Mr. SOUDER. Thank you.
I am going to move to Mr. Brown next because he has an airplane to catch.

STATEMENT OF JOE BROWN

Mr. BROWN. Thank you, sir. Thank you, Mr. Chairman and members of the subcommittee, for inviting me today. My name is Joe Brown. I am a State coordinator for the Parkinson’s Action Network, a founding member and vice president of Texans for Advancement of Medical Research, and a founding member of the Alliance for Medical Research. I have been an advocate for 20 years.

As someone living with chronic disease, as a patient and an active caregiver, I was dismayed when I read the memorandum published by the committee that appeared to reach pertinent conclusions before this hearing was convened. It mistakenly concluded that somatic cell nuclear transfer [SCNT], is not supported by current science, and those who support this research have created an unjustified hype that plays on the hopes of suffering patients.

I am not going to talk about theory and intellectual concepts. I am going to talk about life—my life, my wife’s life, and the lives of you and your families.

Having watched a genetic form of Parkinson’s slowly steal the quality of life from my beautiful wife, I am concerned for my children and grandchildren. I have lived 70 years with a genetic heart condition that has sudden death as its most significant side effect. I have been fortunate enough to survive three heart attacks, bypass surgery, cardiac arrest, and cancer.

I have reason to hope, especially since I have benefited from research that was thought to be wrong and unethical. I was the ninth person in the United States to receive a procedure that took me from being unable to walk from one room to another and days filled with countless hours of angina, to being able to carry my grandchild up a flight of stairs.

This procedure, which actually gives the patient a heart attack to reduce obstructive heart muscle, was originated by a Swiss cardiologist. Switzerland didn’t believe that giving heart attacks was ethical and wouldn’t allow the procedure. The quality of my life was improved because Dr. Sigwart was forced to leave his country, just as American scientists are doing today in order to pursue stem cell research.

So yes, as a patient, I do have hope that SCNT will succeed. But it is not unjustified hope. The breakthroughs have been exciting and amazing, but I recognize that sound research takes time. It took 52 years for the polio vaccine to get to market. I don’t expect the scientific community to have these treatments or cures available in my lifetime, but if we don’t start now and start solving the problems that we have with communication with each other, the cures won’t be there for our children and grandchildren.

When I visited the University of Texas Medical Branch in Galveston, scientists working with adult stem cells told me the most significant advances in adult stem cell research have occurred since embryonic stem cells were first isolated in 1998. The reason these scientists gave me is the embryonic stem cells are teaching them
how to work with adult stem cells. To promote one form of stem cell research to the exclusion of another is counterproductive.

I am astounded that there are those who don’t recognize, while there may be fraudulent researchers, by definition, it is impossible for research in and of itself to be fraudulent. We don’t stop basketball games when a player is called on a foul, nor do we stop having congressional sessions due to a Representative’s misconduct.

In the future, as the past, scientific fraud will be detected when peers are unable to replicate the results. And unfortunately, this self-policing mechanism has been disengaged in our country because the Federal Government isn’t supporting the research.

The fact that one scientist apparently procured egg donations without appropriate attention to the welfare of the patients doesn’t mean that everyone else will do the same. Women have a right to donate eggs for the benefit of others when properly informed and with informed consent.

It is incumbent on the United States, where both the quality of science and dignity of life are of uppermost concern in all of our minds, to take the lead in creating an appropriate framework for stem cell research while promoting and protecting its progress.

On behalf of my family and the more than 1 million Americans with Parkinson’s disease who would benefit from this research moving forward, I appreciate the opportunity to provide testimony to the subcommittee today.

[The prepared statement of Mr. Brown follows:]
Joe Brown  
Parkinson’s Action Network State Coordinator, Texas  
March 7, 2006

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