How Can My Genes Be Patented?

Presented by:

Jaydee Hanson, International Center for Technology Assessment

Eric Hoffman, Friends of the Earth

Karuna Jaggar, Breast Cancer Action
Goals of this Webinar

Provide background info and context:
• BRCA gene patent
• Gene patents broadly
  - What are they?
  - Why do they matter?
• BCAction’s position on the BRCA patent
• Info and update on the Myriad lawsuit
• How you can take action
BRCA 1 & 2

- BRCA gene is in everyone
- BRCA mutations increase risk of breast and ovarian cancer
- Patents owned by Myriad
- Testing available through Myriad
- Limits of tests currently
What is a patent?

- A license granted by a government to an inventor.
What else is important to know?

- How long does a patent last? Normally 20 years.
- What standards are used?
  - Novelty
  - Not Natural
  - Useful
  - Not a discovery
The US Patent Office allows gene patents

- Under current Patent Office practice, it's possible to hold a patent on a piece of human DNA, otherwise known as a gene.
- Currently, over 4,000 genes have been patented.
Supreme Court ruling on bacteria patent led to gene patents

- **1980**: Diamond v. Chakrabarty - The Supreme Court found in favor of Ananda Mohan Chakrabarty, who claimed to engineer a bacteria to eat oil.

- **2011**: Thousands of gene patents
  - Patents on gene tests
  - Patents on copies of genes
  - Patents on parts of genes
Why patent genes?

- Holding a patent on a human, plant or animal gene gives the holder control over commercial exploitation of that gene. i.e. diagnosis or therapy

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Can a Patent stop Research?

Yes and No
Companies and Gene Patents

- **Winners:** Companies that “discovered the gene”

- **Losers:** Other companies that want to develop products that use knowledge of the gene, i.e. tests, drugs
Most Genetically Associated Diseases Have Multiple Genes or Genetic Variants

- Alzheimer's
- Heart Disease
- Asthma
- Diabetes
- Most Cancers
- MS
Multiple Sclerosis Study finds 29 variants

The UK study compared DNA from 9,772 people with MS with that from 17,376 healthy people. Largest study of the disease.

Photograph: Rex Features
Problems with Gene Patents
Limit Patient Access to Genetic Tests

- Prohibitively high costs for tests
- Not all health insurance providers (particularly Medicaid) cover costs of patented tests
- Prevent second opinion testing
Limit Researchers’ Access to Genetic Information

- 53% of genetics labs stopped doing research due to concerns about patented genes.
- 49% of American Society of Human Genetics members limited research due to gene patents.
- Significant decline in published material on patented genetic information.
- Prevent more affordable and effective tests from being developed.
Profit-Driven Research

- Patents not needed for test development,
- Patents provide economic incentive to find genetic correlations to disease
- Research driven towards what can be patented and profitable
- Shifts focus away from environmental factors of disease
Not Just Breast Cancer Gene Patents

- Other gene patents have stopped research and harmed patients:
  - Hemochromatosis (Mercator Genetics)
  - Myotonic dystrophy (MIT, University of Wales)
  - Canavan disease (Miami Children’s Hospital Research Institute)
  - Huntington’s disease (The General Hospital Corporation)
  - Long QT syndrome (University of Utah)
Other Concerns

- Not just human genes are patented
  - Thousands of plant, animal, bacteria, and viral genes have been patented
  - Ex: SARS and Avian Flu virus patent races
- Bio-piracy
- Religious concerns
BCAction opposes the BRCA patent

We believe:

- Companies cannot own our genes
- Gene patents impede research & innovation
- Myriad’s monopoly harms patients
  - Restricted access to expensive genetic tests
  - Inability to get 2nd opinions
  - Limitations on current test utility
ACLU Lawsuit

• ACLU representing 18 plaintiffs:
  – Researchers
  – Genetic counselors & clinicians
  – Individual women affected
  – Breast cancer and women's health groups
  – Professional associations

• BCAction is the only breast cancer organization named as a plaintiff!
Where are we now?

- March 2010: U.S. District Court rules genes to be unpatentable facts of nature.
- July 2011: Federal Court of Appeals overturned decision; Myriad's gene patents are valid.
- BCAction has been a plaintiff in this lawsuit since 2009. We will continue to inform members of opportunities to take action.
Liberate the Breast Cancer Genes

ACLU video on ACLU and BCAction websites:

How you can take action!

- Orgs can submit *amicus curiae* briefs.
- Individuals can support legislation banning gene patents – call your legislators.
- Talk with others about the harms of gene patents.
- Become a BCAction member & support our work.
Works Cited


3. Myriad Genetic Laboratories. BRCA1 and BRCA2 Prevalence Tables for Mutations Detected by Sequencing, the 5-site Rearrangement Panel (LRP) and the BRACAnalysis® Large Rearrangement Test (BART™) in High Risk Patients. Available at: http://www.myriad.com/lib/brac/BART-table-faq.pdf.


Breast Cancer Action

More questions? Contact us!
Email: info@bcaction.org
Toll-free: 877-2STOPBC

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