



UNIVERSITY OF MICHIGAN

CENTER FOR STATISTICAL GENETICS

Sequence Analysis Workshop Dec. 8-12, 2014

## **Viewing your genetic information - What are the risks?**

# General Information

- Low sequencing coverage
  - Clinical tests typically aim for very deep coverage of coding regions (> 80 – 100x) or of the entire genome (> 30 – 50x).
- You can keep your data for your own purposes.
- One week after the end of the workshop all data will be deleted from our servers, DNA and saliva will be destroyed.
- Samples were coded before sending them to the lab

# Laboratory is not CLIA-certified

- The sequencing was not done in a lab that complies with the Clinical Laboratory Improvement Amendment regulations.
- The results may be incorrect. If you think you have discovered a disease risk variant, **please contact your physician** and ask him or her to order genetic testing through a CLIA-certified lab. **This is NO SUBSTITUTE for a CLIA-certified test** at a hospital.
- Make no major decisions until you have consulted with a physician.
- Samples could have been swapped.

→ More information about CLIA certification and genetic testing:  
<http://ghr.nlm.nih.gov/handbook/testing/validtest>

# Be careful with sharing your results

- Your genetic information directly affects your relatives. If you think you have discovered a disease risk variant ask your relatives whether they want to know about this or not. **Members of your family may not want to know their genetic information, and therefore may not want to know yours.** Please consider and respect their wishes before sharing your results.
- Sharing your genetic information with the public or on social media (e.g. Facebook) might not be a good idea! Even if you think it's meaningless – today.

# Protection of Health Insurance and Employment (1)

**The Genetic Information Nondiscrimination Act of 2008 (GINA) is a federal law that protects individuals from genetic discrimination in health insurance and employment.**

GINA makes it against the law for health insurances to request, require, or use genetic information to make decisions about:

- Your eligibility for health insurance
- Your health insurance premium, contribution amounts, or coverage terms

GINA's protections apply to **most** health insurers. Other insurers have policies in place that provide protections similar to GINA

# Protection of Health Insurance and Employment (2)

GINA makes it against the law for employers to use your genetic information in the following ways:

- To make decisions about hiring, firing, promotion, pay, privileges or terms
- To limit, segregate, classify, or otherwise mistreat an employee

GINA applies to all employers with **15 or more employees**.

While this may seem like a good thing, please remember that laws change but your genes do not. There is no guarantee that GINA or similar laws will always hold, either in the U.S. or elsewhere.

→ More information: <http://www.ginahelp.org/GINAhhelp.pdf>

# Risks to Other Kinds of Insurance

The GINA law does not include all types of insurance:

- **Life Insurance:** GINA does not prohibit life insurance companies from using the results of genetic testing to make decisions about your coverage. If a life insurance company discovers that you have a harmful mutation they could legally use that information. They could make you pay more for the same policy. They may reduce your benefits from that policy.
- **Disability Insurance:** In the same way, GINA makes no prohibition on disability insurance. Your insurer, if they are aware of the results of your genetic test, may use that information to make decisions about your insurance policy.
- **Long-term Care Insurance:** Insurance that covers long-term care, including nursing homes and hospices, is also not included in GINA prohibitions.

# Still want it?

You can still decide not to work with your own data.

If you do:

- Keep in mind that sequencing was not done in a CLIA-certified lab.
- Be careful with sharing!
- Have fun!