Press Release

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Statement of Daniel Perry
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National Bioethics Advisory Commission

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Members of the Committee:

Thank you for the opportunity to discuss recent discoveries involving human embryonic stem cells. I am here to provide a view of some of the clinical and ethical issues of human stem cells that reflect the thinking of my organization, and that of many other groups of health care consumers and patients who will one day benefit from this research.

I wish to begin by applauding the important and historic statement made here today by Dr. Harold Varmus. The Director of the National Institutes of Health has conveyed the opinion of the Clinton Administration that research on pluripotent stem cell lines is clinically and ethically a different proposition from currently prohibited direct experiments on human embryos. It is vitally important that the view expressed by Dr. Varmus today should prevail in federal policy. If that view does prevail, it is likely many of the best prepared and best equipped research scientists in the nation will move quickly to begin revealing new insights into human cellular biology, made possible by one of the most important discoveries of our time. Americans, and people everywhere, will be well served as public as well as private funding becomes available to advance understanding of fundamental biological mechanisms, by looking through the "window" opened by human stem cells that rejuvenate and retain the ability to become any cell in the human body.

As the head of a not-for-profit group eager to find cures and preventions for diseases related to the aging process, and committed to overall better health and vitality for people as they age, my views are formed by a recognition of the medical needs of the growing population of older Americans. The Alliance for Aging Research, which I represent, works to stimulate academic, governmental, and privately-sponsored research into the chronic diseases of human aging. We anticipate there will be concerns in some quarters regarding embryonic stem cells, which to date have been derived either from fetal tissue or from portions of donated in vitro fertilized reproductive cells. However, it is the position of the Alliance, which I hope the Commission will share, that this research it too momentous, its potential benefits too overwhelming, to impede, to slow or to stop.

The United States, along with much of the world, is experiencing a profoundly and wholly unprecedented demographic shift toward greater longevity for human beings. Every day in the United States, another 6,000 people celebrate a 65th birthday. Meanwhile, America's Baby Boomers are entering their 50s in even greater numbers, about 10,000 a day.

In the decade between ages 50 and 60, the risks to the average person of being diagnosed with hypertension, arthritis, or diabetes more than triples. By 2030, the United States population over age 65 will double to more than 70 million people. As of today, the risk those over 65 being diagnosed with a chronic age-related disease - doubles every five to seven years. Adding up the costs of eight major diseases of aging - osteoporosis, stroke, depression, arthritis, diabetes, Alzheimer's disease, cancer and heart disease- approaches $600 billion annually. The incidence of the diseases of aging and the costs of treating those diseases will not decrease unless new discoveries from biomedical research will allow us to delay or prevent them to work for people as they age, the burden on Medicare and private insurance will be crushing as the baby boom moves into the high-risk years.

The alternative to aggressive pursuit of biomedical research, is to let the population age under the same conditions as now exist and watch as the diseases of aging and their associated costs grow exponentially. If, in the absence of real breakthroughs from research, we are left to rely on nursing homes and today's medicines that treat only the outward manifestations of disease, we will overwhelm our financial and social resources caring for a burgeoning population of disabled elders.

Fortunately, there is a wiser, less expensive and more humane alternative to the path we are on. The alternative, and, I believe, proper, course is to encourage rapid advances and applications from our medical research infrastructure to hasten the discovery of the means to forestall the declining health status that we now commonly associate with old age.

Even a brief delay in the onset of age-related disability translates into dramatic savings for our economy. For example, postponing physical dependency among older Americans by just one month would save the U.S. at least $5 billion a year in health care and nursing costs. Postponing the average onset of Alzheimer's disease by five years would, over time, save $50 billion a year in health care costs. A five-year delay in the beginnings of cardiovascular disease could save $69 billion a year. These are just a few examples from a long list of potential savings.

But we must then ask: What kind of magic will it take to fine tune the aging process so that we can actually delay the ravages of age-related diseases by months or even years? Can people actually hope that diseases of aging might be put on hold? Is it reasonable to think that scientific understanding of aging at the level of cells and genes might buy many people several additional years of active life expectancy, with overall time of sickness and disability at the end of life reduced to a bare minimum? That is indeed the promise that is raised by the advances that are emerging from many scientific disciplines in the field of human aging. This research is being supported by universities, by government, by the pharmaceutical industry, by biotechnology companies large and small, and by private philanthropy. Combined with better management of geriatric health from the behavioral sciences and medical effectiveness research, and better training of doctors and nurses in geriatrics, the benefits for today's aging population could be enormous.

Understandably there was great excitement in recent months with the first reports of long-lived cultures of human stem cells. These cells have the capacity to become a full array of transplant material for people who cannot find suitable doctors. The Commission has already heard the details of that research from the scientists involved, presented with great detail and authority.

We understand that before, the full pay-off of stem cell technology is ready for patients, it could take many years of further research, and major technical hurdles must be overcome. It will also likely take millions, if not billions, of dollars to realize the full therapeutic potential. However, from the perspective of health advocates and patients, here is what we believe is in the offing.

We believe stem cell technology will bring a deeper understanding by scientists to how and why cells multiply and divide, grow, age and die. Unraveling the processes by which cells form into different cell types, with different functions, offers a unique platform to understand and harness nature's mechanisms of

cell development, tissue growth and repair. The will advance the critical field of developmental biology and could be the basis of innovative new medical therapies.

Secondly, this technology could allow some to produce unlimited quantities of normal human differentiated cells in vitro. These laboratory cultures of human cells then could be used for highly specific drug screening and testing, and for drug toxicology studies. This would be far more efficient and accurate than current testing and extrapolations taken from testing on animal tissues. Greater efficiencies in new drug development will mean more effective new medicines getting to patients faster.

Most promising of all, from the vantage point of the patient, is the advances this is likely to mean for transplantation medicine. The potential therapeutic impact of human embryonic stem cells in replacing cells and tissues damaged by disease or aging is enormous. We have heard from scientists close to this field that self-renewing cells and tissues derived from stem cells could conceivably replace damaged heart muscle cells that normally do not proliferate during adult life. Congestive heart failure is the single greatest cause of hospitalization among American's after age 65, affecting some 5 million people. Another 1.5 million people in the U.S. each year experience a heart attack which damages heart muscle. About one-third of heart attack victims die immediately. Of those who survive, damaged heart cells from an ischemic attack raise risks for later attacks and premature death. Transplants of stem cell derived heart muscle tissue have already been performed on mice and dogs, showing exciting potential for replacing damaged tissue. Similar use of stem cells and tissues as therapy for heart disease in humans seems likely in the future.

Increasingly medical researchers tell us that stem cells one day will be able to produce youthful cells, that won't be rejected by the host, and which could produce, for instance, dopamine, the brain chemical that is not produced in Parkinson's sufferers. Stem cells could be used to replicate healthy Islet cells in the pancreas, and thus produce insulin needed by diabetics. Further speculation suggests applications of this technology for the relief of age-related blindness, atherosclerosis, cancer, spinal cord injuries, Alzheimer's disease, and for the promotion of wound healing. Despite the time and money it will take to realize some or all of these applications, it is understandable that there is so much hope among patients and their families, and such urgency that the research move ahead with all appropriate speed and support.

To deny the opportunity for benefit from this research to reach our older citizens, and younger people with chronic diseases as well, would be a tragic reversal of dramatic recent biomedical progress, and a great frustration for public expectations. While some may oppose federal participation and financing of stem cell research, they must know that will not stop it altogether from going forward. A lack of federal funding would only affect a segment of the overall research effort, albeit a significant portion of the total U.S. research initiative. Stem cell research will go forward - in the United States, using non-governmental funding, and in other countries, using both public and private funding. The effect of a denial of federal funding would be to deny government agencies, especially the NIH, the oversight we believe they should have. The bell of stem cell research cannot be unrung. It will continue to apace in the private sector and will produce remarkable discoveries for the foreseeable future. If federal government funding is available, then appropriate federal oversight and review will be available and this will serve to better manage the research while assuring appropriate ethical guidelines are followed.

With increasing understanding of the mechanisms of aging and increasing interest in aging, continued support of this type of research is vital to the effort to uncover new discoveries that will increase the health and independence of a growing number of older Americans. If stem cell research is allowed to proceed, with the guidance and oversight of NIH and other appropriate governmental and scientific organizations, our society will be better able to develop much-needed cures for aging-related diseases and conditions.

The vast majority of Americans strongly support the advancement of biomedical research through the application of their tax dollars. Surveys consistently show Americans want to see greater efforts against serious life-threatening diseases. That public support helped biomedical research advocates in Congress

substantially increase this year's appropriated budget for the NIH. Many in Congress and many of us in the public are eager to see the NIH budget double over a period of five years. This is an audacious, but vitally important national goal. These increases in medical research funding should be used wisely and without arbitrary restrictions. Heightened opportunities to find new preventive and curative measures will be seriously undercut if inappropriate obstacles are placed against this enterprise for political or ideological purposes.

We agree that policymakers, ethicists, scientists, and patient groups must continue to discuss and evaluate advances in science that increasingly will touch upon the fundamental mechanisms that create and define human life. In the end it is imperative that promising research go forward without inappropriate bars. The present dramatic breakthroughs in the life sciences, and the profound implications of what we are learning, will inevitably raise public concerns, but we are confident that most Americans will recognize that there could be nothing more unethical than impeding the effort to find help for those patients and their families in greatest need.