

41. Thrombophilia and Health and Life Insurance

Last Updated: 2/15/2004

Q1: "I have been trying to get private health insurance and I haven't found any insurance company that will give me a policy yet. They say I am not eligible because of FVL."

A1: It appears that in the U.S. there may not be a problem for individuals with factor V Leiden to get onto a group health plan, but that there is a problem for some people to get individual health insurance.

Q2: "I was turned down when we went to get another life insurance policy on me. I fought it and it went to review and I was told they could not insure me. I did not mention my DVT on the question, just listed FVL."

A2: In the U.S. there may be a problem getting life insurance if an individual has FVL. If somebody wants to get tested for FVL it may be advisable getting life insurance before testing.

Q3: "I have factor V Leiden and I am very glad I got tested. I have not had a DVT or PE and I have not been denied life insurance. We just increased ours after I found out I had FVL, and the insurance agent nurse just shrugged it off."

A3: Some people with factor V Leiden fortunately do not have problems getting life insurance.

Q4: "I have had 2 superficial blood clots but never had a DVT or PE; I was tested and found to have factor V Leiden. Recently I came up for life insurance renewal. The insurance adjuster made inquiries and told me that I was originally assessed as a "Table D" risk, which would correspond to a rate of \$260.35/month; however, when the claim was adjusted to include that I had the FVLeiden mutation, I was deemed a "Table H" risk, corresponding to a rate of \$427.17/month. This represents an increase of 49% in the price of the life insurance premium"

A4: Life insurance discrimination due to genetic status does appear to occur in the U.S.

A genetic counselor's comments on health and life insurance issues in thrombophilia (from Liz Varga, University of Kansas Medical Center):

"There are laws and protections in place to help individuals tested for genetic thrombophilias from health insurance and employment discrimination. An overview of the US legislation can be found at the government website <http://www.genome.gov/11510231>."

Here are some of the protections in place:

- The U.S. government's Health Insurance Portability and Accountability Act (HIPAA) passed in 1996 protects all individuals covered under group insurance plans from genetic discrimination. Group health plans are provided through employers, unions or professional organizations. HIPAA laws do not apply to individuals covered under individual plans (for people who are self-employed or are not provided insurance by employers). Under the HIPAA law, an individual's genetic information cannot be used to deny or limit insurance coverage if no diagnosis of a condition is made.

For example, if a person has tested positive for the factor V Leiden gene but has never had a clotting episode (DVT), that individual cannot be dropped from an insurance plan or have his/her coverage change based on the genetic test results. In addition, under HIPAA, an individual's genetic information cannot be considered a pre-existing condition. This means that no matter what type of insurance you have now, if you ever switch plans, you cannot be denied coverage, as long as the new plan is a group plan. HIPAA also states that you cannot be charged more based upon your genetic information. Because genetic information is not considered a pre-existing condition, premiums cannot be increased based upon this information alone.

- On October 14, 2003 the U.S. Senate passed a law to expand the protections on genetic discrimination. The details of this law can be found at:

<http://thomas.loc.gov/cgi-bin/bdquery/z?d108:SN01053:@@L&summ2=m&>

This law "prohibits a group health plan, a health insurance issuer, or an issuer of Medicare supplemental policies from using/disclosing genetic information for purposes of underwriting, determining eligibility to enroll, or premium rating for medical insurance. The law prohibits insurers from using or disclosing genetic information for

the creation, renewal, or replacement of a plan, contract, or coverage." Employment discrimination based on genetic tests is also illegal. Note: these protections are not in place yet; the House of Representatives still needs to pass the law before it goes into effect.

- Disability and life insurance are NOT covered under federal laws for genetic discrimination. This means a person's genetic information can be used to deny, limit coverage, or adjust premiums. However, some STATES have put protections in place to prevent this type of discrimination. You can search your state law at: <http://www.genome.gov/11510231>

Some people consider obtaining life and/or disability insurance before pursuing genetic testing.

- There are no federal laws governing a health insurance company from accessing genetic information or from asking results of genetic testing or screening. Some states do have laws about this. Insurers can not require that you have genetic testing.

Dr. Moll's comment

Members of the FVLeiden LISTSERVE (ca. 800) were asked in February 2002 about their experience obtaining health and life insurance. Interpretation is very limited, since this type of survey does not make it clear whether insurance denial decisions were based on the fact that the patient had had a thrombosis or has a genetic abnormality. 24 people responded.

	Have you been denied health insurance because of your genetic abnormality?	Have you had to pay higher health insurance premiums because of your genetic abnormality?	Have you been denied life insurance because of your genetic abnormality?	Have you had to pay higher life insurance premiums because of your genetic abnormality?
yes	6 *	0	3	1
no	7	3	4	1
*It appears that some patients had problems getting health insurance on individual plans; nobody described problems getting onto group plans.				