Oversight and Investigations Hearing on Human Cloning

Testimony before the House Committee on Energy and Commerce Subcommittee on Oversight and Investigations Hearing on Human Cloning

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The Genetic Alliance, the largest coalition of genetics consumer and professional organizations worldwide, calls for an immediate halt to all efforts to clone human beings and recommends open and informed societal dialogue on this crucial issue.

The Genetic Alliance provides a unified voice for millions of people living with common genetic disorders such as diabetes and breast cancer, as well as rare conditions such as cystic fibrosis and sickle cell anemia. Our families and communities look forward to the tremendous potential of biomedical research and technologies to improve health and well being. We know that cellular, tissue and organ cloning holds significant promise for generating treatments and cures for common and rare diseases. We also underscore the fact that creating a living human being through cloning is very distinct to working with cells in culture to achieve new medical benefits. The Board of Directors of the Genetic Alliance maintains that efforts to clone human beings - in contrast to cellular, tissue and organ cloning - pose significant safety, medical, ethical, legal and social risks, far outweighing any current potential benefits.

The Genetic Alliance expresses grave concerns about recently announced plans by several individuals to attempt to clone human beings. Based on recent scientific reports about the current status of mammalian cloning, we know that there are tremendous potential human safety risks for mother and child. The track record for mammalian cloning indicates that these medical risks are formidable and extreme, even dire. The fact is that current cloning techniques to produce a genetically identical human being do not come close to meeting the rigors of minimum human protection, safety, efficacy and medical standards.

Moreover, societal dialogue is urgently needed to identify and understand the social, legal and ethical risks posed by the application of this technology. Rapidly emerging scientific research and technologies - such as human cloning - force us to examine the very essence of what it means to be human. The immensity of these issues demands that we halt all current efforts to clone human beings and engage all stakeholders in open and informed debate about the implications and impact of this technology. At every step in advancing technology, we must ask ourselves whether we are propelled by justifiable societal needs or simply by new biomedical opportunities. As a society, we must discuss and debate the full range of ethical,
legal and social issues surrounding the cloning of human beings. It is critical that this broad-based dialogue engages families and communities within the context of culture and faith.

Central to this dialogue is consideration of the role and responsibility of society in preventing harm to individuals and families. Debate about the cloning of human beings highlights a fundamental necessity that all research and clinical projects, regardless of funding source, come under the spotlight of human subjects regulatory protections. This is the only way to ensure, in a landscape of escalating biomedical technologies, the well being and safety of families and communities. In addition, protections must extend beyond current levels to encompass all research and clinical projects, regardless of whether the funding comes from the government or private sector. The discovery of a new technology should not automatically translate into availability of that technology without regard for public safety and well being.

The Genetic Alliance recognizes that biomedical technologies are quickly outpacing the development of appropriate policies to inform the decision-making of researchers and the general public on many issues, including genetic testing, medical privacy, genetic discrimination and others. Grounded in the personal experiences of people already at the frontlines of technologies, the Genetic Alliance works to ensure the potential benefits of biomedical research, while promoting meaningful and informed public policies about the implications, impact and promise of these technologies. Our stance in calling for a halt to the cloning of human beings reflects the Genetic Alliance commitment to establishing the highest levels of medical, social, legal and ethical protections.

In summary, the Board of Directors of the Genetic Alliance recommends that Congress take immediate action to halt all cloning of human beings. However, we must take care not to obstruct current cellular, tissue and organ cloning that may result in significant health improvements for our families and communities. Moreover, the Genetic Alliance urges Congress to call for immediate and broad-based societal dialogue about the implications and impact of cloning human beings. The Genetic Alliance looks forward to being an active partner and resource in the open, informed and broad-based debate that must guide public policy deliberations about the translation of biomedical technologies into mainstream medicine.