Approved: 3-1-07 Date

# MINUTES OF THE HOUSE HEALTH AND HUMAN SERVICES COMMITTEE

The meeting was called to order by Chair Brenda Landwehr at 1:30 P.M. on February 5, 2007 in Room 526-S of the Capitol.

All members were present except:

Tom Holland- excused

Committee staff present:

Norman Furse, Revisor's Office Melissa Calderwood, Legislative Research Mary Galligan, Legislative Research Patti Magathan, Committee Assistant

Conferees appearing before the committee:

Dr. Paul Terranova, KU Medical Center

Dr. David Prentice, Family Research Council

Others Attending:

See Attached List.

Chair Landwehr opened the floor for bill introductions. There were none.

Chair Landwehr announced that there will be a luncheon on February 6 in Room 313-S. The speaker will provide an overview of "The Connector." The same speaker will present to a joint session of our committee and the Senate Committee on Health Care Strategies at 1:30.

Chair Landwehr then opened hearings on <u>HB2098</u> - <u>Defining certain terms relating to human cloning.</u>

**Dr. Paul Terranova**, Vice Chancellor for Research at University of Kansas Medical Center, testified from a neutral position on **HB 2098**. (Attachment 1) Dr Terranova stated that he would not address ethical or emotional issues related to embryonic stem cells. He did point out that some of the definitions in **HB 2098** are not consistent with the definitions developed by the National Academies of Sciences (N.A.S.), and strongly encouraged the committee to use the N.A.S. guidelines in their legislative work. He then reviewed terms used in **HB2098** and supplied the N.A.S. definitions for them, pointing out that using the term "cloned embryo" to differentiate between embryos created through somatic cell nuclear transfer and embryos created through sexual reproduction is not appropriate since identical twins are natural clones. He also suggested that the committee review the Kansas Health Policy Stem Cell Legislative Study since it provides a comparison of terms.

**Dr. David Prentice**, Family Research Council, testified as a proponent of **HB 2098**. Dr. Prentice went thru a slide show presentation which provided definitions of terms with corresponding pictures. (<u>Attachment 2</u>) Dr. Prentice stated that his understanding of HB 2098 is to nail down terms which are difficult to define. The bill does not take a position for or against cloning, but merely defines terms. There is no federal restriction on human cloning. Congress has instead prohibited use of taxpayer funds for research. Private funds may still be used for research.

Written testimony was provided by proponents Kansans for Life, Kansas Catholic Conference, and Concerned Women of America. (Attachments 3, 4, and 5)

Opponents providing written testimony were Kansas Coalition for Life Saving cures, Biotechnology Industry Organization, and Americans for Stem Cell Therapies & Cures. (Attachments 6, 7 and 8)

Chair Landwehr closed hearings on **HB 2098.** Meeting was adjourned at 3:10 P.M. Next meeting is February 6 at 1:30 in room 231-N. This will be a joint meeting with the Senate committee on Health Care Strategies.

# HOUSE HEALTH AND HUMAN SERVICES COMMITTEE GUEST LIST

DATE: February 5, 2007

REPRESENTING
Hein Law Form



# House Health and Human Services Committee

Monday, February 5, 2007

#### **HB 2098**

An Act Providing for the Defining of Certain Terms Relating to Human Cloning
Neutral Testimony Offered by the University of Kansas Medical Center

Conferee: Paul Terranova, Ph.D.

Vice Chancellor for Research, Office of the Executive Vice Chancellor

University of Kansas Medical Center

Senior Associate Dean for Research and Graduate Education

School of Medicine

Director, Center for Reproductive Sciences

Professor, Department of Molecular & Integrative Physiology and Obstetrics & Gynecology

# **Testimony**

#### Introduction

Good morning, Madam Chair. Thank you for the opportunity to provide testimony on House Bill 2098. As Vice Chancellor for Research at the University of Kansas Medical Center, my purpose in appearing today is to provide an objective, scientific viewpoint.

First, let me tell you briefly about my education and research background. Both my undergraduate and my master's degrees are in Biology. I received my Ph.D. in Physiology from Louisiana State University. I then completed a National Institutes of Health postdoctoral fellowship in the Department of Obstetrics and Gynecology and Anatomy at KU Medical Center. I then became an assistant professor at KUMC and worked my way up through the ranks of tenured associate professor, professor, associate dean and center director, then finally my current position of Vice Chancellor.

I am an NIH-funded scientist. Currently, my NIH research is in the areas of reproductive sciences. In the past I have received grants from the National Cancer Institute, National Institute of Child Health and Human Development and Environmental Protection Agency and conducted research on ovulation, various aspects of ovarian function, ovarian cancer and early pregnancy.

House Health and Human Services

DATE: 2-5-07

My research background provides evidence that I understand the issues associated with stem cell research. I will not address ethical or emotional issues relating to embryonic stem cells. I do want to address the fact that some of the definitions in HB 2098 are not consistent with the definitions developed by the National Academies of Sciences (NAS), and I would strongly encourage you to use NAS guidelines in your legislative work. The NAS is this country's premier authority on science, medicine, and engineering. It brings together the nation's top scientists and physicians in these disciplines and serves as an advisory body to the highest-level policymakers in our federal government. Our own Executive Vice Chancellor, Dr. Barbara Atkinson, is a member of the prestigious Institute of Medicine, which is the medical academy within the NAS.

#### **Comments on Certain Terms**

Allow me to highlight some of the terms in HB 2098 that could be better understood and utilized if they were given the NAS definitions.

- Asexual reproduction
  - This term is not used often enough in biomedical research to be relevant in this legislation. It is primarily used in the literature in reference to plant and invertebrate reproduction
- Blastocyst
  - The NAS defines this term as "a preimplantation embryo of 50-250 cells
    depending on age. The blastocyst consists of a sphere made up of an outer layer
    of cells (the trophectoderm), a fluid-filled cavity (the blastocoel), and a cluster of
    cells on the interior (the inner cell mass)
  - I would also note that it is not useful to define "blastocyst" and "blastocyst stage" separately
- Cloned embryo
  - Should be eliminated from the legislation. Consider that one of the pair of identical twins is a clone (not by SCNT)
- Cloning-to-produce-children
  - It would be more accurate to say "reproductive cloning"
- Cloning-for-biomedical-research
  - It would be more accurate to say "therapeutic cloning"

# Diploid

Means the chromosome number in a somatic cell or zygote

# • Gene (molecular) cloning

This term is used in biomedical research. A more useful terminology could be:
 "replication of DNA." I am unsure how this applies to embryonic stem cell research.

# Human cloning

I would again refer you to the term "reproductive cloning" as the most accurate
way to convey the concept of cloning a whole human being. An identical twin is
considered a clone by your definition

# Embryo

- HB 2098's definition is different from the NAS definition of an embryo; HB 2098
  defines embryo as a developing organism from the time for fertilization until
  significant differentiation has occurred. The NAS definition, however, helps to
  eliminate some ambiguity by detailing what sorts of characteristics to look for in a
  developing organism when trying to determine what stage of development it is in
- NAS states an embryo is, "An animal in the early stages of growth and differentiation that are characterized by cleavage, laying down of fundamental tissues, and the formation of primitive organs and organ systems; especially the developing human individual from the time of implantation to the end of the eighth week after conception, after which it becomes known as a fetus." The difference between HB2098 and NAS is that HB2098 includes early stages of development (from fertilization) to the fetal stage whereas NAS includes from implantation (of the blastocyst) to the end of the 8<sup>th</sup> week, the fetal stage. The fertilized egg is known as a zygote. Cell division of the zygote produces a ball of cells known as a morula after which further cell division and migration produces an internal cavity and the organized cells are then referred to as a blastocyst. The blastocyst implants into the uterine wall about day 7 after fertilization and is thereafter referred to as an embryo until the end of the 8<sup>th</sup> week after conception.

# Enucleated egg

• I would suggest that this term be eliminated, simply because it is not useful in this context. Enucleated is simply an adjective meaning "without a nucleus"

- Epigenetic modification, epigenetic reprogramming, and eugenics
  - I am also not sure these terms are very useful in the context of this legislation
  - Nevertheless, if used, the term epigenetic refers to modifications in gene
    expression that are controlled by heritable but potentially reversible changes in
    DNA methylation or chromatin structure without involving alteration of the DNA
    sequence.
  - In SCNT, genes are altered to allow cell division and differentiation by a process known as epigenetic reprogramming (of the chromosomal DNA).

#### Gamete

 The scientific definition identifies a gamete as a "mature germ cell" rather than a "reproductive cell"

# Infertility

Infertility is generally defined as the inability to conceive after 6-9 months of
unprotected intercourse. There are numerous reasons for infertility such as at the
level of the ovaries (failure to ovulate), tubes (blocked), uterus (endometriosis),
and testis (low sperm count) as well as numerous others and combinations of the
above.

#### Mitochondria

• This portion of a cell is not particularly relevant to stem cell research

#### Multipotent cell

 The bill also includes definitions of "pluripotent" and "totipotent," which are the more commonly used terms in science. It appears redundant to also use the term "multipotent"

## Nuclear transfer

"Replacing the nucleus of one cell with the nucleus of another cell"

## Parthenogenesis

• "Development in which the embryo contains only maternal chromosomes"

## Pluripotent cell

"A cell that has the capability of developing into cells of all germ layers
 (endoderm, ectoderm, and mesoderm)"; your definition of multipotent (produce
 several different types of differentiated cells) and pluripotent (give rise to many
 different types of differentiated cells) are very similar

- Somatic cells
  - "Any cell of a plant or animal other than a germ cell or germ cell precursor"
- Somatic cell nuclear transfer (SCNT)
  - "The transfer of a cell nucleus from a somatic cell into an egg (oocyte) whose nucleus has been removed." Do not include intent to produce a cloned embryo.
     The SCNT process may be used to study cell growth and differentiation.
- Stem cells are cells that have the ability to divide for indefinite periods and give rise to specialized cells
- Totipotent
  - Definition uses "complete organism"; thus, no need for "and all of its tissues and organs"

Considering the use of the term "germ cell" in several other important definitions, you may also want to include a definition of germ cell, which the NAS states is "A sperm or egg or a cell that can become a sperm or egg. All other body cells are called somatic cells."

# **Appropriate Use of Terms**

- Cloned embryo
  - It is not logical to use this term to differentiate between embryos created through somatic cell nuclear transfer and embryos created through sexual reproduction since identical twins are natural clones

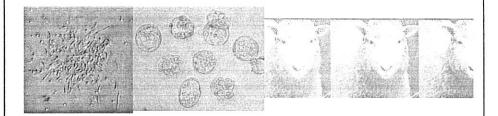
## Conclusion

Thank you for your time today. I would be happy to answer any additional questions you might have about the science behind this terminology and related research. The government affairs staff at KUMC is also available any time – in or out of session – if you need further information on this or any other health care, medical education, or biomedical research issue.

Contact Information:

University of Kansas Medical Center Department of External Affairs Dorothy Hughes, Public Policy Analyst 913-588-0256 dhughes@kumc.edu

# **Accurate Terminology for Cloning Legislation**



David A. Prentice, Ph.D.
Family Research Council
Washington, D.C., USA

#### LEGISLATIVE DEFINITIONS

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.

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.

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.

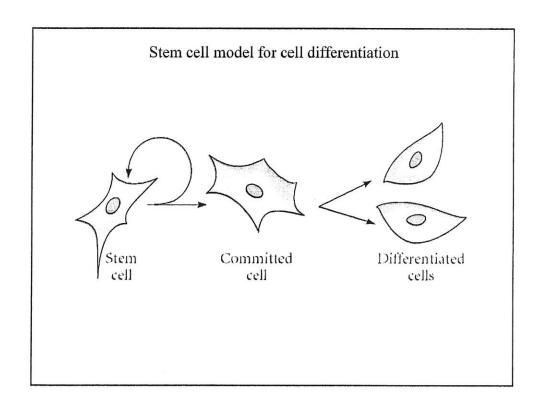
"Cloning" means the use of asexual reproduction to create or grow a human embryo from a single cell or cells of a genetically identical human.

House Health and Human Services

DATE: 2.5.07

# **U.S. FEDERAL LEGISLATION**

- LHHS Appropriations language (since 1996) SEC. 509.
  - (a) None of the funds made available in this Act may be used for (1) the creation of a human embryo or embryos for research purposes; or (2) research in which a human embryo or embryos are destroyed, discarded, or knowingly subjected to risk of injury or death greater than that allowed for research on fetuses in utero under 45 CFR 46.208(a)(2) and section 498(b) of the Public Health Service Act (42 U.S.C. 289g(b)).
  - (b) For purposes of this section, the term "human embryo or embryos" includes any organism, not protected as a human subject under 45 CFR 46 as of the date of the enactment of this Act, that is derived by fertilization, parthenogenesis, cloning, or any other means from one or more human gametes or human diploid cells.





#### A human cell.

A human cell.

Each of the 100 trillion cells in the human body texcept red blood cells contains the entire human genome—all the genetic information necessary to build a human being. This information is encoded in 6 billion base pairs, subunits of DNA. (Egg and sperm cells each have half this amount of DNA.)

#### The cell nucleus.

Inside the cell nucleus, 6 tect of DNA are packaged into 25 pairs of chromosomes one chromosome in each pair coming from each pair coming from each parent).



#### A chromosome.

Each of the 46 human chromosomes contains the DNA for hundreds or thousands of individual genes, the units of heredity.



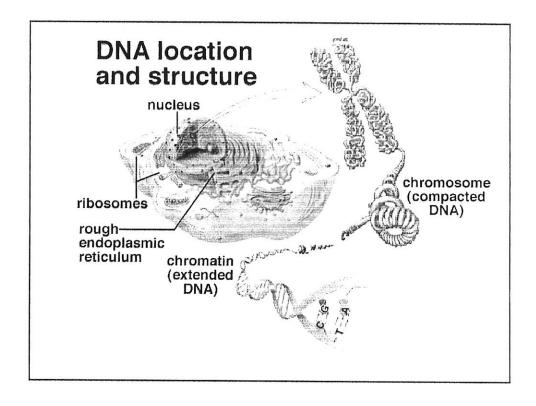
A gene.

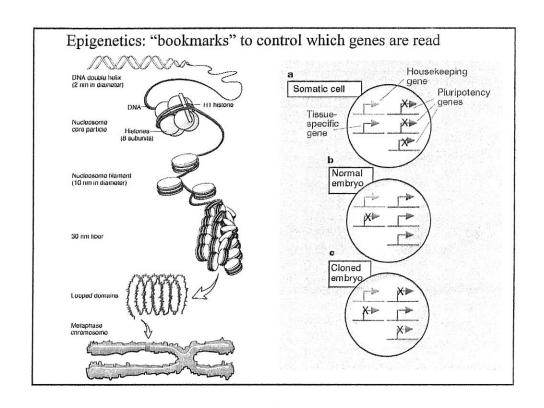
Each gene is a segment of doublestranded DNA that holds the recipe for
making a specific molecule, usually a
protein. These recipes are spelled out in
varying sequences of the four chemical
bases in DNA; adenine: A., thymine (T.,
guanine (G), and cytosine: C., The
bases form interbocking pairs that can
fit together in only one way: A pairs
with T; G pairs with C.

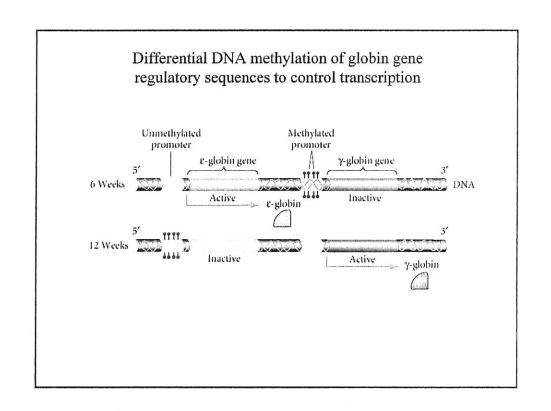


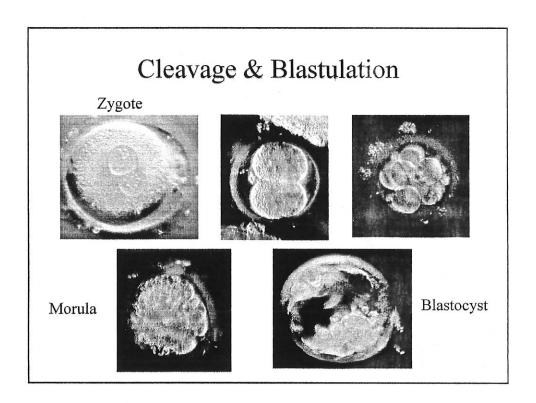
#### A protein.

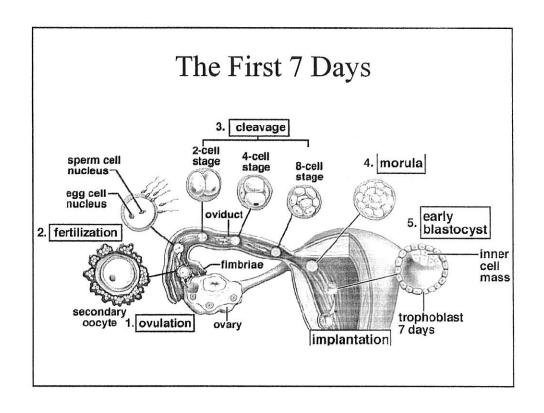
Proteins, which are made up of amino acids, are the body's workhorses—essen tial components of all organs and chemical activities. Their func-tion depends on their shapes, which are determined by the 50,000 to 100,000 genes in the cell nucleus.

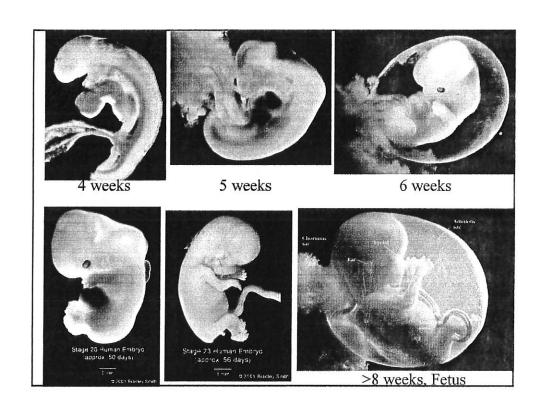












#### EMBRYO vs. PRE-EMBRYO

"The term 'pre-embryo' is not used here for the following reasons: (1) it is ill-defined because it is said to end with the appearance of the primitive streak or to include neurulation; (2) it is inaccurate because purely embryonic cells can already be distinguished after a few days, as can also the embryonic (not pre-embryonic!) disc; (3) it is unjustified because the accepted meaning of the word embryo includes all of the first 8 weeks; (4) it is equivocal because it may convey the erroneous idea that a new human organism is formed at only some considerable time after fertilization; and (5) it was introduced in 1986 'largely for public policy reasons' (Biggers). ... Just as postnatal age begins at birth, prenatal age begins at fertilization."

RONAN O'RAHILLY AND FAIOLA MULLER, Human Embryology & Teratology, 3rd ed. (New York: Wiley-Liss, 2001), p.88

"Embryo: An organism in the earliest stage of development; in a man, from the time of conception to the end of the second month in the uterus."

Dox, Ida G. et al. The Harper Collins Illustrated Medical Dictionary. NY: Harper Perennial, 1993, p. 146

"From the time of conception until the eighth week, the developing baby is known as an **embryo**."

1989 edition of the "American Medical Association Encyclopedia of Medicine"

The term **embryo** covers the several stages of early development from conception to the ninth or tenth week of life."

Considine, Douglas (ed.). Van Nostrand's Scientific Encyclopedia. 5th edition. New York: Van Nostrand Reinhold Company, 1976, p. 943

"Almost all higher animals start their lives from a single cell, the fertilized ovum (zygote)... The time of fertilization represents the starting point in the life history, or ontogeny, of the individual."

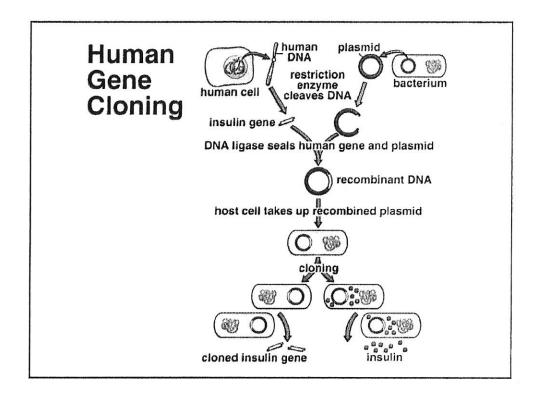
Carlson, Bruce M. Patten's Foundations of Embryology. 6th edition. New York: McGraw-Hill, 1996, p. 3

**Embryo**—In humans, the developing organism from the time of fertilization until the end of the eighth week of gestation, when it becomes known as a fetus.

Blastocyst—A preimplantation embryo of about 150 cells. The blastocyst consists of a sphere made up of an outer layer of cells (the trophectoderm), a fluid-filled cavity (the blastocoel), and a cluster of cells on the interior (the inner cell mass).

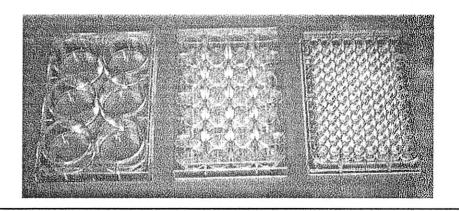
National Institutes of Health website, (http://stemcells.nih.gov/info/glossary.asp)

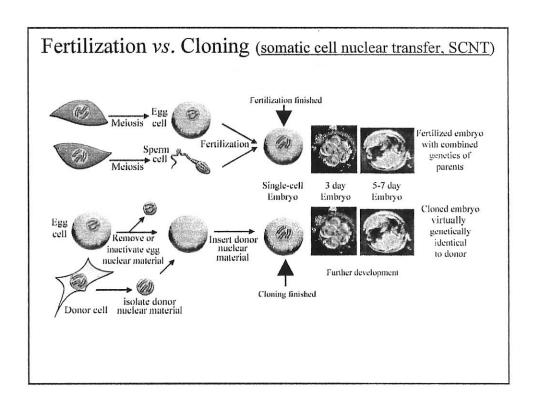
Embryo - In humans, the developing organism from the time of fertilization until the end of the eighth week of gestation, when it becomes known as a fetus.
Stem Cells and the Future of Regenerative Medicine, Report of the National Academy of Sciences and the Institute of Medicine, National Academy Press, Washington, DC, Sept. 2001; Pg. 47

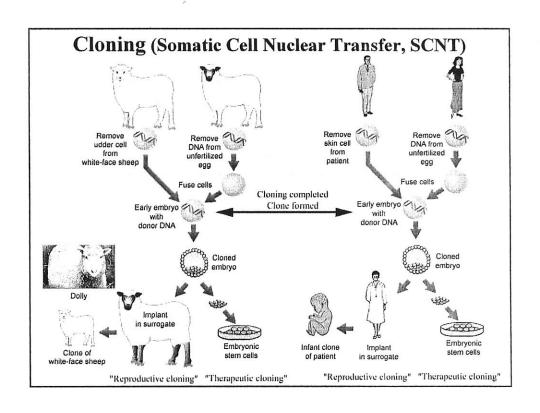


# **Cell Cloning**

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











# Somatic Cell Nuclear Transfer (SCNT) or Therapeutic Cloning

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# ETHICS COMMITTEE REPORT

# Human somatic cell nuclear transfer (cloning)

The Ethics Committee of the American Society for Reproductive Medicine American Society for Reproductive Medicine, Birmingham, Alabama

Within 2 years of the announced birth in 1997 of Dolly, the lamb cloned from the mammary cells of an adult ewe, research groups announced that they had cloned nice and calves by using differentiated somatic cells (1–3). In the cloning technique used to produce Dolly, the nucleus of a somatic cell of the ewe

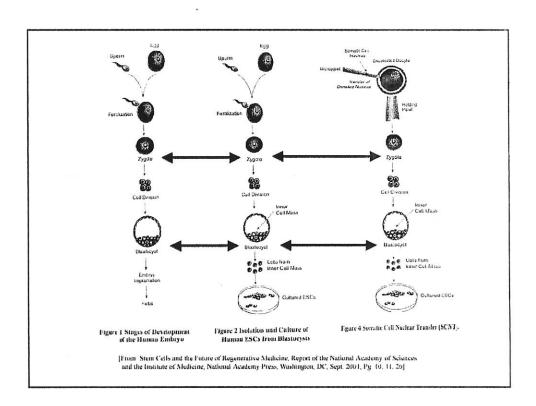
onic stem cells for persons who need tissue or organ transplants, which raises issues not addressed in this report (6). If undertaken, the development of SCNT for such therapeutic purposes, in which embryos are not transferred for pregnancy, is likely to produce knowledge that could be used to achieve reproductive

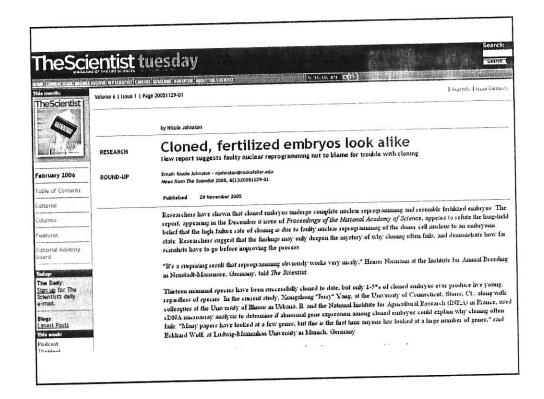
# Cloning (SCNT) produces a human embryo

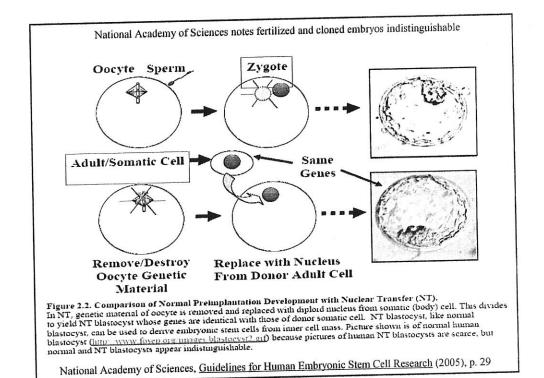
Q: The people who use nuclear transfer generally say that the technique is optimized for producing the stem cells rather than making babies. They would not want to equate this with the process that produces embryos that were fit for implantation, and they'd argue that they're using the reproductive process differently ...

A: "See, you're trying to define it away, and it doesn't work. If you create an embryo by nuclear transfer, and you give it to somebody who didn't know where it came from, there would be no test you could do on that embryo to say where it came from. It is what it is. It's true that they have a much lower probability of giving rise to a child. ... But by any reasonable definition, at least at some frequency, you're creating an embryo. If you try to define it away, you're being disingenuous."

Stem-cell pioneer does a reality check. James Thomson reflects on science and morality By Alan Boyle Science editor MSNBC 4:13 p.m. ET June 22, 2005







# Cloning (SCNT) produces a human embryo

"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

"cloning means creating a new individual by replacing an egg cell nucleus (with only one-half of the genetic complement) with a nucleus from the body cell of a different individual (containing the full genetic complement)."

Society for Developmental Biology website

# Cloning (SCNT) produces a human embryo

"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

- Clone 1) An exact genetic replica of a DNA molecule, cell, tissue, organ, or entire plant or animal. 2) An organism that has the same nuclear genome as another organism.
- Cloning The production of a clone. (For the purpose of this report, generating an individual animal or person that derives its nuclear genes from a diploid cell taken from an embryo, fetus, or born individual of the same species.)
- Embryo A group of cells arising from the egg that has the potential to develop into a complete organism. In medical terms, embryo usually refers to the developing human from fertilization (the zygote stage) until the end of the eighth week of gestation when the beginnings of the major organ systems have been established.

Scientific and Medical Aspects of Human Reproductive Cloning (2002), p. 261-262.

- "While use of the term embryo can be polarizing, it can also promote clarity, even where some feel it has too great a political, emotional or social "charge." Thus, for the purposes of this report, we have chosen to use the term cloned embryo to describe the product of nuclear transplantation."
- ... For purposes of this workshop, the term "reproductive cloning" will refer to human cloning (i.e., nuclear transplantation) for the purpose of initiating a pregnancy and producing a baby. The term "research cloning" will refer to human cloning for the purpose of conducting biomedical research on stem cell derived from cloned embryos."

Regulating Human Cloning, A report on the workshop held March 11, 2003, by the American Association for the Advancement of Science. p. 4, p. 11-12

EDITORIALS

NATURE Vol 436, 7 July 2005

# Playing the name game

Stem-cell biologists should not try to change the definition of the word 'embryo'.

ast month's meeting of the International Society for Stem Cell Research in San Francisco witnessed a bizarre semantic debate.

Delegates discussed a proposal to refrain from using the term 'embryo' when referring to the blastocysts from which human embryonic stem cells are harvested. The scientists involved reject the accusation that they are creating and destroying human lives, and fear that the word 'embryo' is a lightning rod that attracts negative scrutiny.

It is true that embryo is an emotive term, but there is little scientific justification for redefining it. Whether taken from a fertility clinic or made through cloning, a blastocyst embryo has the potential to become a fully functional organism. And appearing to deny that fact will not fool die-hard opponents of this research. If anything, it will simply open up scientists to the accusation that they are trying to distance themselves from difficult moral

issues by changing the terms of the debate.

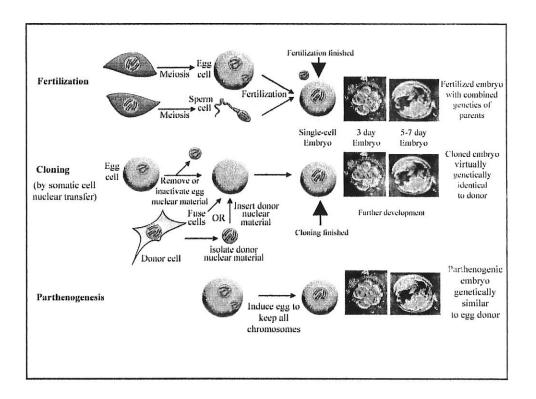
At the equivalent meeting last year, the society decided to formally adopt the term 'somatic cell nuclear transfer' to describe the procedure in which an adult cell nucleus is transplanted into an egg to produce embryonic stem cells. This procedure had been called 'therapeutic cloning' to distinguish it from 'reproductive cloning', which would use the same technique in an attempt to make a baby.

But the work is far from yielding any therapies, and scientists realized that the word cloning was generating public concern. So they decided to adopt a more technical term less likely to stir up strong emotions. At least that re-branding had the positive effect of toning down the hype surrounding therapeutic cloning.

The name change debated at last month's meeting would be a step too far, however. In the future, researchers may isolate pluripotent stem cells from biological entities that do not have the same developmental potential as embryos. This may justify the creation of a new set of words. Until them, stem-cell biologists should stick to debating the merits and ethics of their work using clear and simple language. They have a strong case to make that will not be helped by playing semantic games in an effort to evade scrutiny.

2

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LEON R. KASS, M.D., PH.D., Chairman.

Addie Clark Harding Professor, The College and the Committee on Social Thought, University of Chicago. Hertog Fellow, American Enterprise Institute.
ELIZABETH H. BLACKBURN, PH.D., D.SC.

Professor, Department of Biochemistry and Biophysics, University of California-San Francisco. STEPHEN L. CARTER, J.D.

William Nelson Cromwell Professor of Law, Yale Law School. REBECCA S. DRESSER, J.D., M.S.

Daniel Noves Kirby Professor of Law, Washington University School of Law. Professor of Ethics in Medicine, Washington University School of Medicine.

DANIEL W. FOSTER, M.D.

Donald W. Seldin Distinguished Chair in Internal Medicine, Chairman of the Department of Internal Medicine, University of Texas Southwestern Medical School.

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Bernard Schwartz Professor of International Political Economy, Paul H. Nitze School of Advanced International Studies, Johns Hopkins University.

MICHAEL S. GAZZANIGA, PH.D.

David T. McLaughlin Distinguished Professor in Cognitive Neuroscience,

Director, Center for Cognitive Neuroscience, Dartmouth

ROBERT P. GEORGE, D.PHIL., J.D.

McCormick Professor of Jurisprudence, Director of the James Madison Program in American Ideals and Institutions, Princeton University.

MARY ANN GLENDON, J.D., M.COMP.L.

Learned Hand Professor of Law, Harvard University.

ALFONSO GÓMEZ-LOBO, PH.D.

Ryan Family Professor of Metaphysics and Moral Philosophy,

Georgetown University

WILLIAM B. HURLBUT, M.D.

Consulting Professor in Human Biology, Stanford University. CHARLES KRAUTHAMMER, M.D.

Syndicated Columnist

WILLIAM F. MAY, PH.D.

Cary M. Maguire Professor of Ethics Emeritus, Southern Methodist University.

PAUL MCHUGH, M.D.

Henry Phipps Professor of Psychiatry, Director of the Department of Psychiatry and Behavioral Sciences, Johns Hopkins University School of Medicine. Psychiatrist-in-chief, the Johns Hopkins Hospital.

GILBERT C. MEILAENDER, PH.D.

Richard & Phyllis Duesenberg Professor of Christian Ethics,

University

JANET D. ROWLEY, M.D., D.SC.

Blum-Riese Distinguished Service Professor of Medicine, Molecular Genetics and Cell Biology, and Human Genetics; Pritzker School of

Medicine, University of Chicago, MICHAEL J. SANDEL, D.PHIL.

Professor of Government, Harvard University.

JAMES Q. WILSON, PH.D.

James A. Collins Professor of Management and Public Policy Emeritus, University of California-Los Angeles.

President's Council on Bioethics Report: Human Cloning and Human Dignity, July 2002



1-800-928-LIFE (5433) www.kfl.org Wichita Office

2501 E. Central Wichita, KS 67214 (316) 687-LIFE (5433) FAX: (316) 687-0303

e-mail: kfl@kfl.org

**Topeka Office** 

919A S. Kansas Ave. Topeka, KS 66612 (785) 234-2998 FAX: (785) 234-2939

e-mail: Topeka@kfl.org

Kansas City Region

7808 Foster Overland Park, KS 66204 (913) 642-5433 FAX: (913) 642-7061

e-mail: kansansforlife@aol.com

# TESTIMONY IN SUPPORT OF HB 2098 February 5, 2007

Kathy Ostrowski, Kansans for Life Legislative Director

Chairwoman Landwehr and members of the committee.

Kansans for Life is thankful to have this hearing today in your committee, leading to adoption of a standard "bio-tech dictionary" for Kansas.

The proponents of cloning and destructive embryonic research have wreaked havoc with the democratic process here in Kansas, as they have done in Missouri.

They have used many millions of dollars, and the influence of the major newspapers and chambers of commerce, to incorrectly "spin" information to the public.

They have utilized deceptive telephone polling and engaged celebrities to mislead and muddy the science.

They have created slick propaganda websites and sham "coalitions for cures."

They have put a full court press on lobbying lawmakers: wining, dining, and "tutoring" them while lining their campaign chests.

All of these tactics relied on the invention of non-scientific, advocacy terms like "early stem cells" and "therapeutic" cloning. It is understood that battles can be won merely by re-defining language. That is why the accurate definitions of scientific terms in the area of human cloning and destructive embryonic research must be put into law.

HB 2098 creates a bio-tech dictionary, based on the 2002 Summary of the President's Council on Bioethics. These definitions were agreed upon by the members of that Council, which included both opponents and proponents of these bio-technologies.

These very definitions were supposed to be adopted after review by a legislative interim committee. But House and Senate leadership broke the deal and illegitimately sought pronouncements from the Health Policy Authority, an administrative agency.

The President's Council recognized that clarity in bio-tech terminology is of the greatest urgency in forming public policy that respects human dignity. Kansas has been held hostage for too long by a well-funded pro-cloning "Newspeak." Please pass HB 2098.

House Health & Human Services Room 526S, 1:30 p.m. February 5, 2007



6301 ANTIOCH • MERRIAM, KANSAS 66202 • PHONE/FAX 913-722-6633 • WWW.KSCATHCONF.ORG

# **TESTIMONY IN SUPPORT OF H.B. 2098 Defining Certain Terms relating to Human Cloning**

Madame Chair, Members of the House Health and Human Services Committee,

Thank you for the opportunity to submit written testimony in support of H.B. 2098. My name is Beatrice Swoopes, and I am the Associate Director of the Kansas Catholic Conference, the public policy office of the Catholic Church in Kansas.

H.B. 2098 is about definitions, the defining of certain terms relating to human cloning. In fact the bill's sole purpose is stated in Section 1. "In the construction of the statutes of this state and for the purpose of legislative committee studies and inquiries, the following terms relating to human cloning shall have the meaning as specified in this section: ..."

According to the *New Illustrated Webster's Dictionary of the English Language*, the word **definition** "is a description or explanation of a word or thing, by its attributes, or relations, that distinguishes it from all other things; the act of stating or showing what a word means, what a thing is, or what the content of a conception is; the act of defining."

The dictionary contains the words of a language with explanation so that we might be able to communicate with each other clearly. When a word has two or more meanings confusion can result unless there is agreement on the use of the word.

H.B. 2098 serves both supporters and opponents in the debate on whether human cloning should be banned in Kansas. Without both sides speaking the same language the public and legislators will be confused.

During last year's legislative session an attempt was made to establish a bi-partisan committee of legislators to create a vocabulary for authentic and honest discussion by the legislature of policy relating to human cloning and stem cell research. In 2002 work had already been done by the President's Council on Bioethics in establishing accurate scientific definitions of words relating to these topics. The legislature was urged to accept these definitions. Through maneuvers and pressures coming from the bio-tech industry that attempt failed.

MOST REVEREND RONALD M. GILMORE, S.T.L., D.D. DIOCESE OF DODGE CITY

MOST REVEREND MICHAEL O. JACKELS, S.T.D. DIOCESE OF WICHITA

MOST REVEREND JOSEPH F. NAUMANN, D.D.

Chairman of Board

ARCHDIOCESE OF KANSAS CITY IN KANSAS

MICHAEL P. FARMER Executive Director House Health and Human Services

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You may ask why the Catholic Church is involved in this debate. We believe that our position against human cloning and embryonic stem cell research does not conflict with accurate scientific fact that establishes the humanity of the human embryo.

The Pontifical Academy for Life, at its International Congress on *The human embryo in the preimplantation phase: Scientific aspects and bioethical considerations*, stated: "It can be concluded from this data that the human embryo in the phase of preimplantation is already: a) a being of the human species; b) an individual being; c) a being that possesses in itself the finality to develop as a human person together with the intrinsic capacity to achieve such development."

We strongly urge your support of H.B. 2098 to enable a consensus on the definitions of words used in debating this critical, ethical issue.

Respectfully submitted,

Associate Director

Beatrice Swoopes



# Testimony in favor of HB 2098 House Health and Human Services Committee

Chairman and members of the committee:

When scientific endeavors are being discussed, it is essential that accurate scientific definitions be used. This bill uses definitions that are consistent with the glossary of terms currently found on the National Institutes of Health web site and the President's Council on Bioethics, a diverse group of individuals with very different beliefs about whether human cloning or embryonic stem cell research could continue. But they did agree on these definitions. These are also the definitions most of us remember from high school Biology textbooks.

In issues such as cloning, stem cell research, and the use of taxpayer dollars for those endeavors, which are potentially controversial, it becomes even *more* important that participants in the debate use the same definitions. When the definitions are agreed upon in advance of the debate, everyone will be clearly understood. If these definitions are codified in the law, there is an additional level of accountability and credibility in the debate.

Clearly defining terms is part of almost every endeavor. Since this is the SuperBowl season, consider football. Everyone knows (or can know) what the term "offside" means. The players know, and try very hard to not be caught at the transgression. The coaches know; the referees obviously know; and the announcers know and can inform their listeners. If a fan doesn't know what it means, he or she can easily discover and understand the meaning. That is true for all of the rules (definitions) of the game. They are written down and explained in the "NFL Rulebook," which is easily accessible on NFL's web site.

Now, think for a moment, what would happen if one team did not abide by that definition. Any game that they participated in would result in chaos. Tempers would flare; the fairness of the referees would be called into question; fans would get frustrated; and, announcers would have an extremely difficult time explaining the action to their listeners.

We strongly support the clear, accurate definitions in this bill. We believe it will be very advantageous to all of the "players."

Thank you for your consideration.

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CWA of Kansas ♥P. O. Box 11233 ♥Shawnee Mission, KS 66207 ♥Phone & Fax: 913-491-1380 E-mail: director@kansas.cwfa.org ♥Web site: .http://kansas.cwfa.org

# STATEMENT IN OPPOSITION TO HB 2098 HOUSE HEALTH & HUMAN SERVICES COMMITTEE **FEBRUARY 5, 2007** LORI HUTFLES, EXECUTIVE DIRECTOR

The Kansas Coalition for Lifesaving Cures is opposed to HB 2098.

The Coalition members include nearly 10,000 Kansans statewide and more than 60 patient advocacy and medical research organizations. They all agree that any stem cell research, therapies or cures permitted by federal law should remain legal in Kansas provided that such activities are conducted ethically and safely and do not involve human reproductive cloning.

HB 2098 seeks to define certain scientific terms used in stem cell research in a manner that conflicts with definitions endorsed by national scientific organizations such as the National Institutes of Health and the National Academies of Sciences. In doing so, the legislation could imperil that research in our state and prevent hundreds of thousands of Kansas patients from having access to future stem cell therapies approved by the Food and Drug Administration and available to other Americans.

Virtually all medical researchers accept and use stem cell research definitions that are recognized by the NIH and NAS. Although there may be a few scientists who disagree with those definitions, it would be imprudent for Kansas legislators to enshrine such idiosyncratic opinions in state law.

If politicians in every state chose to give nonstandard definitions to scientific terms used in research, collaborative work among scientists would at the least be significantly impaired and potentially could cease.

The majority of Kansans support all forms of stem cell research and will demand equal access to any future cures resulting from that research. HB 2098 is a step in the wrong direction.

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# Statement in Opposition to House Bill 2098 House Health and Human Services Committee Representative Brenda Landwehr, Chair

Thank you Madam Chair and members of the Health and Human Services Committee, my name is Duane Simpson and I am testifying on behalf of the Biotechnology Industry Organization (BIO) in opposition to HB 2098.

BIO is the national trade association representing more than 1100 biotechnology companies, academic institutions, state biotechnology centers and related organizations in all 50 US states and 33 foreign nations. BIO members are involved in the research and development of healthcare, agricultural, industrial and environmental biotechnology projects.

Kansas has established itself as a leader in the area of biomedical and life science research and development. The Kansas Economic Growth Act and the creation of the Kansas Bioscience Authority are model pieces of legislation for the rest of the country. We are now seeing the fruits of this Legislature's labor as we attempt to recruit the National Bio and Agro Defense Facility to Kansas. The current growth in the Kansas economy is due to biotechnology and the future of the Kansas economy depends on expansion of Kansas' role in biotechnology research.

House Bill 2098 is another attempt to marginalize Kansas in the global biotechnology marketplace without any foreseeable benefit to the state. It is unprecedented for a bill to be introduced that does nothing but define terms for future legislative debate absent current policy. Without context, it is difficult for legislators considering this legislation to know whether a definition is appropriate or not. Most bills that cover subject matter that is not already defined in statute include the definition along with the policy so legislators can see if the definition is appropriate. In fact, the other bills related to human cloning have definitions within the bill. Ironically, some of the definitions in HB 2252 and HB 2255 are different than the ones in HB 2098 despite all of the bills being written by opponents to Somatic Cell Nuclear Transfer.

Just last year, the Legislature ordered a study be done to find the proper definition for terms used in debating human cloning. The Legislative Coordinating Council assigned that study to the Kansas Health Policy Authority whose report this committee has just received. HB 2098 was drafted and introduced prior to the Legislature receiving the report it ordered.

As KHPA noted, there are numerous definitions of complex scientific terms related to cloning. The National Institute of Health, National Academies of Sciences and the Report of the

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President's Council on Bioethics all have differing definitions. Of the 42 terms defined in KHPA's report, 16 of them are only defined by one of the three organizations. Only 6 of the terms are defined by all three organizations. As you can see, simply deciding which terms need a definition is a task that could take this committee months if it wished to properly analyze each definition. Of course, none of these terms need a definition in statute unless there is a policy that will refer to those definitions, which leads us back to why this bill exists. This bill is a thinly veiled attempt to pass legislation that seems innocuous that has a definition for "human cloning" that includes therapeutic cloning. By having such a definition, future Legislatures would be able to criminalize therapeutic cloning by using the more politically palatable term human cloning.

The proponents of this legislation and HB 2252 and HB 2255 are well aware of the public's perception of what human cloning is. They understand that the public perceives human cloning to be what the proponents have defined as "cloning-to-produce-children." By having the ability to define "human cloning" to include more than "cloning-to-produce-children" the proponents of this bill hope the public will think future legislation banning "human cloning" is only banning "cloning-to-produce-children." Since future legislation would not need to be burdened with actual definitions, the public could easily be deceived.

Finally, this legislation puts bad definitions into statute for future use. The definitions used come from political activists and political appointees. If this committee wishes to have a scientific definition of these terms, it should use the definitions created by the National Institute of Health. These terms should be defined by scientists, not political activists. If the goal is to debate whether or not SCNT research should be done in Kansas, that debate can occur without the need to pass HB 2098.



# Americans for Stem Cell Therapies & Cures

February 9, 2007

Honorable Legislators:

Thank you for this opportunity to offer thoughts on House Bill 2098, "An Act providing for the defining of certain terms relating to human cloning".

It is vital that scientific definitions be provided by respected scientific organizations, such as the National Academy of Sciences, not by political appointees, ideological groups, or religious lobbyists.

HB 2098, unfortunately, appears designed to reflect and advance a political agenda.

The definitions in HB 2098 are drawn from the politically-appointed White House Council on Bioethics. It is supported by religious lobbyist David Prentice, an employee of the Family Research Council, whose stated mission (according to its website) is to promote the Judeo-Christian worldview. It is further backed by Kansans for Life, an anti-abortion group.

The clear implication of the definitions in HB 2098 is to redefine human life as beginning at the union of sperm and egg. This is not only illogical (as it completely ignores the contribution made by the mother, without whom there cannot be any life at all) but it completely violates the separation of church and state. Every religion has a central belief about when life begins. Most religions do not believe the above definition, and to legislate this view of when life begins is wrong. Additionally, it would deny millions of patients who are living with devastating diseases and injuries the potential therapies that could help reduce their suffering.

The impact of language upon legality is immeasurable. Accepting these politically-derived definitions into law could provide legal groundwork to forbid embryonic stem cell research: make all blastocysts, even those slated to be thrown away, unlawful for research leading to therapies and possible cure.

For Kansans, and all who suffer incurable disease or disability, this would be a tragic error.

We respectfully request either the rejection of 2098, or the substitution of language from the National Academies of Science.

Thank you,

Amy Daly, RN Executive Director Americans for Stem Cell Therapies & Cures House Health and Human Services

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