

**Written Testimony of Weyman Johnson  
One-Page Summary of Speaking Points**

**Individual Living with Multiple Sclerosis  
Chairman of the Board, National Multiple Sclerosis  
Society**

**Energy and Commerce Committee  
Subcommittee on Health  
U.S. House of Representatives  
“Stem Cell Science” Hearing on May 8, 2008**

- Summary of my personal and family experiences with a chronic, disabling disease.
- Speak to a patient perspective on my own diagnosis with multiple sclerosis.
- Speak to the position of a national voluntary health organization, as chairman of the board of the National Multiple Sclerosis Society.
- Speak to the need for continued research and the hope it brings for people living with chronic diseases and conditions nationwide.
- Support the need for the Committee and Congress to remain committed to legislation like the Stem Cell Research Enhancement Act.
- Embryonic stem cell research holds an incredibly unique promise for people living with chronic diseases and conditions, and the progress

made to date on embryonic stem cell lines should not be abandoned.

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Thank you Chairman Pallone and Ranking Member Deal. Thank you members of the Committee. I am honored to be invited to speak here today among many distinguished panelists and to represent patients who live with chronic disease.

Many diseases could benefit from expanded embryonic stem cell research. But today I will focus on one—multiple sclerosis. Not because it is more important than others, but because I *know* multiple sclerosis.

I remember multiple sclerosis and how it entered my life as a child, in 1964, just barely 13 years old. My father received a diagnosis of MS suddenly. He died in 2001. His sister, my aunt Allene, also had MS. Research into this disease, into genetics was just starting to evolve in the 1960s.

There were good doctors then, but they did not recognize a genetic connection. They said MS in my family was a mere coincidence. Because of research, we now know that is not true.

My own sister, who's only a few years older than I, lives with MS. She uses a power wheelchair, her hands don't work well anymore, she can no longer teach the way she did, or play the piano the way she did. A few years after she was diagnosed, so was I. We hate this disease, its impact on our family, and the threat it poses to our future generations.

We are making progress into the genetic factors involved in multiple sclerosis. However there are still more questions than answers. The research must continue.

I remember being told that MS is a disease that doesn't affect my friends in the African American community. This is only for white people from Minnesota. With good science, we have found that's not true. The research must continue.

We also used to hear that this disease does not happen to children. But that is not true either. We now know there are thousands of children in the United States, thousands of children throughout the world, who live with this disease. The research must continue.

Before 1993, there were no treatments at all for multiple sclerosis. Now we have six. But there is a wide spectrum among people living with MS. Most of the therapies will only work for those of us on the lucky end of the spectrum like me. But for people like my sister, on the more unlucky end, there's still not much out there that provides effective treatment. So the research must continue.

Every hour, someone new is diagnosed with MS. It's an unpredictable, often disabling disease of the central nervous

system. The progress, severity, and specific symptoms of MS in any one person *still* cannot be predicted. The cause is unknown, and there is no cure. But embryonic stem cell research holds an incredibly unique promise to repair nerve cells, to slow the progression of MS, to help find a cure.

One area that holds great promise, but is often misunderstood, is Somatic Cell Nuclear Transfer. We have seen some exciting breakthroughs. But as with all science, this research takes time. We are still exploring this avenue for medical research. I have hope that SCNT will succeed because of its promise to repair nerve cells, creating new tissues, and more. I know that researchers are focused on the idea of creating cells and tissues for transplantation and research. They are trying to understand how different genes are turned on and off. They are not focused on cloning. I know that as we explore somatic cell nuclear transfer research more, we will see greater potential for developing individualized cell and tissue therapies. That holds great promise for people living with MS like me, whose body's own defense system is attacking the myelin surrounding and protecting our central nervous system.

I am but one person living with a chronic disease. But I am also fortunate to serve as chairman of the board of the National Multiple Sclerosis Society. We believe that all promising avenues of research that could lead to new ways to prevent, repair, slow the progression, or cure *MS must* be explored, with adherence to the strictest ethical and procedural guidelines. The National Multiple Sclerosis Society believes that all promising avenues of research that could lead to the cure or prevention of multiple sclerosis or relieve its symptoms must be explored. The Society supports the Stem Cell Research Enhancement Act to expand the number of approved stem cell lines that are available for federally funded research. The Society supports the conduct of scientifically meritorious medical research, including research using human cells, in accordance with federal, state, and local laws and with adherence to the strictest ethical and procedural guidelines.

Research on all types of stem cells is critical because we have no way of knowing which type of stem cell will be of the most value in MS research. Stem cells – adult or embryonic – could have the potential to be used to protect and rebuild tissues that are damaged by MS, and to deliver molecules that foster repair or protect vulnerable tissues from further injury.

So I ask you to expand the federal policy on embryonic stem cell research and ensure that research continues ... for the more than 400,000 other Americans who live with MS and 100 million Americans with other diseases and conditions. Research on all types of stem cells is critical because we have no way of knowing at this point which type of stem cell will be of the most value ... for multiple sclerosis, for Parkinson's, for Alzheimer's, for cancer, for heart disease, for spinal cord and brain injuries, for many other conditions.

Just like with genetics and race and age, there is so much left to learn about how to treat and cure MS ... about how to treat and cure other diseases. Expanding our embryonic stem cell research is

just one avenue. But it is an avenue of research that *must* continue. Federal barriers must be lifted.

You might see that I am not the only person living with MS on Capitol Hill today. *Hundreds* of MS activists are visiting with their legislators on the Hill right now, talking about the need to advance medical research.

Embryonic stem cell research remains one of the most promising avenues of research to cure diseases and end suffering. I am not a scientist, but I am an observer of science. And I know that science is a matter that requires some patience. That's why we must expand the important work done to date with embryonic stem cell lines. The research must continue. So we can improve the lives of people with chronic diseases and conditions. So we can improve the lives of families for generations to come. For my grandchildren and for yours.

We need your commitment to not give up on legislation like the Stem Cell Research Enhancement Act. We don't have the luxury of

time. Like many others who live with a chronic disease, I know ... maybe not today, maybe not next week, but I pray soon ... with patience and continued research ... that there will be no more disease. Thank you for helping us move closer, and thank you for your time.

**National Multiple Sclerosis Society  
Policy Position**

**Embryonic Stem Cell Lines Available  
for Federally Funded Research**

**Position:** The National Multiple Sclerosis Society believes that all promising avenues of research that could lead to the cure or prevention of multiple sclerosis or relieve its symptoms must be explored. The Society supports the Stem Cell Research Enhancement Act (H.R. 3 and S. 5) to expand the number of approved stem cell lines that are available for federally funded research.

The Society supports the conduct of scientifically meritorious medical research, including research using human cells, in accordance with federal, state, and local laws and with adherence to the strictest ethical and procedural guidelines. Research on all types of stem cells is critical because we have no way of knowing which type of stem cell will be of the most value in MS research. Stem cells – adult or embryonic – could have the potential to be used to protect and rebuild tissues that are damaged by MS, and to

deliver molecules that foster repair or protect vulnerable tissues from further injury.

**Request:** We urge Congress to support the Stem Cell Research Enhancement Act of 2007 (H.R. 3 and S. 5) at all levels of the legislative process. This legislation would increase the number of approved embryonic stem cell lines that can be used in federally funded research by allowing new lines to be generated from embryos that have been donated for research purposes by people using the services of in vitro fertilization clinics, while establishing important ethical protections.

**Supporting Rationale:** There is broad agreement that the policy limiting the number of stem cell lines available for federally funded research is flawed.

- An insufficient supply of stem cell lines currently exists, as only 22 of the 70 approved lines are available to researchers. In addition, all of the available lines are contaminated by nutrients from mouse feeder cells. Many in the scientific community believe that these stem cell lines are unsuitable for research and

hinder U.S. scientists' ability to capitalize on the potential breakthroughs from embryonic stem cell research.

- At the same time, it has become increasingly clear that stem cell research holds tremendous promise for MS and many other diseases and disorders. Research suggests that stem cells might have many uses: for delivery of growth factors and drugs, for tissue culture systems for drug and gene discovery, for understanding and modeling MS, and for repairing or protecting brain tissue.
- However, our scientific advisors have told us that we still don't know which type of stem cells will be most valuable for MS research, and thus we must support policies that promote the conduct of research using all types of stem cells.