DISCUSSION GUIDE

MAPPING STEM CELL RESEARCH
TERRA INCOGNITA

BY MARIA FINITZO

Some consider stem cell research the Holy Grail of regenerative medicine. Others view the idea as morally wrong. But what would you do if your child became paralyzed from the waist down and you had access to the research that might allow them to walk again one day? These are questions our society continues to grapple with. Follow a respected neurologist into the unknown territory of stem cell research.

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LETTER FROM THE FILMMAKER

In early 2001, after I had finished 5GIRLS, I began to do research for my next film. I had been interested for many years in doing a film about what it takes to do modern science. I knew of course, that I had to find the right story, in order to really engage an audience. The controversy surrounding stem cell research was in the news on an almost daily basis at this time, and like most people, I barely understood either the actual science, the promise this research held for curing disease or the implications of President Bush's decision to limit federal funding for this research. Furthermore, mainstream media wasn't much help in clarifying what was at stake. For the most part, articles reduced the issues to fears of "the slippery slope" and human cloning, while the debate itself was often polarized into black and white, missing critical nuances of gray. I believe that genuine insight into complex issues like stem cell research can be achieved by connecting an audience to a compelling human story. I wanted to find a deeply personal story that would really get to the heart of the matter, putting a human face on stem cell research. The first time I read about Dr. Jack Kessler and his decision to change the course of his research to seek a cure for spinal cord injury using embryonic stem cells, following his daughter's skiing accident, I knew I had found the story I was searching for.

Their story was incredibly powerful on so many levels–I hoped that once my viewers were invested in their lives, I would be able to lead them to a greater understanding of the political, religious, ethical and scientific issues surrounding this promising but controversial science.

One of the greatest things about being a documentary filmmaker is getting to learn everything there is to know about the subject of your film. In order to make a documentary about stem cell research, I had to understand everything I could about the science of stem cell biology, including why it is so controversial. Dr. Jack Kessler and his grad students, Vicki and Vibhu, were great and patient teachers.

MAPPING STEM CELL RESEARCH is the story of Dr. Jack Kessler, a leading scientist and neurologist passionately involved in the scientific process, who believes deeply that embryonic stem cells may just be the Holy Grail of regenerative medicine and the way to help thousands of people recover their health. However, it is also a story of the resilience of two young women, Allison (Jack's daughter) and Carrie (the daughter of one of Jack's colleagues), who undergo traumatic life-changing accidents that leave them wheelchair bound. As the story unfolds, we experience how each of these women come to terms with their loss, in effect, healing themselves. They choose not to wait for a cure, but instead move on, to live full and rewarding lives.
Stem cell research may not work, as Dr. Laurie Zoloth, the film's bioethicist, reminds us at the end of the story. Nonetheless, it is important to understand the issues surrounding this research because the debate about the use of embryonic stem cells, with its competing moral appeals, is the archetypical scene of moral philosophy.

The challenge to find consensus in a society that is both pluralistic and deeply divided over accepted norms speaks not only to our notions of social justice, but to the very nature of who we are as citizens, the vastness of our power and the responsibility that comes with it. For all of us, it is important to understand the most effective ways to discuss this complex, volatile issue. Can we develop a common language that is respectful of differences? Do we have a societal responsibility to alleviate pain and disease? If we can't find common ground in public policies, the corporate world will make their own profit-motivated decisions. If that is the case, how will the research be regulated, and who will have access to its outcomes?

The decisions we make and the actions we take go way beyond whether or not stem cell research should move forward. They speak instead to the very nature of who we are, how we manifest our agency and how we perceive our accountability for the future of humanity.

Maria Finitzo

THE FILM

Dr. Jack Kessler is a neurologist with an expertise in stem cells. When his daughter Allison injured her spine in a skiing accident, Kessler turned his energies toward finding a method to repair damaged spinal cords. He has focused his research on developing a therapy using embryonic stem cells to regenerate the damaged parts of the nervous system. His research has taken him into a politically very sensitive area in which Catholic and fundamentalist Christian views about the beginning of life exert a powerful influence.

Kessler uses his position to educate the public about the benefits of stem cell research through public speaking engagements and articles for the newspaper. In his work with two graduate students, Vicki and Vibhu, he guides them through a painstaking experiment on mice with spinal damage. In addition, during one of the weekly lab meetings with his students, Kessler discusses the religious objections and misunderstandings regarding stem cell research. His colleague, Dr. Laurie Zoloth, who shares in Kessler's public education efforts, also delves into the moral and ethical questions surrounding the research in her classes on bioethics. Clearly, the questions are difficult ones, involving different religious beliefs and the meaning of human suffering.

Responding to the views of the majority of Americans, Congress passed the Stem Cell Research and Enhancement Act of 2005, which was vetoed by President Bush. Another bill supporting stem cell research made its way though Congress in 2007 and also received a presidential veto. However, the discussion and debate continue as individual states pass laws affecting stem cell research and other countries move ahead in this field. Science, religion and politics continue to grapple with the implications of stem cell research for human society; progress is slow and much work remains to finding a common path we can all follow.

Selected people featured in MAPPING STEM CELL RESEARCH: Terra Incognita

Dr. Jack Kessler
Chairman, Dept. of Neurology
Northwestern University

Allison Kessler
Daughter of Jack Kessler

Dr. Laurie Zoloth
Bioethicist
Northwestern University

Dr. Samuel Stupp
Professor of Materials Science,
Chemistry & Medicine
Northwestern University

Vicki Tysseling-Mattiace
Vibhu Sahni
Graduate students & researchers
in Dr. Kessler's lab

Dr. Dale Kaufman
Northwestern Memorial Hospital

Carrie Kaufman
Daughter of Dale Kaufman

Rev.Tadeusz Pacholczyk, Ph.D.
National Catholic Bioethics
Center

BACKGROUND INFORMATION

Spinal cord facts

The spinal cord is about 18 inches long and extends from the base of the brain, down the middle of the back, to about the waist. It is encased within the spinal column, the series of bony vertebrae that form the backbone. Nerves within the spinal cord carry the messages back and forth from the brain to the spinal nerves along the spinal tract. The spinal nerves that branch out from the spinal cord to the other parts of the body exit and enter at each vertebral level and communicate with specific areas of the body.

The spinal vertebrae are named according to their location. The eight vertebrae in the neck are the cervical vertebrae, or C-1 through C-8. The thoracic vertebrae are the 12 vertebrae in the chest, or T-1 through T-12. The first thoracic vertebra, T-1, is where the top rib attaches. Lower down, between the thoracic vertebrae and the pelvis are the five lumbar vertebrae, or L-1 through L-5, and below that are the five sacral vertebrae, S-1 through S-5.

What is spinal cord injury?

Spinal cord injury (SCI) is damage to the spinal cord that results in a loss of mobility or feeling. Depending on the location and extent of the damage, the injury may cause partial or complete paralysis. The spinal cord does not have to be severed in order for a loss of functioning to occur. In fact, in most people with SCI, the spinal cord is intact. In the United States, approximately 11,000 people per year sustain spinal cord injuries.

In general, the higher in the spinal column the injury occurs, the more dysfunction a person will experience. Injuries in the cervical area usually result in quadriplegia or loss of function in the arms and legs. SCIs in the thoracic region usually affect the chest and the legs and result in paraplegia. Injuries to the five lumbar vertebrae (L-1 thru L-5) and similarly to the five sacral vertebra (S-1 thru S-5) generally result in some loss of functioning in the hips and legs.

What treatments are available?

At present, there is no treatment that will repair the spinal cord and restore full functioning to the injured person. Some treatments can decrease the damage if given at the time of the injury. For example, certain steroid drugs reduce swelling, which is a common cause of secondary damage at the time of injury. Injections of large amounts of cold saline solution, started at the time of injury, seem to hold some promise. There are experimental drugs that appear to reduce loss of function, but they are not completely understood. Finally, medical research shows stem cell transplants may have the potential to reduce or cure paralysis caused by spinal injury.

What are stem cells?

Stem cells are basic, or undifferentiated, cells that have no specific function in the body; they are so called because every cell in the body stems from this type of cell. When a stem cell divides, each new cell has the potential to either remain a stem cell or become another type of cell with a more specialized function, such as a muscle cell, a red blood cell or a brain cell. It all depends on stimulating the appropriate biochemical switch that tells it what type of cell to become.

Characteristics of stem cells:

- They can divide indefinitely.
- They can replicate themselves indefinitely.
- Embryonic stem cells have the potential to become any other kind of cell in the body.

Categories of stem cells

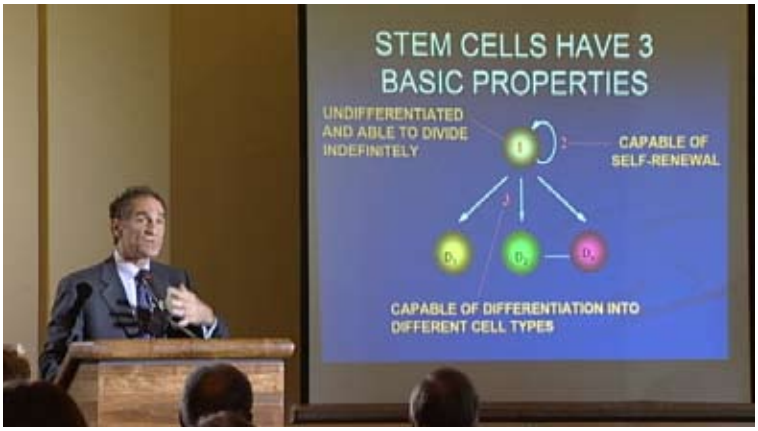
Embryonic stem cells are derived from the inner cell mass of the blastocyst, or early stage embryo that is approximately four to five days old in humans and consists of 50–100 cells. Embryonic stem cells can develop into each of the more than 200 cell types of the adult body when given sufficient and necessary stimulation for a specific cell type.

Adult stem cells are any cell in a developed organism that has two properties: the ability to divide and create another cell like itself and also divide and create a cell more differentiated than itself. Also known as *somatic stem cells*, they can be found in children and adults.

Cord blood stem cells are found in the umbilical cord at birth and can produce all of the blood cells in the body. Cord blood is currently used to treat patients who have undergone chemotherapy to destroy their bone marrow due to cancer or other blood-related disorders.

Therapeutic vs. reproductive cloning

Both types of cloning start with a process known as *somatic cell nuclear transfer* (SCNT) in which the nucleus from a donor adult cell (somatic cell) is removed and then transferred to an egg whose nucleus has been removed. The goal of *reproductive cloning* is to create animals that are genetically identical. The egg is stimulated to divide and if it does so normally, it is transferred into the uterus of the surrogate mother. In *therapeutic cloning* the cell produced through SCNT is used to start a new line of stem cells that can be used to produce cells, specific body parts and organs to be utilized for medical purposes. A clear, simple graphic of the SCNT process can be found on Wikipedia (see Resources).



Some useful definitions

Axon, or nerve fiber – a long, slender projection of a nerve cell or neuron that conducts electrical impulses away from the neuron's cell body.

Blastocyst – an early stage of human development, comprising 50-100 cells. It is the structure found in early pregnancy before implantation. The sequence of development is fertilized egg, blastocyst, embryo.

DNA, or deoxyribonucleic acid – substance found in the nucleus of cells; it contains the genetic instructions for the development and functioning all living organisms.

Nanoengineering – the practice of engineering in the field of *nanotechnology*, or the control of matter on the molecular level in scales smaller than one billionth of a meter.

Somatic cell nuclear *transfer*, or SCNT – the process in which the nucleus from an adult cell (somatic cell) is removed and then transferred to an egg whose nucleus has been removed. This is the first step in both reproductive and therapeutic cloning.

The stem cell debate: a brief summary of the arguments

Opposing

- Research using human embryos effectively destroys life.
- Other treatments using adult stem cells are available to treat conditions such as Parkinson's disease and spinal cord injuries.
- Stem cell research necessitates harvesting a woman's eggs, which could be physically harmful to women or lead to commercial exploitation of women.
- Embryonic stem cell research puts science on a slippery slope toward reproductive cloning.

Supporting

- Unused frozen embryos from fertility clinics would otherwise be destroyed, so using these for research is ethical.
- Adult stem cells lack the versatility of embryonic stem cells, making them less likely to lead to medical break throughs.
- Federally-funded stem cell research requires scientists to share data,which is not the case with private research.
- Reputable researchers are totally opposed to cloning humans.

Federal legislative activity

- August 2001 – President Bush enacted a ban on federal funding of research that created new embryonic stem cell lines from fertilized embryos.
- July 2006 – The Stem Cell Research Enhancement Act of 2005 was the first legislation vetoed by President Bush. The act would have provided support for research using excess human embryos from fertility clinics, donated with written informed consent and without financial inducements.
- June 2007 – The Stem Cell Research Enhancement Act of 2007 was vetoed by President Bush. This bill had essentially the same provisions as the 2005 bill. After his veto, the president issued an executive order encouraging government agencies to support research that creates useful stem cells without destroying embryos.

THINKING MORE DEEPLY

1. Were some of your ideas changed or clarified as a result of seeing this film? Why do some of the myths about stem cell research persist?

2. What is your reaction to Father Tad's statements about human suffering, that is, that it changes us for the better and that it offers some very positive outcomes? Do you agree with his view comparing embryonic stem cell research with slavery?

3. Our current national policy does not prohibit the creation of more stem cell lines, but it bans federal funding for such research. Some in the scientific community feel that such a ban impedes research that could alleviate human suffering. Do you agree? Is there a realistic compromise that can satisfy both those who oppose stem cell research on religious grounds and those who feel that science should be fully supported to forge ahead in this area without any restraints?

4. Is it inevitable for religion and science to be in conflict? If you were to speculate about how the conflict over stem cell research will play out, what would you see taking place? What parallels, if any, do you see between the stem cell controversy and other science-religion conflicts such as Galileo's dispute with the Church over Earth's position in the heavens?

5. What questions do you have about stem cell research as a result of seeing this film?

SUGGESTIONS FOR ACTION

Together with other audience members, brainstorm actions that you might take as an individual and that people might do as a group. Here are some ideas to get you started:

1. Educate yourself about the science of stem cell research and about the reasons for the controversy surrounding this research.

2. Organize a forum, or teach-in, to educate members of your community about the scientific, religious and political issues related to stem cell research. Invite local experts to speak at your event.

3. Volunteer at a rehabilitation center that treats paralysis patients.

4. Many military personnel have returned from Iraq with serious injuries, including spinal cord injuries. Find out what resources are available in your community to help the injured troops adjust. Speak with your congressional representatives about the resources available to meet the needs of these soldiers.

For additional outreach ideas, visit www.pbs.org/independentlens/get-involved, the Web site of *Independent Lens*. For local information, check the Web site of your PBS station.

RESOURCES

Information about stem cells/stem cell research
http://mbbnet.umn.edu/scmap.html – This site contains a map showing the status of stem cell research around the world.

http://stemcells.nih.gov/info/basics – Stem Cell Information from the NIH provides basic information, definitions and FAQs.

http://www.stemcellresearchnews.com – News of the latest developments in stem cell research.

http://www.ornl.gov/sci/techresources/Human_Genome/elsi/cloning.shtml#whatis – The Human Genome Project Cloning Fact Sheet explains the differences between reproductive and therapeutic cloning.

http://dels.nas.edu/bls/stemcells/ - Stem cell research information compiled by The National Academies, experts in various medical and technical fields who serve pro bono to address critical national issues and give advice to the federal government and the public.

Religious and ethical perspectives
http://religioustolerance.org/res_stem.htm – This site of the Ontario Consultants of Religious Tolerance addresses stem cell research as well as other ethical issues and topics of importance within various belief systems.

http://www.cbhd.org/resources/stemcells – The Web site of the Center for Bioethics and Human Dignity provides a Christian-based view of stem cell research.

Research guidelines
http://www.aaas.org/spp/cstc/briefs/stemcells/index.shtml – The Science and Policy section of the Web site of the American Association for the Advancement of Science contains *Policy Brief: Stem Cell Research.*

Information on Legislation
http://thomas.loc.gov/cgi-bin/query/z?c110:S.5: – The Library of Congress Web site provides information on the Stem Cell Research and Enhancement Act of 2007.

http://www.sourcewatch.org/index.php?title=U.S._federal_stem_cell_legislation – Part of Congresspedia, this site contains information on legislation and the pros and cons of the stem cell debate.

www.cnn.com/SPECIALS/2001/stemcell – This CNN site covers the stem cell debate, defining the issues, explaining the science and politics, and offering analysis.

Spinal injuries
http://www.themiamiproject.org/x21.xml – The Miami Project to Cure Paralysis is the world's largest comprehensive spinal cord injury research center.

http://www.spinalcordinjury.org/links.htm – This site of the Spinal Cord Injury Network International provides a listing of selected resources on the Web for spinal cord injury information.

http://www.spinalinjury.net/ and http://en.wikipedia.org/wiki/Spinal_cord_injury – Both of these sites offer basic information about the spine and spinal injuries, including graphics.

A Google image search of "spinal cord" results in three enlargeable graphics, along with a list of sites with spinal cord information.

MAPPING STEM CELL RESEARCH: Terra Incognita WILL AIR NATIONALLY ON THE EMMY AWARD-WINNING PBS SERIES *INDEPENDENT LENS* ON January 15, 2008. CHECK LOCAL LISTINGS. MAPPING STEM CELL RESEARCH: Terra Incognita was produced by Maria Finitzo. The Emmy Award-winning series *Independent Lens* is jointly curated by ITVS and PBS and is funded by the Corporation for Public Broadcasting (CPB) with additional funding provided by PBS and the National Endowment for the Arts.

ITVS COMMUNITY is the national community engagement program of the Independent Television Service. ITVS COMMUNITY works to leverage the unique and timely content of the Emmy Award-winning PBS series *Independent Lens* to build stronger connections among leading organizations, local communities and public television stations around key social issues and create more opportunities for civic engagement and positive social change. To find out more about ITVS COMMUNITY, visit www.itvs.org/outreach.