

# PUBLIC SUBMISSION

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**Docket:** EBSA-2008-0020

Prohibiting Discrimination Based on Genetic Information in Health Insurance Coverage and Group Health Plans

**Comment On:** EBSA-2008-0020-0023

Interim Final Rules Prohibiting Discrimination Based on Genetic Information in Health Insurance Coverage and Group Health Plans

**Document:** EBSA-2008-0020-DRAFT-0062

Comment on FR Doc # E9-22504

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## Submitter Information

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## General Comment

I have some comments regarding the final Rules Prohibiting Discrimination Based on Genetic Information in Health Insurance Coverage and Group Health Plans (Document ID EBSA-2008-002-0023) I am a 6 year breast cancer survivor who has undergone genetic testing for the only currently know test, BRACA I & II. I did this because of other relatives who have had breast cancer and I wanted to do everything on my part to give my 3 daughters all the information they need for their health and well being.

I have concerns regarding how this act is going to truly protect my genetic testing information. I have already felt the "under the table" effect and have been denied coverage by 11 insurance agencies when forced to find a new insurance. And if I was offered coverage, it was extremely expensive. I worry for my daughters and how this has already affected their own insurance coverage (I had to take out a separate insurance instead of having a family coverage).

Thank you for your time and consideration.

Xan C. Kali

Salt Lake City, Utah

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## Attachments

**EBSA-2008-0020-DRAFT-0062.1:** Comment on FR Doc # E9-22504

November 30, 2009

RE: Interim Final Rules Prohibiting Discrimination Based on Genetic Information in Health Insurance Coverage and Group Health Plans (Document ID EBSA-2008-0020-0023)

I would like to voice my agreement, disagreement and concerns surround the changes to the rules for prohibiting discrimination based on genetic information in health insurance coverage and group health plans.

I strongly support the part under part II Overview of the Regulations: 2) Definitions and how far reaching the umbrella is for protecting the individual and up to fourth-degree relatives when it comes to the privacy of genetic traits. Because in the past this information has been used as reasons for health insurance coverage and plans to either refuse to provide health insurance or a means by which to significantly increase a person's premiums as well as outrageous out of pocket expense to pay for medical bills.

II Overview of the Regulations: 5) Prohibition on Collection of Genetic Information

I am very concerned that a person's genetic information is venerable when collected. Even though it is clearly stated what is considered genetic testing and information, that information is still there in a person medical record that then become red flags to insurance agencies. There are bill to the insurance companies that can clearly indicate that there is at least some concern surrounding a person's health. I speak as a person who has gone through breast cancer and for the concern for my daughters; I did undergo the BRACA testing to see if I was a carrier. And while it showed that I was not positive for the BRACA I or II, there is a belief in the medical industry that the BRACA tests for only two specific genes. And as they search for better tests and better cures, this doesn't say that I may not be a carrier of another gene that causes breast cancer and has yet to be found

This information is in my medical record. I have medical bills that continue to show I am a survivor of breast cancer. I went through a period after my breast cancer where I had to change medical insurance. I was denied by 11 different insurance companies because of my pre-existing condition. Being a single head of household to 3 daughters, I could not obtain a family insurance. I was forced to place my children under separate plans. And even though my prior "tests" were supposed to not be taken into consideration, there is no way that the insurance companies couldn't connect the dots and come up with their decisions.

I find it very difficult to believe that a person's medical record, redacted or not, can't hide the fact that the person had something going on with them that was genetically in question or confirmed.

Insurance companies require that you agree for them to obtain your medical records for review in order to determine if they are even going to allow you to enroll. And if you are enrolled, the premiums are so high most people cannot afford them. There has to be a better safety net in place for the protection of a person's history regarding if they or a relative have undergone genetic testing.

And then there are the HRAs. It is great that people want others to be healthy, but I believe that HRA's used for the purpose of improving the one's health should focus on the basics and that genetic testing should not be a part of their records. Information about one's genetic testing or that they should be tested is something that should be between their own doctor and no one else. This could turn out to be a "guilt by association" type of mentality that can be used by the insurance industry. There is no real protection that a person's medical history, specifically genetic testing, will be kept private and not under the table used to prevent them from obtaining insurance coverage. HRAs should continue to be voluntary, but who has access to this information must be strongly restricted and better safe guards in place to ensure a person's privacy.

#### IV. Economic Impact and Paperwork Burden

3a) I believe the costs numbers are going to be low. The health care industry is out of control which is why the government is going through a health care reform. And costs are always pushed off to the people which are why the cost of health care continues to go up.

3b) this part is concerning. It discusses a projection of how much it is going to cost in order for medical records to be redacted regarding genetic information. What about the information leading up to the genetic tests? Is this going to be redacted? And if so, how much extra is that going to cost? And if indeed someone is really going to go through a person's medical record and redact ALL of the information regarding genetic testing before sending it off to insurance companies, what insurance is there that the information is really going to be redacted? If it is written down, is a person really going to sit down and redact the information, all of the information, or even do it at all? And now that there is a movement to move to paperless charting, how is that going to look when read by the insurance companies when there are fragmented sentences and paragraphs?

I was thrilled when the Genetic Discrimination Act came out. But it brought along with it a lot of concern. Every insurance company asks about your medical history and your family history. They won't even begin to process your application until you have given them your life history, family history and sign a form allowing them to request all of your medical records. Anyone who is at all familiar with the health care system knows when things don't add up. If your report you have breast cancer then next question asks if there is a family history. Then they look at your medical records and there is this big blank when it comes to the possibility of genetic testing. And even though they are not to take that into consideration regarding your application, I believe they then deny your enrollment for other reasons that are contributed to your history.

I strongly support GINA. But I still worry that my being tested will always loom over how much my premiums, if any future insurance companies will continue to deny me coverage and what the impact is going to be on my daughters in the future. I cannot stress enough that there needs to be harsh penalties for agencies and individuals responsible for protecting this information as well as how the information is used.

Thank you for your time and consideration,  
Xan C. Kali