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Sent: Monday, February 7, 2022 10:44 AM
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Subject: [External] Follow-up on S.247

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Senator Cummings and the Senate Finance Committee,

On behalf of Dr. Leonard and Dr. Wildin, we wanted to express our appreciation for the Committee's willingness to take up S.247, an act relating to prohibiting discrimination based on genetic information. In addition to their testimonies ([here](#) and [here](#)), the material I submitted in January ([fact sheet](#), [New England Journal of Medicine article](#) and [Journal of Law, Medicine and Ethics article](#)), and the [written informed consent we use with patients](#), we wanted to clarify a few points that were raised in testimony yesterday. We understand you will be discussing S.247 again on Wednesday. Please do not hesitate to be in touch with me to seek additional information or discussion.

The representatives from ACLI warned of the likelihood of **adverse selection** if S.247 is adopted. There is not clear evidence to support this.

- The prohibition on use of genetic information leading to adverse selection has not occurred in health insurance – an equally likely outcome of such a prohibition – even though GINA has prohibited health insurers from using genetic information in underwriting for the last 13 years. GINA also prohibits the use of family history.
- The industry's own data shows that those who seek out and buy life insurance actually *live longer* than those who don't – their best customers are people who are inherently more cautious and interested in self-preservation. Living longer is in the insurer's interest.
- The underwriting risk tables are based on aggregate experience, which already incorporates a certain amount of presumed adverse selection. It is hard to fathom that adverse selection from this bill would result in such a significant tipping of the risk scales.

A representative from ACLI argued that S.247 would prohibit them from **using family and medical history in underwriting**. It is our belief that S.247 clearly allows for the continued use of family and individual medical history for life insurance underwriting and issuance decisions. We have been in contact with DFR and will continue to work with the Department and Legislative Counsel to understand if any additional language is necessary to clarify this point.

Some committee members asked for **examples of and fear of discrimination**. An [article](#) from the Genetic Literacy Project titled "Life insurance companies deny coverage to those with cancer genes like BRCA" details two issues discussed during your hearing: real examples of people

being discriminated against as a result of knowing their genetic information (in this case, a 36 year old woman who tested for the BRCA 1 gene), as well as instances when individuals chose not to access their genetic information out of fear of future discrimination (25% of people refusing to participate in a research study because their genetic information could be used to discriminate against them or their future children if it became linked to their medical record).

We wanted to remind the committee about the experience in Florida. In early 2020, Florida enacted a [comprehensive ban](#) on the use of genetic information in life insurance underwriting. This was a bi-partisan proposal - passing the House on a vote of 117 - 1 and the Senate 35 - 3. We have not found any published evidence of negative consequences for life insurance consumers in Florida since the passage of the law.

Thank you. We look forward to continuing this important discussion.

Best, Jason

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