Open Letter
Monday, October 16th 2023

Recently, the UK Government called for input on a revamp to procedures related to how their insurance industry may use so-called "predictive" genetic tests when determining insurability, rates, or insurance limits. As the fear of genetic discrimination stalks our families, we submitted comments on behalf of the international hereditary ALS & FTD community, including the UK. We have adapted our submission to this open letter.

Creating artificial lines between "diagnostic" and "predictive" genetic tests is inappropriate as progress in medicine requires us to constantly push to prevent complications of diseases rather than force patients to deal with symptoms as the only way to start treating the condition. Demanding medical professionals, researchers, and patients to dance around these definitions puts guardrails around issues that should always be a continuum rather than a line of demarcation. We do not deny insurers may be interested in understanding the health of individuals they consider for policies. Still, if someone is healthy, they should not have any genetic test used against them.

Currently, the Code disincentivizes people impacted by Huntington's Disease to avail themselves of genetic testing. It may seem of little concern as no approved treatments exist for a person with an HTT mutation to ameliorate their chance of developing Huntington's complete phenotype. That does not account for the fact this could change at any moment. Any time a person with the HTT variant debates whether to access a potential treatment for Huntington's or prioritize protecting their right to insurance products, an unintended incentive appears. Rational options such as family planning or research participation can be propelled by knowing one's genetic status, and the current discriminatory framework disincentivizes that. Expanding these issues to other genetic diseases multiplies these issues potentially exponentially. Further, looking at this from a societal lens, more is known about all diseases by increased genetic knowledge. We should protect the avenues that make that possible.

No attempt at separating genetic tests based on any standard will alleviate our fundamental human rights concern with the concept as a whole. Why should people impacted by any genetic

disease be disincentivized from attempting to lessen their risk, or the risk to their descendants, either now or in the future? People with genetic predispositions to diseases should be encouraged to address their risk of those diseases in whatever way is appropriate, and we should acknowledge that what is suitable for each disease will change with time.

Providing further details for actions lacking compassion and reason does not improve anything. We call for broadening protections for individuals to know their genetic status and oppose narrowing those rights. More genetic diseases will have worse outcomes due to increased fear of genetic discrimination in insurance products. This policy also risks endangering the government's Our Future Health initiative, which aims to sequence 5 million UK citizens. If the public becomes more fearful of the risks of genetic knowledge, they will not participate, regardless of the fact research participation is not at issue here directly.

Discriminating on the basis of genetics is wrong and violates the fundamental right of people to be treated equally regardless of any gene they possess.

Jean Swidler
Executive Director
Genetic ALS & FTD: End the Legacy
EndTheLegacy.org