



## **Update on the Genetic Information Non-Discrimination Act (GINA) April 2010**

### **What is GINA?**

The Genetic Information Non-Discrimination Act or GINA became law (P.L. 110-233) on May 21, 2008. The primary goals of GINA are to protect individuals against discrimination based on their genetic information with regards to health insurance coverage and employment. GINA is divided into two sections: Title I prohibits genetic discrimination in health insurance coverage; and, Title II prohibits genetic discrimination in employment.

### **What does GINA mean for people with PKD with regards to health insurance?**

In the group health insurance market, insurers cannot:

- increase premiums for the group based on the results of one enrollee's genetic information;
- deny enrollment;
- impose pre-existing condition exclusions; or,
- conduct other forms of underwriting based on genetic information.

In the individual health insurance market, issuers cannot use genetic information to:

- deny coverage;
- raise premiums; or,
- impose pre-existing condition exclusions.

In addition in both the group and individual health insurance markets, insurers cannot request, require or buy genetic information for underwriting purposes or prior to and in connection with enrollment. Finally, plans and issuers are generally prohibited from asking individuals or family members to undergo a genetic test.

### **What does GINA mean for people with PKD with regards to employment discrimination?**

- In general, an employer may not use genetic information in making decisions regarding hiring, promotion, terms or conditions, privileges of employment, compensation or termination.



- An employer, employment agency, labor organization, or training program may not limit, segregate, or classify an employee or member, or deprive that employee or member of employment opportunities, on the basis of genetic information.
- An employment agency, labor organization, or training program may not fail or refuse to refer an individual for employment on the basis of genetic information, nor may the agency, labor organization, or training program attempt to cause an employer to discriminate against an individual on the basis of genetic information.

### **What GINA doesn't cover?**

In general, GINA does *not* apply to life insurance, disability insurance or long term care insurance. GINA also does not cover the U.S. military (or the TRICARE military health system), veterans' health care administered by the Veterans' Administration, the Federal Employees Health Benefits Plan or the Indian Health Service.

### **Is GINA working for me now?**

It takes time for the federal government to create guidance, hammer out details and implement a law. Since May 2008, the federal government has issued guidance and details publically through a series of regulations. As of November 2009, GINA and its protections are in full effect.

### **Now that GINA protects me, should I tell everyone I have PKD?**

GINA has yet to be tested in a court of law. Given this, GINA protections are still relatively unknown, and it is difficult to determine the full extent of the protections until cases work their way through the courts. Until GINA's full protections are known, you should use caution when determining the amount of genetic information you choose to share.

### **Is GINA affected by the new health care reform law?**

GINA was carefully considered in the construction of the Patient Protection and Affordable Care Act (P.L. 111-148). The new law does not preempt protections under GINA but rather works to enhance those protections especially with regards to discrimination in health status. The new law is in the early stages of implementation, and it is too soon to know exactly how GINA and the new law will interact.



### **What do I do if I have been discriminated on the basis of my genetic information?**

When genetic discrimination is suspected in employment, contact the U.S. Equal Employment Opportunity Commission (1-800-669-4000) as soon as possible.

When genetic discrimination is suspect regarding health insurance, you may file a complaint with the Department of Health and Human Services (HHS): Office of Civil Rights ([Click here](#)) and/or seek legal counsel.

## **Additional Resources**

### **Coalition for Genetic Fairness**

*“What does GINA Mean? A Guide to the Genetic Information Nondiscrimination Act”*  
<http://www.geneticfairness.org/ginaresource.html>

### **Title I: Health Insurance Coverage**

U.S. Department of Health and Human Services (HHS)

<http://www.hhs.gov/ocr/privacy/hipaa/understanding/special/genetic/>

U.S. Department of Labor

<http://www.dol.gov/ebsa/newsroom/fsGINA.html>

U.S. Department of Treasury

<http://www.treas.gov/offices/management/hr/oeod/laws-regs/laws.shtml>

### **Title II: Employment**

U.S. Equal Employment Opportunity Commission (EEOC)

<http://www.eeoc.gov/laws/types/genetic.cfm>