UCI HD-CARE: Huntington's Disease Community Advocacy, Research & Education

To: California Institute for Regenerative Medicine January 23, 2025

Reference: CLIN2-17081

Dear CIRM Directors and CIRM Independent Oversight Committee:

My name is Frances Saldaña. I'm writing to thank you for supporting Huntington's disease research and enabling our scientists to achieve amazing breakthroughs, and I'm writing to ask for your support of CLIN2-17081. CIRM has given our Huntington's disease family members so much hope for a treatment. I lost the father of my children and all three of my children to Huntington's disease. My two grandchildren are now "at risk" of inheriting the fatal disease.

The realization that we still do not have a treatment for HD continues to frighten me, as my two grandchildren are now young adults. They live with the uncertainly and fear that they too may succumb to what I call, "the worst disease known to mankind". They saw their beautiful and loving mother wither away in the most unrecognizable way until she couldn't hold on to life any longer. My grandchildren never got to meet their grandfather, as he died at the age of 42. They're literally running scared and probably will not test for the disease until they feel confident that there may be a treatment soon.

My own children were all patient advocates, raising awareness about HD, even from a wheelchair and while in pain. They even donated skin cells for HD research, but a treatment was not realized in time for them. Not having a treatment for HD soon will mean a continued new cycle of HD families and the resultant tragedy that takes the lives of thousands who have already inherited the mutant gene, as well as future generations who will also inherit HD.

HD-CARE was an active participant of the of the recent Community Engagement Studio to meet with HD families to discuss the HNSC trial, and we are so motivated by the positive perspectives of the HD trial. Through our 30 years of advocacy, we've had the opportunity of meeting so many HD family members and have become a large extended family. Every time we lose another HD family member, we all suffer and the tragedy continues, from one generation to the next. Many who have passed away were children or young adults, such as my own children. In spite of our continued advocacy, we still do not have a treatment, and the disease has taken millions of HD family members, from one generation to the next. I will remain committed to supporting HD research and patient care. My most ardent wish is that it will happen in my own lifetime.

Please consider allowing the CLIN2-17081 application to move forward for an HD clinical trial.

Respectfully,

Frances D. Saldaña

Frances D. Saldaña
President Emeritus, HD-CARE