FORCE
Facing Our Risk of Cancer Empowered
Fighting Hereditary Breast and Ovarian Cancer

# Statement on Health Care and Genetic Privacy
# May 2017

Recent events related to proposed changes in health care and genetic privacy laws have spurred concern and uncertainty in the hereditary cancer community. Some media stories have disseminated inaccurate information, which has intensified people's unease. We prepared this briefing to dispel some of the misinformation and allay some of the fears that have been expressed by members of our community.

## Genetic Protections & Privacy

FORCE was a key player in the passage of Genetic Information Nondiscrimination Act (GINA) in 2008, which prohibits health insurance companies and employers from discriminating against people based on a genetic or inherited predisposition to any disease. The law also prohibits employers from asking employees to reveal personal or relatives' health or genetic information. It also bars employers from using genetic information when making hiring, firing, job assignment, or promotion decisions.

The Preserving Employee Wellness Programs Act (HR 1313) was introduced in early March, and garnered a great deal of attention. **If passed,** this piece of legislation would overrule important aspects of GINA by allowing workplace wellness programs to request protected genetic information such as family history of disease or genetic test results from employees. Employees who do not share this information could face higher health insurance costs.

FORCE and many other organizations vehemently opposed this measure and mobilized to fight the legislation. A letter expressing serious concerns was sent to the House Committee on Education and the Workforce. The bill has been put "on hold" due to intense pressure from the public and media, **and likely will not move forward without significant revisions**—including changes to the genetic information protections.

Importantly, HR 1313 is currently not law. FORCE and other organizations will oppose any efforts to weaken GINA now and in the future. While concern is certainly warranted, it is important to note that this legislation would only apply to employer-sponsored wellness programs. The majority of these programs are operated by third parties—not employers. Even if permissible by law, most wellness programs would not demand sensitive health information—or impose large penalties for nonparticipation. It would remain illegal for an employer to access or use an employee's genetic information in any way. Also, it may be comforting to know that very few complaints and legal cases citing genetic discrimination by employers have been filed since the law passed in 2008.

**Health Care / Insurance** _____

Repeal and replacement of the Affordable Care Act (aka Obamacare) is a priority for the Trump administration and many members of Congress. On May 4th, the U.S. House of Representatives passed legislation called the American Health Care Act (AHCA). However, the bill is still far from being signed into law. If passed, here are some of the changes that would happen:

Pre-existing conditions:

- Currently, insurance companies are not allowed to charge people with a pre-existing condition higher health insurance premiums. AHCA would allow states to opt-out of this requirement.
- Similarly, if a person with a pre-existing condition allows their health insurance policy to lapse, then s/he could be charged more by the insurance company when signing up for another plan. Americans who are insured in the individual market are most likely to be impacted if they live in a state that is granted a waiver. Most people who receive health insurance coverage through their employer, Medicaid, Medicare, or the VA will not be affected by this waiver provision.

The legislation also abolishes mandatory coverage of essential health benefits such as maternity care, mental health, and preventive screenings with no out-of-pocket costs to patients. Among other services, this includes genetic counseling and testing for BRCA mutations as outlined by the United States Preventive Services Task Force.

In states that eliminate or weaken essential health benefits, insurers could impose coverage limits on anything from emergency services to inpatient care to prescription drugs. Similarly, plans would also no longer have to cap consumers' out-of-pocket costs.

It's important to understand that AHCA's passage in the House of Representatives is only the first in a number of steps required to change the U.S. health system. The U.S. Senate will review the proposed legislation next and a significant rewrite is likely. We encourage members of our community to make your voices heard. We can drive change that promotes health care reform that preserves or improves access to care for every American.

**Pre-Existing Conditions and Manifest Disease** _____

A major misconception in the hereditary cancer community is that carrying an inherited genetic mutation associated with increased risk of cancer (i.e. BRCA, PALB2, PTEN, etc.) is considered a pre-existing condition. In fact, the Genetic Information Nondiscrimination Act (GINA) prohibits treating genetic information or a family history of disease as a pre-existing condition in regard to health insurance coverage. A pre-existing condition is typically a manifest disease or condition such as diabetes, colitis, or a cancer diagnosis.

We frequently see misconceptions about the laws that relate to health insurance in people with known inherited genetic mutations.

1. Some people mistakenly believe that having an inherited genetic mutation can be considered a pre-existing condition. Under the current GINA law, having an inherited mutation that *increases the risk for a disease is not considered a pre-existing condition as long as the individual does not have the actual disease.*

   So, for example, a woman with a PALB2 mutation who has not been diagnosed with cancer, would not have a pre-existing condition under GINA. Even if the ACA is repealed, as long as GINA remains law, she cannot be charged a higher health insurance premium based on her mutation alone.

2. Other people mistakenly believe that GINA protects everyone with an inherited mutation from any discrimination. In health insurance, *GINA protections only apply to genetic information for previvors (aka unaffected carriers) who have not been diagnosed with the related disease.* Once a person receives a diagnosis (such as cancer), it is considered **manifest disease**. Manifest disease is not protected under GINA.

   So a woman with a BRCA1 mutation who was diagnosed with ovarian cancer, will likely be considered to have a pre-existing condition. **The Affordable Care Act** (ACA) currently protects her from health insurance discrimination, but because she has had cancer, she is not protected under **GINA**. If the ACA is repealed and replaced with the ACHA, a health insurance company could be allowed to charge her higher premiums because of her cancer diagnosis.

   It's important to note that GINA does not apply to life, long-term care, or disability insurance. In other words, it is legal for an insurer to deny these types of insurance to a person with a BRCA or other inherited genetic mutation without manifest disease. Many insurers choose not to take advantage of this "legal discrimination" option but we encourage people who are denied to explore policies with other insurers if possible.

3. The term **manifest disease** is not always straightforward. For example, before someone has a full-blown disease, they may have signs or symptoms that relate to being at high risk. Pre-diabetes or colon polyps could be examples where protections under GINA may be fuzzy. This is why the passage of the Affordable Care Act, which contained the clause prohibiting any discrimination for any predisposition to or manifest disease was so important to our community in order to close the gaps that remained even after the passage of GINA.

Pre-existing conditions other than cancer would also be affected by repeal and replacement of the Affordable Care Act. Depending on the final law that replaces ACA, health insurers in states that have opted out of the "pre-existing condition clause" may be allowed to establish which diseases or conditions they consider pre-existing, such as diabetes, colitis, hypertension, or even a prior surgery or injury. It is difficult to predict the impact of repeal and replacement until the final law is written.

Finally, it is crucial to understand that GINA and the ACA are completely separate laws. Likewise, any law that replaces ACA will be entirely independent of GINA. There are currently no indications that GINA will be revised to compromise the protections it offers in regard to health insurance. Overturning or revising GINA would require legislative action and groups like FORCE are working to ensure that this doesn't happen. Similarly, as of now, ACA remains the law of the land. We urge you to communicate with your elected officials about what's important to you as they consider how to revise or replace ACA. FORCE will continue advocating in support of legislation that protects all members of our community and provides access to affordable health care.