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Maria Felt *JHS*

THE WHITE HOUSE

WASHINGTON

July 26, 1999

MEMORANDUM FOR JOHN PODESTA

CC: DOUG SOSNIK
STEPHANIE STREETT
LORETTA UCELLI
LARRY STEIN
CHRIS JENNINGS
MARY BETH CAHILL
DAVID BEIER
DAN MENDELSON

FROM: NEAL LANE *Thus for NL*

SUBJECT: Stem Cell Event: Healthcare Advances for the 21st Century

Purpose

- The rationale for holding this event is to enable the President to associate his Administration with medical research that holds enormous promise for finding new treatments and cures for diseases that afflict approximately 128 million Americans, nearly half the population of the United States. "Such research," states Harold Varmus, head of the National Institutes of Health (NIH) "has the potential to revolutionize the practice of medicine." The ability of the NIH to fund research using human embryonic stem cells is being threatened by some in Congress who want to tighten the Congressional ban on human embryo research. A White House event that makes clear the President's position in support of human stem cell research *within the context of current law* will help conservative Members who support stem cell research hold the line against efforts to broaden the ban against such research.
- As has been widely reported, the White House, at this time, is endorsing a more moderate scope of research activities than NBAC has concluded should be eligible for federal funding. Nonetheless, by thanking NBAC for their report in a public ceremony, the White House can align itself with their core message, which is that stem cell research should proceed cautiously under appropriate ethical guidance. The President can use this event to take a strong stand that human stem cell research must be done according to the highest ethical standards, and direct that NIH put appropriate guidelines and oversight in place to ensure those standards are met. The President's efforts could be viewed as rolling up our sleeves and directing that fresh troops, namely, our nation's world-class Federally-funded medical research establishment, be fully dedicated to learning how to harness stem cells to treat people with diabetes, heart disease, Parkinson's disease, cancer, and spinal cord injuries.
- Seventy-four percent of Americans responded favorably to a public opinion poll on the use of Federal funds for research using human embryonic stem cells. A White House event that endorses that view, emphasizes the need to maintain high ethical standards, and directs NIH to move ahead with all deliberate speed, will resonate strongly with the majority of Americans who are desperately searching for cures and treatments for themselves and their loved ones.

Background

- On the political landscape, the use of human embryos in research has been a hot button topic for the last several years. The House Pro-Life Caucus was successful in attaching a rider to DHHS's appropriations bill for the last four years that prohibits federal funding for any research in which human embryos are created or destroyed. An HHS legal interpretation of this ban permits Federal funding for research that uses human embryonic stem cells (because stem cells are not embryos), but Representatives Dickey (R-AR) and Bliley (R-VA) oppose this research as well and have stated their intention to broaden the ban to include stem cells. The patient advocacy groups have been active in lobbying Congress very strongly to commit public funds and resources to allow such research. Their efforts apparently are paying off in that neither Dickey nor Bliley have acted on their statements to date. The timing of this event is critical. Holding it before Congress leaves will help spur the advocacy efforts of these patients groups during the month of August in Congressional Districts across the nation. A nationwide coalition of over 110 patient groups and professional and academic organizations have drafted a letter in support of Federal funding of stem cell research (attached), and it could be released in conjunction with this event.

Outline of event:

- The President meets briefly with the National Bioethics Advisory Commission, and then in the East Room, or the Rose Garden, accepts the Commission's report, briefly discusses the importance of stem cell research, and charges NIH to move ahead with all deliberate speed to put the necessary oversight process in place to ensure that Federally-funded stem cell research is conducted according to the highest ethical standards. Other speakers might include Secretary Shalala, Harold Varmus, or a parent with an ill child with a cell-failure disease.

President's suggested remarks:

- The control of human stem cells may open the door to the greatest medical discoveries since antibiotics. Every parent whose child has diabetes or any cell-failure disease is going to be riveted to this research, because it *is* the answer.
- The President would thank NBAC and acknowledge their efforts, discuss the importance of stem cell research, paint a vision of the future in which certain dreaded diseases could be defeated. Additionally, he would charge NIH to develop and implement an oversight process for stem cell research that will ensure that our ethics are as good as our science; and that our newest technologies must always incorporate our oldest values.
- Would also acknowledge the critical role of voluntary patient groups in raising public awareness regarding stem cells and their potential medical benefits.
- Would acknowledge the past and current Federal investments in science and technology that made this breakthrough possible, and urge Congress to provide full FY2000 funding for his Twenty-first Century Research Fund budget request.
- Would acknowledge Members of Congress and thank them for their support of biomedical research, and for holding the line so that stem cell research can proceed.

Attachments

Americans Affected by Diseases Stem Cell Research May Help

Stem cell research could help as many as 128 million Americans. Following are facts about the diseases that scientists say may be treated or cured with advancements in stem cell research.

<u>Condition</u>	<u>Americans Affected</u>
Cardiovascular Diseases	58,000,000
Autoimmune Diseases	30,000,000
Diabetes	16,000,000
Osteoporosis	10,000,000
Cancer	8,200,000
Alzheimer's	4,000,000
Parkinson's	1,500,000
Burns (Severe)	300,000
Spinal Cord Injuries	250,000
Birth Defects	150,000/ per year
Total Americans	128,400,000

- Diabetes kills one American every three minutes.¹
- Approximately 1.5 million Americans are afflicted with Parkinson's disease while roughly three million more have at-risk, pre-symptomatic dopamine cell loss.²
- Five Boeing 747 jumbo jets crashing *every day* for a year equals the 563,100 Americans who die each year from cancer.³
- Cardiovascular diseases remain the number one cause of death among Americans. They accounted for 41 percent of all deaths in 1996.⁴
- In the U.S. today, 10 million individuals already have osteoporosis and more than 18 million additional people have low bone mass, placing them at increased risk for the disease.⁵
- Every year in the United States two million people are burned, 300,000 of which are severe burns.⁶

- There are more than 80 known autoimmune diseases such as lupus, multiple sclerosis, rheumatoid arthritis and Graves' disease. Autoimmune diseases occur when the immune system attacks its own tissue.⁷
- By developing therapies for those who have spinal cord injuries and preventing injuries, the U.S. could save as much as \$400 billion on future direct and indirect lifetime spinal cord injury costs.⁸
- Birth defects are the leading cause of infant death and a major cause of disability in young people, affecting more than 150,000 babies each year.⁹
- About 2.7 million Americans care for people with Alzheimer's disease.¹⁰

¹Juvenile Diabetes Foundation

²Parkinson's Action Network

³National Coalition for Cancer Research

⁴American Heart Association

⁵National Osteoporosis Foundation

⁶Onhealth.com

⁷American Autoimmune Related Diseases Assn.

⁸American Paralysis Association

⁹March of Dimes

¹⁰The Alzheimer's Association

Stem Cell Research Polling Information

Opinion Research Corporation International was commissioned by Patients' Coalition for Urgent Research (Patients' CURE) to conduct polling on the subject of stem cell research. Several questions were included in our CARAVAN® Survey, a weekly omnibus telephone survey.

Between May 6-9 the survey of 1,005 adults was conducted. Chosen through a random-digit-sample, the adults included 503 men and 502 women 18 years of age or older, living in private households in the continental United States.

Prior to asking a question specifically addressing federal funding for stem cell research, a definition of the research was given. Following is the definition that was used:

As you may already know, a stem cell is the basic cell in the body from which all other cells arise. Medical researchers have been able to isolate stem cells from excess human embryos developed through *in vitro* fertilization and fetal tissue that has been donated to research. Medical researchers believe that human stem cells can be developed into replacement cells to cure diseases such as diabetes, Parkinson's, Alzheimer's, cancer, heart disease, arthritis, burns or spinal cord problems.

After hearing the definition, 74 percent of respondents said they favored the funding of stem cell research by the National Institutes of Health.

- Men are more likely than women to be in favor of the research funding (79% vs. 71%).
- Americans who have had at least some college education are more likely to favor the funding of research than those without any college education (78% vs. 71%).

Date: TBD

The Honorable _____
U.S. House of Representatives
Washington, DC 20515

Dear Representative _____:

This past February we wrote to you regarding our support for federal funding of research using human pluripotent stem cells. With the Appropriations process progressing we write now to reiterate that support and to urge you to allow this research to move forward.

Human pluripotent stem cells have enormous potential for treatment of disease because they have the ability to form into any type of cell in the body. But only a fraction of the work that will be necessary to transform this potential into reality has yet begun, and only a fraction of the biomedical research community has been able to participate because the federal government has not yet funded any of this work. The National Institutes of Health are in the process of completing guidelines that will permit and govern the use of these cells by federally funded investigators. Only when these guidelines are in place will it be possible to unleash the full capability of the biomedical research workforce toward bringing the remarkable potential of human pluripotent stem cells to fruition.

It is also clear that the American public supports federal funding of this research. A recent nationwide survey conducted by Opinion Research Corporation International has found that 74% of those polled favor funding of stem cell research by the NIH.

Some have argued that "adult" stem cells will be sufficient in our pursuit of treatments or cures of various diseases. While we believe that research in the area of adult stem cells is vital to the research effort, we are concerned that to restrict work to that area alone will prove insufficient and would be a grave mistake. The prospect of cutting off an avenue of research as promising as that with embryonic stem cells at this very early stage of discovery deeply troubles those of us who conduct and promote health research. Such a prohibition could delay possible treatments for diseases like diabetes, cancer, Alzheimer's and Parkinson's by years. Past work on animals has shown us that it is the embryonic stem cells that hold the greatest potential in their ability to be manipulated for treatments of disease.

We are also concerned by the argument that embryonic stem cell research can be left to the private sector. While it is clear that a few privately funded centers are working on pluripotent stem cell research, it is not generally the practice of private companies to conduct this kind of basic research into fundamental developmental processes. That is why it has been and remains the role of the federal government to make the lion's share of the investment in basic research, which has then been used by biotechnology and pharmaceutical companies to develop products used for treating diseases. And that is why we cannot rely on private industry to conduct the kind of basic research necessary to move the field of stem cell research from the laboratory bench to the clinic.

Our intent is simply to ensure that research on stem cell lines is not unduly restricted. With appropriate ethical safeguards, such as those being developed by the National Institutes of Health, we believe that a balance can be achieved, which respects both the moral status of the embryo and the public's sensitivity to this issue while ensuring progress in critical medical research. As we have said before, the government can play an important role of oversight so that our nation's federally funded scientists can conduct this critical work. Federal support will also increase the financial resources directed to this area of research, which will speed the pace of scientific discovery.

With the great hope pluripotent stem cell research provides to patients ailing or dying from devastating diseases we urge the Congress to allow this research to move forward with federal support.

Sincerely,

Academy of Clinical Laboratory Physicians and Scientists
Alliance for Aging Research
Alliance for Lung Cancer Advocacy, Support and Education
American Academy of Allergy, Asthma and Immunology
American Academy of Child and Adolescent Psychiatry
American Academy of Ophthalmology
American Association for Dental Research
American Association of Anatomists
American Association of Dental Schools
American Association of Immunologists
American Autoimmune Related Diseases Association
American Burn Association
American College of Clinical Pharmacology
American College of Neuropsychopharmacology
American College of Obstetricians and Gynecologists
American College of Physicians - American Society of Internal Medicine
American Gastroenterological Association
American Medical Association
American Neurological Association
American Pediatric Society
American Physiological Society
American Society for Biochemistry and Molecular Biology
American Society for Bone and Mineral Research
American Society for Cell Biology
American Society for Clinical Nutrition
American Society for Investigative Pathology
American Society for Microbiology
American Society for Pharmacology and Experimental Therapeutics
American Society for Reproductive Medicine
American Society of Clinical Oncology
American Society of Hematology

American Society of Human Genetics
American Thoracic Society
American Veterinary Medical Association
Americans for Medical Progress
Association for Research in Vision and Ophthalmology
Association of Academic Health Centers
Association of American Cancer Institutes
Association of American Medical Colleges
Association of American Universities
Association of Chairs of Departments of Physiology
Association of Independent Research Institutes
Association of Medical and Graduate Departments of Biochemistry
Association of Medical School Pediatric Department Chairs
Association of Medical School Psychologists
Association of Professors of Medicine
Association of Subspecialty Professors
Association of Teachers of Preventive Medicine
Association of University Radiologists
Boston University School of Medicine
Cancer Research Foundation of America
Citizens for Public Action on High Blood Pressure and Cholesterol
Coalition for American Trauma Care
Columbia University
Cure for Lymphoma Foundation
Dartmouth Medical School
Duke University
East Carolina University School of Medicine
Easter Seals
The Endocrine Society
Eye Bank of America
Federation of American Societies for Experimental Biology
Fred Hutchinson Cancer Research Center
Genetics Society of America
Glaucoma Research Foundation
Harvard University
Interstitial Cystitis Association of America, Inc.
Johns Hopkins University
Joint Council of Allergy, Asthma, and Immunology
Juvenile Diabetes Foundation International
Krasnow Institute for Advanced Study
March of Dimes
Massachusetts Institute of Technology
Medical College of Wisconsin
Myasthenia Gravis Foundation of America, Inc.
Myositis Association of America, Inc.
National Alliance for Eye and Vision Research

National Alliance for the Mentally Ill
National Association of State Universities and Land-Grant Colleges
National Caucus of Basic Biomedical Science Chairs
National Childhood Cancer Foundation
National Coalition for Cancer Research
National Health Council
National Osteoporosis Foundation
The National Pemphigus Foundation
National Psoriasis Foundation
National Spinal Cord Injury Association
New York University School of Medicine
Oncology Nursing Society
Osteogenesis Imperfecta Foundation
Paralyzed Veterans of America
Parkinson's Action Network
The Protein Society
Research!America
Resolve, the National Infertility Association
Roswell Park Cancer Institute
Scleroderma Foundation
Sjogren's Syndrome Foundation
Society for Investigative Dermatology
Society for Pediatric Research
Society for Reproductive Endocrinology and Infertility
Society for the Advancement of Women's Health Research
University of California
University of California, San Diego, School of Medicine
University of Florida
University of Illinois at Chicago
University of Michigan Medical School
University of Pittsburgh
University of Rochester Medical Center
University of Utah Health Sciences Center
University of Washington
University of Wisconsin-Madison
UPMC Health System
Vanderbilt University Medical Center
Yale University