



A PATIENT-CENTERED FORUM OF NATIONAL ADVOCACY ORGANIZATIONS ADDRESSING PUBLIC POLICY ISSUES IN CANCER

February 22, 2000

VIA TELECOPY

Stem Cell Guidelines
National Institutes of Health
Office of Science Policy
1 Center Drive
Building 1, Room 218
Bethesda, Maryland 20892

To Whom It May Concern:

The undersigned organizations, representing individuals with cancer, their families, their caregivers, and cancer institutes are pleased to comment on the Draft Guidelines for Research Involving Human Pluripotent Stem Cells published by the National Institutes of Health (NIH) in December 1999. Stem cell research holds great scientific and medical promise, and it should proceed under appropriate guidelines. NIH has established standards which achieve appropriate ethical protections while allowing this research to proceed.

Ensure Appropriate Ethical Controls

We believe federal involvement in stem cell research is critical, not only to ensure that there is adequate funding of this research, but also to guarantee that the research is conducted according to appropriate ethical standards. NIH has established reasonable procedures for obtaining informed consent for the donation of spare embryos from in vitro fertilization (IVF) procedures. Prohibition of payment for donation and separation of the decision to donate from the IVF process ensure that individuals will truly be able to give informed consent without undue pressure from financial or other incentive.

Avoid Unnecessary Burdens on Researchers

Under the proposed guidelines, the researcher who wishes to utilize stem cell lines must certify that those cells were derived according to NIH standards. The researcher, because he or she is not involved in the derivation process, may find it difficult to provide the required certification. NIH should assume responsibility for guaranteeing that a stem cell line meets its guidelines, and researchers would be allowed to use only those approved lines. Because there is a limited number of derived stem cell lines, NIH certification should not represent a real burden on the agency and will guarantee that the guidelines are enforced.

Establish Appropriate Oversight

We support the decision of NIH to establish a Human Pluripotent Stem Cell Review Group to oversee stem cell research. Policymakers and the public will continue to seek assurances that stem cell research is being conducted according to ethical standards, and this review panel will not only provide information about the conditions under which this research is conducted but also data about its benefits. We assume the work of the Review Group will be conducted in a public fashion according to the requirements of the Federal Advisory Committee Act.

We strongly support biomedical research, and we support policies that create a positive environment for such research. The NIH guidelines generally achieve the proper balance of ensuring that stem cell research proceeds ethically without creating unreasonable burdens on the researcher.

Sincerely,

Cancer Leadership Council

Alliance for Lung Cancer Advocacy, Support and Education
American Society of Clinical Oncology
Association of American Cancer Institutes
Cancer Care, Inc.
Cancer Research Foundation of America
Cure For Lymphoma Foundation
Kidney Cancer Association
National Coalition for Cancer Survivorship
National Patient Advocate Foundation
North American Brain Tumor Coalition
Oncology Nursing Society
Y-ME National Breast Cancer Organization

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