

# The US President's Council on Bioethics (2001-2009)

The US President's Council on Bioethics was an organization headquartered in Washington D.C. that was chartered to advise then US President George W. Bush on ethical issues related to biomedical science and technology. In November 2001, US President George W. Bush created the President's Council on Bioethics (PCB). Convened during a nationwide cloning and embryonic stem cell research debate, the Council stated that it worked to address arguments about ethics from many different perspectives. The organization enacted a model for analyzing bioethical issues through deliberation instead of through the consensus approach. US President Barack Obama replaced the PCB in 2009 with his Presidential Commission for the Study of Bioethical Issues.

On 9 August, 2001, US President Bush gave a national television address in which he announced his administration's stance on the federal funding of human embryonic stem cell (ESC) research. Bush stated that he would allow federal funding for what he claimed were more than sixty existing ESC lines and that he would restrict federal funding for the creation of new ESC lines. He stated that his position would allow ESC research while remaining sensitive to the citizens who claimed that embryos are morally significant. Near the end of his speech, Bush proposed the creation of a council to examine the ethical concerns surrounding stem cell research and recommend stem cell research guidelines. The President's Council on Bioethics officially commenced three months later through presidential executive order 13237.

As head commissioner of the President's Council on Bioethics, Bush nominated Leon Kass, a professor at the University of Chicago in Chicago, Illinois and the author of several books about biological research. Prior to his appointment, in the 1997 article, "The Wisdom of Repugnance," Kass argued against the legalization of technology that could lead to cloning, and he discussed moral and ethical consequences of cloning technology. In a New York Times profile published a month before the first meeting of the President's Council, Kass remarked on the need to have discussions about science that addressed not only how biotechnologies work, but also what they mean for humanity.

Kass nominated the other seventeen members of the PCB, all of whom were subsequently approved by Bush. Members came from a wide range of disciplines including law, political theory, biology, medicine, moral philosophy, metaphysics, and religious ethics. Most members were professors and several members were practicing physicians. Kass said that he did not want the council to be composed entirely of professional bioethicists. Rather, he said that he selected members based on their ability to think deeply about complicated issues. Many opponents of the Bush Administration's new embryonic stem cell policy argued that most members held conservative views. Defenders of the PCB noted that at least half of the members had publicly supported the creation of stem cell lines from embryos.

The President's Council on Bioethics continued a tradition of presidential bioethics commissions assembled in the 1970s to address issues posed by new biotechnologies. Some commentators said that PCB differed extensively from previous advisory boards in its methods of addressing bioethics issues. The executive order that created the PCB stated that while the council's purpose was to advise the president, the organization should not be guided by the need to develop consensus positions on the issues. In comparison, the previous bioethics commission under President William J. Clinton had crafted unanimous consensus statements and policy recommendations for embryonic stem cell research funding.

The PCB said that its primary mission was to develop a comprehensive awareness of the issues and to provide a forum for national discussion. Kass opened PCB's first meeting in January 2002 with a reading of Nathaniel Hawthorne's 1846 story "The Birthmark," in which a scientist becomes

obsessed with eradicating a small blemish on his wife's cheek, the only flaw detracting from her extraordinary beauty. In the end, the scientist's quest for perfection eliminates the birthmark but kills the wife. Kass connected the meaning of the story to the council's prospective examination of the possible consequences resulting from humanity's use of biotechnologies. Some commentators praised the council's humanistic exploration, while critics bemoaned that policy recommendations regarding stem cell research were going to be based on literature and aesthetics, and not on facts.

The council discussed the ethics of human cloning and experimentation on cloned human embryos from January through July 2002. Even though President Bush had already created and implemented his embryonic stem cell research policy, the consequences of cloning remained contentious amongst scientists, policy makers, and the public.

Two types of human cloning are called reproductive cloning and therapeutic cloning. In reproductive cloning, a nucleus from a non-reproductive cell is inserted by scientists into a reproductive cell that has had its own nucleus removed. The mid 1990s cloning of Dolly the sheep is an example of reproductive cloning.

Similarly, in therapeutic cloning, a nucleus from a non-reproductive cell is inserted by scientists into a reproductive cell that lacks a nucleus. However, the process differs in purpose. Scientists use therapeutic cloning to create and harvest stem cells, terminating the development of the embryo within fourteen days of transferring the nucleus. Many scientists argue that cloned stem cells may provide treatments for many diseases, including Parkinson's, Alzheimer's, juvenile diabetes, and spinal-cord paralysis.

Previous US presidential bioethics organizations discussed and produced reports on human cloning. While previous reports focused on formulating policy and law recommendations, the PCB focused on different aspects of the human cloning debate in its report *Human Cloning and Human Dignity*, published in July 2002. The council's report reviewed ethical arguments for and against reproductive and therapeutic cloning.

The policy recommendations presented in *Human Cloning and Human Dignity*, provoked reactions within and beyond the scientific community. PBC unanimously recommended a total ban on reproductive cloning. However it was divided on therapeutic cloning. Some council members argued that the possibility of future medical treatments enabled by the cloning of embryos merited approval for therapeutic cloning. Other members argued that the destruction of embryos was morally impermissible in this context, and thus voted for a total ban of therapeutic cloning. The report ultimately recommended a four-year national moratorium on therapeutic cloning. The recommended temporary ban applied to all institutions and researchers in the US, regardless of whether or not they used federal funding.

Simultaneously, during the first half of 2002, the PCB discussed reproductive and therapeutic cloning, while the US National Academy of Sciences in Washington, D.C. issued a report that called for a ban on reproductive cloning but reaffirmed its support for research on therapeutic cloning. The National Academy of Sciences is research organization whose members advise the US government on scientific matters. Many biomedical scientists supported the National Academy of Sciences's position, and they argued that the two different kinds of cloning, therapeutic and reproductive, were incorrectly conflated in the public's mind. That year three leaders of the biomedical research community—Bruce Alberts, the president of the National Academy of Sciences, Kenneth Shine, president of the Institute of Medicine, and Bert Vogelstein, chairman of the National Research Council, all headquartered in Washington, D.C.—published an article titled "Please Don't Call It Cloning!" The authors requested that public policy officials use proper scientific terminology when discussing the different types of cloning in order to more accurately distinguish between embryos cloned for research purposes and embryos cloned with the intent of growing people. The article recommended that policy officials stop using the term therapeutic cloning, and instead call the technique nuclear transplantation.

The President's Council on Bioethics addressed terminology when discussing the types of cloning in *Human Cloning and Dignity*. In a chapter dedicated to terminology, the council stated that policy makers should aim for both accuracy and fairness when phrasing contentious issues because the choice of names can shape the way questions are posed and determine how answers are given.

However, the PCB disagreed with the statements made by scientists that policy makers should use more scientific terms such as nuclear transplantation. Instead, the report claims that the most accurate and fair terminology to describe the two types of cloning are cloning-to-produce-children and cloning-for-biomedical-research.

Other organizations also disagreed with PCB's recommendations. Anti-abortion organizations were not satisfied that the PCB recommended a moratorium instead of a ban on ESC research. The American Life League, an anti-abortion organization headquartered in Stafford, Virginia, published a statement in which they claimed that Bush had failed to uphold his commitment to anti-abortion policies.

Kass argued that journalists concentrated all of their attention on the political implications of the report instead of on the reasons that supported the recommendations. To avoid future criticism, Kass restructured subsequent reports published by the President's Council to describe opposing moral positions on issues connected with biotechnology and to offer few policy recommendations from council members. In October 2003, the council published *Beyond Therapy: Biotechnology and the Pursuit of Happiness*, which the authors described as an ethical inquiry about the purposes and motivations underlying biomedical science.

Kass's claim that the most important task of a public bioethics council was to provide a forum for robust national deliberation continued to shape the council's proceedings. In December 2003 the council published *Being Human: Readings from The President's Council on Bioethics*, an anthology of history, philosophy, religious text, and literature. The organization's web site archived the transcripts of all the Council's meetings; records of deliberations that several bioethicists labeled as models of vigorous and civil philosophical disagreement.

In 2005 Kass stepped down as head commissioner but remained a member of the council under the leadership of Edmund Pellegrino. Pellegrino was Professor of Medicine and Medical Ethics and professor of Philosophy at Georgetown University, in Washington D.C. Pellegrino shared many of Kass's core values and remained head commissioner until the council was dissolved four years later. From September 2005 through December 2008 the council published two reports on end-of-life care, one report on newborn genetic screening, and a collection of essays titled *Human Dignity and Bioethics*.

The Council's work on end-of-life care and newborn genetic screening sparked less debate than did their publications about embryonic stem cells. *The Challenging Moral Focus of Newborn Screening*, published in December 2008, argues against the expansion of mandatory newborn screening for genetic diseases for which no treatments exist.

The PCB's recommendations ran counter to the position of major professional organizations, like the American Academy of Pediatrics, headquartered in Elk Grove Village, Illinois, which endorsed the use of new screening technologies for the early detection of genetic conditions even when no known treatment exists. In March 2008, The President's Council compiled an anthology of essays written by council members and guest authors titled *Human Dignity and Bioethics*, which aimed to describe various meanings of the term human dignity – a phrase invoked frequently in many of the Council's reports. The preface to *Human Dignity and Bioethics* asserted that the collection of essays was an educational resource for the public, similar to the Council's first anthology published in 2003. The contributing authors of *Human Dignity and Bioethics* argued that assorted conceptions of dignity can be grounded in reflections on the possible consequences of biotechnologies.

Ruth Macklin, a professor of medical ethics at the Albert Einstein College of Medicine in New York, New York, and Harvard University professor Steven Pinker in Cambridge, Massachusetts, published responses to the PCB's use of the term dignity. They advocated that the government—including presidential bioethics commissions—should take a hands-off approach about the moral implications of biomedical research and consider only the safety of biotechnologies, leaving the more personal questions to the public.

Bush's term as US President ended in 2008, and Barack Obama was elected as the next US president. In 2009, Obama's administration dissolved the President's Council on Bioethics two weeks before its charter was set to expire. The letter terminating the members' appointments explained that

Obama valued an advisory commission that was objective and non-ideological. A White House press officer explained to the media that the new president would appoint a commission with a mandate to provide practical policy options. On 24 November 2009, President Obama signed Executive Order 13521, establishing the Presidential Commission for the Study of Bioethical Issues led by Amy Gutmann, president of the University of Pennsylvania, in Philadelphia, Pennsylvania.

Some commentators praised the Bush's President's Council on Bioethics for its willingness to ask what they called essential questions about what it means to be human and how humanity's fundamental values might be affected by specific uses of innovative biotechnology. Other commentators, including many members of the bioethicist community, declared the PCB a failed experiment because it did not construct practical policy recommendations. The disagreement about the PCB's methods prompted many to question the purpose of bioethics advisory boards at the political level, especially when addressing morally contentious issues like embryonic stem cell research.

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