Submitter:	David Farr
On Behalf Of:	Self and My Fellow EDS and HSD cohorts
Committee:	Senate Committee On Rules
Measure, Appointment or Topic:	HCR4

Last May, my life changed. For the good. After almost thirty years of dozens of "mysterious" symptoms, the efforts of our community to bring to my attention the HSD and the EDS--or, as I call them, Collagen Dysfunctional Syndromes (CDS), to highlight the essential role collagen, the protein affected by these chronic, complex and often disabling illnesses, has to wellness; it exists in EVERY ORGAN, SYSTEM and FUNCTION of our physiology, anatomy, neurology and the behaviors the help determine. When May HSD/EDS awareness month broke through to me I thought, "Finally! Something to explain what I was experiencing"--more than half a million world-wide. My doubts about my sanity were swept away. My fear of telling friends and family I was chronically ill banished! Resources galore became apparent to me to assist me in collaborating with my medical providers from THOUSANDS OF EVIDENCE-BASED, peer reviewed journal articles, conference presentations, and books from experts in the clinic, the research field, their overlap, and by patient experts like me. This abundance of credible, reliable, scientific knowledge, so suddenly on my radar, still overwhelms at times--and it grows by the day. So when I hear that there are actually still physicians gaslighting us, calling our suffering "self-pathologizing," "overdiagnosis," it deeply saddens me. We suffer physically, mentally, emotionally, and physiologically from chronic, complex diseases and several common co-occurring conditions, and we NEED a paradigm shift in thinking about such diseases. AWARENESS is crucial to making this shift truly paradigmatic. The medical school and medical clinic establishments, along with the hundreds of thousands of people they influence, are finally starting to WAKE UP to the facts. But we still have a LONG WAY TO GO. As long as even ONE doctor still thinks that one of us is a hypochandriac, harm is being committed by that person. That's why it is crucial to pass this bill. To fail to do so would be an egregious slap in the face to the thousands of us in this State who know, for a fact, that not only is OUR SUFFERING REAL, but our symptoms SIGNAL ACTUAL CLINIC DISEASE ENTITIES. It's not just in our heads. How could tens of thousands of people worldwide mass hallucinate an illness? Similar things were said about tuberculosis, breast cancer and AIDS before their respective awareness campaigns. It's not just in our heads. It's ALL throughout our BODIES too, and it affects every ORGAN and SYSTEM in our bodies, and hence EVERYTHING we DO, or, as is often case CANNOT DO. NOT PASSING this bill WOULD be a a vote BLAME THE VICTIMS. We didn't choose to have these conditions, and we do not have victim mentalities. But we have been victimized by these syndromes. To vote against this bill would only pile on. Don't victimize us more. LEGITIMIZE US!! We need the world to know these truths, and to know that they are 100% backed up by decades of clinician experience and/or evidence-based science. Please Vote to PASS THIS BILL.

SELECTED SOURCES:

-BMJ Journals: https://bmjopen.bmj.com/content/9/11/e031365

-EDS Society: https://www.ehlers-danlos.com/prevalence/#:~:text=The%20combined%20prevalence%20of%20HSD,has%20not%20been%20studied%20yet.

-Purdin, H.

--Physical Therapist in Portland, owner of Good Health PT & Wellness, co-author of Taming the Zebra: https://goodhealthphysicaltherapy.com/how-common-are-hypermobility-spectrum-disorder-hsd-and-ehlers-danlos-syndrome-eds/

--https://goodhealthphysicaltherapy.com/basics-of-eds/#:~:text=The%20single%20most%20common%20type%20of%20EDS,919%20(0.02%)%20of%20the%20population%20with%20hEDS

-Sontag, Susan: Illness as Metaphor and AIDS and Its Metaphors: Picador, 2001.