From Genealogy to Genetics: Library Programming to Explore Your Roots

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U.S. National Library of Medicine
National Network of Libraries of Medicine
New England Region
Objectives

- Evaluate family genetics in health
- Discover the basics of pedigree lines
- Identify evidence-based, reliable resources for genetics
From Genealogy Programs...
Examples of Programs

**Series on Genealogy How-Tos.** Four-week services lead by genealogist. Introduction to Genealogical Research; Census and Vital Records; Immigration, Naturalization and Migration; Unique Records (military records, land records, wills and probate, DNA).

**Open Labs with Volunteers.** Genealogy Open Lab every Tuesday and Thursday to receive assistance from experienced volunteers and to use the library's valuable resources (Ancestry, Fold3, Heritage Quest, FamilySearch microfilm, books, etc).

**Using Archival Resources to Deepen Your Search.** Learn how to use historic maps to add your genealogical knowledge with retired civil engineer.
… to Genetics Programs
NNLM Support for Programming

Traveling Exhibit on Precision Medicine. *In development.*

Speakers on Genetic Counseling. *In development.*

Moodle Course on Precision Medicine. *This summer!*

Funding Opportunities for Citizen Science and Health Literacy Programs. *Contact your [NNLM region](#) for more information.*
To Find Your Region
Pedigree charting - The Genetic Family Tree

CATHERVNE MARTIN, M.ED.
NATIONAL NETWORK LIBRARIES OF MEDICINE
NEW ENGLAND REGION
Why are we using genetic testing?

- Disease or health risk
- Ancestry or genealogy
- Kinship (biologically related)
- Lifestyle
Learn.Genetics

Family Health History

**RISK**

If a certain disease runs in your family, you may be at risk. To be at risk for a disease means you have a chance of getting it. But you also maybe able to prevent it.

**COMMON RISK-ASSOCIATED DISEASES**

Most common diseases result from a combination of genetic and environmental factors. We inherit genetic factors that make us more or less susceptible to developing a particular disease. But our overall health is also a product of our environment.

Learn more about these diseases, who is at risk, and how that risk can be reduced.

- **HEART DISEASE**
- **ASTHMA**
- **HIGH BLOOD PRESSURE**
- **DIABETES**
- **OSTEOPOROSIS**
- **CANCER**

[https://learn.genetics.utah.edu/content/history/](https://learn.genetics.utah.edu/content/history/)
Basic Pedigree Lines – Family “health tree”

- **Marriage/Mating Line**: horizontal line connecting 2 symbols at the center of each symbol

- **Separated, Divorce, Relationship no longer exists Line**: horizontal line connecting 2 symbols with 2 diagonal hash marks

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**Basic symbols**

- Living Unaffected female: Clear circle
  - [Image: Clear circle]

- Living Unaffected male: Clear square
  - [Image: Clear square]

- Deceased male of female: Black circle or square
  - [Image: Black circle]
  - [Image: Black square]

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[https://medicine.uiowa.edu/humangenetics/resources/how-draw-pedigree/basic-pedigree-symbols](https://medicine.uiowa.edu/humangenetics/resources/how-draw-pedigree/basic-pedigree-symbols)
Drawing the Sibling lines

Sibling Line: Horizontal line above the offspring and connected by vertical lines. Example: brother and sister siblings.

Brother and sister siblings with two parents

Children from a previous partner (stepchildren).
Ex. Mike and Jane have one son, and Jane has a daughter from a previous marriage.
No children: A vertical line with 2 hash marks at the end. Indicate if an adult does not have children by choice (c), infertility (i).

Dizygotic Twins (non-identical): Indicated by two diagonal vertical lines originating at the same point.

Monozygotic Twins (Identical): Indicated by two diagonal vertical lines originating at the same point.
Maternal grandparents (2nd cousins)

- Maternal grandparents: d. 88, dx. Colon CA

Paternal grandparents

- Paternal grandparents: d. 57, MVA CA, d. 90, dx. Bladder

Parents

- Parents: 96 years old, d. 89, Stroke

Key

- Colon cancer
- Bladder cancer

Second-degree relatives
Maternal grandparents were 2nd cousins

Lebanese
- d. 88
- CA

Paternal grandparents
- d. 57
- MVA
- dx. 88 y.o. Bladder cancer non smoker

Parents
- 96 y.o.
- dx. 95 y.o. MI

First-degree relatives

Colon cancer
- 61 y.o.
- obstruction
- 74 y.o.
- dx. 37 y.o. Multiple sclerosis

Bladder cancer
- 60 y.o.

Small bowel cancer
- 58 y.o.
- dx. 78 y.o. Stroke

MVA
- d. 88 y.o. Bladder cancer non smoker
- dx. 88 y.o. Colon

Key
- Colon cancer
- Bladder cancer
- Small bowel cancer
Maternal grandparents were 2nd cousins.

<table>
<thead>
<tr>
<th>Age</th>
<th>Diagnosis</th>
</tr>
</thead>
<tbody>
<tr>
<td>d.88</td>
<td>Colon CA</td>
</tr>
<tr>
<td>36 y.o.</td>
<td>Colon CA</td>
</tr>
</tbody>
</table>

Parents

<table>
<thead>
<tr>
<th>Age</th>
<th>Diagnosis</th>
</tr>
</thead>
<tbody>
<tr>
<td>d.57</td>
<td>MVA</td>
</tr>
<tr>
<td>d.90</td>
<td>Bladder cancer</td>
</tr>
</tbody>
</table>

Colon cancer

Bladder cancer

Small bowel cancer

First-degree relatives, cont.

dx. 87 y.o. seizure
dx. 78 y.o. Stroke
d. unknown

dx. 61 y.o.
dx. 60 y.o.
dx. 58 y.o.
d. 62

dx. 37 y.o. Multiple sclerosis
What does it mean to have a genetic predisposition to a disease?

A genetic predisposition (sometimes also called genetic susceptibility) is an increased likelihood of developing a particular disease based on a person's genetic makeup. A genetic predisposition results from specific genetic variations that are often inherited from a parent. These genetic changes contribute to the development of a disease but do not directly cause it. Some people with a predisposing genetic variation will never get the disease while others will, even within the same family.

Genetic variations can have large or small effects on the likelihood of developing a particular disease. For example, certain mutations in the BRCA1 or BRCA2 genes greatly increase a person's risk of developing breast cancer and ovarian cancer. Variations in other genes, such as TP53 and PTEN, also increase breast cancer risk, but the contribution of these genetic changes to a person's overall risk appears to be much smaller.

Current research is focused on identifying genetic changes that have a small effect on disease risk but are common in the general population. Although each of these variations only slightly increases a person's risk, having changes in several different genes may combine to increase disease risk significantly. Changes in many genes, each with a small effect, may underlie susceptibility to many common diseases, including cancer, diabetes, heart disease, and mental illness.

In people with a genetic predisposition, the risk of disease can depend on multiple factors in addition to an inherited genetic change. These include other genetic factors (sometimes called modifiers), as well as lifestyle and environmental factors. Diseases that are caused by a combination of factors are described as multifactorial. Although a person's genetic makeup cannot be altered, some lifestyle and environmental modifications (such as having more frequent disease screenings and maintaining a healthy weight) may be able to reduce disease risk in people with a genetic predisposition.
GARD: Genetic and Rare Diseases Information Center

About GARD

The Genetic and Rare Diseases Information Center (GARD) is a program of the National Center for Advancing Translational Sciences (NCATS) and is funded by two parts of the National Institutes of Health (NIH): NCATS and the National Human Genome Research Institute (NHGRI). GARD provides the public with access to current, reliable, and easy-to-understand information about rare or genetic diseases in English or Spanish.

Read more about GARD.

https://rarediseases.info.nih.gov/
All of Us Research Program

- Identify risk factors for certain diseases.
- Join people with the right clinical studies.
- Figure out which treatments work for different types of people.
- Explore how technology can encourage people to take better care of their health.

https://nnlm.gov/all-of-us
The NNLM *All of Us* Community Engagement Network (CEN) is part of a partnership between the NIH's *All of Us Research Program* and the National Library of Medicine. The CEN consists of a regional network of health libraries whose mission it is to improve access to biomedical information in the United States, support communities with consumer health information and education to increase health literacy, and raise awareness of the NIH *All of Us Research Program* to accelerate medical breakthroughs and improve individual treatment, prevention, and care for all of us.

[https://nnlm.gov/all-of-us/resources/programming](https://nnlm.gov/all-of-us/resources/programming)
Resources

- Certified Health Information Specialist (CHIS) [https://nnlm.gov/gmr/guides/public-libraries/earn-your-chis](https://nnlm.gov/gmr/guides/public-libraries/earn-your-chis)
- How to Draw a Pedigree Chart [https://medicine.uiowa.edu/humangenetics/resources/how-draw-pedigree](https://medicine.uiowa.edu/humangenetics/resources/how-draw-pedigree)
- Genetic and Rare Diseases Information Center (GARD) [https://ncats.nih.gov/engagement](https://ncats.nih.gov/engagement)
- Medical Library Association [https://www.mlanet.org/p/cm/ld/fid=329](https://www.mlanet.org/p/cm/ld/fid=329)
- Healthy Community Tools for Public Libraries [https://publiclibrary.health/](https://publiclibrary.health/)
Resources, cont.

- The Office of the Surgeon General: My Family Health Portrait (Tool that allows you to enter, print and update your family health history) [https://familyhistory.hhs.gov/](https://familyhistory.hhs.gov/)

- The National Institute of Aging provides suggestions on how to obtain a health history from older individuals [www.nia.gov/health/obtaining-older-patients-medical-history](http://www.nia.gov/health/obtaining-older-patients-medical-history)


- Printable Consumer Health Resources: [https://nnlm.gov/ner/training-education-materials](https://nnlm.gov/ner/training-education-materials)

- Genetic Alliance (My Family Health Portrait & a tool to create personalized booklets) [www.geneticalliance.org](http://www.geneticalliance.org)
Please feel free to contact us with any Questions.

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