

# HSP KENTUCKY

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April 11, 2015

Sen. Mitch McConnell  
317 Russell Senate Office Building  
2 Constitution Avenue NE  
Washington, DC 20002

Re: Hereditary Spastic Paraplegia/Pulmonary Lateral Sclerosis patients

Dear Senator McConnell:

After serving for twenty-six years, I chose not to run again for the office of Hickman County Judge Executive in 2014, primarily to spend time fighting a new enemy, Hereditary Spastic Paraplegia. I have known I have this slowly debilitating physical condition since 2005. HSP is an upper motor neuron disease, a cousin to ALS (Lou Gehrig's disease), causing progressive weakening in the legs. One of the leading doctors in the country on this disease, Dr. John K. Fink, scolded me in 2013 that I should retire in order to spend significant time in physical therapy, trying to prolong my life without a wheelchair. I know you find this hard to believe, but I really thought I could successfully fight it while continuing to serve. By January, 2014, I had to admit he was right-that I could not do both as well and as successfully as I wanted and needed.

The worst part of this condition for me is the "hereditary" component. Eleven in my family over the past three generations have had it. My father is currently in a rest home since 2008 because of his mobility problem. Every descendent of mine has a 50/50 chance of dealing with it. The thought of my children and grandchildren dealing with this is reason enough to devote my time and energy in an attempt to make a difference in finding treatments and cures.

On the same date I announced I would not seek reelection, I received an invitation to serve on the board of directors of a national non-profit working to find those treatments and cures, the Spastic Paraplegia Foundation. I have enclosed a copy of our president's annual report. You will find information there concerning some of the research we are currently funding through fund raising efforts. We also have a website under the same name with much more information. One of my tasks as a board member is to assist in networking and communicating with any organization which may be able to assist in our research. I write you because research by the National Institute of Health is of primary importance not only for our disease, but for the other 7,000 rare diseases individuals in our country have.

I realize we have many financial issues and priorities with which you and our Congress are dealing. I simply ask your consideration in doing two things. First, I ask that you support increased funding for the NIH. We find that scientists and doctors who have been conducting important research sometimes find themselves out of research because funding may have been cut. We need those researchers to continue their work toward finding those treatments and cures. Secondly, I would respectfully ask that your staff person that deals with the NIH and these kinds of health issues contact me by e-mail in order that I may communicate with you concerning these important questions and issues. As you can imagine, this has become one of my greatest priorities, and I sincerely appreciate the opportunity and possibility of maintaining a discourse with you and your staff about it.

Thank you for the opportunity to share this concern and new mission with you. I sincerely appreciate your public service for Kentucky, and look forward to working with you on this new challenge of mine as we have in the past on other public needs and issues.

Very truly yours,

Gregory D. Pruitt