

# Patient Petition Supporting Stem Cell Funding Presented to HHS Policy Czar

Campaign by Chronically Ill Gathers 13,000 Signatures in Dramatic Appeal

COTATI, CA - May 14, 2001 -- A petition containing 13,000 signatures, authored by members of the Massachusetts General Hospital Neurological Web Forum, urging President Bush to continue public funding for embryonic stem cell research, was presented last week to Health and Human Services Senior Policy Advisor Mary Kay Mantho to be given to HHS Secretary Tommy Thompson.

"Federal guidelines currently allow such funding, but have been criticized by President Bush," said Greg Wasson, petition author and Parkinson's sufferer. Thompson is reviewing the guidelines at the president's request. The controversy over stem cells, "master cells" that can transform into any cell type, has grown in recent weeks.

80 Nobel Prize winners have urged the president to fund stem cell research, asserting it may soon cure Alzheimers, Diabetes, ALS, and Parkinson's, as well many other diseases - even heart disease. Many right-to life organizations oppose such research, however, claiming it destroys the lives of unborn children.

The petition, including 750 pages of signatures and comments by persons with chronic illnesses and other citizens, was presented by Ilyce Randell, a Canavan's Disease advocate. Canavan's is an incurable fatal childhood illness. Her son Max, who was at the meeting, suffers from the disease. "Canavan's is a disease which strikes only 400 children a year," said Ms. Randell. "Without therapies that can be applied to many different illnesses, which are likely to result from stem cell research, Canavan's will never attract enough dollars to produce a cure. Stem cell research offers the only hope for Max to live a normal life."

Wasson said members of the Internet forum decided to write a petition after President Bush, who was expected to nullify the present guidelines, referred the matter to Thompson for review. The delay presented an opportunity to give a voice to those with the biggest stake in stem cell research -- the chronically ill. They put the petition online (<http://www.petitiononline.com/stmcll/petition.html>), and began a grassroots campaign to collect signatures, contacting family, friends, and disease organizations. Those contacted were asked to forward the request to others on their own e-mail lists. They also created a website to provide information about stem cells.

"The response was phenomenal," said Wasson. In addition to signatures by the chronically ill, the petition garnered signatures from leading scientists such as Ole Isacson, head of Parkinson's research at Harvard. Dan Perry, chair of the CURE coalition of 123 organizations that has urged President Bush to delay a decision on the guidelines, said "Congratulations...the compelling voice of individuals and families confronting Parkinson's, ALS, and other devastating health problems is the most potent weapon we have in this fight."

"I wish we had more time to gather signatures before sending the petition to Washington. But with a decision on the horizon, this was one party we didn't want to be late for," said John Davis, a petition organizer and ALS sufferer.

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