GENOMICS: WHY SHOULD WE CARE?

The importance of being: genomic literate

genomic informed
“We can provide you with a healthy and thriving newborn, but why stop there? All of our children are born stronger and healthier. At BrightBorn Technologies we’re making the world a better place, one baby at a time.”
News Headlines

Scientists Say They Hope To Create A Human Genome In The Lab

Humans will be 'irrevocably altered' by genetic editing, warn scientists ahead of summit

An open letter from 150 scientists, campaigners and health experts is calling for a worldwide ban on genetic editing ahead of a summit in Washington

The Genetic Tool That Will Modify Humanity

Crispr allows scientists to control the blueprints of life, for better or worse.

Clinical Genetics Has a Big Problem That's Affecting People's Lives

Unreliable research can lead families to make health decisions they might regret.

British Scientists Seek Permission To Edit DNA In Human Embryos

Having a baby? Best to run a gene screening test

Genetically Modified Humans?

How Genome Editing Works

Birth of Baby With Three Parents’ DNA Marks Success for Banned Technique
Health Literacy
Genomic Literacy

- Genomic health literacy
- Genomic science literacy
- Role of media in genomic literacy
Leading causes of death

1. Heart disease: 614,348
2. Cancer: 591,699
3. Chronic lower respiratory diseases: 147,101
4. Accidents (unintentional injuries): 136,053
5. Stroke (cerebrovascular diseases): 133,103
6. Alzheimer's disease: 93,541
7. Diabetes: 76,488
8. Influenza and pneumonia: 55,227
9. Nephritis, nephrotic syndrome, and nephrosis: 48,146
10. Intentional self-harm (suicide): 42,773
Definitions

- **Genomic Health Literacy**
  - The capacity to obtain, process, understand, and use genomic information for health related decision making.

- **Genomic Science Literacy**
  - The knowledge of basic genetics and genomics concepts and processes needed to build conceptual understanding, and the necessary mathematical knowledge to support this comprehension.
Health Professional Literacy

- Most have no formal training in genetics
- Many lack basic genomic knowledge
- Patients ill-informed, inflated expectations
- Lack of time to keep up to date with the genetic advances
- Uncertainty of relevance and how to incorporate in general practice
- Need to improve medical education and beyond initial training

PMID 19341496 http://www.ncbi.nlm.nih.gov/pmc/articles/PMC2664958/
Health Professional Literacy

Genetic Medicine & Primary Care

- **7 Key Roles of the Primary Care Provider**
  - Evaluate through Screening and Surveillance
  - Use family health history for primary prevention of chronic diseases and to identify patients' need for increased surveillance.
  - Educate Patients and Their Families
  - Discuss the importance of screening, early diagnosis, and how genetic tendencies may be present as an acute manifestation of disease.
  - Explain the Results
  - Review and discuss the meaning of screening, test results, and what to expect from genetic consultation and referral.
  - Make Appropriate Referrals
  - Provide information based on clinical history and ensure soybean follow-up for patients.
  - Coordinate Care with a Subspecialist
  - Initiate co-management plan, including treatment and diagnostic testing when appropriate.
  - Counsel Patients and Families
  - Help them understand and adapt to the implications of a genetic diagnosis.
  - Provide Long-Term Follow-Up and Care
  - Continue to support patients and families and provide primary care through an ongoing relationship within the medical home.

- **Genomics**

Genetics are the key to unlocking answers about many diseases. Testing can be used for screening a variety of diseases and gene mutations.

**GENOMICS**

Genetic testing is now available to the public without the help of a primary care provider.

- Nurses directly interact with patients and will need to be GENOMICALLY COMPETENT.
  - They may guide and counsel patients through results from genetic testing.
  - They may be expected to educate patients about the basics or relevance of genomics.
Consumer Genomic Health Literacy

- Lack biology basics
- Lack mathematical concepts
- Low health literacy
Genomic Science Literacy

- K-12 education unable to keep up with scientific advancements
- Low emphasis on genomics
- Some teachers have misconceptions about genetics/genomics and little understanding
- Teachers need updated skills and have little access to genetic/genomic quality science curriculum
- Encourage partnerships with scientists
- Empower students entering the age of personal genomic medicine
Media role in genomic literacy

- Scientists lack training when communicating with media and general public
- Popular and mass media lack knowledge and often relay incorrect information
- Educators and researchers need to adapt and learn to inform through newer media platforms such as social media and podcasts
NCBI Bookshelf

Genes and Diseases

- Organized by the parts of the body that genetic disorders affect
- Over 80 genetic disorder summaries
- Images and interesting facts
- PDF downloads of chapters
- Links to related research literature and pertinent websites

Genes and Diseases
http://www.ncbi.nlm.nih.gov/books/NBK22183/
National Coalition for Health Professional Education in Genetics (NCHPEG)
Literacy/Education Resources

- CDC Centers for Disease Control and Prevention
- ACMG Translating Genes Into Health
- Public Health Genomics
- Personal Genetics Education Project
- ASHG American Society of Human Genetics
- GENETIC LITERACY PROJECT
- Genes in Life
- Genome UnLocking: Life's Code
Tips for communicating to patients

- Listen, pay attention, respond
- Use plain language
- Use patient’s words
- Slow down
- Limit and repeat content
- Show examples
- Invited patient participating
- Use teach back

Health Literacy and Precision Medicine
Tips for communicating to healthcare professionals

- Bring a family member or a friend
- Write down or record the information
- Speak your mind
- Repeat the information as you understand it
- Ask questions (who, what, where, why, how)
- Ask for more information (website, printed handout, a library)
My Family Health Portrait
U.S. Surgeon General

The Surgeon General's Family Health History Initiative

To help focus attention on the importance of family history, the Surgeon General, in cooperation with other agencies with the U.S. Department of Health and Human Services, has launched a national public health campaign, called the Surgeon General's Family Health History Initiative, to encourage all American families to learn more about their family health history.

Surgeon General's Family Health History Initiative:
My Family Health Portrait

Find out how learning your family’s health history can help you discover your genetic heritage and risks, and guide you in making healthy environment and lifestyle choices. Learn about how to obtain and create a family health history.

- [My Family Health Portrait](https://www.genome.gov/27527640/family-history-my-family-health-portrait/)
- [Family History: Resources and Tools](https://www.cdc.gov)
- [Family Health History Tools](https://geneticalliance.org)
- [NIHSeniorHealth: Creating a Family Health History](https://nhseniorhealth.gov)
My Family Health History

Enter Personal Information

Your Personal Information

We start the family health history with you. Enter the required personal information and your health history information. At the bottom of the page (you may need to scroll), press the 'Next' button. You will then be asked to tell the system which family members you would like to add to the health history.

- Name: 
- Gender:  Male  Female
- Date of Birth:  mm/dd/yyyy
- Were you born a twin?  No  Yes - Identical (Same)  Yes - Not Identical (Fraternal)
- Were you adopted?  Yes
- Height:  Feet  Inches  OR  Centimeters
- Weight:  lbs

Your Health Information

In the list below, select a Disease or Condition (if any) from the dropdown box. Then select the Age at Diagnosis and press the Add button. You may repeat this process as necessary.

<table>
<thead>
<tr>
<th>Disease or Condition</th>
<th>Age at Diagnosis</th>
<th>Action</th>
</tr>
</thead>
<tbody>
<tr>
<td>Please Select a Disease</td>
<td>Select Age at Diagnosis</td>
<td>Add</td>
</tr>
</tbody>
</table>

Your Family Background Information

Check here if your parents are related to each other in any way other than marriage. Multiple races and ethnicities may be selected.

- Race:  American Indian or Alaska Native  Asian  Black or African-American  Native Hawaiian or Other Pacific Islander  White
- Ethnicity:  Hispanic or Latino  Ashkenazi Jewish  Not Hispanic or Latino

Why are we asking about Ashkenazi Jewish heritage?
Does It Run In the Family? toolkit

Consumer Websites
Section: Genetics/Birth Defects

Health Topic pages:
- Genetics
- Genetic testing
- Genetic counseling
- Genetic disorders
- Genes and gene therapy
- text word search
<table>
<thead>
<tr>
<th>Health Topics</th>
<th>Drugs &amp; Supplements</th>
<th>Videos &amp; Tools</th>
</tr>
</thead>
<tbody>
<tr>
<td>Genetics/Birth Defects</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

- Abnormalities see Birth Defects
- Achondroplasia see Dwarfism
- Adrenoleukodystrophy see Leukodystrophies
- Alpha-1 Antitrypsin Deficiency
- Amniocentesis see Prenatal Testing
- Anencephaly see Neural Tube Defects
- Arnold-Chiari Malformation see Chiari Malformation
- Ataxia see Friedreich's Ataxia
- Ataxia Telangiectasia
- Birth Defects
- Blood Coagulation Disorders see Hemophilia
- Brain Disorders, Inborn Genetic see Genetic Brain Disorders
- Brain Malformations
- Canavan Disease see Leukodystrophies
- Cephalic Disorders see Brain Malformations
- Cerebral Palsy
- Charcot-Marie-Tooth Disease
Results 1 - 10 of 945 for **genomics**

1. **Frequently Asked Questions about Genetic and Genomic Science** (National Human Genome Research Institute)
   ... this page Frequently Asked Questions About Genetic and Genomic Science What are genetics and genomics? Why are ... genomic technologies? Additional Resources What are genetics and genomics? Genetics is a term that refers to the ... https://www.genome.gov/18016904 - External Health Links

2. **Genomics and Health Impact Update** (Centers for Disease Control and Prevention)

3. **Brief Guide to Genomics: DNA, Genes and Genomes** (National Human Genome Research Institute)
   ... Breve guía de genómica A Brief Guide to Genomics DNA, Genes and Genomes Deoxyribonucleic acid (DNA) is ... genetic basis for health and disease. Implications of Genomics for Medical Science Virtually every human ailment has ... https://www.genome.gov/18016863 - External Health Links

4. **Genomic Testing** (Centers for Disease Control and Prevention)
Health Conditions

Explore the signs and symptoms, frequency, genetic cause, and inheritance pattern of various conditions, diseases, and syndromes.

Browse by Category

Browse by First Letter

A-1, see aplastic anemia
AAA, see triple A syndrome
AAA syndrome, see triple A syndrome
AADC deficiency, see aromatic L-amino acid decarboxylase deficiency
Aarskog syndrome, see Aarskog-Scott syndrome
Aarskog-Scott syndrome
AAS, see Aarskog-Scott syndrome
AAGA dehydrogenase deficiency, see pyridoxine-dependent epilepsy
AAS syndrome, see Diamond-Blackfan anemia
AAS-Smith syndrome II, see Diamond-Blackfan anemia
AAT, see alpha 1-antitrypsin deficiency

Learn More about Health Conditions

- What does it mean if a disorder seems to run in my family?
- What are the different ways in which a genetic condition can be inherited?
- What are complex or multifactorial disorders?
- What does it mean to have a genetic predisposition to a disease?
breast cancer

- Description
- Frequency
- Genetic Changes
- Inheritance Pattern
- Diagnosis & Management
- Other Names for This Condition
- Additional Information & Resources
- Sources for This Page
- Images

Description

Most cases of breast cancer are not caused by inherited genetic factors. These cancers are associated with somatic mutations in breast cells that are acquired during a person's lifetime, and they do not cluster in families.

In hereditary breast cancer, the way that cancer risk is inherited depends on the gene involved. For example, mutations in the BRCA1 and BRCA2 genes are inherited in an autosomal dominant pattern, which means one copy of the altered gene in each cell is sufficient to increase a person's chance of developing cancer. Although breast cancer is more common in women than in men, the mutated gene can be inherited from either the mother or the father.

In the other syndromes discussed above, the gene mutations that increase cancer risk also have an autosomal dominant pattern of inheritance. It is important to note that people inherit an increased likelihood of developing cancer, not the disease itself. Not all people who inherit mutations in these genes will ultimately develop cancer.

In many cases of breast cancer that cluster in families, the genetic basis for the disease and the mechanism of inheritance are unclear.

Frequency

- Diagnosis & Management

- Inheritance Pattern

- Genetic Changes

- Related Information
  - What does it mean if a disorder seems to run in my family?
  - What are the different ways in which a genetic condition can be inherited?
  - More About Inheriting Genetic Conditions
Resources

Each of the following categories provides links to useful genetics resources on the web.

- Support and Advocacy
- Financial Assistance
- General Genetics
- Genetic Testing
- Classroom Resources
- Clinical/Professional Resources
- Genetics Research
- Bioinformatics Databases
- Genetics News
Genetics Home Reference

Help Me Understand Genetics

Help Me Understand Genetics provides an introduction to fundamental topics related to human genetics, including illustrations and basic explanations of genetics concepts.

- Cells and DNA
- Mutations and Health
- How Genes Work
- Gene Families
- Inheriting Genetic Conditions
- Genetics and Human Traits
- Genetic Consultation
- Genetic Testing
Search Results

**Viewing: All**

- **What is precision medicine?**
  The Centers for Disease Control and Prevention covers precision medicine in its Genomics and Health.

- **What is the difference between precision medicine and personalized medicine?**
  There is a lot of overlap between the terms “precision medicine” and “personalized medicine”.

- **What was the Human Genome Project and why has it been important?**
  GeneEd from the National Library of Medicine and the National Human Genome Research Institute.

- **What were some of the ethical, legal, and social implications addressed by the Human Genome Project?**
  The ELSI (Ethical, Legal, and Social Implications) program was to identify and address issues.

- **What is a genome?**
  A genome is an organism’s complete set of DNA, including all of its genes. Each genome contains all...
Health
Information about genetics and genomics, rare diseases, patient care and more

For Patients and the Public
- Community Engagement and Community Health
- Family History
- Genetics & Genomics Science & Research
- Genetic & Rare Diseases Information Center
- Genomic Medicine and Health Care
- Online Health and Support Resources
- Specific Genetic Disorders

For Health Professionals
- Competency & Curricular Resources
- Genetics 101
- Genomic Medicine and Health Care
- Inter-Society Coordinating Committee (ISCC)
- New Horizons and Research
- Patient Management
- Policy and Ethics Issues

Highlights
NIH awards $55 million to build million-person precision medicine study
Bethesda, Md., Thurs., July 7, 2016 - The U.S. Food and Drug Administration (FDA) has announced two draft guidances to support President Obama’s Precision Medicine Initiative. The guidances will help provide oversight for tests based on next generation sequencing, a technology that examines a person’s DNA to detect medically important differences in genomic make-up that could increase the risk for disease.

See Also
NHGRI https://www.genome.gov/
Direct to Consumer Testing

Genetic Testing
Direct to Consumer Testing
Genomic Testing- Athletic Ability

- Over 36 companies marketing genetic tests
- Endurance and power
- Poor quality control
- Targeted to coaches and parents
- Individuals also wanting to focus training
Genomic Testing - Consensus Statement

Direct-to-consumer genetic testing for predicting sports performance and talent identification: Consensus statement

Nick Webbom,1 Alun Williams,2 Mike McNamee,3 Claude Bouchard,4 Yannis Pittalis,5 Ilidos Ahmetov,6 Euan Ashley,7 Nuala Byrne,8 Silvia Camporesi,9 Malcolm Collins,10 Paul Dijkstra,11 Nir Eynon,12 Noriyuki Fukui,13 Fleur C Garton,14 Nils Hoppe,15 Søren Holm,16 Jane Kaye,17 Vassilis Klissouras,18 Alejandro Lucia,19 Kamil Maase,20 Colin Moran,21 Kathryn N North,14 Fabio Pigozzi,22 Guan Wang5

ABSTRACT

The general consensus among sport and exercise genetics researchers is that genetic tests have no role to play in talent identification or the individualised prescription of training to maximise performance. Despite the lack of evidence, recent years have witnessed the rise of an emerging market of direct-to-consumer marketing (DTC) tests that claim to be able to identify children's athletic talents. Targeted consumers include mainly coaches and parents. There is concern among the scientific community that the current level of knowledge is being misrepresented for commercial purposes. There remains a lack of universally accepted guidelines and legislation for DTC testing in relation to all forms of genetic testing and not just for talent identification. There is concern over the lack of clarity of information over which specific genes or variants are being tested and the almost universal lack of appropriate genetic counselling for the interpretation of the genetic data to consumers. Furthermore independent studies have identified issues relating to quality control by DTC laboratories with different results being reported from the evidence in relation to genetic testing and the limitations of current knowledge. This article reviews the issues around the currently available evidence behind the genetic testing, comments on the ethical considerations and makes recommendations about such tests.

STATEMENT ON BACKGROUND TO THE CONSENSUS PROCESS

A group of world experts in the field of genomics, exercise, sport performance, disease, injury and antidoping gathered with the International Federation of Sports Medicine (FIMS) Scientific Commission for a symposium to discuss the current state of knowledge and to share ideas. One key concern was the misuse of research evidence and the misinformation about genetic testing, particularly when marketed directly to the public, coaches or parents. This is known as DTC testing for the purpose of talent identification and to assess potential for future sports performance. There have been
Concerns

- Privacy
- Legality
- Who has access?
- How useful now?
- What all is being done now and in the future with the information?
- Unexpected surprises?
- Test results can vary among companies
- Validity of tests
- No counseling provided
- Who can get the testing?
Benefits

- Learn more about own health
- More effective medical treatments
- Learn more about ethnicity and family history
- Bring awareness to family health issues for future generations
- Motivation to work on health habits
- Encourages patient engagement
- Contributing to advancement of healthcare and science
- Moral obligation
(example of test results from 23andMe)
What is direct-to-consumer genetic testing?

Traditionally, genetic tests have been available only through healthcare providers such as physicians, nurse practitioners, and genetic counselors. Healthcare providers order the appropriate test from a laboratory, collect and send the samples, and interpret the test results. Direct-to-consumer genetic testing refers to genetic tests that are marketed directly to consumers via television, print advertisements, or the Internet. This form of testing, which is also known as at-home genetic testing, provides access to a person's genetic information without necessarily involving a doctor or insurance company in the process.

If a consumer chooses to purchase a genetic test directly, the test kit is mailed to the consumer instead of being ordered through a doctor's office. The test typically involves collecting a DNA sample at home, often by swabbing the inside of the cheek, and mailing the sample back to the laboratory. In some cases, the person must visit a health clinic to have blood drawn. Consumers are notified of their results by mail or over the telephone, or the results are posted online. In some cases, a genetic counselor or other healthcare provider is available to explain the results and answer questions. The price for this type of at-home genetic testing ranges from several hundred dollars to more than a thousand dollars.

For more information about direct-to-consumer genetic testing:

The American College of Medical Genetics, which is a national association of doctors specializing in genetics, has issued a statement on direct-to-consumer genetic testing [link].

The American Society of Human Genetics, a professional membership organization for specialists in genetics, has also issued a statement on direct-to-consumer genetic testing in the United States.
American College of Medical Genetics and Genomics

Folic Acid
Folic Acid and Neural Tube Defects

Genetic Discrimination
Points to Consider in Preventing Unfair Discrimination Based on Genetic Disease
Risk: A Position Statement of the American College of Medical Genetics and Genomics

Genetic Services
Clinical utility of genetic and genomic services: a position statement of the American College of Medical Genetics and Genomics

Genetic Testing
ACMG Revised Position Statement on Direct-to-Consumer Genetic Testing
ACMG position statement on prenatal/preconception expanded carrier screening
Technical report: ethical and policy issues in genetic testing and screening of children
Risk categorization for oversight of laboratory-developed tests for inherited conditions
Genetic Testing in Adoption (ACMG/ASHG)

Genomic Sequencing
ACMG Policy Statement: Updated Recommendations Regarding Analysis and Reporting of Secondary Findings in Clinical Genome-Scale Sequencing
ACMG Recommendations for reporting of incidental findings in clinical exome and

ACMG https://www.acmg.net/
Ethics and Privacy
Societal Concerns

- Who should have access to personal genetic information, and how will it be used?
- Who owns and controls genetic information?
- How does personal genetic information affect an individual and society's perceptions of that individual?
- What are the larger societal issues raised by new reproductive technologies?
- How will genetic tests be evaluated and regulated for accuracy, reliability and utility?
- How do we prepare healthcare professionals and the public?
- What is considered acceptable diversity?
- Where is the line between medical treatment and enhancement?
- Should testing be performed when no treatment is available?
GINA

GINA Help http://ginahelp.org/
NIH National Human Genome Research Institute

Issues in Genetics
Policy, legal and ethical issues in genetic research

Coverage and Reimbursement of Genetic Tests
Information about insurance coverage for genetic testing

Regulation of Genetic Tests
How the federal government regulates genetic tests.

Intellectual Property and Genomics
Can a gene be patented?

Human Subjects Research
Human subject participation for biomedical, clinical and social-behavioral research

Privacy in Genomics
How best to ensure that genomic information remains private

Genetics and Public Policy Fellowship
A fellowship for genetics professionals interested in public policy

Genetic Discrimination
How Americans are protected from discrimination based on their genetics

Informed Consent
The rights of participants when consenting to research projects

Genome Statute and Legislation Database
A database of state statutes and bills from 2007-2016 U.S. state legislative sessions

Highlights
FDA requests comments on draft guidance for Precision Medicine Initiative

The U.S. Food and Drug Administration (FDA) has announced two draft guidances to support President Obama’s Precision Medicine Initiative. The guidances will help provide oversight for tests based on next generation sequencing.

See Also
Policy and Program Analysis Branch
Staff Contact Information
Ethical, Legal and Social Implications Research Program
NHGRI’s Extramural Research Program
GenomeTV
American Academy of Pediatrics
American College of Medical Genetics and Genomics

Ethical and Policy Issues in Genetic Testing and Screening of Children

COMMITTEE ON BIOETHICS, COMMITTEE ON GENETICS, AND, THE AMERICAN COLLEGE OF MEDICAL GENETICS AND, GENOMICS SOCIAL, ETHICAL, AND LEGAL ISSUES COMMITTEE

Abstract

The genetic testing and genetic screening of children are commonplace. Decisions about whether to offer genetic testing and screening should be driven by the best interest of the child. The growing literature on the psychosocial and clinical effects of such testing and screening can help inform best practices. This policy statement represents recommendations developed collaboratively by the American Academy of Pediatrics and the American College of Medical Genetics and Genomics with respect to many of the scenarios in which genetic testing and screening can occur.

Informing the Public
Precision Medicine

“...a bold new research effort to revolutionize how we improve health and treat disease.”

PMI announcement https://www.whitehouse.gov/precision-medicine
Mission statement:

To enable a new era of medicine through research, technology, and policies that empower patients, researchers, and providers to work together toward development of individualized care.

PMI announcement https://www.whitehouse.gov/precision-medicine
Precision Medicine is...

- Precision medicine is an emerging approach for disease treatment and prevention that takes into account individual variability in genes, environment, and lifestyle for each person.
- Instead of what treatment is right for this disease it is what treatment is right for this patient.
Precision Medicine Initiative

- **Near Term goals:**
  - Clinical trials focusing on pediatric cancers and drug therapies for adults
  - Use of combination therapies
  - Overcoming drug resistance

- **Long Term Goals:**
  - Create research cohort of 1 million volunteers
  - New model of medicine
    - engage participants
    - responsible data sharing
    - privacy protection
  - Advance pharmacogenomics
  - Identify new targets for treatment and prevention
  - Test if mobile devices encourages healthy behaviors
  - Lay scientific foundation for many diseases

[PMI Infographic](http://syndication.nih.gov/multimedia/pmi/infographics/pmi-infographic.pdf)
Two ways to participate

1. Through the cohort website
2. With participating health care provider organization
NIH and Precision Medicine Initiative

Far too many diseases do not have a proven means of prevention or effective treatments. We must gain better insights into the biological, environmental, and behavioral influences on these diseases to make a difference for the millions of Americans who suffer from them. Precision medicine is an emerging approach for disease treatment and prevention that takes into account individual variability in genes, environment, and lifestyle for each person. While some advances in precision medicine have been made, the practice is not currently in use for most diseases.

Genomics health blog
http://blogs.cdc.gov/genomics/
Adventures in Precision Medicine: A Major Public Research Initiative and its Implications for Healthcare Consumers and Institutions

September 21, 2016

Presenter: Malia Fullerton, Associate Professor of Bioethics and Humanities at the University of Washington School of Medicine
Library role

“Preparing the public to make educated personal and family health decisions in a time of rapidly evolving genetic and genomic knowledge will require new partnerships between the education system, health care systems, the government, community advocacy organizations, consumers and the media.”
The 1000 Genomes Project was undertaken in order to increase the ________ of the genomes represented in public databases.

What term refers to strategies for determining what treatment is right for an INDIVIDUAL rather than what treatment is recommended for a DISEASE?

Clinicians are not concerned about all genetic variants – only those that are __________.

True or False? GINA (Genetic Information Nondiscrimination Act) protects you from life insurance discrimination.

True or False? A genetic variant may originally be classified as “likely pathogenic” and later classified as “likely benign.”

What resource would you recommend to consumers who wanted to learn more about a genetic condition?

What is a good starting place for finding genetic information for clinicians?
Questions?

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Biomedical & Translational Sciences Librarian
UW Health Sciences Library
DKNL@uw.edu

Carolyn Martin, MLS, AHIP
Consumer Health Coordinator
NN/LM PNR
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Presentation resources
https://nnlm.gov/pnr/training/presentations