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Re: SB 212

Dear Senators,

I am here today to provide support for the genetic testing protection act of 2023 (SB212). I am a Professor of Neurology and Neuroscience at the Johns Hopkins School of Medicine. My specialty is neuromuscular disease especially amyotrophic lateral sclerosis. I've practiced at Johns Hopkins since 1986 and founded the Johns Hopkins ALS clinic in 1995. We run one of the largest ALS clinics in the United States supported by an outstanding team of health professionals dedicated to alleviating suffering from this disease and carrying out fundamentally important research. In addition, I have run dozens of experimental clinical trials in ALS in hopes of advancing new therapies. I also run a basic science lab focusing on understanding the causes of ALS and aiding in developing new experimental therapies. This research in fact led to the first FDA-approved drug for ALS in 1995, and supported multiple subsequent national and international clinical trials. I founded the Robert Packard Center of ALS research at Johns Hopkins 25 years ago to advance Preclinical Research to identify new therapies and understandings of the disease by engaging top-line researchers from around the world to work together collaboratively to tackle this disease.

In my career, to date, at Johns Hopkins I have seen or evaluated well over 10,000 ALS patients and am quite familiar with the diagnosis and course of this terrible disease. To remind you ALS is a progressive invariably fatal neuromuscular disease robbing patients of their ability to carry out any voluntary muscle activity ultimately culminating in death due to respiratory failure ...that is suffocation. It is one of the most devastating adult diseases. There is no curative therapy—but genetic therapies provide incredible and realistic hope. Today we know that ALS can be inherited in a subpopulation of patients. In fact, all patients today are tested for genetic mutations that underlie ALS, as some of these mutations can be found in people without any family history of the disease. Advances in medicine especially what are known as gene therapies have had a tremendous impact in changing the course of ALS. Excitingly, in only a few weeks the newest gene therapy comes before the FDA with a high likelihood of approval. These new genetic-based therapies can offer the possibility of extending life by many years and possibly even halting the progression of the disease. In fact, trials now are administering the gene therapies even before the disease begins thereby providing the real opportunity of an individual never actually succumbing to the disease. These advances for patients are only possible because of the ability to carry out genetic testing without any repercussions from at times injurious and disruptive insurance companies, in my long experience, which can often impede the ability of patients to be afforded top-line care and thereby enhance the quality of life. The proposed bill would

certainly act to substantially protect patients against this disruption of proper care and the ability to understand their own health future.

I strongly support the passage of this bill for not only my patients but for all of you who one day may face such medical trauma.

Sincerely,

Jeffrey D. Rothstein

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The John W. Griffin Director of the Pedersen Brain Science Institute

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