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Taking the Stem Cell Debate to the Public

In their essay in the April 2004 issue of *PLoS Biology*, Elizabeth Blackburn and Janet Rowley (2004), two distinguished cellular biologists and members of the President's Council on Bioethics, strongly question the scientific foundation of two reports from the Council (President's Council on Bioethics 2003, 2004). The Council on Bioethics was formed by executive order "to advise the President on bioethical issues that may emerge as a consequence of advances in biomedical science and technology." An open discussion between ethicists and scientists is critical to the advisory system. The recent administrative dismissal of Dr. Blackburn from the Council is very alarming. By stacking the deck with conservative opinions,

and not accurately discussing the scientific issues, the Bioethics Council has become irrelevant to the scientific community and presents a jaundiced view to the public.

Stem cell research and its applications have the potential to revolutionize human health care. Recent polls show support for embryonic stem cell research, even with conservative voters. The public, as the major benefactor of biomedical research and the target population of beneficial clinical advances, has the right to a fact-based discussion of the science regarding stem cells. It is therefore time that the debate on stem cell research, with its risks and benefits, be taken to the public. A debate on stem cell research restricted to the

President's Council on Bioethics is a disservice to the public.

Nearly three decades ago, the advent of recombinant DNA technology and in vitro fertilization (IVF) techniques, raised similar concerns regarding research. Contrary to apprehensive expectations, recombinant DNA technology has boosted enormous advances in the health care and pharmaceutical industry. IVF evolved to be a widely accepted, safe medical

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procedure, with over one million healthy babies born by IVF and related treatments. Similarly, once stem cells are successfully used in the clinic, most of today's political and ethical issues will evaporate.

The International Society for Stem Cell Research (ISSCR), a society whose membership encompasses the bulk of the stem cell research brain trust, holds the position that research on both adult and embryonic stem cells will guarantee the fastest progress in scientific discovery and clinical advances. The ISSCR also strongly opposes reproductive cloning and supports the National Academy of Science's proposal to develop voluntary guidelines to encourage responsible practices in human embryonic stem cell research.

One of the original recommendations of the President's Council on Bioethics was a four-year moratorium

on stem cell research. The purpose of this moratorium was theoretically to open a large, national discourse on the topic of stem cell research, a debate intended to bring all sides into thoughtful reflection on the issue. To that end, the ISSCR has repeatedly and consistently offered an open forum for all sides in the debate at our conferences, and has carefully offered invitations to join our society and to speak at our annual meeting to members of the President's Council, including colleagues whose opposition to stem cell research has been clear. None have accepted. Dr. Kass, in particular, has received several direct appeals but has turned down every such opportunity to make his case to the researchers who arguably are his discourse partners, from whom he could learn much, and whom he should be actively engaged in teaching. It is tragic that voices of dissent and

debate are stilled, for it is this very quality of open debate that is at the heart of both the scientific method and an ethically directed American democracy—surely a goal that we all share. ■

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Beyond Therapy ...

It is indeed regrettable that a distinguished and thoughtful scientist such as Elizabeth Blackburn should have been dismissed from the President's Council on Bioethics. Scientific perspectives such as hers are surely needed on this committee.

Her dismissal was apparently the consequence of her disagreement with some of the text of the Council's report, "Beyond Therapy: Biotechnology and the Pursuit of Happiness" (2003). The thrust of this report is that some of the directions of current biological research will, if carried to fulfillment, result in major changes in the nature of human life—changes that the report regards with foreboding.

In their essay, Drs. Blackburn and Rowley (2004) try to bypass these concerns with the argument that we really are not able to accomplish any of these changes yet and, indeed, some may never be possible.

I would suggest that as scientists we should face these issues forthrightly. We should not seek refuge in present-

day uncertainties. The authors of the report are not naïve nor ignorant. Yes, if these lines of research are successful, their outcome will change the nature of human life.

As an example, consider current research into the causes of aging. Clearly, we do not at present know how to achieve major increases in the human life span (although we are able to do so in lower life forms). But it is plausible that we will learn how to do so. And surely a, say, doubling of the human life span would change the nature of human life.

Likewise, if we learn to modify the human gene pool so as to produce exceptional individuals or to alter human capabilities, or if powerful drugs are developed that may commandeer the human psyche, the nature of human life will be altered.

But so be it. The nature of human life has changed repeatedly and profoundly in the past—with the invention of agriculture, with the invention of writing, with the development of machines and mechanical power, with the advent of

modern science and medicine. The nature of human life is different in 2004 a.d. from what it was in 1000 a.d. or 46 b.c. or 5000 b.c. or 10,000 b.c., and it will change again in the future.

The concerns expressed in the report are earnest, and they should be confronted in earnest. ■

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Ethics as Our Guide

Blackburn and Rowley's (2004) criticism of a report on embryonic stem cell research from the President's Council on Bioethics (2004) is puzzling. Where is the bioethics? The nub of their complaint is that some details of the report have been partisan and have distorted 'the potential of biomedical research and the motivation of some of its researchers'. No doubt their quibbles are well-founded, as every committee report is a compromise.

However, it does not follow that if the benefits of embryo stem cell research had been presented more persuasively and in greater detail, then the case for 'non-commercial, federal, peer-reviewed funding' would be unassailable. Such a view appears

to be based squarely on a utilitarian view of the moral status of embryos: that the good flowing from destructive research outweighs the evil of embryo destruction. Far from being a neutral scientific analysis, this expresses a commitment to the proposition that biomedical progress is more important than the defence of human life.

If twentieth century philosophy of science has taught us anything, it is that the aspiration to pure scientific objectivity is a dangerous illusion. Research programs always embody philosophical and moral assumptions that must be openly defended. If Blackburn and Rowley want government support for embryo stem cell research, they must justify their bioethical approach and not hide

behind a smokescreen of indignation over Blackburn's unwilling departure from the Council. ■

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Scientists and Bioethics Councils

I read with interest the article in a recent issue of *PLoS Biology* by Elizabeth Blackburn and Janet Rowley, two of the scientific members of President Bush's Council on Bioethics. Invited by the President to serve on this Council, they say that it was 'a difficult invitation to accept'. Maybe, but that they did accept the invitation is to be applauded. As the Council's report 'Monitoring Stem Cell Research' states, 'fairness in ethical evaluation and judgment depends on ... fair and accurate description of the relevant facts of the case at hand'. In other (fewer) words, sound ethics requires a solid base in sound science. It is crucial that any bioethics committee or council made up of ten to twenty members should include at least two or three scientists broadly acquainted with the field in general, and with recent published findings. I was only sorry to read that Elizabeth Blackburn (who works in California but is a Fellow of the Royal Society, the United Kingdom Academy of Sciences)

had her Council term terminated by White House directive on February 27, 2004.

Of course, any bioethics committee or council (and I have served on several such, both in the UK and elsewhere in Europe) is likely also to include philosophers, lawyers, theologians, sociologists, and probably 'lay' people of appropriate interests. The scientists may well find that other members of the group have 'strong opposing views' on ethical issues, as well as on the costs and benefits of technologies arising from biomedical research. Elizabeth Blackburn and Janet Rowley were assured, both by Leon Kass, the chairman of the Council, and by President Bush himself, that their voices would be heard and integrated into the Council statements. It is therefore disappointing to learn that, in the 'Beyond Therapy' report (which I have not yet read), their requests for revision of certain aspects was declined. Were they not offered the option of a brief minority report? It would be

expected in such circumstances that dissenting opinions would be recorded (as was done, for example, in the 1984 UK report by the Committee on Human Fertilisation and Embryology chaired by Mary Warnock (1984), and in some of the Opinions offered by the European Group of Ethics to the European Commission). This would be particularly appropriate, and indeed essential, when recommendations are put forward.

The 'Monitoring Stem Cells Research' report (which I have read) contains no recommendations, but includes a rather comprehensive survey of the various ethical positions relating to human embryonic stem cell

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research, a historical account of the development up to the present time of federal law and policy, and a chapter on recent (almost entirely United States) developments in human stem cell research and therapy. The scientists must have contributed substantially to this section of the report. Emphasis is put on the need for research on both adult and embryonic stem cells, since at present there is no way to assess which approach has the more promising therapeutic potential for which diseases. Some funding figures are given: on human embryonic stem cell research the US National Institutes of Health spent \$10.7 million in 2002 and \$17 million in 2003, with an estimated total spent by US companies of \$70 million, while in the same two years the National Institutes of Health spent \$170 million in 2002 and \$181.5 million in 2003 on adult stem cell research. However, it is not obvious that there are any US scientists wanting to work on human embryonic stem cells within the constraints of US federal funding who are prevented from doing so by lack of money.

To my mind, the major deficiency in the 'Monitoring Stem Cells Research' report is the almost complete lack of reference to what Elizabeth Blackburn and Janet Rowley correctly call 'years of rigorous and careful research in animal models'. Some mention is made of experiments with human embryonic stem cells in immunologically handicapped mice, but in any such model both the stem cells and the mice are difficult to work with. Much of the science-based optimism that human embryonic stem cells may eventually prove of therapeutic value springs from the results of experiments with mouse embryonic stem cells in intact mice. Curiously, only a single such experiment is cited: an impressive but somewhat recondite piece of work from Jaenisch's laboratory (Rideout et al. 2002), using cloned and genetically modified mouse embryonic stem cells to treat a form of mouse hepatitis. A wider consideration of work on animal models, together with some emphasis on the potential use of human embryonic stem cells for toxicity testing and drug design by pharmaceutical

companies, is in part what Elizabeth Blackburn and Janet Rowley believe 'would help the public and scientists better assess the content of the report'. If they requested inclusion of such material, it is unfortunate that their requests were declined. ■

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A Voice for Research, a Voice for Patients

In the very thoughtful essay "Reason as Our Guide" by Drs. Elizabeth Blackburn and Janet Rowley (2004), the authors highlight a key concern with the reports published by the President's Council on Bioethics—the lack of credible scientific information being passed on to policy makers.

Blackburn and Rowley point out many areas of the report "Monitoring Stem Cell Research" that needed correction from a scientific standpoint. While it is impossible to include every suggestion in a report that seeks to draw consensus from a large panel of members, in a heated, political debate like that surrounding embryonic stem cell research and therapeutic cloning, providing the most accurate and complete scientific information to policy makers is crucial. Unfortunately, with the recent dismissal of Dr. Blackburn from the Council, there

will now be one less voice for scientific research and for the potential the research holds for curing disease and alleviating the suffering of millions.

Speaking for the Coalition for the Advancement of Medical Research, our concern is not only the small number of researchers on the Council and lack of complete scientific data being shared with policy makers, but the absence of patient representation on the Council itself. With the exception of public comment periods, patient organizations have no voice in the work of the Council as it discusses issues that profoundly impact them. Now, with one less member standing up for research and thus patients, our concern grows even stronger.

The Blackburn and Rowley essay also correctly points out that there is more published work on adult stem cell research because of a "paucity of

funding for research using embryonic stem cells." Despite this lack of federal and private funding, advances continue to be made—but just think of the advances we could have had if only there were a supportive federal policy that encouraged embryonic stem cell research instead of stifling it. We hope—in light of scientific advances made over the past several years and the strong support of the scientific community, including the National Institutes of Health, the Health and

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Human Services Department, and the National Academy of Sciences—that the President will reevaluate the current federal policy for stem cell research and consider easing the restrictions.

We commend Drs. Blackburn and Rowley for trying to set the record

straight in their essay, and applaud their efforts to stand up for medical research, which has the potential to benefit us all. ■

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Ethereal Ethics

It is a great pity when vested interest and dogma dominate what should be a well-informed and rational debate. The essay by Elizabeth Blackburn and Janet Rowley (2004), about the output and the workings of the President's Council on Bioethics, therefore prompted in me a strong reaction of sadness and despair, although I have to admit not one of surprise.

In the United Kingdom, we have had an almost continuous debate since the mid 1980s on topics relating to research on early human embryos. I myself have been involved in some of this debate, especially over the last few years, relating to human embryonic stem cells and nuclear transfer. I will not dwell on the political outcomes of this debate, which are widely known, but I want to stress that it has been one that has been very well informed, with contributions from all sides, including many highly respected moral philosophers and bioethicists. These include notable individuals such as Dame Mary Warnock and bodies such as the Nuffield Bioethics Council, who have been especially valuable because of their independence.

So why are the conclusions reached by bioethicists in the UK, who are generally supportive of research involving human embryos, different from those of the President's Council on Bioethics? The same scientific information is available on both sides of the Atlantic. The rules of logic are the same. So it has to be the way the information is interpreted or filtered. This implies bias or vested interest or the input of dogma that is based on belief rather than rational thought.

Some examples of this are discussed in the Blackburn and Rowley essay, and they are very worrying. The scare mongering about preimplantation genetic diagnosis is ridiculous—simple mathematics shows that it is implausible to use this technique to screen the usual number of embryos obtained in one round of in vitro fertilisation for more than two or three genetic traits, while we know that intelligence must rely on many more. I am a great fan of science fiction, but I can recognise it as such. I worry that some members of the President's Council seem unable to do this. Many of these daft ideas were already promoted in a book by Francis Fukuyama (2002), and while they can be a harmless way of promoting debate, they should not be included in documents meant to inform policy makers.

It is certainly very unfortunate if the input of real science in the Council is to be reduced. The scientific issues are complex. For example, we certainly do not know nearly enough about either adult or embryonic stem cells to say which will be the best for therapies, and of course it is possible that both will turn out to be useful for different problems. Both also offer exciting new ways to explore human disease and the influence of genetics and environment without having to rely on human experimentation. But any committee looking into what is ethically acceptable has to be provided with a balanced view of what will be possible in the near future. There is no point in being too speculative, in part because it is also difficult to predict what will be ethically acceptable in the future. If cures come from the use of human embryonic stem

cells, then I suspect that there will be widespread acceptance, as happened with heart transplants and with in vitro fertilisation, both of which were initially greeted with horror by many.

It is impossible to have an informed debate without accurate and appropriate information, and there seems little point in having a debate that is not informed. Because of various sensitivities, it seemed to me before the creation of the President's Council on Bioethics that for far too long the issues relating to embryo research had not been considered properly within the United States. The President's Council was therefore an opportunity to redress this situation. But from the evidence I fear it will not succeed. Moreover, it does the general public a disservice to pretend to have a serious committee exploring issues of bioethics when that committee fails to live up to the ideals of impartiality and rationality. ■

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