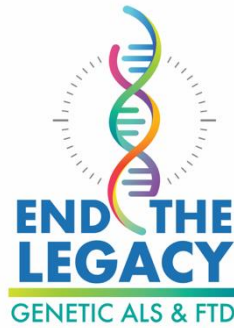


4-7-2026

California State Assembly

Insurance Committee

Privacy and Consumer Protections Committee



Honorable Committee Members:

We are writing with enthusiastic support for the advancement and ultimate passing of AB 1798 on Genetic Testing Protections authored by Assembly person Wilson.

We are a patient advocacy organization dedicated to those impacted by inherited or genetic ALS and FTD. These are two terrible ways to leave one's life and having it be witnessed in generation after generation in families is very impactful. Of note the most common gene responsible for these diseases has a very wide distribution of age of normal symptom onset stretching from the 40s to one's 70s. This means only through monitoring would peace of mind be allowed to one at risk to be assured the onset of the symptomatic stage has not begun. Unfortunately, today this reasonable form of medical care is discouraged for our families due to the theoretical risk of genetic insurance discrimination. We would welcome the subtraction of one barrier to this vulnerable community.

We would also point to the virtuous cycle this bill would promote. Taking away some fear from genetic medicine would allow more Californians to make use of those pathways when indicated by their medical team and lead to better health outcomes in CA. We especially point to the example of Florida's protection of genetic Testing in 2020 and how that state had no changes to the insurance industry as a result. Insurers can still use family history questionnaires to make underwriting decisions. This bill has only upsides, and little or no downsides.

For the health and well-being of all Californians we urge approval of AB 1798.

With Appreciation,

Jean Swidler

Genetic ALS & FTD: End the Legacy

Endthelegacy.org

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