myGenome Resource List

General Disease Resources:
- GeneReviews: https://www.ncbi.nlm.nih.gov/books/NBK1116/
- Genetic and Rare Diseases Information Center (GARD): https://rarediseases.info.nih.gov/
- Global Genes: https://globalgenes.org/
- Mayo Clinic: https://www.mayoclinic.org/diseases-conditions
- National Heart, Blood, and Lung Institute: https://www.nhlbi.nih.gov/
- National Human Genome Research Institute: https://www.genome.gov/
- National Organization for Rare Disorders (NORD): https://rarediseases.org/
- Online Mendelian Inheritance in Man (OMIM): https://www.omim.org/
- Orphanet: http://www.orpha.net/consor/cgi-bin/index.php

Disease Specific Resources:
- Alpha 1 Antitrypsin Deficiency
  - Alpha-1 Foundation: https://www.alpha1.org/
- Alzheimer Disease
  - Alzheimer’s Association: https://www.alz.org/
- Alzheimer’s Prevention Registry: https://www.endalznow.org/
- Cancer
  - American Cancer Society: https://www.cancer.org/
  - National Cancer Institute: https://www.cancer.gov/
  - American Society of Clinical Oncology (ASCO): https://www.cancer.net/
- Cardiac Disorders
  - American Heart Association: http://www.heart.org/HEARTORG/
- Chronic Kidney Disease
  - National Kidney Foundation: https://www.kidney.org/
- Clotting Disorders
  - National Blood Clot Alliance: www.stoptheclot.org
- Cystic Fibrosis
  - Cystic Fibrosis Canada: http://www.cysticfibrosis.ca/?lang=en
  - Cystic Fibrosis Foundation: www.cff.org
- Hereditary Hemochromatosis
  - Hemochromatosis.org: https://www.hemochromatosis.org/
  - Iron Disorders Institute: http://www.irondisorders.org/
- Pulmonary Fibrosis
  - Pulmonary Fibrosis Foundation: http://www.pulmonaryfibrosis.org/
- Malignant Hyperthermia
  - European Malignant Hyperthermia Group: https://www.emhg.org/
  - Malignant Hyperthermia Association of the United States: https://www.mhaus.org/
• Pancreatitis
  ○ National Pancreas Foundation (NPF): www.pancreasfoundation.org
  ○ Pancreatica.org: www.pancreatica.org
  ○ Pancreatic Cancer Action Network: www.pancan.org

• Parkinson Disease
  ○ American Parkinson Disease Association (APDA): www.apdaparkinson.org
  ○ Michael J. Fox Foundation for Parkinson's Research: www.michaeljfox.org
  ○ Parkinson's Foundation: www.parkinson.org

• Prion Disease
  ○ Creutzfeldt-Jakob Disease Foundation, Inc.: www.cjdfoundation.org

Societal Statement and Guidelines:
• American College of Medical Genetics and Genomics (ACMG): https://www.acmg.net/
• American College of Obstetricians and Gynecologists (ACOG): https://www.acog.org/
• Association of Molecular Pathologists (AMP): https://www.amp.org/
• American Society of Human Genetics (ASHG): http://www.ashg.org/
• European Society of Human Genetics (ESHG): https://www.eshg.org/home.0.html
• National Comprehensive Cancer Network (NCCN): www.nccn.org
• National Society of Genetic Counselors (NSGC): www.nsgc.org
• UpToDate: https://www.uptodate.com

General Information on Personalized Medicine:
• Personalized Medicine Coalition (PMC): http://www.personalizedmedicinecoalition.org/

Genetic Testing Resources:
• Concert Genetics: https://www.concertgenetics.com/
• Genetic Test Registry: https://www.ncbi.nlm.nih.gov/gtr/

Genetic Discrimination:
• Genetic Alliance: http://www.geneticalliance.org/advocacy/policyissues/geneticdiscrimination
• Genetic Information NonDiscrimination Act (GINA): http://ginahelp.org/
• National Human Genome Research Institute: https://www.genome.gov/10002328/genetic-discrimination-fact-sheet/

Clinical Trials:
• National Cancer Institute: https://www.cancer.gov/about-cancer/treatment/clinical-trials/search
• NIH: https://clinicaltrials.gov/

Pharmacogenomics:
• Clinical Pharmacogenetics Implementation Consortium (CPIC): https://cpicpgx.org/
• DrugBank: https://www.drugbank.ca/
• Food and Drug Administration (FDA): https://www.fda.gov/Drugs/ScienceResearch/ucm572736.htm
• Mayo Clinic: http://mayoresearch.mayo.edu/center-for-individualized-medicine/drug-gene-testing.asp
• National Human Genome Research Institute: https://www.genome.gov/27530645/faq-about-pharmacogenomics/
• NCBI Medical Genetics Summaries: https://www.ncbi.nlm.nih.gov/books/NBK61999/
• PharmGKB: https://www.pharmgkb.org/
• PharmVar: https://www.pharmvar.org/

Variant Databases and Resources:
• ExAC: http://exac.broadinstitute.org/
• Gnomad: http://gnomad.broadinstitute.org/
Genetics Specialist Locator:

- United States
  - National Society of Genetic Counselors: [https://www.nsgc.org/page/find-a-genetic-counselor](https://www.nsgc.org/page/find-a-genetic-counselor)
  - American College of Medical Genetics: [http://www.acmg.net/ACMG/Genetic_Services_Directory_Search.aspx](http://www.acmg.net/ACMG/Genetic_Services_Directory_Search.aspx)

- Canada
  - Canadian Association of Genetic Counsellors: [https://www.cagc-accg.ca](https://www.cagc-accg.ca)

- Mexico
  - Inmegen: [http://www.inmegen.gob.mx/](http://www.inmegen.gob.mx/)

- United Kingdom
  - GeneHealth UK: [https://www.genehealthuk.com/](https://www.genehealthuk.com/)

- Europe
  - European Society of Human Genetics: [https://www.eshg.org/76.0.html](https://www.eshg.org/76.0.html)

- France

- Australia, New Zealand, and Southeast Asia
  - Genetic Counselling Asia: [https://gc-asia.com/contact-us/](https://gc-asia.com/contact-us/)

- Asia Pacific
  - Asia Pacific Society of Human Genetics: [http://www.psgca.org/programs.html](http://www.psgca.org/programs.html)

- South Africa
  - Health Professions Council of South Africa: [http://isystems.hpcsza.co.za/register/](http://isystems.hpcsza.co.za/register/)

- India
  - Genetics India: [http://www.geneticsindia.org/GeneticCounslingCenter.aspx](http://www.geneticsindia.org/GeneticCounslingCenter.aspx)

- Israel
  - State of Israel Ministry of Health: [https://www.health.gov.il/English/Topics/Genetics/checks/Pages/genetic_counseling_institute.aspx](https://www.health.gov.il/English/Topics/Genetics/checks/Pages/genetic_counseling_institute.aspx)

- Dubai
  - Eastern Biotech and Life Sciences: [http://www.geneticcounseling.ae/](http://www.geneticcounseling.ae/)
  - Dubai Genetics Center (under Dubai Health Authority): [https://www.dha.gov.ae/en/SpecialtyCentres/GeneticsCenter/Pages/About.aspx](https://www.dha.gov.ae/en/SpecialtyCentres/GeneticsCenter/Pages/About.aspx)

Additional Disease Specific Resources:

- Hereditary Breast and Ovarian Cancer syndrome
  - Bright Pink: [https://www.brightpink.org/take-action/get-support/](https://www.brightpink.org/take-action/get-support/)
  - Susan G. Komen: [https://ww5.komen.org/](https://ww5.komen.org/)

- Li-Fraumeni syndrome
  - Li-Fraumeni Syndrome Association: [https://www.lfsassociation.org/](https://www.lfsassociation.org/)
  - Living LFS: [https://www.livinglfs.org/](https://www.livinglfs.org/)

- Lynch syndrome
  - Lynch Syndrome International: [https://lynchcancers.com/](https://lynchcancers.com/)

- Gastrointestinal polyposis syndromes (including Familial Adenomatous Polyposis (FAP, AFAP) syndrome, Juvenile polyposis, Lynch, MYH/MUTYH-Associated Polyposis (MAP), and Peutz-Jeghers syndromes)
  - Colorectal Cancer Alliance: [https://www.ccalliance.org/](https://www.ccalliance.org/)

- Von Hippel-Lindau syndrome
- VHL Alliance: https://www.vhl.org
- PTEN hamartoma tumor syndrome (Cowden syndrome)
  - PTEN Foundation: https://ptenfoundation.org/
- Retinoblastoma
  - American Childhood Cancer Organization: https://www.acco.org/
  - Retinoblastoma.com: http://retinoblastoma.com/
  - World Eye Cancer Hope: https://wechope.org/
- Hereditary paraganglioma-pheochromocytoma syndrome, Multiple endocrine neoplasia types 1 and 2, and Familial medullary thyroid cancer
  - American Multiple Endocrine Neoplasia Support: http://amensupport.org/
  - Association for Multiple Endocrine Neoplasia Disorders (AMEND): https://www.amend.org.uk/
  - Pheo Para Troopers: www.pheoparatroopers.org
- Tuberous sclerosis complex
  - TSC Canada: http://www.tscanada.ca
  - Tuberous Sclerosis Alliance: https://www.tsalliance.org/
  - Tuberous Sclerosis Association: http://www.tuberous-sclerosis.org
- Neurofibromatosis type 2
  - Children’s Tumor Foundation: http://www.ctf.org/
  - Neurofibromatosis Network: https://nfnetwork.org/
  - Neuro Foundation: https://www.nfauk.org/
  - Tumor Foundation of BC: http://www.tumourfoundation.ca/
- Ehlers-Danlos syndrome, vascular type
  - Ehlers-Danlos Society: https://www.ehlers-danlos.com
- Marfan and Loeys-Dietz syndromes
  - Genetic Aortic Disorders Association Canada: http://www.gadacanada.ca/
  - Hypermobility Syndromes Association: http://hypermobility.org/
  - National Marfan Foundation: http://www.marfan.org
- Familial thoracic aortic aneurysms and dissections
  - John Ritter Research Program in Aortic and Vascular: http://www.johnritterresearchprogram.org/
  - Thoracic Aortic Disease Coalition: http://www.tadcoalition.org/
- Hypertrophic and Dilated Cardiomyopathies and Arrhythmogenic right ventricular hypertrophy
  - Cardiomyopathy UK: https://www.cardiomyopathy.org/
  - Dilated Cardiomyopathy Research Project: https://dcmproject.com/
  - Hypertrophic Cardiomyopathy Association: https://www.4hcm.org/index.asp
  - Sarcomeric Human Cardiomyopathy Registry (SHaRe): https://theshareregistry.org/
- Fabry Disease
  - The Society for Mucopolysaccharide Diseases (MPS): http://www.mpssociety.org.uk/
  - National Fabry Disease Foundation: www.mpssociety.co.uk
- Romano-Ward long-QT syndromes type 1, 2, and 3, Catecholaminergic polymorphic ventricular tachycardia, and Brugada syndrome
  - Sudden Arrhythmia Death Syndromes (SADS): http://www.sads.org
- Familial hypercholesterolemia
  - British Heart Foundation: https://www.bhf.org.uk/heart-health/conditions/familial-hypercholesterolaemia
  - FH Foundation: https://thefhfoundation.org/
- Wilson disease
  - American Liver Foundation: www.liverfoundation.org
  - Canadian Liver Foundation: http://www.liver.ca/
● Wilson Disease Association: http://wilsonsdisease.ca

○ Ornithine transcarbamylase deficiency
  ○ Children Living with Inherited Metabolic Diseases (formally known as CLIMB): https://www.metabolicsupportuk.org/
  ○ National Urea Cycle Disorders Foundation: www.nucdf.org
  ○ Urea Cycle Disorders Consortium: https://www.rarediseasesnetwork.org/cms/ucdc

● Malignant hyperthermia susceptibility
  ○ European Malignant Hyperthermia Group: https://www.emhg.org/
  ○ Malignant Hyperthermia Association of the United States (MHAUS): https://www.mhaus.org/