

## **myGenome Resource List**

### **General Disease Resources:**

- Clinical Genome Resource (ClinGen): <https://www.clinicalgenome.org/>
- GeneReviews: <https://www.ncbi.nlm.nih.gov/books/NBK1116/>
- Genetics Home Reference (GHR): <https://ghr.nlm.nih.gov/>
- 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 Institute of Diabetes and Digestive and Kidney Disorders: <https://www.niddk.nih.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.endalznw.org/>
- National Institute on Aging: <https://www.nia.nih.gov/health/alzheimers-disease-fact-sheet>
- 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](http://www.stoptheclot.org)
- Cystic Fibrosis
  - Cystic Fibrosis Canada: <http://www.cysticfibrosis.ca/?lang=en>
  - Cystic Fibrosis Foundation: [www.cff.org](http://www.cff.org)
- Hereditary Hemochromatosis
  - Hemochromatosis.org: <https://www.hemochromatosis.org/>
  - Iron Disorders Institute: <http://www.irondisorders.org/>
- Pulmonary Fibrosis
  - ALA: [www.lung.org/lung-health-and-diseases/lung-disease-lookup/pulmonary-fibrosis/](http://www.lung.org/lung-health-and-diseases/lung-disease-lookup/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](http://www.pancreasfoundation.org)
  - Pancreatca.org: [www.pancreatca.org](http://www.pancreatca.org)
  - Pancreatic Cancer Action Network: [www.pancan.org](http://www.pancan.org)
- Parkinson Disease
  - American Parkinson Disease Association (APDA): [www.apdaparkinson.org](http://www.apdaparkinson.org)
  - Michael J. Fox Foundation for Parkinson's Research: [www.michaeljfox.org](http://www.michaeljfox.org)
  - Parkinson's Foundation: [www.parkinson.org](http://www.parkinson.org)
- Prion Disease
  - Creutzfeldt-Jakob Disease Foundation, Inc.: [www.cjdfoundation.org](http://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](http://www.nccn.org)
- National Society of Genetic Counselors (NSGC): [www.nsgc.org](http://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 Intitute: <https://www.genome.gov/10002328/genetic-discrimination-fact-sheet/>
- US Equal Employment Opportunity Commision: <https://www.eeoc.gov/laws/types/genetic.cfm>

#### **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:**

- ClinVar: <https://www.ncbi.nlm.nih.gov/clinvar/>
- ExAC: <http://exac.broadinstitute.org/>
- Gnomad: <http://gnomad.broadinstitute.org/>
- Human Gene Mutation Database (HGMD): <https://portal.biobase-international.com/hgmd/pro/start.php>

## Genetics Specialist Locator:

- United States
  - National Society of Genetic Counselors: <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>
- Mexico
  - Inmegen: <http://www.inmegen.gob.mx/>
- United Kingdom
  - Association of Genetic Nurses and Counsellors (AGNC):  
<http://www.agnc.org.uk/information-education/genetics-centres/>
  - GeneHealth UK: <https://www.genehealthuk.com/>
- Europe
  - European Society of Human Genetics: <https://www.eshg.org/76.0.html>
- France
  - French association of genetic counselors: <http://af-cg.fr/cg-par-region-2/>
- Australia, New Zealand, and Southeast Asia
  - Human Genetics Society of Australasia: <https://www.hgsa.org.au/asgc/find-a-genetic-counsellor>
  - Genetic Counselling Asia: <https://gc-asia.com/contact-us/>
- Asia Pacific
  - Asia Pacific Society of Human Genetics: <http://www.psgca.org/programs.html>
- South Africa
  - Health Professions Council of South Africa: <http://isystems.hpcsa.co.za/iregister/>
- India
  - Genetics India: <http://www.geneticsindia.org/GeneticCounselingCenter.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)
  - Hadassah Medical Center:  
<http://www.hadassah-med.com/medical-care/departments/genetics-and-metabolic-diseases>
- Dubai
  - Eastern Biotech and Life Sciences: <http://www.geneticcounseling.ae/>
  - Dubai Genetics Center (under Dubai Health Authority):  
<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/>
  - Facing Our Risk of Cancer Empowered (FORCE): <http://www.facingourrisk.org/index.php>
  - Susan G. Komen: <https://www5.komen.org/>
- Li-Fraumeni syndrome
  - Li-Fraumeni Syndrome Association: <https://www.lfsassociation.org/>
  - Living LFS: <https://www.livinglfs.org/>
- Lynch syndrome
  - Lynch Syndrome International: <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/>
  - Hereditary Colon Cancer Takes Guts (Hereditary Colon Cancer Foundation):  
<http://www.hcctakesguts.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](http://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>
  - Ehlers-Danlos Support UK: <https://www.ehlers-danlos.org/what-is-eds/information-on-eds/vascular-eds/>
- Marfan and Loeys-Dietz syndromes
  - Genetic Aortic Disorders Association Canada: <http://www.gadacanada.ca/>
  - Hypermobility Syndromes Association: <http://hypermobility.org/>
  - Loeys-Dietz Syndrome Foundation: <http://www.loeysdietz.org/en/>
  - 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](http://www.mpssociety.co.uk)
- Romano-Ward long-QT syndromes type 1, 2, and 3, Catecholaminergic polymorphic ventricular tachycardia, and Brugada syndrome
  - Centre for Genetics Education Australia Fact Sheet: <http://www.genetics.edu.au/publications-and-resources/facts-sheets/fact-sheet-58-primary-arrhythmogenic-c-disorders>
  - 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 Australasia Network: <https://www.athero.org.au/fh/>
  - FH Foundation: <https://thefhfoundation.org/>
- Wilson disease
  - American Liver Foundation: [www.liverfoundation.org](http://www.liverfoundation.org)
  - Canadian Liver Foundation: <http://www.liver.ca/>

- Wilson Disease Association: <http://wilsonsdisease.ca>
- Ornithine transcarbamylase deficiency
  - European registry and network for intoxication type metabolic diseases: <http://www.e-imd.org/en/index.phtml>
  - Children Living with Inherited Metabolic Diseases (formally known as CLIMB): <https://www.metabolicsupportuk.org/>
  - National Urea Cycle Disorders Foundation: [www.nucdf.org](http://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/>