embryo | 5-7 day Embryo | 4-week Embryo | 6-week Embryo



Infant



Adult

David A. Prentice

Embryonic Stem (ES) cells
Totipotent

Embryonic Germ (EG) cells
(primordial germ cells)
Pluripotent

Fetal Tissue Stem cells
Pluripotent or Multipotent

Cord Blood Stem cells
Placental Stem cells
Pluripotent or Multipotent

"Adult" Stem cells
Pluripotent or Multipotent

Teratocarcinoma (germ cell tumor)

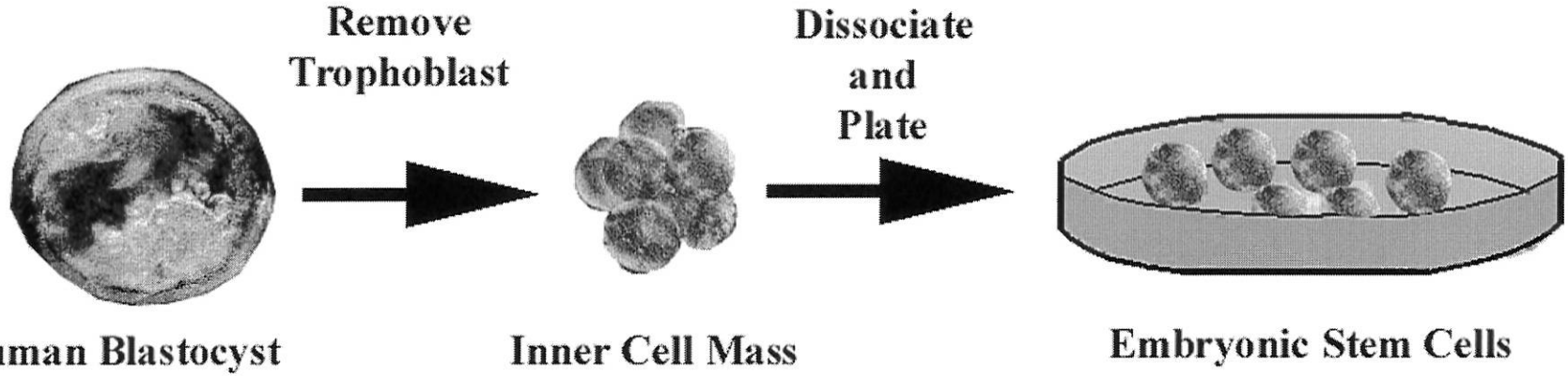
Embryonal Carcinoma (EC) cells
Pluripotent

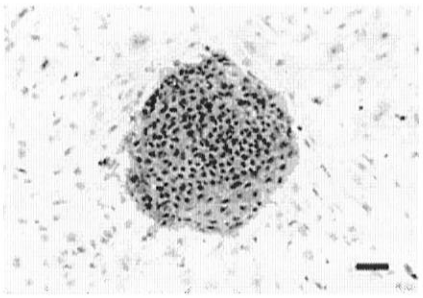
Isolation & Culture of Embryonic Stem Cells
(Human-1998; Mouse-1981)

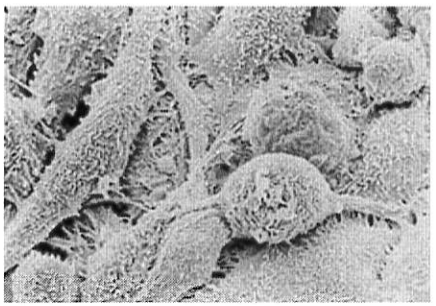
1-5

Method patented
U.S. patent held by Univ. Wisconsin

Purported Advantages:
1) Proliferate indefinitely
2) Form any tissue







Promises, Premises, and Published Data…

Claims unsubstantiated for embryonic stem cells

1-6

Current or potential embryonic stem cell problems:

- Difficult to establish and maintain
- Difficulty in obtaining pure cultures in the dish
- Potential for tumor formation and tissue destruction
- Questions regarding functional differentiation

  *Hansson M *et al.*, "Artifactual insulin release from differentiated embryonic stem cells", *Diabetes* 53, 2603-2609, October 2004
  *Sipione S *et al.*, "Insulin expressing cells from differentiated embryonic stem cells are not beta cells", *Diabetologia* 47, 499-508, 2004 (published online 14 Feb 2004)
  *Rajagopal J *et al.*; "Insulin staining of ES cell progeny from insulin uptake"; *Science* 299, 363; 17 Jan 2003
  *Zhang YM *et al.*; "Stem cell-derived cardiomyocytes demonstrate arrhythmic potential"; *Circulation* 106, 1294-1299; 3 September 2002
- Problem of immune rejection

  *Swijnenburg R-J *et al.*, Embryonic stem cell immunogenicity increases upon differentiation after transplantation into ischemic myocardium, *Circulation* 112, I-166-I-172, 30 August 2005
- Genomic instability

  *Maitra A *et al.*, Genomic alterations in cultured human embryonic stem cells, *Nature Genetics* online 4 Sept 2005
  *Cowan CA *et al.*, "Derivation of embryonic stem-cell lines from human blastocysts", *New England Journal of Medicine* 350, 1353-1356, 25 March 2004
  *Draper JS *et al.*, "Recurrent gain of chromosomes 17q and 12 in cultured human embryonic stem cells", *Nature Biotechnology* 22, 53-54; January 2004
  *Humpherys D *et al.*; "Epigenetic instability in ES cells and cloned mice"; *Science* 293, 95-97; 6 July 2001
- Few and modest results in animals, no clinical treatments
- Ethically contentious

Human embryonic stem cell "contamination"

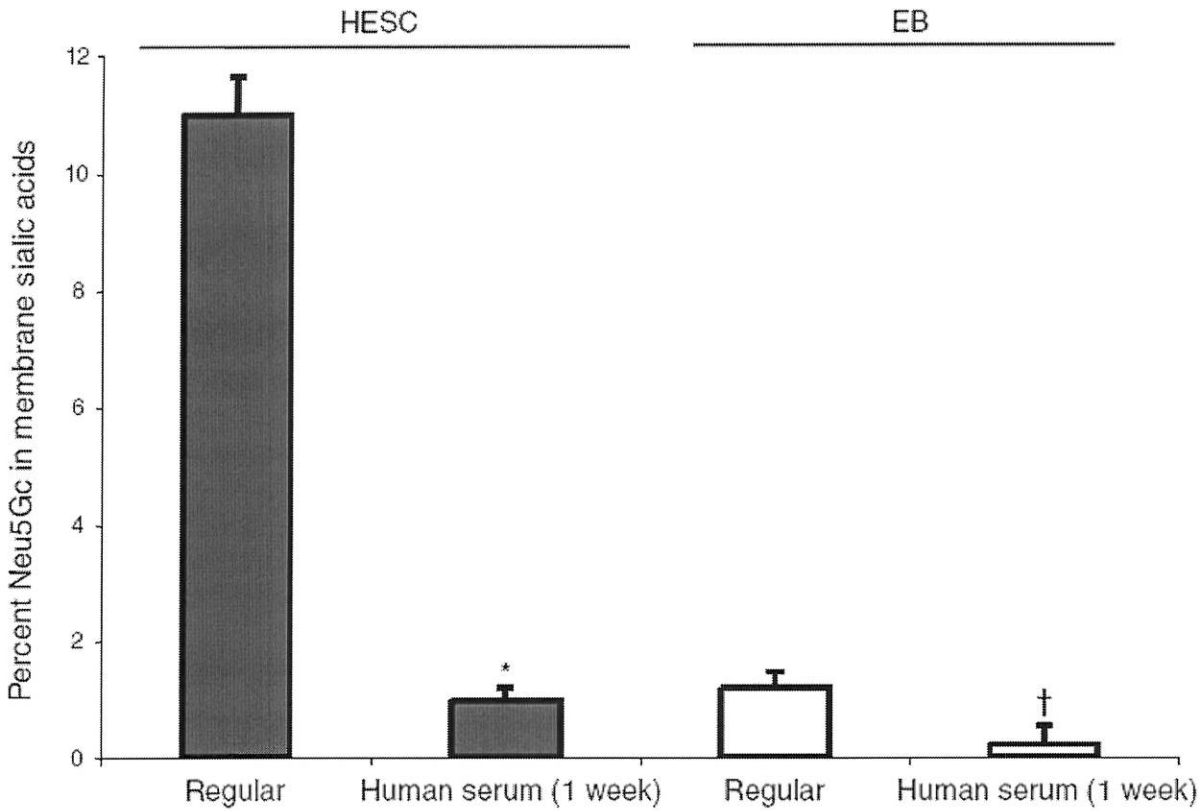


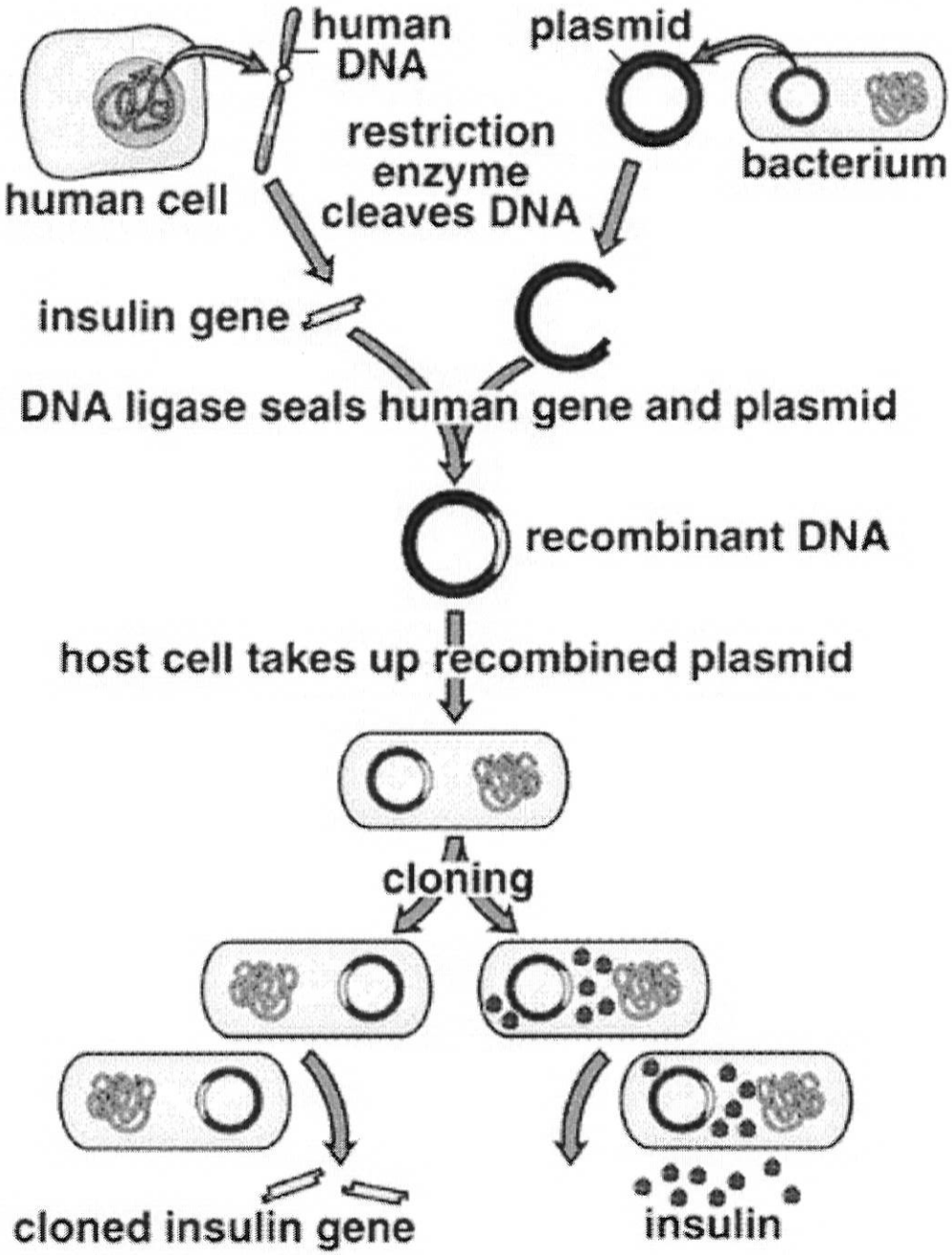
Figure 3 Effect of growth in NHS on Neu5Gc content of HESC and embryoid bodies. HESC or embryoid bodies were grown in NHS instead of the standard serum replacement. Membrane-bound sialic acids were studied for percentage of Neu5Gc as described in the **Fig. 1b** legend. Data represent the mean of two different experiments (mean ± s.d.). $*P < 0.005$, $\dagger P < 0.01$.

From: Martin MJ et al., Human embryonic stem cells express an immunogenic nonhuman sialic acid, Nature Medicine 11, 228-232, February 2005

Human Cloning

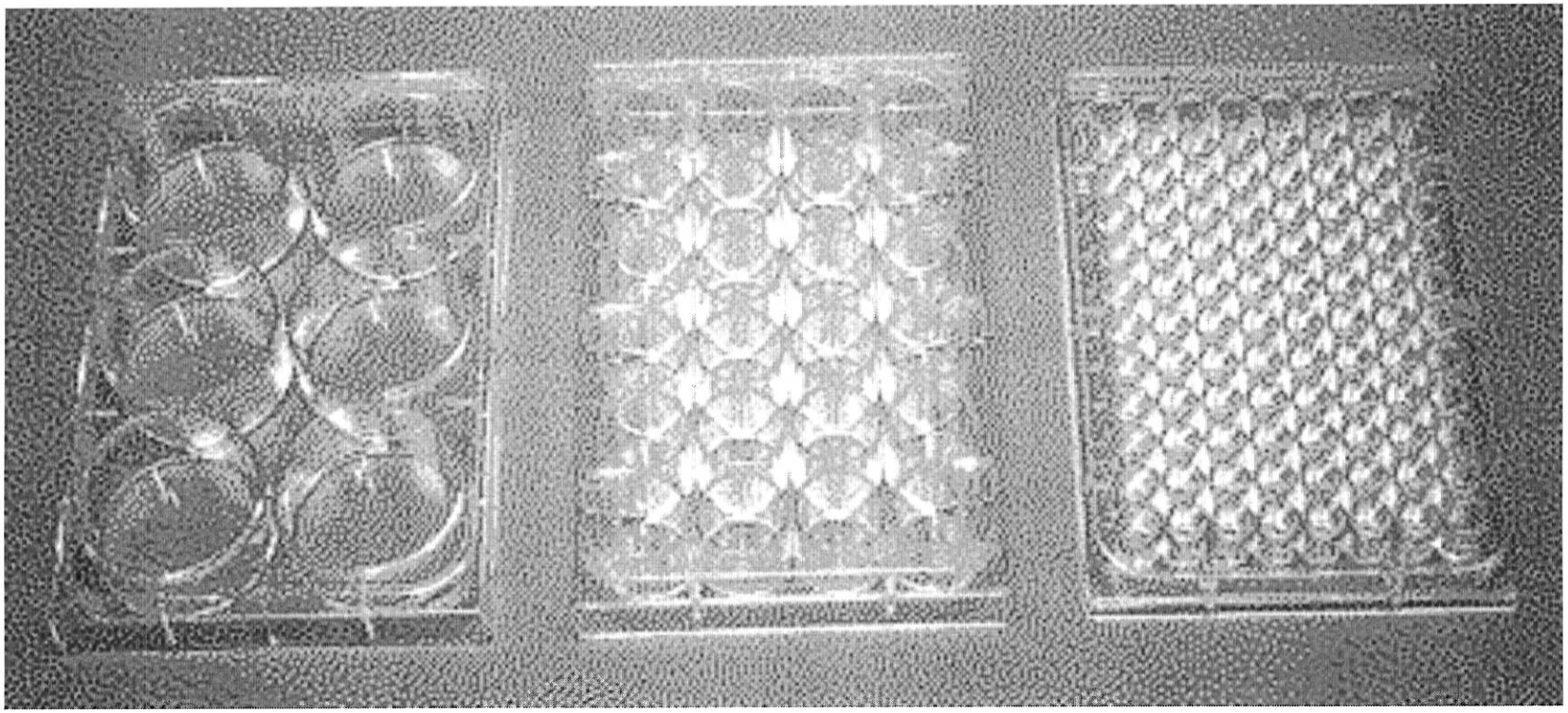
Good grief! I've been cloned!!

Human Gene Cloning

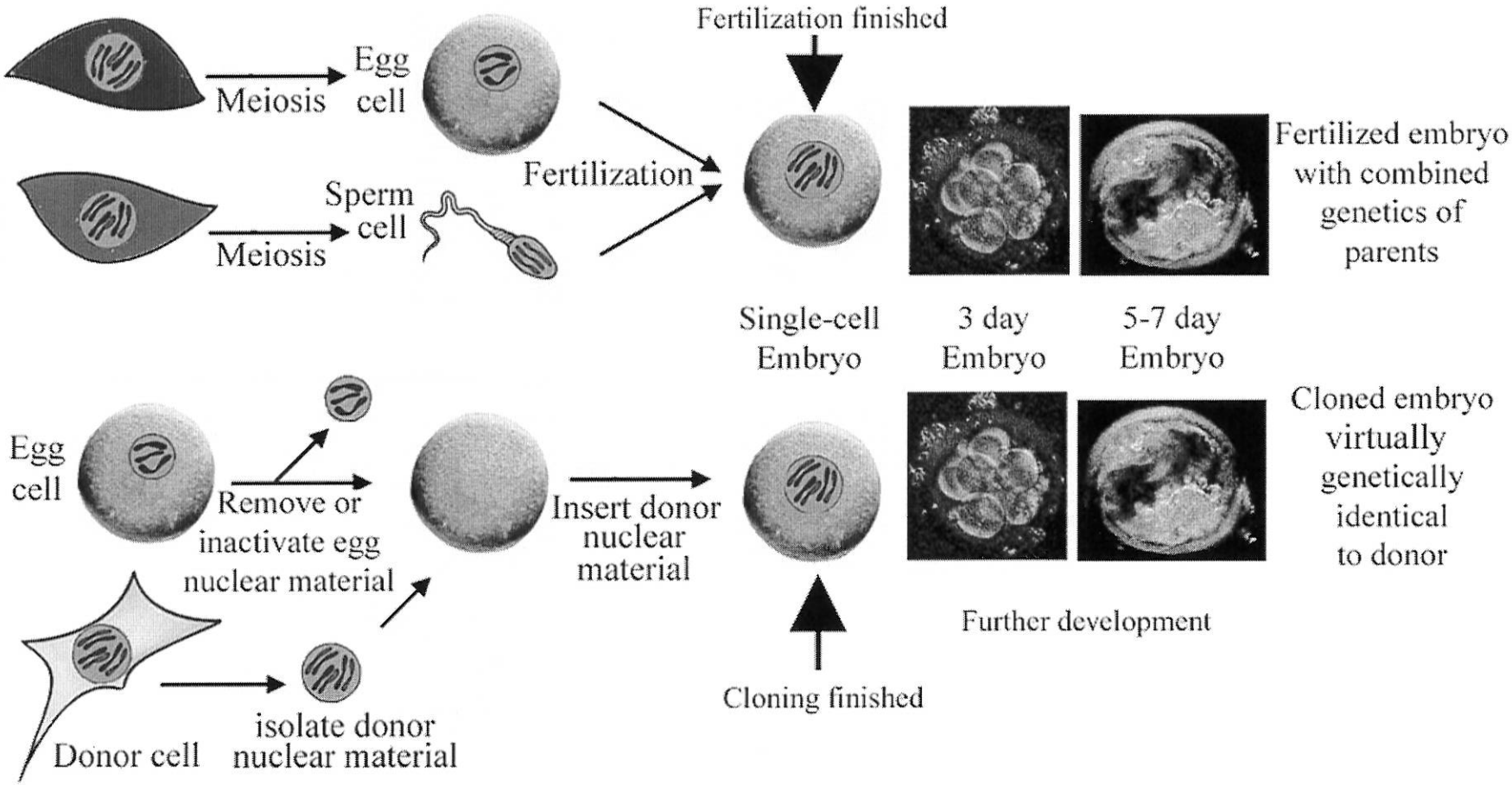


Cell Cloning

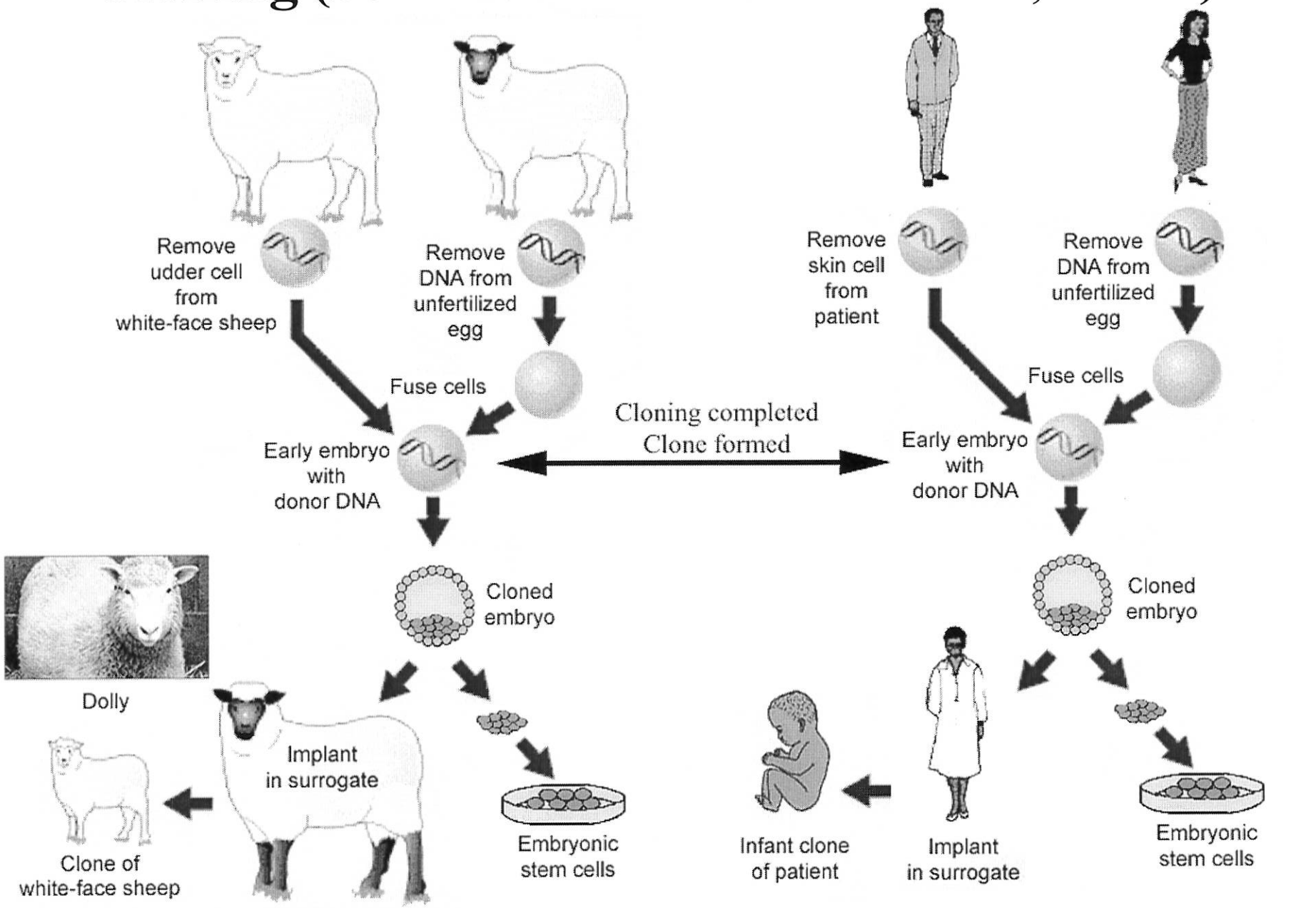
One cell is placed into the dish or well by itself. The cell divides and forms a population of identical cells (cell clones.)



Fertilization *vs*. Cloning (somatic cell nuclear transfer, SCNT)



Cloning (Somatic Cell Nuclear Transfer, SCNT)



Cloning (SCNT) produces a human embryo

1-13

"The Commission began its discussions fully recognizing that any effort in humans to transfer a somatic cell nucleus into an enucleated egg involves the creation of an embryo, with the apparent potential to be implanted in utero and developed to term."
Cloning Human Beings: Report and Recommendations of the National Bioethics Advisory Commission (Rockville, MD: June 1997), p. 3

"The first product of SCNT is, on good biological grounds, quite properly regarded as the equivalent of a zygote, and its subsequent stages as embryonic stages in development."
Human Cloning and Human Dignity: An Ethical Inquiry, Report of the President's Council on Bioethics, July 2002; p.50

Cloning (SCNT) produces a human embryo

1-14

"The method used to initiate the reproductive cloning procedure is called either nuclear transplantation or somatic cell nuclear transfer."

Scientific and Medical Aspects of Human Reproductive Cloning, Report of the National Academy of Sciences and the Institute of Medicine, National Academy Press, Washington, DC, Jan 2002

"anything that you construct at this point in time that has the properties of those structures to me is an embryo, and we should not be changing vocabulary at this point in time. It doesn't change some of the ethical issues involved."

Dr. John Gearhart, Johns Hopkins University, 25 April 2002; before the U.S. President's Council on Bioethics.

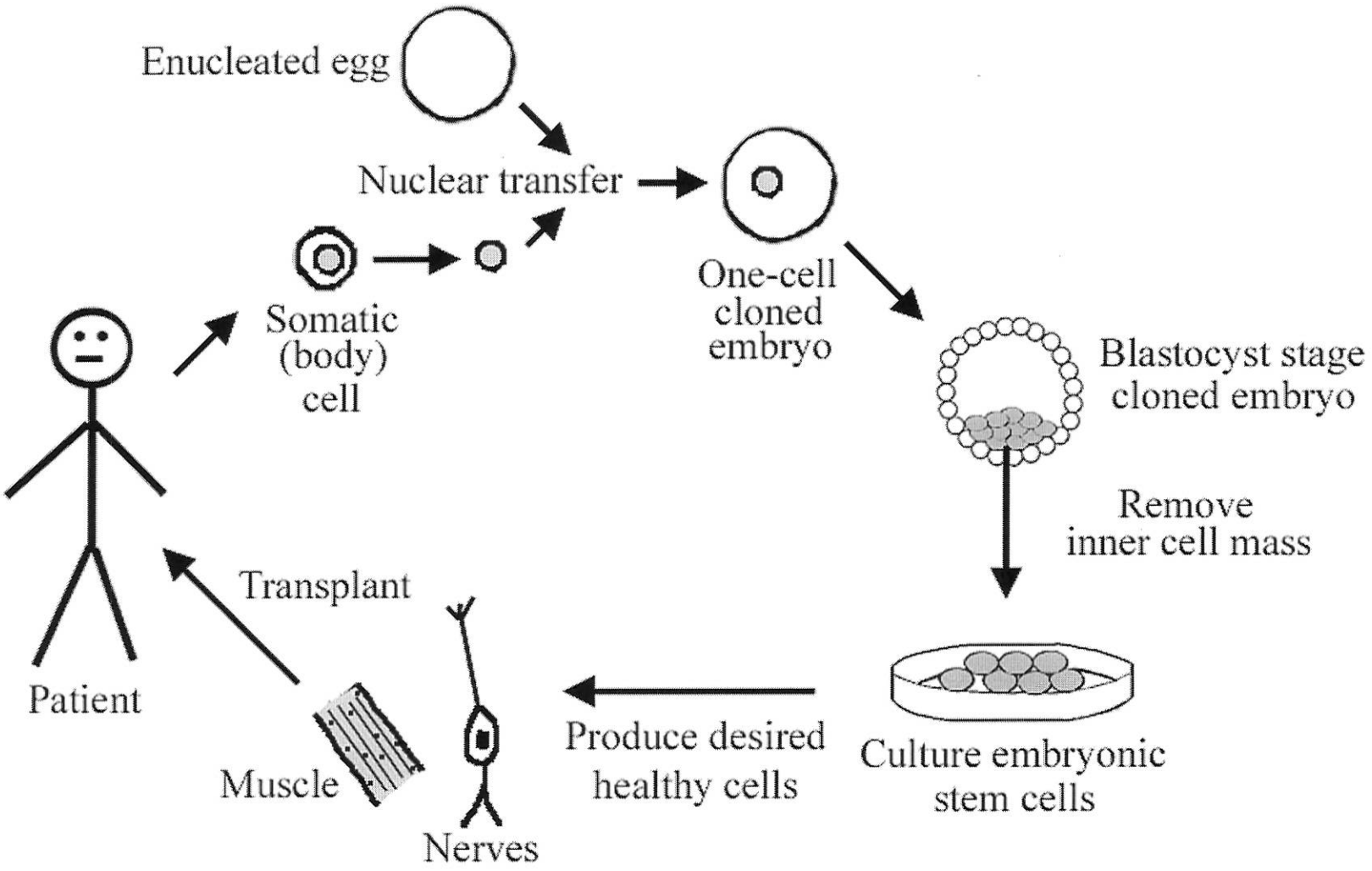
"Therapeutic" Cloning creates an embryo for destruction

"Moreover, because therapeutic cloning requires the creation and disaggregation ex utero of blastocyst stage embryos, this technique raises complex ethical questions."

"CRNT [Therapeutic cloning] requires the deliberate creation and disaggregation of a human embryo."

Robert P. Lanza, Arthur L. Caplan, Lee M. Silver, Jose B. Cibelli, Michael D. West, Ronald M. Green; "The ethical validity of using nuclear transfer in human transplantation"; *The Journal of the American Medical Association* 284. 3175-3179: Dec 27. 2000.

Theoretical Concept of "Therapeutic Cloning"



Therapeutic Cloning is a Failure

- **Transplanted cells from cloned mouse embryo rejected**

*WM Rideout *et al.*, "Correction of a genetic defect by nuclear transplantation and combined cell and gene therapy," *Cell* 109, 17-27; 5 April 2002 (published online 8 March 2002)

"Our results raise the provocative possibility that even genetically matched cells derived by therapeutic cloning may still face barriers to effective transplantation for some disorders."

- *RYL. Tsai, R Kittappa, and RDG McKay; "Plasticity, niches, and the use of stem cells"; *Developmental Cell* 2, 707-712; June 2002

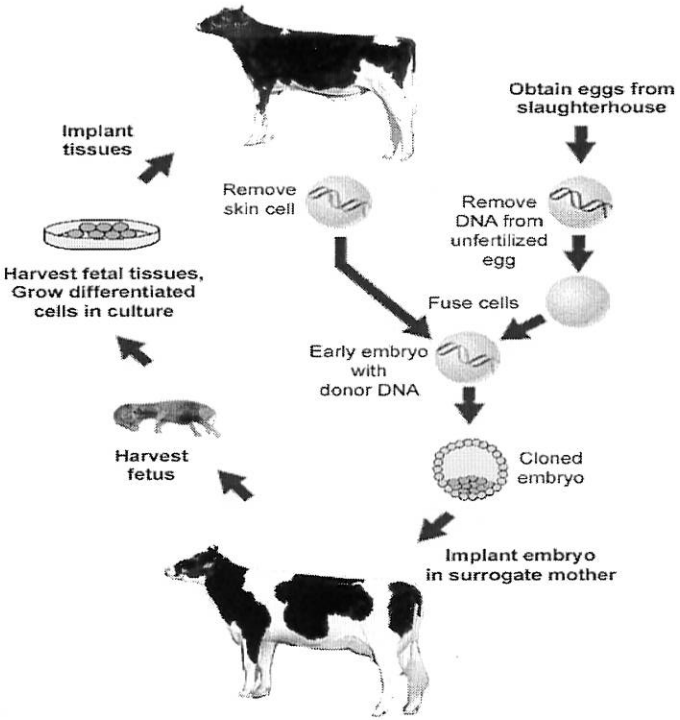
"Jaenisch addressed the possibility that ES clones derived by nuclear transfer technique could be used to correct genetic defects… However, the donor cells, although derived from the animals with the same genetic background, are rejected by the hosts."

- **Clones may need to be gestated to "harvest"already-differentiated tissues**

*R Lanza *et al.*; "Generation of histocompatible tissue using nuclear transplantation," *Nature Biotechnology* 20, 689-696; July 2002

*R Lanza *et al.*, "Regeneration of the infarcted heart with stem cells derived by nuclear transplantation," *Circulation Research* 94, 820-827, April 2004

*R Lanza *et al.*, "Long-term bovine hematopoietic engraftment with clone-derived stem cells", *Cloning and Stem Cells* 7, 95-106, July 2005



9-1

Cloning will not provide the claimed medical treatments

1-17

Unlikely chance of success in clinical use:

Dr. James Thomson, USA—Odorico JS *et al.*; "Multilineage differentiation from human embryonic stem cell lines," *Stem Cells* 19, 193-204; 2001

Dr. Alan Trounson, Australia—Trounson AO; "The derivation and potential use of human embryonic stem cells", *Reproduction, Fertility, and Development* 13, 523-532; 2001

Dr. Peter Mombaerts, USA, "Therapeutic cloning in the mouse", *Proceedings of the National Academy of Sciences USA* 100, 11924-11925; 30 Sept 2003 (published online 29 August 2003)

Transplant Rejection will still occur using cells from cloned embryos:

Dr. Irving Weissman—13 February 2002; before the President's Council on Bioethics

Dr. John Gearhart—25 April 2002; before the President's Council on Bioethics.

Cloning not commercially viable: Thomas Okarma, CEO, Geron Corporation (Denise Gellene, "Clone Profit? Unlikely", Los Angeles Times, May 10, 2002)

Developing "therapeutic" cloning techniques can lead to "reproductive" cloning

Robert P. Lanza, Arthur L. Caplan, Lee M. Silver, Jose B. Cibelli, Michael D. West, Ronald M. Green; "The ethical validity of using nuclear transfer in human transplantation"; *The Journal of the American Medical Association* 284, 3175-3179; 27 Dec 27 2000

American Society for Reproductive Medicine Ethics Committee; "Human somatic cell nuclear transfer (cloning)"; *Fertility and Sterility* 74, 873-876; November 2000

"Therapeutic" cloning places women at risk

1-18

Because both cloning and embryonic stem cell production are extremely inefficient, a tremendous number of eggs will be required.

For example, to treat only the 17 million Diabetes patients in the U.S.:

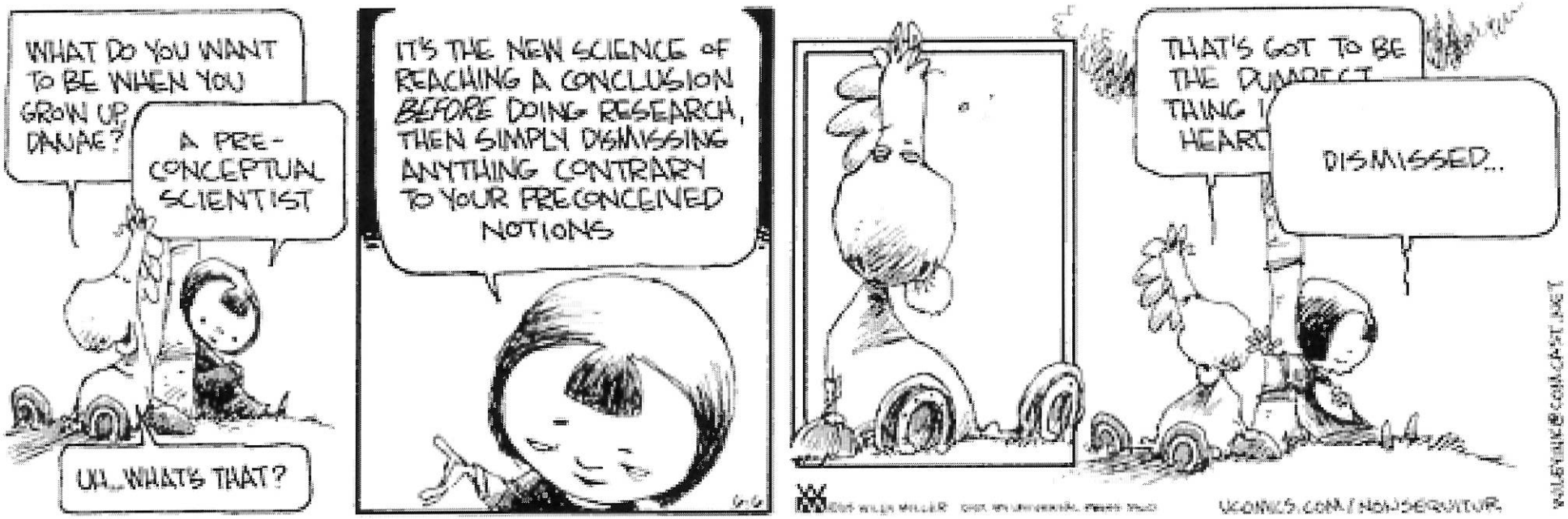
Will require at least 1.7 billion human eggs
(Optimistically 100 human eggs/patient, estimated cost US$100,000-200,000)
Mombaerts P, "Therapeutic cloning in the mouse", *Proceedings of the National Academy of Sciences USA* 100, 11924-11925; 30 Sept 2003; Prentice DA, Stem Cells and Cloning, 1st edition, San Francisco: Pearson Education/Benjamin-Cummings, July 2002

--Collecting 10 eggs/donor:
Will require at least 170 million women - childbearing age donors

Health risks—High-dose hormone therapy and surgery to obtain eggs risks the donor's health and future reproductive success

Commercial exploitation—of women globally

SOUTH KOREAN HUMAN CLONING FRAUD
Cloned human embryos?? no cells, faked data, paying women for eggs, coercion of women students


WHAT DO YOU WANT TO BE WHEN YOU GROW UP, DANAE?
A PRE-CONCEPTUAL SCIENTIST
UH... WHAT'S THAT?
IT'S THE NEW SCIENCE OF REACHING A CONCLUSION BEFORE DOING RESEARCH, THEN SIMPLY DISMISSING ANYTHING CONTRARY TO YOUR PRECONCEIVED NOTIONS
THAT'S GOT TO BE THE DUMBEST THING I HEARD
DISMISSED...
UCOMICS.COM/NONSEQUITUR
WALTHEW@COMCAST.NET

Adult Stem Cells

Bone Marrow

Marrow
Bone
Cartilage
Tendon
Muscle
Fat
Liver
Brain/Nerve
Blood cells
Heart
All Tissues

Stem Cells from Fat

Bone
Cartilage
Muscle
Nerves

Peripheral Blood

Bone Marrow
Blood cells
Nerves

Hair Follicle

Skin Brain
Smooth Muscle Fat

Gastrointestinal

Esophagus Small Intestine
Stomach Large Intestine/Colon

Placenta

Bone Nerve
Cartilage Muscle Tendon
Bone Marrow Blood vessel

Skeletal Muscle

Skeletal muscle
Smooth muscle
Bone
Cartilage
Fat
Heart

Brain

Brain
Nerves
Blood cells
Muscle
All Tissues
Cornea
Retina
Pancreas
Liver
Heart
Lung
Spermatogonia
Amniotic Fluid
Umbilical Cord Matrix

CORD BLOOD

Various Tissues

David A. Prentice

Evidence that Some Adult Stem Cells show Pluripotent Capacity

Umbilical Cord Blood Stem Cells with embryonic-like stem cell properties

McGuckin CP *et al.*, Production of stem cells with embryonic characteristics from human umbilical cord blood, *Cell Proliferation* 38, 245-255, August 2005

Placental Amniotic Stem Cells express Oct-4, nanog; potentially form any tissue, no tumors

Miki T *et al.*, Stem cell characteristics of amniotic epithelial cells, *Stem Cells* published online 4 Aug 2005; doi:10.1634/stemcells.004-0357

Nasal Stem Cells form multiple tissues.

Murrell W *et al.*, "Multipotent stem cells from adult olfactory mucosa, *Developmental Dynamics* 233, 496-515, June 2005

Common Pluripotent Adult Stem Cell isolated from multiple mouse tissues

Case J *et al.*, Clonal multilineage differentiation of murine common pluripotent stem cells isolated from skeletal muscle and adipose stromal cells, Annals NY Acad Sci 1044, 183-200, June 2005

Bone Marrow Stem Cells can form all 3 germ layers, and regenerate damaged heart.

Yoon Y-s *et al.*, "Clonally expanded novel multipotent stem cells from human bone marrow regenerate myocardium after myocardial infarction", *Journal of Clinical Investigation* 115, 326-338, February 2005

Human Cord Blood stem cells show pluripotent potential and extensive proliferation

Kögler G *et al.*, "A new human somatic stem cell from placental cord blood with intrinsic pluripotent differentiation potential", *J. Experimental Medicine* 200, 123-135, 19 July 2004

Human Bone Marrow Adult Stem Cells with pluripotent potential, Oct-4 expression

D'Ippolito G *et al.*, "Marrow-isolated adult multilineage inducible (MIAMI) cells, a unique population of postnatal young and old human cells with extensive expansion and differentiation potential", *J. Cell Science* 117, 2971-2981, 15 June 2004

Peripheral blood stem cells can form cells from all 3 germ layers

Zhao Y *et al.*; "A human peripheral blood monocyte-derived subset acts as pluripotent stem cells"; *Proceedings of the National Academy of Sciences USA* 100, 2426-2431; 4 March 2003

Adult stem cells from bone marrow can form new neurons in the human brain.

Mezey E *et al.*; "Transplanted bone marrow generates new neurons in human brains"; *Proceedings of the National Academy of Sciences USA* 100, 1364-1369; 4 Feb 2003

Adult stem cells from bone marrow can form all body tissues

Jiang Y *et al.*; "Pluripotency of mesenchymal stem cells derived from adult marrow"; *Nature* 418, 41-49; 4 July 2002

A single adult mouse bone marrow stem cell can form multiple functional tissues

Krause DS *et al.*; "Multi-Organ, Multi-Lineage Engraftment by a Single Bone Marrow-Derived Stem Cell"; *Cell* 105, 369-377; 4 May 2001

Adult stem cells effective in tissue repair

1-22

Stroke—Adult stem cells from brain, bone marrow, and umbilical cord blood provide therapeutic benefit after stroke. First clinical trials under way.

*Shyu W-C *et al.*, "Functional recovery of stroke rats induced by granulocyte colony-stimulating factor-stimulated stem cells", *Circulation* 110, 1847-1854, 2004

*Willing AE *et al.*, "Mobilized peripheral blood stem cells administered intravenously produce functional recovery in stroke", *Cell Transplantation* 12, 449-454; 2003

*Arvidsson A *et al.*; "Neuronal replacement from endogenous precursors in the adult brain after stroke"; *Nature Medicine* 8, 963-970; Sept 2002

*Riess P *et al.*; "Transplanted neural stem cells survive, differentiate, and improve neurological motor function after experimental traumatic brain injury"; *Neurosurgery* 51, 1043-1052; Oct 2002

*Li Y *et al.*; "Human marrow stromal cell therapy for stroke in rat"; *Neurology* 59, 514-523; August 2002

*Chen J *et al.*; "Intravenous administration of human umbilical cord blood reduces behavioral deficits after stroke in rats"; *Stroke* 32, 2682-2688; November 2001

Adult stem cells effective in tissue repair

1-23

Spinal Cord Injury—Adult stem cells capable of re-growth and reconnection in spinal cord. Clinical trials started in Portugal, South Korea and Australia.

**Kang K-S *et al.*, A 37-year-old spinal cord-injured female patient, transplanted of multipotent stem cells from human UC blood, with improved sensory perception and mobility, both functionally and morphologically: a case study, *Cytotherapy* 7, 368-373, September 2005

*Sigurjonsson OE *et al.*, Adult human hematopoietic stem cells produce neurons efficiently in the regenerating chicken embryo spinal cord, PNAS 102, 5227-5232, 5 April 2005

*Lu J *et al.*, Olfactory ensheathing cells promote locomotor recovery after delayed transplantation into transected spinal cord, *Brain* 125, 14-21, 2002

*Ohta M *et al.*, Bone marrow stromal cells infused into the cerebrospinal fluid promote functional recovery of the injured rat spinal cord with reduced cavity formation, Experimental Neurology 187, 266-278, 2004

*Hofstetter CP *et al.*, "Marrow stromal cells form guiding strands in the injured spinal cord and promote recovery", *Proc Natl Acad Sci USA* 99, 2199-2204; Feb 19, 2002

*M. Sasaki *et al.*, "Transplantation of an acutely isolated bone marrow fraction repairs demyelinated adult rat spinal cord axons," *Glia* 35, 26-34; July 2001

*A. Ramon-Cueto *et al.*, "Functional recovery of paraplegic rats and motor axon regeneration in their spinal cords by olfactory ensheathing glia," *Neuron* 25, 425-435; Feb 2000.

*M.S. Ramer *et al.*; "Functional regeneration of sensory axons into the adult spinal cord," *Nature* 403, 312-316; Jan 20, 2000.

*Shihabuddin *et al.*; "Adult spinal cord stem cells generate neurons after transplantation in the adult dentate gyrus," *J Neurosci* 20, 8727-8735; Dec 2000.

*Barnett *et al.*; "Identification of a human olfactory ensheathing cell that can effect transplant-mediated remyelination of demyelinated CNS axons," *Brain* 123, 1581-1588, Aug 2000

*A. Ramon-Cueto *et al.*, "Long-distance axonal regeneration in the transected adult rat spinal cord is promoted by olfactory ensheathing glial transplants," *J Neurosci* 18, 3803-3815; May 15, 1998

Adult stem cells effective in tissue repair

1-24

Diabetes—Pancreatic, liver, intestinal, spleen or bone marrow cells can form insulin-secreting islets. FDA approval of first clinical trial, Denise Faustman, Harvard.

*Sapir *et al.*, Cell-replacement therapy for diabetes: generating functional insulin-producing tissue from adult human liver cells, *Proceedings of the National Academy of Sciences USA* 102, 7964-7969, 17 May 2005

*Seaberg BM *et al.*, "Clonal identification of multipotent precursors from adult mouse pancreas that generate neural and pancreatic lineages", *Nature Biotechnology* 22, 1115-1124, Sept 2004

*Oh S-H *et al.*, "Adult bone marrow-derived cells transdifferentiating into insulin-producing cells for the treatment of type I diabetes," *Laboratory Investigation* 84, 607-617, 1 May 2004

*Kodama S *et al.*, "Islet regeneration during the reversal of autoimmune diabetes in NOD mice", *Science* 302, 1223-1227; 14 Nov 2003

*Hess D *et al.*, "Bone marrow-derived stem cells initiate pancreatic regeneration", *Nature Biotechnology* 21, 763-770; July 2003

*Steptoe RJ *et al.*; "Transfer of hematopoietic stem cells encoding autoantigen prevents autoimmune diabetes"; *Journal of Clinical Investigation* 111, 1357-1363; May 2003

*Suzuki A *et al.*; "Glucagon-like peptide 1 (1-37) converts intestinal epithelial cells into insulin-producing cells"; *Proc Natl Acad Sci USA* 100, 5034-5039; 29 April 2003

*Ianus A *et al.*; *In vivo* derivation of glucose competent pancreatic endocrine cells from bone marrow without evidence of cell fusion; *Journal of Clinical Investigation* 111, 843-850; March 2003

*Yang L *et al.*; "*In vitro* trans-differentiation of adult hepatic stem cells into pancreatic endocrine hormone-producing cells"; *Proceedings of the National Academy of Sciences USA,* 99, 8078-8083; 11 June 2002

*S. Ryu *et al.*; "Reversal of established autoimmune diabetes by restoration of endogenous ß cell function," *J. Clin. Invest.* 108, 63-72; July 2001

*Ramiya VK *et al.*; "Reversal of insulin-dependent diabetes using islets generated in vitro from pancreatic .tem cells," *Nature Medicine* 6, 278-282, March 2000.

Adult stem cells effective in tissue repair

1-25

Heart Damage—Bone marrow, muscle, and heart stem cells repair heart.

**Ince H *et al.*, Prevention of left ventricular remodeling with granulocyte colony-stimulating after acute myocardial infarction, *Circulation* 112, I-73-I-80, 30 August 2005

*Dawn B *et al.*, "Cardiac stem cells delivered intravascularly traverse the vessel barrier, regenerate infarcted myocardium, and improve cardiac function", *Proceedings of the National Academy of Sciences USA* 102, 3766-3771, 8 March 2005

*Yoon Y-s *et al.*, "Clonally expanded novel multipotent stem cells from human bone marrow regenerate myocardium after myocardial infarction", *Journal of Clinical Investigation* 115, 326-338, February 2005

**Wollert KC *et al.*, "Intracoronary autologous bone-marrow cell transfer after myocardial infarction: the BOOST randomised controlled clinical trial", *Lancet* 364, 141-148, 10 July 2004

**Britten MB *et al.*, "Infarct remodeling after intracoronary progenitor cell treatment in patients with acute myocardial infarction"; *Circulation* 108, 2212-2218; Nov 2003

**Perin EC *et al.*; "Transendocardial, autologous bone marrow cell transplantation for severe, chronic ischemic heart failure"; *Circulation* 107, r75-r83; published online May 2003

**Stamm C *et al.*; "Autologous bone-marrow stem-cell transplantation for myocardial regeneration"; *The Lancet* 361, 45-46; 4 January 2003

**Tse H-F *et al.*; "Angiogenesis in ischaemic myocardium by intramyocardial autologous bone marrow mononuclear cell implantation"; *The Lancet* 361, 47-49; 4 January 2003

**Strauer BE *et al.*; "Repair of infarcted myocardium by autologous intracoronary mononuclear bone marrow cell transplantation in humans"; *Circulation* 106, 1913-1918; 8 October 2002

*Orlic D *et al.*, "Mobilized bone marrow cells repair the infarcted heart, improving function and survival"; *Proceedings of the National Academy of Sciences USA* 98, 10344-10349, 28 August 2001.

Adult stem cells effective in tissue repair

1-26

Parkinson's Disease—Neural stem cells can form all neuronal types, migrate throughout brain to repair damage, and prevent loss of neurons associated with Parkinson's disease.

*Liker MA *et al.*; "Human neural stem cell transplantation in the MPTP-lesioned mouse"; *Brain Research* 971, 168-177; May 2003

*Åkerud P *et al.*; "Persephin-overexpressing neural stem cells regulate the function of nigral dopaminergic neurons and prevent their degeneration in a model of Parkinson's disease"; *Molecular and Cellular Neuroscience* 21, 205-222; Nov 2002

*Ourednik J *et al.*; "Neural stem cells display an inherent mechanism for rescuing dysfunctional neurons"; *Nature Biotechnology* 20, 1103-1110; Nov 2002

Using the patient's own adult neural stem cells, a group at Los Angeles Cedars-Sinai Medical Center report a reversal of symptoms in the first Parkinson's patient treated.

Lévesque M and Neuman T, "Autologous transplantation of adult human neural stem cells and differentiated dopaminergic neurons for Parkinson disease: 1-year postoperative clinical and functional metabolic result", American Association of Neurological Surgeons annual meeting, Abstract #702; 8 April 2002

Injecting growth signals into the brain stimulates the patients' own adult neural stem cells, provided a 61% improvement.

*Gill SS *et al.*; "Direct brain infusion of glial cell line-derived neurotrophic factor in Parkinson disease"; *Nature Medicine* 9, 589-595; May 2003 (published online 31 March 2003)

Current Clinical Uses of Adult Stem Cells

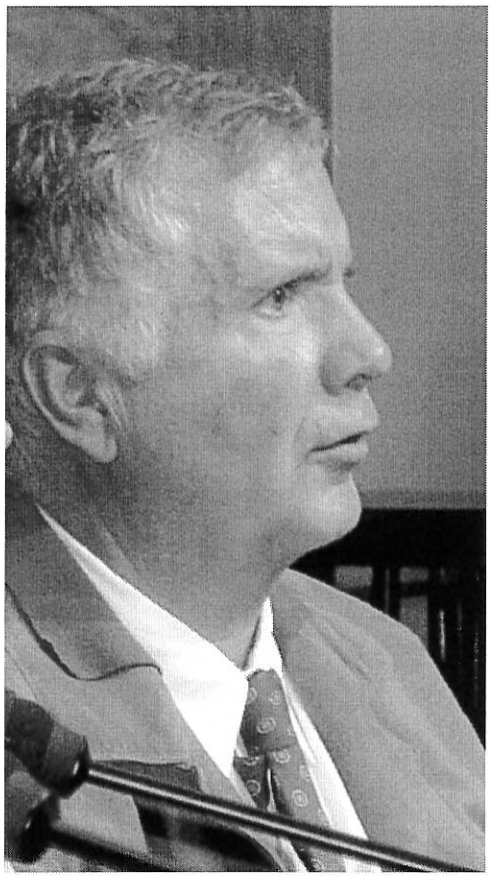
- **Cancers**—Lymphomas, multiple myeloma, leukemias, breast cancer, neuroblastoma, renal cell carcinoma, ovarian cancer
- **Autoimmune diseases**—multiple sclerosis, systemic lupus, rheumatoid arthritis, scleroderma, scleromyxedema, Crohn's disease
- **Anemias** (incl. sickle cell anemia)
- **Immunodeficiencies**—including human gene therapy
- **Bone/cartilage deformities**—children with osteogenesis imperfecta
- **Corneal scarring**-generation of new corneas to restore sight
- **Stroke**—neural cell implants in clinical trials
- **Repairing cardiac tissue after heart attack**—bone marrow or muscle stem cells from patient
- **Parkinson's**—retinal stem cells, patient's own neural stem cells, injected growth factors
- **Growth of new blood vessels**—*e.g.,* preventing gangrene
- **Gastrointestinal epithelia**—regenerate damaged ulcerous tissue
- **Skin**—grafts grown from hair follicle stem cells, after plucking a few hairs from patient
- **Wound healing**—bone marrow stem cells stimulated skin healing
- **Spinal cord injury**—clinical trials currently in Portugal, Italy, S. Korea
- **Liver failure**—clinical trials in U.K.

1-27

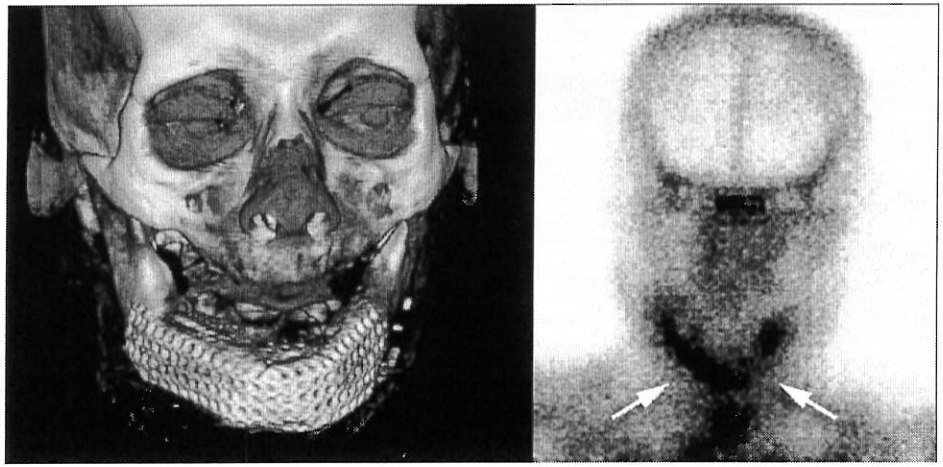
Diseases Treated in Human Patients

1-28

Laura Dominguez and her father.
Treated for spinal cord injury with
her own nasal adult stem cells.

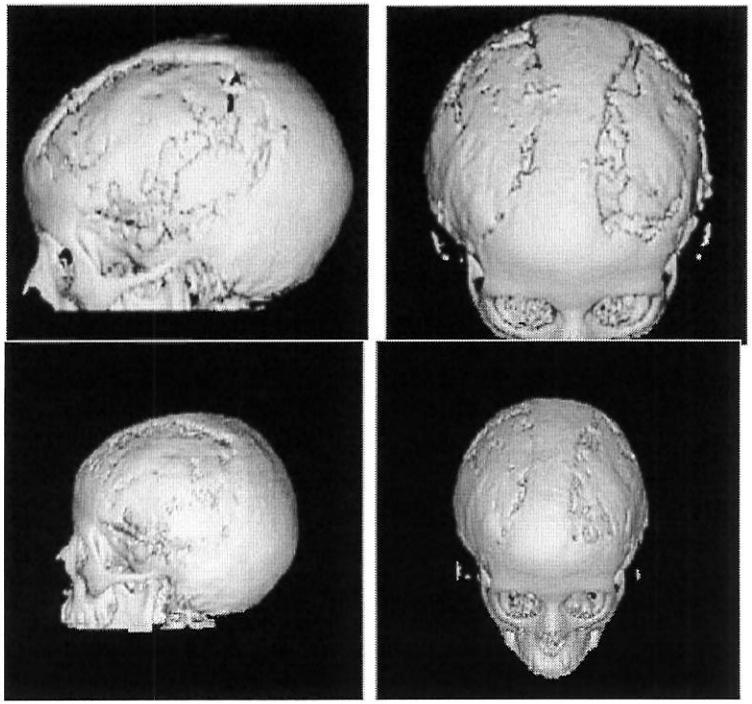


Dennis Turner.
Treated for Parkinson's with
his own brain adult stem cells.



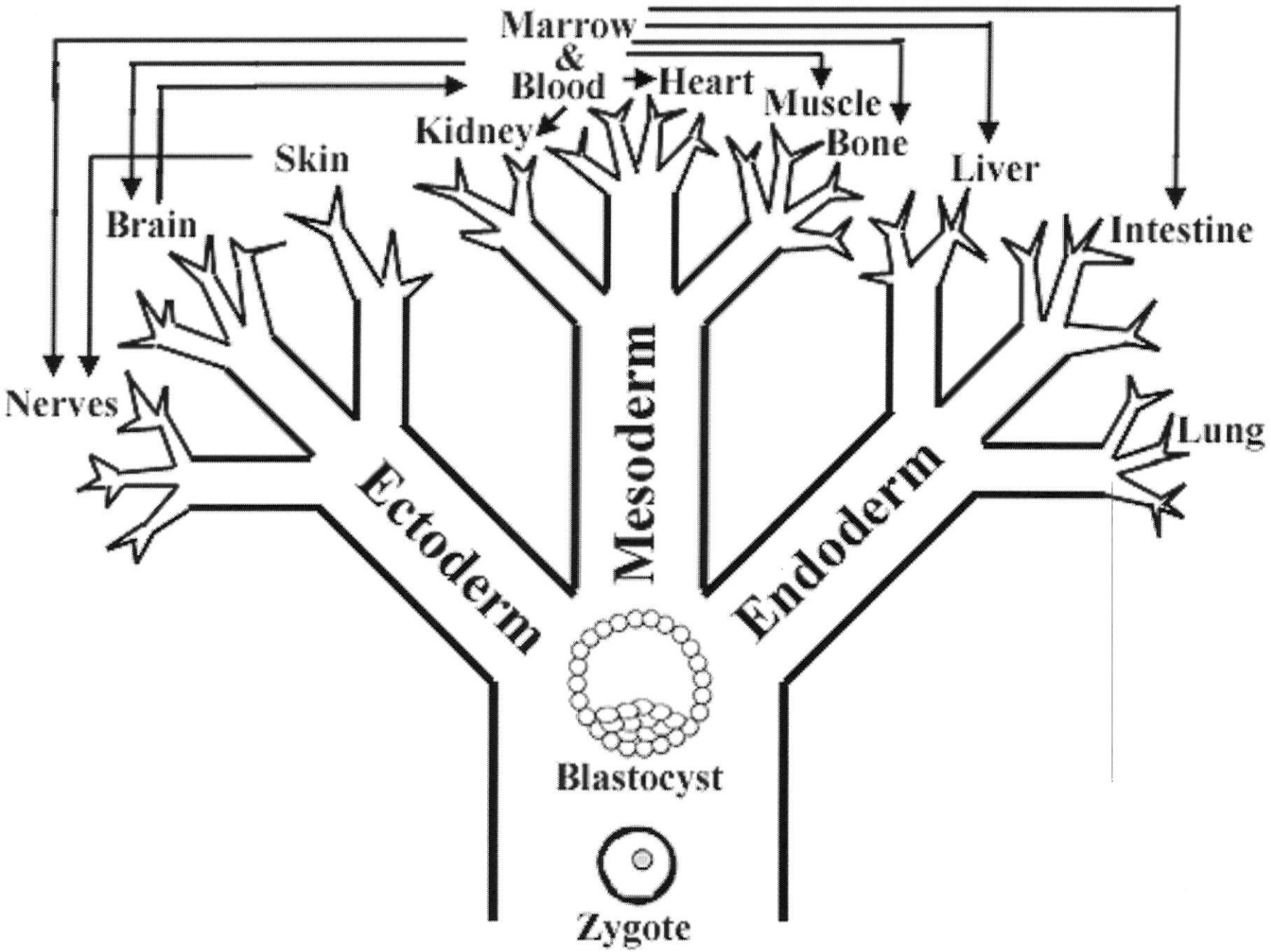
Jaw regrown with adult bone marrow stem cells.

Skull bone grown for 7-year-old girl
using adult stem cells from fat.

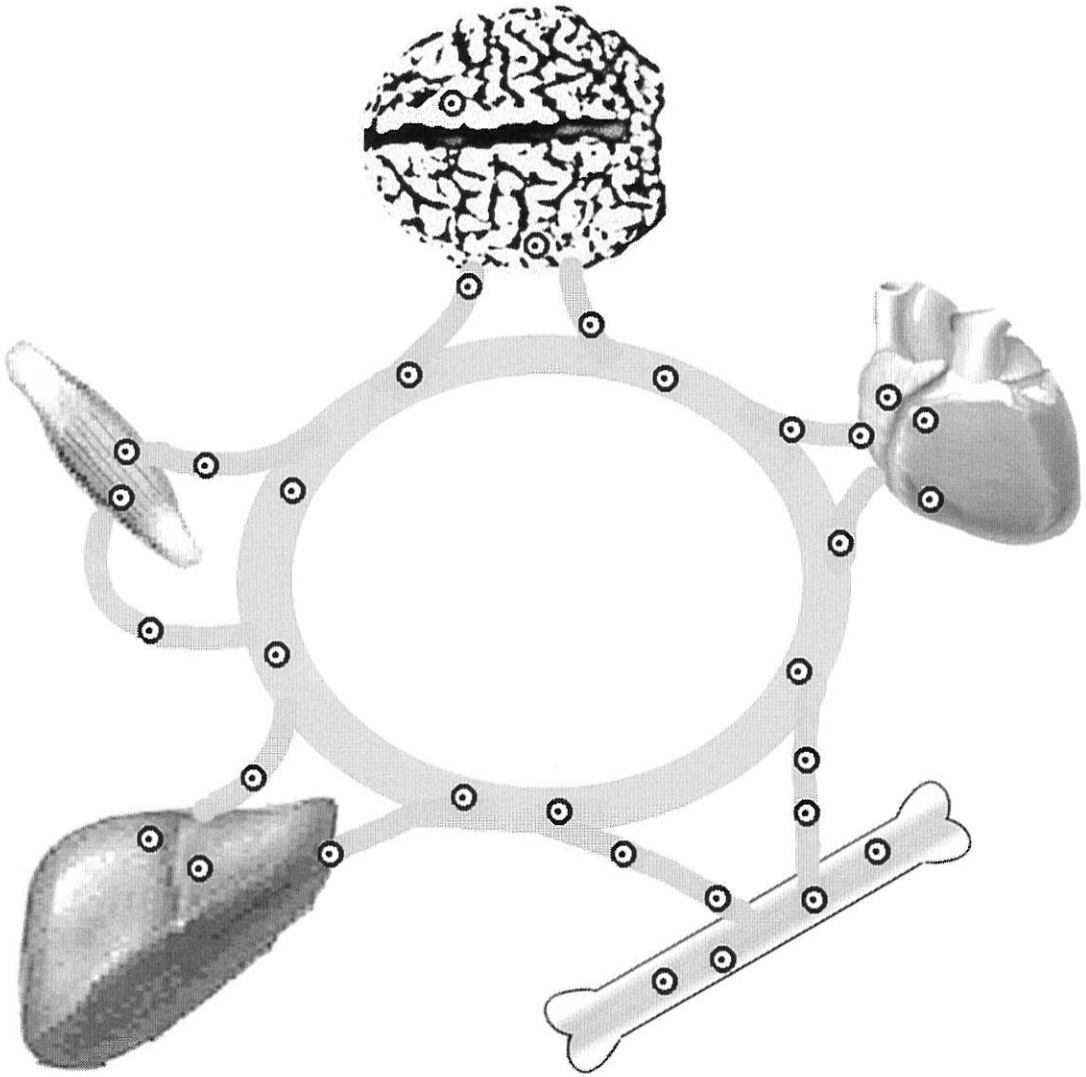


Anthony Dones with his father.
Anthony was successfully treated for osteopetrosis with umbilical cord blood stem cells.

The Developmental "Tree"

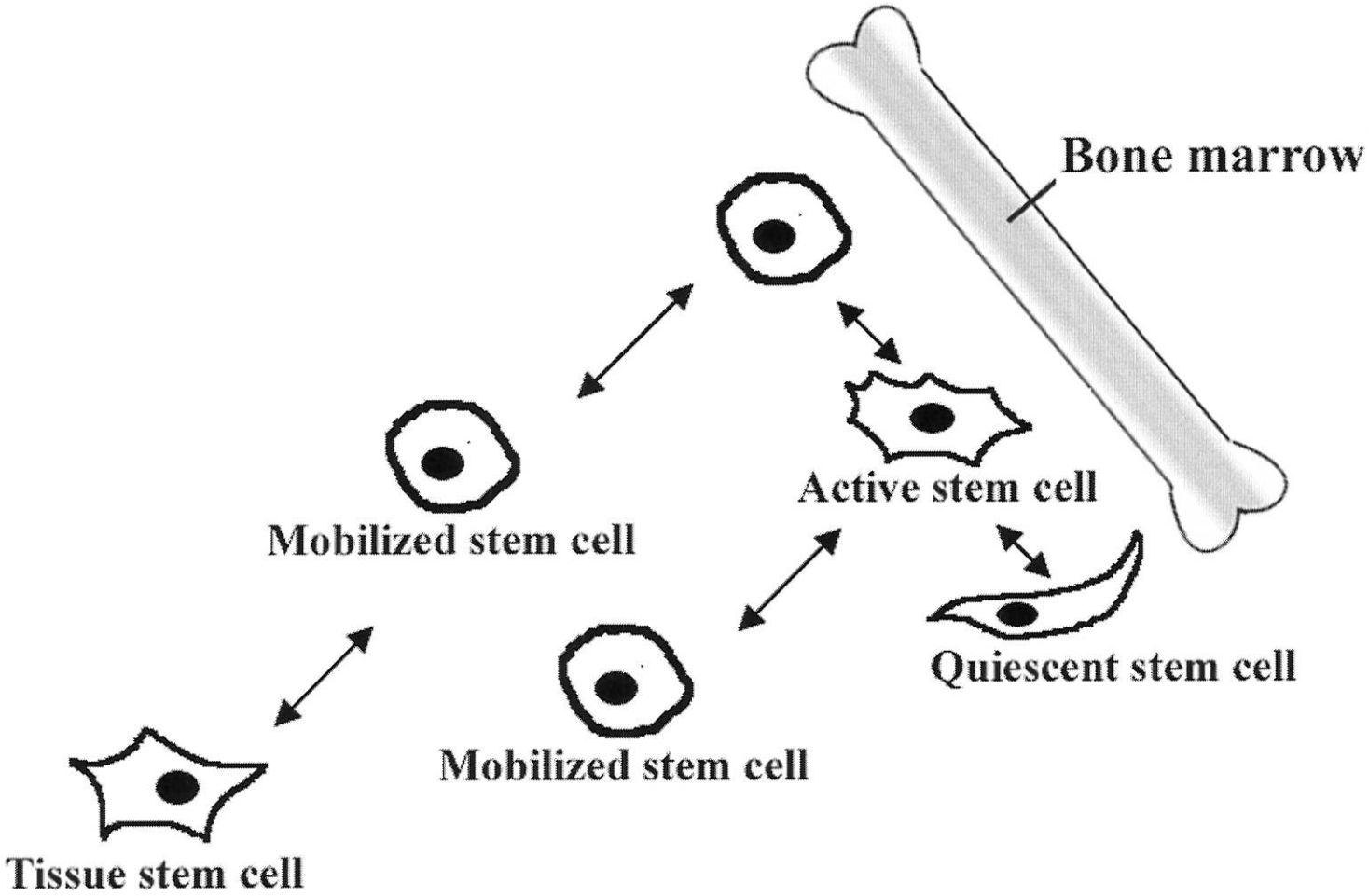


Concept of adult stem cells circulating between various organs for repair and maintenance of tissues



Activation and mobilization of stem cells

Inject cytokines such as GM-CSF to mobilize cells to damaged tissue
(Successful trials with animal models of cardiac damage and stroke, and human patients after heart attack)



Regeneration Mechanism?

(evidence for all of these)

Dedifferentiation-Redifferentiation

Cell fusion with already-differentiated cell

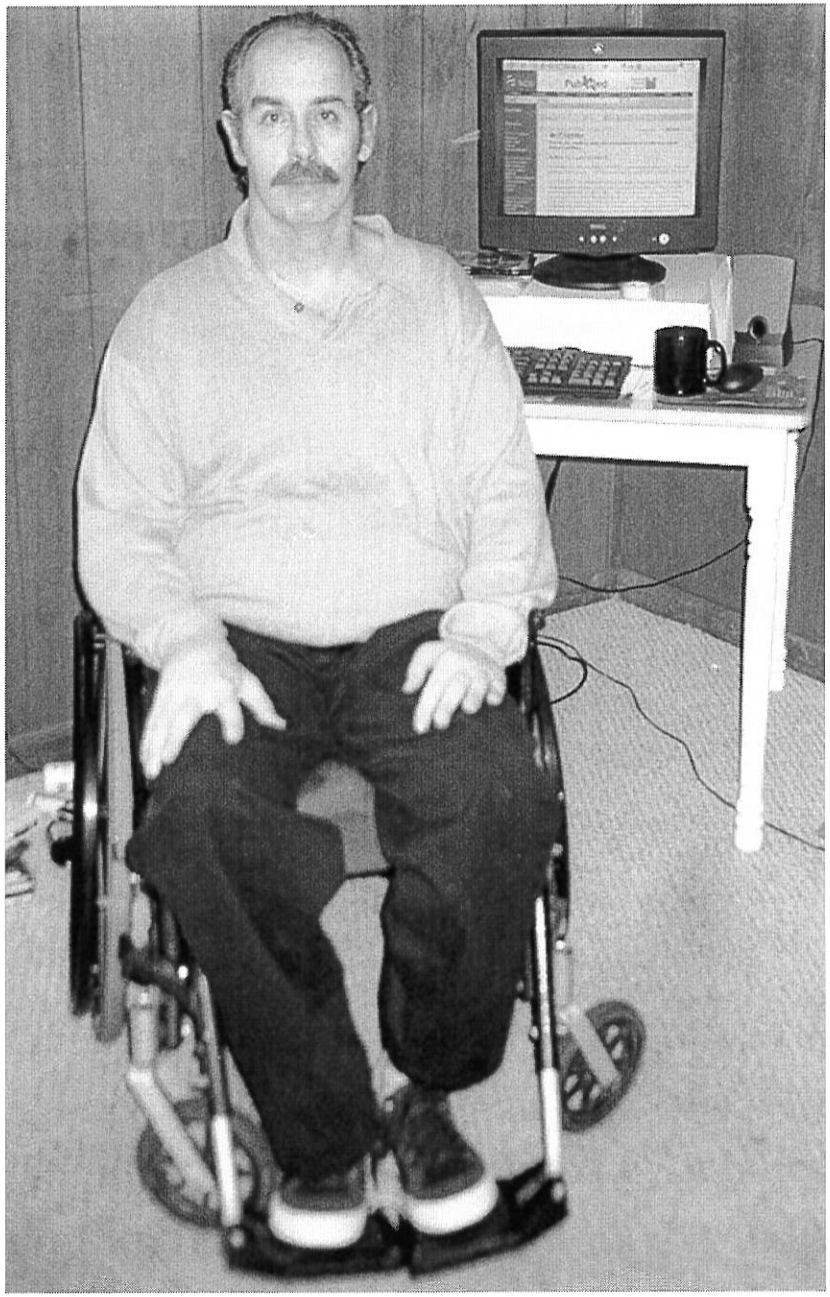
Transdifferentiation

Stimulate Differentiation of Tissue Cells

"[Robert] Lanza noted 'there is ample scientific evidence that adult stem cells can be used to repair damaged heart or brain tissue… if it works, it works, regardless of the mechanism,' he said."
Steve Mitchell, UPI; 12 October 2003

Jim Kelly

Spinal cord injury



Adult Stem Cells

www.stemcellresearch.org

<u>Most promising</u> source for treatments

Able to generate virtually all adult tissues

Can multiply almost indefinitely, providing numbers sufficient for clinical treatments

Proven success in laboratory culture

Proven success in animal models of disease

Proven success in current clinical treatments

Ability to "home in" on damage

Avoid problems with tumor formation

Avoid problems with transplant rejection

Avoid ethical quandary

Topeka Independent Living Resource Center

785-233-4572 V/TTY • FAX 785-233-1561 • TOLL FREE 1-800-443-2207
501 SW Jackson Street • Suite 100 • Topeka, KS 66603-3300

Testimony on HCR 5011 before the House Committee on Health and Human Services
February 15, 2006

Chairman Morrison and members of the committee, thank you for the opportunity to appear before you today. My name is Kevin Siek and I am a disability rights advocate for the Topeka Independent Living Resource Center. Our agency is a civil and human rights organization with a mission to advocate for justice, equality and essential services for all people with disabilities.

I am here today to provide testimony in favor of HCR 5011, a resolution to express the Legislature's recognition and appreciation for family caregivers throughout the state.

80 percent of all long-term home health care in America is provided by family caregivers. 78 percent of all adults receiving such care rely entirely on uncompensated or informal care provided by family and friends. Even among adults with substantial disabilities, those who need assistance with three or more activities of daily living, like folks on our HCBS waiver programs, two thirds of them rely entirely on informal care.

HCR 5011 states, these care-giving services are of inestimable value. While some aspects of these services are inestimable, like the feeling of security a person gets from knowing they have reliable, trustworthy caregivers who they can depend on in an emergency, the economic impact has been estimated by the National Family Caregivers Association.

In Kansas, there are over a quarter of a million family caregivers providing 275 million hours of care annually. If they had been paid market value for all the care they provided it would amount to nearly 2 ½ billion dollars a year.

It is only right that we recognize these family caregivers in, at least, some small way for their selfless service to family and the tremendous contribution they make to their communities and the state of Kansas.

Clearly, we own these caregivers far more that a simple thank you. A good place to start would be to insure a living wage for personal care attendants on the Medicaid Home and Community Based Services Waiver Programs.

HCR 5011 recognizes the work of family caregivers associated with the Department on Aging, but we should not forget the many family caregivers associated with the Department of Social and Rehabilitation Services. We recommend amending HCR 5011 to include language that would allow these caregivers to be recognized as well.

Thank you for the opportunity to testify on HCR 5011. I would be happy to respond to any questions you may have.

Advocacy and services provided by and for people with disabilities.

Attachment 2
HHS 2-16-06

Caregiving Statistics from the National Family Caregivers Association (http://www.nfcacares.org/index.cfm)

CAREGIVING POPULATION

More than 50 million people, provide care for a chronically ill, disabled or aged family member or friend during any given year

Caregiving is no longer predominantly a women's issue. Men now make up 44% of the caregiving population. *Source: National Family Caregivers Association (NFCA) Random Sample Survey of Family Caregivers, Summer 2000, Unpublished.*

Caregivers providing care for a family member over the age of 50 routinely underestimate the length of time they will spend as caregivers - only 46% expected to be caregivers longer than two years. In fact the average length of time spent on caregiving was about eight years, with approximately one third of respondents providing care for 10 years or more. *Source: MetLife Juggling Act Study, Balancing Caregiving with Work and the Costs of Caregiving, Met Life Mature Market Institute, November 1999.*

Most women will spend 17 years caring for children and 18 years helping an elderly parent. *Source: 101 Facts on the Status of Working Women produced by business and Professional Women's Foundation*

ECONOMICS OF CAREGIVING

The value of the services family caregivers provide for "free" is estimated to be $257 billion a year. That is twice as much as is actually spent on homecare and nursing home services. *Source: Peter S. Arno, "Economic Value of Informal Caregiving," presented at the American Association of Geriatric Psychiatry, February 24, 2002.*

Caregiving families tend to have lower incomes than non-caregiving families. Thirty-five percent of average American households have incomes of under $30,000. Among caregiving families the percentage is 43%. *Source: National Family Caregivers Association (NFCA) Rand om Sample Survey of Family Caregivers, Summer 2000.*

Attachment 3
HHS 2-16-06

Of the estimated 2.5 million Americans who need assistive technology such as wheelchairs, 61% can't afford it. *Source: Lisa I. Iezzoni, M.D., M.Sc., 'When Walking Fails: Personal and Health Policy Considerations,' Research in Profile, a National Program of the Robert Wood Johnson Foundation, March 2002.*

Out of pocket medical expenses for a family that has a disabled member who needs help with activities of daily living (eating, toileting, etc.) are more than 2.5% greater (11.2% of income compared to 4.1%) than for a family without a disabled member. *Source: Drs. Altman, Cooper and Cunningham, 'The Case of Disability in the Family: Impact on Health Care Utilization and Expenditures for Non-disabled Members' Milbank Quarterly 77 (1) pages 39 - 75, 1999*

IMPACT OF CAREGIVING

Elderly spousal caregivers with a history of chronic illness themselves who are experiencing caregiving related stress have a 63% higher mortality rate than their non-caregiving peers. *Source: Schulz, R. and Beach, S. R. Caregiving as a Risk Factor for Mortality: The Caregiver Health Effects Study, Journal of the American Medical Association, December 15, 1999, Vol. 282, No. 23*

The stress of family caregiving for person's with dementia has been shown to impact a person's immune system for up to three years after their caregiving ends thus increasing their chances of developing a chronic illness themselves. *Source: Drs.Janice-Kiecolt Glaser and Ronald Glaser 'Chronic stress and age-related increases in the proinflammatory cytokine IL-6', Proceedings of the National Academy of Sciences, June 30, 2003.*

Family caregivers who provide care 36 or more hours weekly are more likely than non-caregivers to experience symptoms of depression or anxiety. For spouses the rate is six times higher; for those caring for a parent the rate is twice as high. *Source: Cannuscio, CC, C Jones, I Kawachi, GA Colditz, L Berkman and E Rimm, Reverberation of family illness: A longitudinal assessment of informal caregiver and mental health status in the nurses' health study. American Journal of Public Health 2002; 92:305-1311.*

Family caregivers providing high levels of care have a 51% incidence of sleeplessness and a 41% incidence of back pain. *Source: National Family Caregivers Association, Caregiving Across the Life Cycle, 1998*

CAREGIVING AND WORK

Thirty-seven percent of employees don't believe that their organizations provide a real and ongoing effort to inform employees of the family -friendly programs that are available. *Source: Families and Work Institute*

Forty two percent of parents of special needs children lack basic workplace supports, such as paid sick leave and vacation time. *Source: Ellen Galinsky and James Bond The 1998 Business Work-Life Study - A Source Book, Families and Work Institute*

Women average 11.5 years out of the paid labor force, primarily because of caregiving responsibilities; men average 1.3 years. *Source: 101 Facts on the Status of Working Women produced by business and Professional Women's Foundation*

American businesses loses between $11 billion and $29 billion each year due to employees' need to care for loved ones 50 years of age and older. *Source: National Alliance for Caregiving/ Met Life Met Life Study of Employer Costs for Working Caregivers*

Both male and female children of aging parents make changes at work in order to accommodate caregiving responsibilities. Both have modified their schedules (men 54%, women 56%). Both have come in late and/or leave early (men 78%, women 84%) and both have altered their work-related travel (men 38%, women 27%). *Source: Sons at Work: Balancing Employment and Eldercare, MetLife Mature Market Institute, June 2003*

CAREGIVING AND HEALTH CARE

Over 40% of U.S. primary care physicians think they don't have enough time to spend with patients. *Source: The Commonwealth Fund Quarterly Report, Fall 2000 Volume 6, Issue 3*

Family caregivers provide the overwhelming majority of homecare services in the U.S., approximately 80%. *Source: US Agency for Healthcare Research and Quality (November 8, 2000). Long-term Care Users Range in Age and Most Do Not Live in Nursing Homes*

In 2000, 50 percent of caregivers reported that different providers gave different diagnoses for the same set of symptoms and 62 percent reported that different providers gave other conflicting information. Another recent survey found that 44 percent of physicians believe that poor care coordination leads to unnecessary hospitalization, and 24 percent stated it can lead to otherwise unnecessary nursing home stays. *Source: Partnership for Solutions, Chronic Conditions: Making the Case for Ongoing Care, Johns Hopkins University, December 2002.*

By the year 2030, nearly 150 million Americans will have some type of chronic illness, a 50% increase since 1995. *Source: Partnership for Solutions Harris Survey Johns Hopkins University, data presented at March 2003 conference, Washington, DC. And Partnership for Solutions, "Chronic Conditions: Making the Case for Ongoing Care," Johns Hopkins University, December 2002.*

Family caregivers who acknowledge their role are more proactive in reaching out for resources and talking with their loved one's doctor than non-acknowledged caregivers. *Source: National Family Caregivers Association, Survey of Self-Identified Family Caregivers, 2001*

Over 40 percent of family caregivers provide some type of 'nursing care' for their loved ones, such as giving medications, changing bandages, managing machinery and monitoring vital signs. *Source: National Family Caregivers Association (NFCA) Random Sample Survey of Family Caregivers, Summer 2000 and C. Levine, Rough Crossings: Family Caregivers' Odysseys through the Health Care System. New York: United Hospital Fund, 1998.*

One-third of family caregivers who change dressings and manage machines, receive no instructions. *Source: Henry J. Kaiser Family Foundation Wide Circle of Caregiving, 1998*

AARP Kansas

February 16, 2006
Representative Morrison, Chair
House Health and Human Services Committee

Good afternoon Chairman Morrison and Members of the House Health and Human Services Committee. My name is Alyce Brown and I am the Southwest Regional Volunteer Coordinator for AARP. AARP Kansas represents the views of our more than 350,000 members in the state of Kansas. Thank you for this opportunity to express our support for HCR 5011 and caregivers of Kansas. Caregiving is a high priority issue for AARP Kansas.

Family caregivers refer to people who provide long-term care services and support to family members, friends, relatives and neighbors. Unpaid caregiver refers to people who provide care without pay.

In the 2004 AARP survey "Caregivers in the U.S., Spotlight on Kansas" it was estimated that approximately 446,000 adults in Kansas, 22 % of the total population, provide unpaid care to a relative or friend 18 or older.

These caregivers are a diverse group. Their caregiving experiences range from those that are relatively easy to those that are burdensome. We know that being a caregiver makes those who assume the heaviest responsibilities vulnerable to risk associated with poorer health, emotional stress and economic hardships.

As the baby boom generation ages over the next 25 years, the ranks of those needing care will swell and the numbers of those available to provide care will decrease. Future caregivers may feel even less choice about becoming caregiver or may provide care for two, three or more recipients. This will increase the caregiver burden.

AARP believes that unpaid caregivers deserve our attention and our assistance by:

- Helping current at-risk caregivers to continue to provide care to family without sacrificing their health, financial security and their quality of life.
- Expanding current caregiver programs to include all caregivers regardless of the age of care recipient.
- Encouraging families and states to begin to plan future needed services for the long-term care population.

As a step in recognizing the efforts of those who carry out the primary role of the unpaid caregiver, we respectfully request your support of HCR 5011 and Kansas caregivers. Thank you for your consideration in this matter.

Respectfully, Alyce Brown

I will stand for questions.

555 S. Kansas Avenue, Suite 201 | Topeka, KS 66603 | 785-232-4070 | 785-232-8259 fax
Marie Smith, President | William D. Novelli, Executive Director and CEO | www.aarp.org

Attachment 4
HHS 2-16-06

Kansas Advocates for Better Care

913 Tennessee, Suite 2
Lawrence, KS 66044-6904
phone: (785) 842-3088
toll-free: (800) 525-1782
fax: (785) 749-0029
e-mail: info@kabc.org
website: www.kabc.org

HCR 5011
Recognition and Appreciation for Caregivers

Thursday, February 16, 2006

Honorable Chairman Morrison
and House Health and Human Services Committee Members:

Kansas Advocates for Better Care (KABC) strongly supports HCR 5011.

While KABC is a statewide non-profit organization of consumers that promotes quality long-term care for persons living in licensed adult care homes, we are very mindful that the care is being provided by not only paid professional caregivers but also volunteer caregivers. There are numerous studies that illustrate the task of caregiver as being very demanding, especially considering many caregivers hold full-time jobs and are attempting to provide hands-on care that will not be provided otherwise. I can imagine that many of you have been in that very situation yourselves.

I, too, have the experience of providing care; it was for my mother who spent six months on hospice. I was able to take time from work to relieve my father from the caregiving duties. His health was suffering from the 24-hour-a-day needs of my mother. He not only needed words of encouragement but he also needed sleep!

This experience and my work with KABC are the reasons that motivate KABC to be a member of the Kansas Alliance for Caregivers. We hope to be helpful to volunteer caregivers as they need information and encouragement.

KABC encourages the Kansas Legislature to recognize family and other volunteer caregivers across our State. KABC encourages the Committee to favorably pass on HCR 5011. Thank you for this opportunity to testify in support of HCR 5011.

Deanne Bacco
Executive Director

Attachment 5
HHS 2-16-06

Testimony in Support of
House Concurrent Resolution No. 5031
Committee on Health and Human Services
February 16, 2006

- Terminology defined:

  - *Advance directive*: a general term used to apply to the health care directive, medical durable power of attorney, living will and informal directives that people make concerning health care treatment decisions

  - *Health care directive*: a document that allows a person to state in writing his/her wishes concerning the use of life-prolonging medical procedures

  - *Medical durable power of attorney*: a document which allows a person to appoint another individual to make health care decisions for the person granting the authority when that person has lost mental capacity

  - *Living will*: a document which allows a person who has a terminal condition to communicate his/her wishes regarding medical treatment; only valid if terminal condition has been confirmed by at least two physicians

- Paucity of Kansans with advance directives—less than 20%

- How to increase numbers of Kansans with advance directives:

  - Intensive state-wide educational programs

  - Incentive (e.g. reduction in health insurance premium for having a valid advance directive)

  - Easy accessibility in public locations/businesses (HR departments in businesses, libraries, drivers' license bureaus, etc.)

Attachment 6
HHS 2-16-06

- Rationale for increasing number of Kansans with advance directives:

Top Five Concerns of the Dying

1. Pain concerns
2. Family/spiritual concerns
3. Death at home /familiar surroundings
4. No mechanical interventions
5. Not to be a financial burden

Statistics

1. 40-50% of Kansans die in moderate to severe pain
2. Majority of people die alone
3. 80% of Kansans die in institutions
4. 40% of Kansans who die in a hospital are on some type of life support measures
5. 30-35% of Kansans lose all or nearly all of their life savings on futile end-of-life care

The greater the number of people with valid advance directives, the more the statistics would mirror the concerns of the dying.

- Benefits of having a valid advance directive:

  - *Reduction* in tension among family members
  - *Reduction* in family anxiety level, guilt, second-guessing of making decision to withhold/withdraw life support
  - *Reduction* in tension among family members and healthcare providers
  - *Reduction* in moral/ethical distress of healthcare providers
  - *Reduction* in the cost of dollars spent on health care

- Value of having a valid advance directive:

  - *Control* for patient in ability to communicate wishes
  - *Comfort* for family in knowing wishes of patient
  - *Confidence* for healthcare providers in knowing they are honoring the patient's wishes

Attachment 7
HHS 2-16-06

Planning the Gift of Love

Presented by: Steven L. Jeffers, PhD
Director, The Institute for Spirituality in Health

"You make a living by what you get.

You make a life by what you give."

Winston Churchill

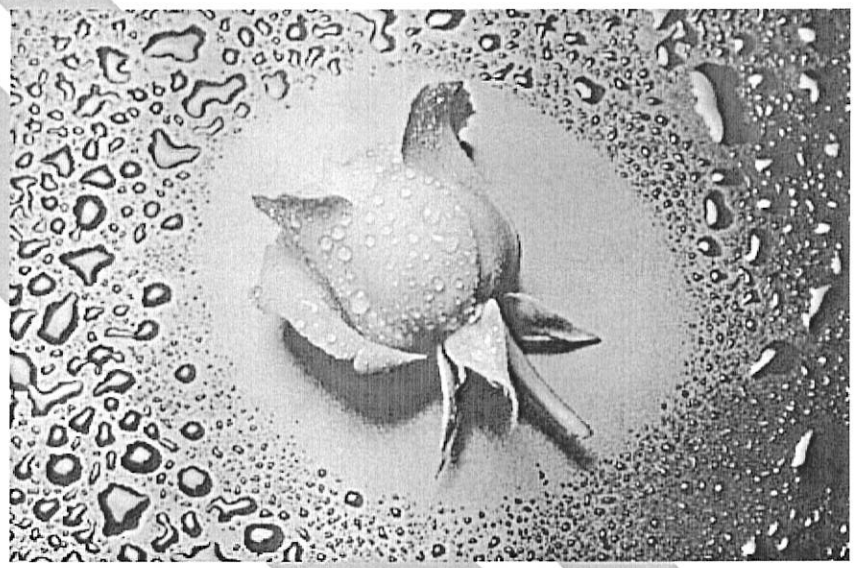
Program Outline

- Decision-Making Considerations
- Barriers and Aids to Effective Planning
- End-of-Life Care Planning Tools
- Advance Directives: A Detailed Discussion
- Heartache of Not Preplanning
- Advance Directives: The Planning Process

Decision-Making Considerations

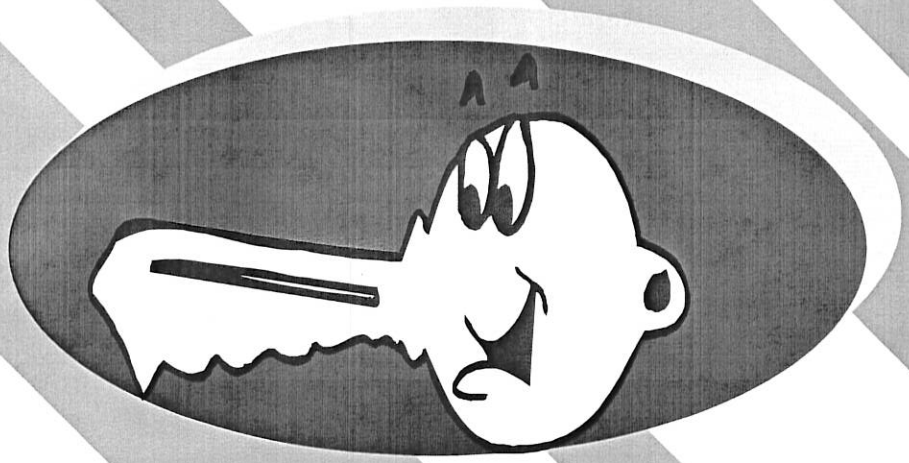
Do You Have A *Gift of Love* Plan?

Your *Gift of Love* Plan Should Include



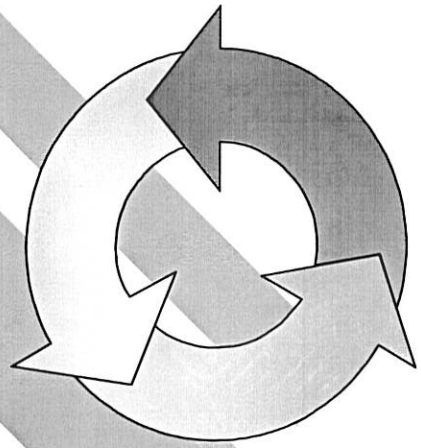
- Savings
- Income Protection – (i.e. Insurance)
- Debt management
- Education Planning
- Investment Planning
- Retirement Planning
- Estate Planning
- Healthcare Planning

The Key to the *Gift of Love* Plan



Quality Decisions

Quality Decision-Making Principles

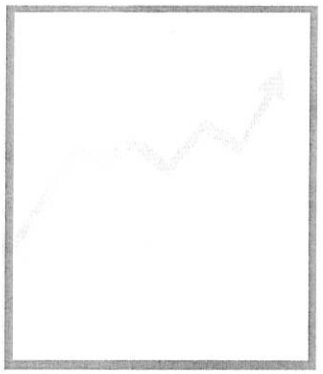


- Accessing pertinent information
- Weighing and balancing options
- Paying attention to thought and feelings
- Meditating and public discussion
- Applying good common sense
- Communicating important end-of-life concerns

Top Five Concerns of the Dying

1. Absence of pain
2. Family/Religious
3. No mechanical interventions
4. Not to be a financial burden
5. Death at Home

Statistics



- More than 50% of personal bankruptcies in America are attributed to medical expenses
- Less than 20% of Americans have advance directives
- 40-50% of Americans die in pain
- Majority of Americans die alone
- 40% of Americans who die in a hospital are on some type of mechanical life support
- 30-35% of American families are financially divested resulting from futile end-of-life care
- 75-80% of Americans die in institutions

Information on Site of Death

	1989	*1997*	*2001*
Percentage of people who died at Home			
KS	**14.1%**	**19.6%**	**20.5%**
US	**16.2%**	**22.5%**	**23.2%**
Percentage of people who died in Nursing Homes			
KS	**24.8%**	**29.2%**	**30.0%**
US	**17.7%**	**23.0%**	**23.7%**
Percentage of people who died in Hospitals			
KS	**60.1%**	**49.4%**	**46.2%**
US	**63.4%**	**51.7%**	**49.2%**

http://www.chcr.brown.edu/dying/brownatlas.htm

Rankings of States with Greatest Proportion Of Deaths at Home 1989-2001

7-12

http://www.chcr.brown.edu/dying/brownatlas.htm

	1989	1997	2001
Alaska	8	3	3
Arizona	50	20	15
Arkansas	22	21	16
Colorado	11	10	12
Connecticut	34	43	49
DC	49	51	51
Florida	3	12	13
Illinois	46	46	41
Iowa	41	45	47
Kansas	40	38	37
Louisiana	51	40	35
Mississippi	28	42	30
Missouri	26	30	22
Montana	18	14	9
N. Dakota	44	50	46
Nebraska	20	15	20
New Mexico	9	4	5
Oklahoma	48	27	17
Oregon	5	1	1
S. Dakota	39	49	50
Utah	1	2	2

"Although important
to discuss and plan
for death and dying,
Americans are uncomfortable
with the topic and do nothing."

STOP

American Health Decisions

Why Don't Americans Plan for Death?

Barriers and Aids to Effective Planning

Barriers and Aids to Effective Planning

- Personal Values (barrier)
- Societal Expectations
- Medical Model
- Personal Values (aid)

Personal Values

"Where There Is Life,
There Is Hope."

Plato

"Life at All Costs."

Aristotle

"Wait and See!"

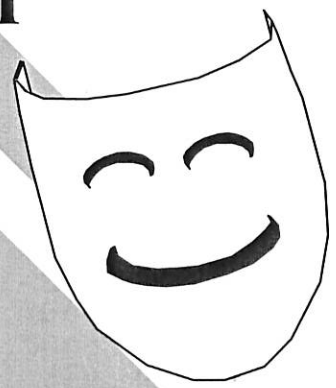
"Do Everything You Can!"

Societal Expectations

Technological Imperative

"If you have it, use it."

Medical Science Has Made Incredible Strides in Keeping Illness From Destroying Our Life Values



- You have a right to medical care
- You have a right to the best treatment your money can buy
- You have a right to a longer life than your parents

"If I'da Known I Was Going to Live So Long, I'da Taken Better Care of Myself."

Mark Twain

Medical Model

Ethic of Cure

- Do everything you can to defeat illness
- Do everything you can to preserve life at all costs
- Defeat the enemy which is death

"Death Is Not the Enemy;
Taxes Are."

Personal Values

Medical Science Can Hold People Captive

- You have the right to refuse treatment
- You have the right not to spend your life savings on futile healthcare
- You have the right to die sooner

"Everyone Knows They're Going to Die, But Nobody Believes It. If We Did, We Would Do Things Differently."

Morrie Schwartz

What Should I Do to Prepare for the Certainty of Death?

End-of-Life Care Planning Tools

What is an Advance Directive?

- General term
- Encompasses the *living will*, *healthcare directive* and *medical durable power of attorney*
- Helps communicate healthcare preferences when self capacity is lost

What is a Living Will?

- Written statement of wishes regarding medical treatment in *terminal situation*
- Only effective if two physicians have confirmed terminal illness

NEW LIVING WILL

I, _____ (fill in the blank), being of sound mind and body, do not wish to be kept alive indefinitely by artificial means.

Under no circumstances should my fate be put in the hands of pinheaded politicians who couldn't pass ninth-grade biology if their lives depended on it.

If a reasonable amount of time passes and I fail to sit up and ask for a cold beer, it should be presumed that I won't ever get better. When such a determination is reached, I hereby instruct my spouse, children and attending physicians to pull the plug, reel in the tubes and call it a day.

Under no circumstances shall the members of the Legislature enact a special law to keep me on life-support machinery. It is my wish that these boneheads mind their own damn business, and pay attention instead to the health, education and future of the millions of Americans who aren't in a permanent coma.

Under no circumstances shall any politicians butt into this case. I don't care how many fundamentalist votes they're trying to scrounge for their run for the presidency. It is my wish that they play politics with someone else's life and leave me alone to die in peace.

I couldn't care less if a hundred religious zealots send e-mails to legislators in which they pretend to care about me. I don't know these people, and I certainly haven't authorized them to preach and crusade on my behalf. They should mind their own business too.

If any of my family goes against my wishes and turns my case into a political cause, I hereby promise to come back from the grave and make his or her existence a living hell.

_____

Signature

_____

Witness

What is a Healthcare Directive?

- Document stating wishes regarding the use of life-prolonging procedures
- Not effective until the person can no longer make/communicate decisions
- Includes diagnoses classified as *terminal* and *non-terminal*
- Includes wishes regarding quality of life

"A man and his wife were sitting in the living room and he said to her:

'*Just so you know, I never want to live in a vegetative state, dependent on some machine and fluids from a bottle. If that ever happens, just pull the plug.*'

His wife got up, unplugged the TV and threw out all of his beer."

What is a Medical Durable Power of Attorney?

- Written document authorizing someone to make healthcare decisions
- Decisions include: power to consent, refuse or withdraw consent to any type of medical treatment, service or procedure
- Effective only during period of patient incapacity

ADVANCE DIRECTIVE

LIVING WILL

HEALTHCARE DIRECTIVE

MEDICAL DURABLE POWER OF ATTORNEY

Living Will *versus* Healthcare Directive

- Living will—only applies to decisions regarding "life-sustaining treatment" in the event of a "terminal illness"
- Healthcare directive—applies to decisions regarding "life-sustaining treatment" in "terminal and non-terminal illnesses" and addresses quality-of-life issues

Need for Healthcare Directive *and* Medical Durable Power of Attorney?

- Recommended to have both
- Healthcare directive outlines one's wishes concerning end-of-life care and quality-of-life issues related to medical interventions
- Medical durable power of attorney gives one's agent the authority to direct that one's wishes for healthcare be followed

What is a DNR Directive?

- Physician's directive stating that the patient wishes to withhold life-sustaining treatment
- Conditions may be applied which might alter the provisions of medical care (e.g. withhold mechanical ventilation but not dialysis)

"*Terminology* proliferates where *Ignorance* abounds."

Sir John Parkinson

"Well done
Is better than
Well said."

Benjamin Franklin

What Do I Do Now?

Advance Directives: A Detailed Discussion

Advance Directives *Can*

- Aid in advance care planning
- Cause people to stop, think and discuss
- Promote dialogue between physician and patient before the latter reaches incapacity
- Empower loved ones and healthcare providers by reflecting the patient's values

Advantages of Preplanning

- Grant doctors written permission/authority to act in concert with expressed desires concerning healthcare treatment
- Take family members "off the hook" with respect to tough decisions concerning healthcare treatment
- Aid in making death a *personal* event rather than a *medical* one

Advance Directives *Cannot*

- Provide "cookbook" directions
- Eliminate personal ambivalence
- Substitute for discussion

Consequences of not Preplanning

- Unable to express wishes or participate in healthcare-treatment decisions when incapacitated
- Very difficult to engage in contemplative preplanning for healthcare-treatment decisions when critically ill
- Hospital environment not conducive to rational thought processes on the part of patient and/or family members

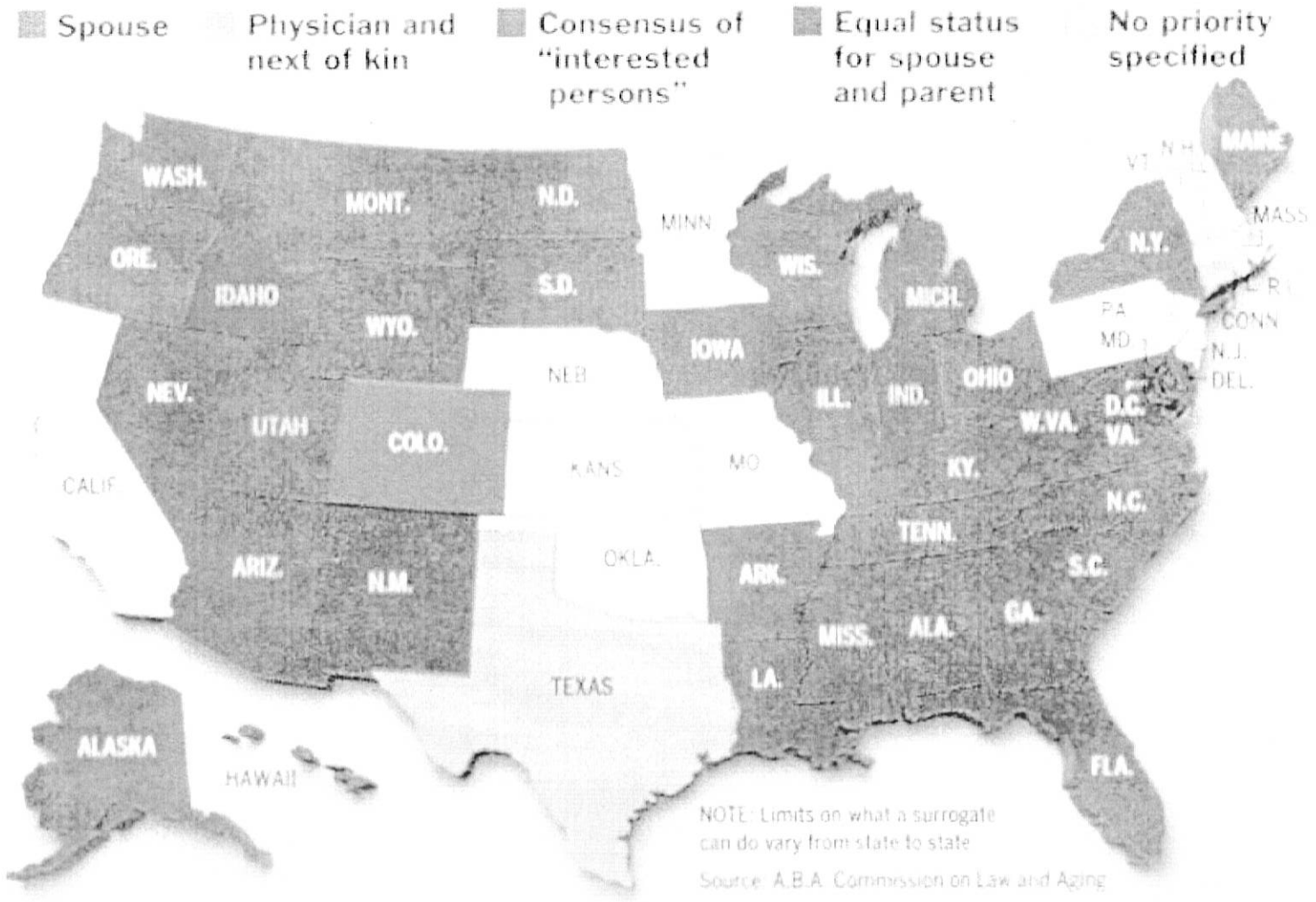
"Do family members have ***legal authority*** to make healthcare treatment decisions for loved ones in the ***absence of an advance directive***?"

Surrogate Decision Makers' Statute

A "*Surrogate Decision Makers*" statute would give the legal authority to family members to consent to treatment in non-emergency situations. A spouse or adult child does not have clear authority under Kansas law to make treatment decisions. Therefore, any dispute among family members or the need for intrusive procedures in non-emergency situations may require the appointment of a guardian or other legal action.

7-52

WHO GETS TO DECIDE? In most states, statutes give priority to the spouse as decision maker for an incapacitated person, assuming there are no advance directives or previously designated agents. Here are surrogate priorities by state:



Time, April 4, 2005, p. 30

*What Happens If I **Do Not** Have an Advance Directive?*

Heartache of Not Preplanning

Medical science is my shepherd, I shall not want.
It maketh me to lie down in hospital beds;
It leadeth me beside the marvels of technology.
It restoreth my brain waves;
It maintains me in a persistent vegetative state
for its name sake.
Yea, though I walk through the valley of the shadow of death,
I shall find no end to life; for thou art with me;
Thy respirator and heart machine, they sustain me.
Thou preparest intravenous feeding for me
in the presence of irreversible disability;
Thou anointest my head with oil;
My cup runneth on and on and on and on and on.
Surely coma and unconsciousness shall follow me all
the days of my continued breathing;
and I shall dwell in the intensive-care unit forever.

Richard D. Lamm

The Heartache of *Not* Preplanning

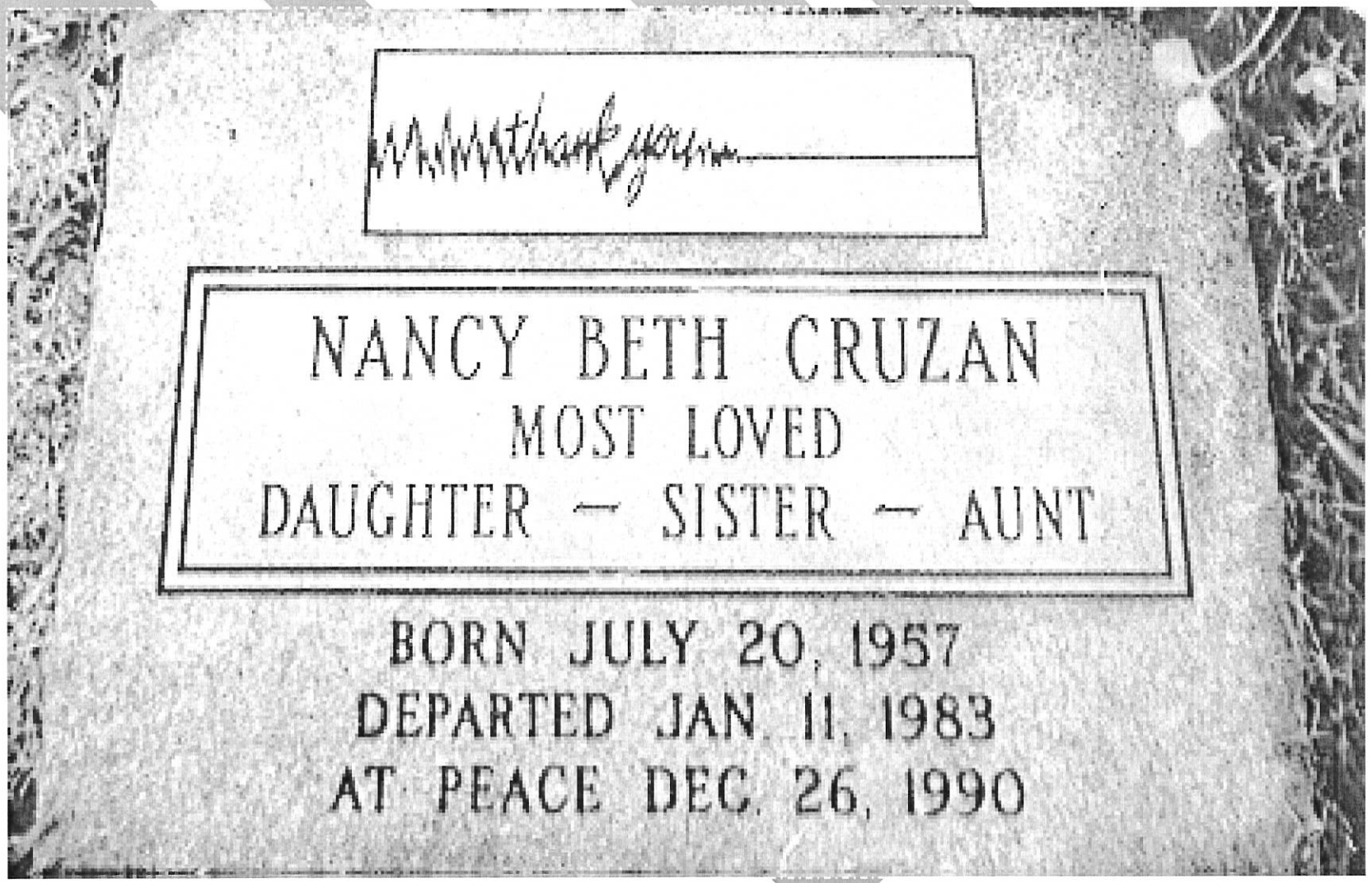
- Karen Ann Quinlan
- Nancy Beth Cruzan
- Theresa Marie Schiavo

"It is another heart-wrenching example of what can happen when there is no advance directive in place."

Chris Cruzan White on the Terry Schiavo Case

"I Pray to God That Someone Would Love Me Enough to Fight to Let Me Die."

Postcard to Joe Cruzan from "Long Goodbye," Bill Colby


thank you
NANCY BETH CRUZAN
MOST LOVED
DAUGHTER — SISTER — AUNT
BORN JULY 20, 1957
DEPARTED JAN. 11, 1983
AT PEACE DEC. 26, 1990

"Today, as the protester's sign says, we give Nancy the *gift of death*. An unconditional *gift of love* that sets her free from this twisted body that no longer serves her. A gift I know she will treasure above all others, the *gift of freedom*. So run free Nan, we will catch up later."

Joe Cruzan

How Can I Avoid the Heartache of Tragic End-of-Life Situations?

Advance Directives: The Planning Process

The Planning Process

- Ask questions
- Have conversations
- Document completion procedures
- The "gift of love" for those you care about and who care about you

Ask Questions

Love Planning Questions

- What or who would be the most important to you in dying?
  - What thoughts, preferences, and values on death have you shared with your friends, family and healthcare team?
  - What information do your religious beliefs convey about serious illness or death?
  - What would you consider as a life not worth living concerning a state of health?
  - Without an acceptable quality of life, how do you feel about life-sustaining measures if you had a condition that would cause you to die soon?

Love Planning Questions (Cont)

- What are you hoping for in death?
  - What would make your death most satisfying?
  - Where would you prefer to die?
  - What is the level of importance in you having the final say in making decisions about your healthcare at the end of life?
  - Whom do you trust the most to make decisions on your behalf regarding end-of-life healthcare?
- What is your greatest fear about dying?

Have Conversations

A Family Conversation

"I Want Someone to Hear My Story. *Will You?*"

Morrie Schwartz

Document Completion Procedures

"Gift of Love" Document

Health Care Directive

Take a copy of this with you whenever you go to the hospital or on a trip.

I, (please print) _____ want everyone who cares for me to know what health care treatments I want when I cannot let others know what I want.

I always expect to be given care and treatment for pain or discomfort, even when such care might make me sleepy, make me feel like not eating, slow down my breathing or be habit-forming.

I want my doctor to try treatments that may get me back to an acceptable quality of life. By acceptable quality of life, I mean living in a way that lets me do the things that are important and necessary to me. Those things are:

_____

_____

Examples: the ability to: • Recognize family or friends • Feed myself • Make decisions • Take care of myself • Communicate

I want to be kept comfortable and have a natural death. Therefore, I direct that no treatment be given just to keep me alive when I have:

- A condition that will cause me to die soon, or
- A condition so bad (including substantial brain damage or brain disease) with no reasonable hope that I will regain a quality of life acceptable to me (as described above).

So, when I have one of the above conditions, I do/do not want included are:	Do Want	Don't Want	Initials
• Surgery	☐	☐	_____
• Doing things to start my heart or breathing, if either stops (CPR)	☐	☐	_____
• Medicine to treat infections (antibiotics)	☐	☐	_____
• Artificial kidney machine (dialysis)	☐	☐	_____
• Breathing machine (respirator, ventilator)	☐	☐	_____
• Food or water given through a tube in the vein, nose or stomach (tube feedings or IVs)	☐	☐	_____
• Chemotherapy (cancer treatment)	☐	☐	_____
• Blood transfusions	☐	☐	_____
• Other treatments _____	☐	☐	_____

My other directions include: _____

_____

Examples: • Hospice care • Death at home, if possible • Donation of organs and/or tissues

Be sure to sign the form on the reverse side of this page.

If you only want to name a Medical Durable Power of Attorney, draw a large "X" through this page with the exception of the first line with your name.

Talk about this form and your ideas about your health care with the person you have chosen to make decisions for you. Moreover, discuss the document and those same ideas with your doctor(s), family, friends, clergy, attorney and any other persons who might also play a role in your end-of-life care. Furthermore, be certain to give each of those individuals a completed copy. Finally, you may cancel or change this form at any time; you should also review it every so often. However, each time you review it, put your initials and date here: _____

This document is provided as a service by Shawnee Mission Medical Center.

For more information, call the Spiritual Wellness department at (913) 676-2305.

Shawnee Mission Medical Center

Medical Durable Power of Attorney

It is important to choose someone to make health care decisions for you when you cannot. ***Tell the person (agent) you choose what you would want.*** *The person you choose has the same right as you do to make decisions and to make sure your wishes are honored. If you DO NOT choose someone to make decisions for you, write* NONE *on the line for the agent's name.*

I appoint the person named below to be my agent to make health care decisions for me when and only when I cannot make decisions or communicate what I want done. My agent **may not** appoint anyone else to make decisions for me. This is a Medical Durable Power of Attorney, and the power of my agent shall not end if I become incapacitated or if there is uncertainty that I am dead. This completed document also revokes any prior Medical Durable Power of Attorney. Furthermore, I and my estate hold my agent and my caregivers harmless and protect them against any claim based upon following this Medical Durable Power of Attorney. Any costs incurred should be paid from my own resources. Moreover, I grant to my agent full power to make all decisions for me about my health care, including the power to direct the withholding or withdrawal of life-prolonging treatment. Finally, in exercising this power, I expect my agent to be guided by my directions as stated in my Health Care Directive *(see reverse side)*. My agent is also authorized to:

- Consent, refuse or withdraw consent to any care, treatment, service or procedure (including artificially supplied nutrition and/or hydration/tube feeding) used to maintain, diagnose or treat a physical or mental condition;
- Make all necessary arrangements for any hospital, psychiatric treatment facility, hospice, nursing home or other health care organization; employ or discharge health care personnel (any person who is authorized or permitted by the laws of the state to provide health care services) as my agent shall deem necessary for my physical, mental or emotional well-being;
- Request, receive and review any information regarding my physical or mental health and/or my personal affairs, including medical and hospital records; execute any releases of other documents that may be required to obtain such information;
- Move me into or out of any state or institution for the purpose of complying with my Health Care Directive or the decisions of my agent;
- Take legal action, if needed, to do what I have directed;
- Make decisions about autopsy, organ donation and the disposition of my body; and
- Become my guardian, if one is needed.

If you DO NOT want the person (agent) you name to be able to do any of the above things, draw a line through it and put your initials at the end of the line.

Agent's name _____ Phone _____

Address _____

Signature (optional) _____

If you do not want to name an alternate, write "none."

First Alternate Agent _____ Second Alternate Agent _____

Address _____ Address _____

City _____ State _____ City _____ State _____

Phone _____ Phone _____

SIGN HERE for the *Medical Durable Power of Attorney* and/or *Health Care Directive* forms. Many states require notarization. Please ask two (2) persons to witness your signature who are not related or financially connected to you or your estate.

Person's name (print) _____

Signature _____ Date _____

Consent of parent/guardian for minor child _____ Date _____

Witness _____ Date _____

Witness _____ Date _____

Notarization: On this _____ day of _____, in the year of _____, personally appeared before me the person(s) signing, known by me to be the person(s) who completed this document and acknowledged it as his/her (their) free act(s) and deed(s). IN WITNESS WHEREOF, I have set my hand and affixed my official seal in the County of _____, State of _____, on the date written above.

Notary Public _____ Commission Expires _____

7-20

Completion Procedures

- Complete all sections of document
  - Select at least 2 agents, a primary and secondary
  - Provide complete contact information
  - Have witnessed and notarized
- Make multiple copies and distribute to:
  - Agents
  - Physician
  - CPA
  - Financial planner
  - Attorney
  - Clergy

Completion Procedures (Cont)

- Make copies to keep in automobile
- Take copy to hospital on admission
- Complete advance directive information card for wallet
- Review and update as needed
- Continue dialogue with loved ones

The Gift of Love

Gift of Advance Directives

- ***Control*** for patients in ability to communicate wishes
- ***Comfort*** for families in knowing wishes of patients
- ***Confidence*** for healthcare providers in knowing they are honoring patients' wishes

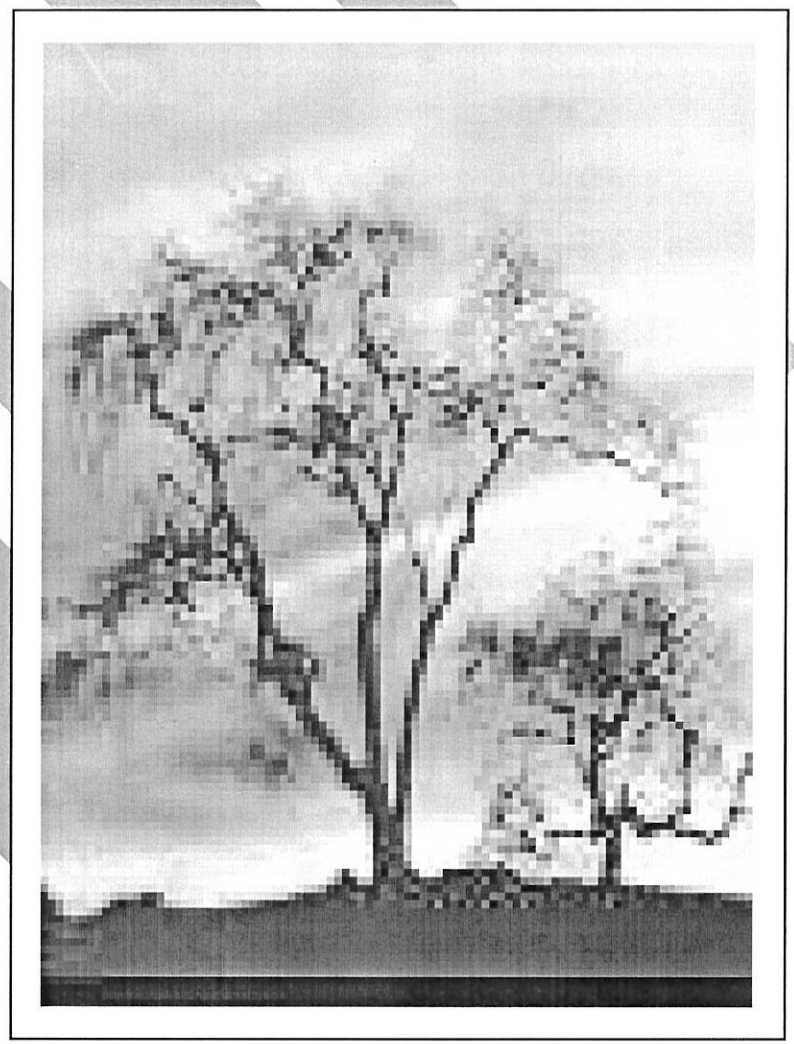
Robert Potter, MD, PhD

Gift of Advance Directives (Cont)

- ***Reduction*** in tension among family members
- ***Reduction*** in family anxiety level, guilt, second-guessing of making decision to withhold/withdraw life support
- ***Reduction*** in tension among family members and healthcare providers
- ***Reduction*** in moral/ethical distress of healthcare providers

Gift of a Good Death

- Death *without pain*
- Death with *family present*
- Death at *home*
- Death *without prolongation of dying*
- Death *without financial burden*
- Death with *reconciled relationships*
- Death having *made a difference in life*



February 13, 2006

The Honorable Jim Morrison, Chairperson
House Committee on Health and Human Services
Statehouse, Room 143-N
Topeka, Kansas 66612

Dear Representative Morrison:

SUBJECT: Fiscal Note for HB 2734 by House Committee on Health and Human Services

In accordance with KSA 75-3715a, the following fiscal note concerning HB 2734 is respectfully submitted to your committee.

HB 2734 establishes a new requirement for boards, commissions and similar bodies that determine the qualifications of individuals for licensure, certification, or registration. The bill would prohibit these agencies from denying applicants from taking the licensure examination, if the denial is based on the fact that some or all of the applicant's course of study was obtained online through the Internet. The denial could not be made as long as the course of study was from an accredited institution or university, and all the requirements for taking the examination have been met.

A number of state agencies were polled to determine whether HB 2734 had any fiscal effect on their operations. Of the 12 agencies contacted, ten responded and indicated that enactment of HB 2734 would have no fiscal effect.

Sincerely,

Duane A. Goossen

Duane A. Goossen
Director of the Budget

cc: Cathy Brown, Healing Arts
Mary Blubaugh, Nursing
Penny Bowie, Optometry
Debra Billingsley, Pharmacy
Susan Somers, Accountancy
Marsha Schrempp, Behavioral Sciences
Mary Lou Davis, Cosmetology
Rocky Vacek, Barber Board
Betty Wright, Dental Board
Mack Smith, Mortuary Arts
Pat Johnson, Technical Professions
Dirk Hanson, Veterinary Examiners

Attachment 8
HHS 2-16-06