

Smart Life Forum

SmartLifeForum.org

Presents

Bernard Siegel, J.D.

on

Stem Cell Advocacy Update

Thursday Mar. 19, 2009, 7 PM

LOCATION: Cubberley
Community Center - Room H1
4000 Middlefield Rd
Palo Alto, CA

FUTURE SPEAKERS

April 16, Dave Steenblock, MD

May 21, Aubrey De Grey, PhD

June 18, Len Saputo, MD

July 16, James Wilson, ND

Aug.20, Frank Shallenberger, MD

October 15, Gary Taubes

Short Presentation Jake Brzakovic, personal trainer, will go into detail on one of the important rules for fitness, starting with “Mechanisms of Dehydration and Rehydration”.

FMBR Mar. 27 – Dr. Olga Louchakova will speak on the “Consciousness of the Heart;” see FMBR.org for details.

Meet Bernard Siegel, J.D.

Bernard Siegel is the founder and executive director of the nonprofit Genetics Policy Institute (GPI), based in Palm Beach Gardens, Florida. He is the founder and the co-chair of the World Stem Cell Summit series of global conferences and editor-in-chief of the *World Stem Cell Report*. He also serves as the co-chair of the Governmental Affairs Committee of the International Society for Stem Cell Research.

Mr. Siegel is a frequent lecturer, panelist and keynote speaker on the subject of stem cells and public policy. He has addressed the United Nations, the Salk Institute, James Baker Institute of Public Policy at Rice University, New York Biotechnology Association, Diabetes Research Institute Foundation, Seoul National University, International Stem Cell Forum (Beijing), World Congress for Freedom of Scientific Research (Rome), Stem Cells European Business Summit (Edinburgh), Stem Cells Europe (Amsterdam),

World Parkinson Congress, Association of American Law Schools, American College of Trial Lawyers, and has spoken at numerous colleges and universities.

Mr. Siegel has appeared as a policy expert on the *CBS Evening News*, *the CBS Early Show*, *CNN*, *CNN International*, *MSNBC*, *Fox and Friends*, *CNBC* and network news shows throughout the U.S. and the world. He was profiled on National Public Radio's *All Things Considered*. He has been quoted in the *New York Times*, *The Washington Post*, *The Boston Globe*, *Wired*, *The Scientist*, *New Scientist*, *The London Times*, *Le Monde*, *Pravda*, *The People's Daily* and many other publications. In 2008, Mr. Siegel was appointed to the Editorial Board of the award-winning journal *Regenerative Medicine*.

Mr. Siegel earned his undergraduate and law degrees from the University of Miami (BA 1972, JD 1975). He has been a member of the Florida Bar since 1975.

Main Presentation

Imagine a time when the promise of regenerative medicine will be fulfilled, where serious diseases are treated with cell therapies rather than drugs or surgery. Stem cell research represents a medical revolution of the first rank. Medical revolutions used to take decades: this revolution will possibly touch our lives and surely extend the lives of our children.

Florida attorney Bernard “Bernie” Siegel, is recognized as one of the foremost stem cell

advocates to make that dream come true. He has participated in the policy debates and has played an important role in charting the future of regenerative medicine.

Mr. Siegel's introduction to stem cells came via a court case. In December 2002, Clonaid, the self-proclaimed "human cloning company" made an announcement in Broward County, Florida that it had cloned the first baby, referred to as "Baby Eve." In the ensuing media firestorm, many pundits believed that Clonaid had the scientific wherewithal and intent to accomplish the task. Its founders, part of a UFO sect called the Raelian Movement, had been somewhat validated. Its leaders appeared before a committee of the United States Congress and at the National Academy of Sciences, where they declared their intention to clone a baby and were being foisted on the public as a serious threat.

While many journalists and the public were uncertain as to the validity of Clonaid's cloning claims, only Bernard Siegel took action to test the truth. He filed a lawsuit, seeking to have appointed a temporary guardian of the alleged cloned child.

Siegel uncovered through sworn testimony that Clonaid lacked a board of directors and even a street address. The case was widely viewed as discrediting the cloning claim and demonstrating that Clonaid was nothing more than a "sham", and its representatives mere publicity seekers. The bubble of cloning hysteria was burst.

After the cloning case, prominent researchers requested that Siegel remain engaged in representing science by serving as a "legal mouthpiece" in the policy debates to defend freedom of legitimate scientific research against those who sought to scare the public or cloak their political agenda by using misleading scientific jargon.

With encouragement of scientists and inspired by patient-advocates, Bernard Siegel (a cancer survivor himself) left his law practice and formally launched the Genetics Policy Institute (GPI) to promote and defend stem cell research. The first intervention occurred in the United Nations, where a form of stem cell research was under threat of being banned by world treaty.

Socially conservative countries (including the United States) sought to impose a global ban and moral condemnation on unsafe, and therefore, unethical reproductive cloning. The proposal was deliberately overly broad and sought a world ban on nuclear transfer (therapeutic cloning), a promising area of research that scientists believed might produce pluripotent stem cells. The attack on nuclear transfer was an effort to delegitimize all embryonic stem cell research. It was evident that many of the same forces aiming to derail research in the US were harnessing support in the UN for an international effort to accomplish their mission.

Siegel became a prominent "whistle blower" alerting the world stem cell community of scientists and patient groups about the impending threat (at the same time real and profoundly symbolic) to stem cell science should the treaty proposal be enacted. GPI served as a principal organizer of the response to this threat. A massive grassroots letter writing campaign was launched resulting in more than 35,000 faxed letters to the United Nations missions. In a stunning turnaround, the UN saved the research in 2003 by a single vote, and in later battles the coalition of organizations that Siegel lead helped derail the treaty altogether.

The United Nations campaign underscored the political challenges to advance embryonic stem cell research.

The then ascendant social conservative forces were pouring resources into United States policy "think-tanks" with bioethics agendas. Organizations such as the Family Research Council, Ethics and Public Policy Center and Discovery Institute provided the political talking points, op-ed editorials and formulated legal initiatives geared to stymie embryonic stem cell research. Certain lawmakers were proposing bills in the US Congress that called for imprisonment and imposition of heavy fines on scientists engaged in nuclear transfer, with even patients being placed in legal jeopardy. The Bush Administration's funding policy relating to embryonic stem cell research severely limited the research grants needed to advance the field.

Mr. Siegel's successful advocacy was a result of a devoted outreach to those impacted by stem cell research. Included were many grassroots advocates who were often overlooked by policy-makers and

unrepresented by mainstream organizations. He became a frontline defender of research, debating opponents in the media and at public events.

He also helped promote and organize the formidable “Pro-Cures Movement.” In presentations around the world, he explained that public support for stem cell research came from a vast consumer movement, where the public saw stem cells a personal health issue. He was active in many state campaigns where grassroots advocates chalked up hard fought victories.

Stem Cells in the Obama Era

With the election of Barack Obama, the political climate for stem cell research has changed for the better. The funding restrictions of the past administration will be lifted and new funding will be available.

Even in the face of bleak economic times, the forecast is bright for innovative stem companies in the nascent ReGEN Industry. Seeds are being planted to grow a potentially \$500 billion industry in the next 20 years.

But make no mistake; the same determined foes are re-arming to present new roadblocks and challenges. Stem cells are not a Democrat or Republican issue, they are a human issue and we are all stakeholders in the “Stem Cell Wars.”

Lifting the Bush funding restrictions will definitely advance the field of human embryonic stem cell research. We will have for the first time clear regulations emanating from the federal government and an increased flow of funding for research on the many new embryonic stem cell lines created after the 2001 policy pronouncement. In many ways the new stem cell lines are an improvement over the 21 lines approved in 2001. The new lines are free of animal proteins and in some cases are disease specific, representing important tools for scientific discovery. The first step is for President Obama to sign an executive order. In order for the new policy to become permanent, a law should be enacted allowing funding for research on cell lines, without regard to the time that they were derived.

A more far reaching goal is for Congress to repeal the Dickey-Wicker Amendment which is the root cause of the confusing American policy. Enacted in 1996 as part of the appropriations budget for the

Department of Health and Human Services, Dickey-Wicker forbids NIH funding on research harming or destroying human embryos. It blocks funding to derive new cell lines or nuclear transfer (therapeutic cloning). The architecture of the Bush policy, and possibly the Obama policy, is to allow some federal funding only for stem cell lines that were created without federal funding in the first place. Using federally funded equipment, supplies and personnel funded with grants from NIH cannot be used to derive new lines (where embryos are harmed or destroyed). Dickey- Wicker forbids such action. To do so would place the entire institution’s funding in jeopardy. It is time to recognize the legal and moral inconsistencies inherent in the policy. The Dickey-Wicker Amendment should be repealed. It remains to be seen whether President Obama and Congress have the farsightedness to take this on.

Future laws should be enacted that fully promote ethically sound embryonic stem cell research. One would be well served to read “The Morality of Embryo Use” by Harvard philosopher Louis Guenin. He sets forth the case that it is morally permissible to decline intrauterine transfer of an embryo formed in vitro. Then from permission of the donors that their embryos be utilized for scientific research only, there follows a consensus justification for using the embryos in service of humanitarian ends. The ethical discussion should be reframed to focus upon donor’s intent. Where the embryo is donated with the strict proviso that the donation is for scientific research only and that the embryo be barred from transfer into a womb, such an embryo cannot become a person because its development is bounded. Rather than the sacrifice of the embryo be in vain, it may be utilized for potentially lifesaving medical research.

Scientists cannot become glued to their microscopes. They must learn to engage in the discourse in the public square. Societies have responsibility to erect fences that delineate what is permissible scientific research and what is not. Scientists would be well served to lead the debate. The consequence of remaining silent is to cede ground to the ever-present and angry voices of ignorance, intolerance and fear.

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