1/23/19

Re: Letter of Support for CLIN1-10953: An hESC-derived hNSC Therapeutic for Huntington's Disease

Dear Ms. Bonneville and Members of the California Institute for Regenerative Medicine Governing Board,

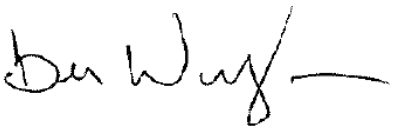
I am writing this letter to offer my strong support towards Dr. Leslie Thompson and her work.

For the past four years I have served as the President of the Orange County chapter of the Huntington's Disease Society of America. While I am not writing this letter within that official capacity, nor am I speaking for the organization, I can tell you that within this role I have engaged with many members of the HD community. Nearly without exception, all of them support testing any form of cure for this disease regardless of the cost. Certainly, safety is of top concern. However, Huntington's disease is fatal, and the inevitable decline towards death is not at all pleasant. Nearly any safety side effect would be worth the cost if it meant a cure to the disease. I express this opinion not merely for myself but as reflective of what I consistently hear from those suffering from the disease. Anything to slow or halt the progression of HD would overshadow possible, or even likely, side effects of the treatment.

Outside of my role with HDSA, I also have a personal stake in the effort. In September, 2017, my mother finally succumbed after over a decade since first becoming symptomatic. Watching her transform from the vibrant, positive lady we had always known into a withered, frail shadow of her former self was heartbreaking. Witnessing the effects it had on my father was tragic as well. My parents celebrated their 40th wedding anniversary by her bedside, without my mom even knowing the significance of the occasion as she was so far down her progression. As if this wasn't enough I also have a brother who is at-risk for the disease. Huntington's disease isn't just death – It's complete and utter devastation to families. I, myself, have tested negative for HD. While this is great news for me it doesn't leave me untouched by the disease. I've lost my mother and could lose my brother and best friend. My wife will never know an amazing mother-in-law. My two daughters will never have the best grandmother ever. My status as a gene-negative individual means I will never show symptoms of HD nor perish from its effects. Unfortunately, it also means I can do nothing to participate in the research myself. If I could, I would. Regardless of the side effects or the cost, I would willingly offer myself if it helped bring us a cure. I would do this now, knowing I will never have or die from HD. This is how passionate we are for a cure.

Testing a stem cell based treatment for HD brings hope to those of us who need it most - for ourselves, our loved ones, and those in the HD community fighting this disease every day. Please, I implore you, approve this project so we can make steps in the right direction. We need to stop losing mothers, brothers, and grandmothers to this disease. And your decision could help.

Thank you for your time and attention.



Bill Waddington