

Testimony of
Mr. Gregg Wasson

March 19, 2003

Good Afternoon.

Thank you Chairman Hatch, Senator Leahy, and members of the Committee for giving me the opportunity me to testify before you today.

The potential of regenerative medicine is something that's important to my life. My name is Greg Wasson and I am here on behalf of the Coalition for the Advancement of Medical Research (CAMR). CAMR is comprised of universities, scientific and academic societies, patient's organizations, and other entities that are devoted to supporting stem cell research.

My task today is to attempt to represent the voice of millions of Americans living with MS, ALS, Parkinson's Disease, and many other illnesses who believe in the promise of regenerative medicine, including therapeutic cloning.

I, along with the Coalition for the Advancement of Medical Research (CAMR), support every effort to criminalize and ban human reproductive cloning. It unsafe and unethical. However, it is imperative that we protect therapeutic cloning. As a person living with Parkinson's disease, I know how urgently a cure is needed. Responsibly regulated regenerative medical research may one day provide better treatments and cures for a number of debilitating and presently incurable conditions.

Eight years ago, at age 43, I was diagnosed with Parkinson's disease. My fiancée, Ann Campbell, who is here with me today, was given the same diagnosis that same year at age 38. I was a lawyer in San Francisco. Ann was an editor and children's book author in New York City. Within five years we were both forced by our disease to retire on disability. Recently, I was also diagnosed with Diabetes, a disease that runs in my family.

Advocacy for a cure of our shared disease brought us together. Clearly our vision is for science to bring about a life that is not plagued by this terrible disease so we can enjoy the rest of our lives together in health. Like millions of other Americans we need your help to make sure that our hope is not forsaken.

An estimated 1 million Americans have Parkinson's, a brain disorder that is presently incurable and the cause of which is unknown. Parkinson's is a progressive and degenerative disease that slowly robs its victims of dopamine, the neurotransmitter that enables us to initiate and regulate movement. Walking, breathing, speaking, swallowing, simply grasping an object, all depend on a sufficient supply of dopamine to transmit the impulses of the brain into action.

Cognitive functioning, thinking, is also impaired by Parkinson's. It is often cognitive impairment that forces people with Parkinson's to stop working. This was the case for both Ann and myself.

We also live with the knowledge that 30% of all Parkinson's patients develop dementia, and that we are three times as likely as the general population to develop Alzheimer's.

After eight years, we have difficulty controlling symptoms such as tremor, stiffness, rigidity, gait, and balance, even though we take several different Parkinson's medications. Currently, I take about 25 pills per day just for Parkinson's, and must redose every 3 hours.

My medications, which cost about \$11,000 per year including diabetes medications, allow me to sit here before you today, and speak, and be understood. I am thankful for these medications. Without them, I would by not be unable to walk, feed or clothe myself. But my 25 Parkinson's pills every day do nothing to slow the progress of my disease. What you see when you look at me today is a medical marvel, but also an illusion - a "chemical costume" I must put on every 3 hours to create the impression of even imperfect health.

Parkinson's medications become less effective over time, which causes different problems for each patient. In my case, I now fluctuate "off" my medications without warning several times each day. An "off" fluctuation can leave me stranded at a mall, or in my living room, or at the movies. Although I still have very little tremor, balance is a serious problem, and I fall several times a day. My voice becomes monotone and is often too soft to hear. I often stutter when I speak, and my enunciation is mushy and indistinct. My face becomes masked and impassive. I shuffle with short, halting steps. I often drool and sometimes I choke on my food. The stiffness and rigidity of my body make it impossible to do the simplest tasks. For me, Parkinson's is all about one telling description of the disease - "poverty of movement."

And for both Ann and myself, the time will come when our medications fail us permanently and we will be totally functionally disabled. At that time we will leave the world that we all currently inhabit, and enter a twilight world of immobility, encased in our bodies as if in tombs, able to think but not speak, understand but not communicate. Eventually some complication of the disease will cause death, a death that may by then be welcome.

And we are not alone. Parkinson's is just one of a score of chronic diseases and conditions that are fatal at worst and leave their victims permanently disabled at best. These diseases and conditions affect more than 100 million Americans. Each of us here today has a loved one or friend who has a disease such as Alzheimer's, ALS, MS, Diabetes or Parkinson's. These are terrible illnesses with dire consequences for their victims.

In 2001 I worked on a stem cell petition with a number of persons suffering from ALS, who became my friends. Now, two years later, most of them are dead. John Davis, an Alabama ALS victim and fellow advocate, once said of embryonic stem cell research, "this dog will hunt." He meant that such research had the potential to save countless lives, and he was right. But this research "will hunt" only if it is not leashed and muzzled. I believe that the same applies to SCNT.

We are not without hope. Regenerative medicine, including responsibly regulated therapeutic cloning, may lead to a cure or treatment for Parkinson's disease and a host of other diseases and conditions. As you have heard today in the scientific panel, human reproductive cloning and cloning for therapeutic medical purposes are not the same scientifically, or otherwise. They have entirely different objectives. The creation of stem cells through SCNT does not involve fertilization of egg by sperm. It is a process that occurs entirely in a petri dish. Cell division is caused by electrical or chemical stimulation rather than the natural joining of sperm and egg. The resulting ball, perhaps 100 cells the size of a pinhead, is neither a human life nor anything near it. The use of SCNT does not destroy human life - it is an attempt to restore human life.

Ann Campbell and I, along with millions of other Americans, are people - living human beings - with terrible diseases that will kill us unless cures are found. The willingness of some here to sacrifice these lives, placing less value on them than on a chemically produced, unfertilized mass of cells perhaps grown from one of our own hair follicles is the real crime, the real shame.

Compassion and common sense must prevail; ignoring the potential of therapeutic cloning would be a national tragedy and a huge mistake. But as with other scientific advances in history, a vocal and well-organized minority is trying to stop this research. Galileo, Columbus, and a high school teacher named John Scopes, all held scientific beliefs that frightened their contemporaries. But the earth does revolve around the sun, the earth is round, and the theory of evolution is now widely accepted as scientific fact. Today the target is therapeutic cloning.

Opponents of stem cell research that employs therapeutic cloning have insisted that there are no studies showing its potential to treat disease. But numerous experts in the field, including witnesses who testified earlier today, have shown that this is not true.

Opponents have also argued that expressly legalizing therapeutic cloning will open the floodgates to a black-market in reproductive cloning. The history of organ transplantation demonstrates that this concern is unwarranted. When organ transplantation was new, objections were raised that it would lead to black markets in harvested organs. This did not occur, and today organ transplantation is strictly and effectively regulated.

Senators, we believe that you understand and appreciate the enormity of the potential for saving human beings from fates such as Parkinson's, ALS, diabetes, and spinal cord injuries. We believe that, individually and collectively, you will make the choice to protect and to restore life. What greater legacy could any government leave its citizens?

And so, because we have hope and faith that this country will recognize the value of research into regenerative medicine, Ann and I are getting married this fall. On our wedding day, we will raise a glass to the promise of a new day when diseases like Parkinson's are simply a terrible memory.

In this committee, in the Senate, and in Congress, we place our highest hopes and trust.

Thank you for your time.