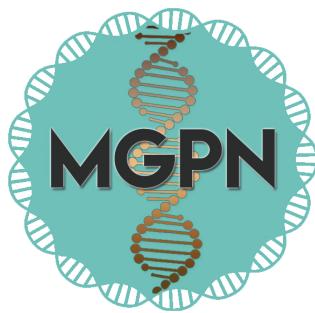


# GENETIC COUNSELING PATIENT RESOURCES EN ESPAÑOL



Brought to you by the MGPN Hispanic/Latinx Subgroup



## OUR GOALS

This document contains links to websites, videos, and documents of Spanish medical genetics resources for patients. These media sources have been vetted by members of the MGPN Hispanic/Latinx subgroup. These members include genetic counselors, genetic counseling students, and prospective students. To celebrate Hispanic Heritage month we felt inclined to give back to our community by compiling and looking over Spanish resources to share among the genetics community. In sharing these resources with the public we hope to reduce the obstacles that exist in communicating complex medical genetic information to Spanish-speaking patients, which is crucial to providing appropriate healthcare.

## DISCLAIMER

These patient educational resources do not belong to MGPN. The links were working as of September 2020; however, we are unable to ensure their service will remain in the future. Furthermore, the content in this document is not intended to be a substitute for professional medical advice, diagnosis, or treatment. Always seek the advice of a physician or other qualified health provider with any questions you may have. Sharing these resources does not constitute endorsement of the information provided. The resources have not been fully vetted for content.

## ACKNOWLEDGEMENTS

Special thanks to the following MGPN Members for their contribution:

Daniela Diaz Caro  
Amanda De Leon  
Laurie Simone  
Carina Aviles  
Jesus Resendiz

## FEEDBACK

If you have additional resources you would like to add to this document or have questions or concerns regarding resources listed here (link broken, information outdated, incorrect information, etc.), please provide us with your feedback by emailing us at [LatinxMGPN@gmail.com](mailto:LatinxMGPN@gmail.com).

# GENERAL

[Medline plus in Spanish](#): large resource of genetic conditions for patients (documents, images)

[Multilingual Toolkit](#): various languages including Spanish, Arabic, American Sign Language, Chinese and more.

[Lexigene](#): vocabulary of genetic terms in Spanish

[Genetic Counseling Glossary](#): common phrases and conditions in Spanish

[Talking Glossary of Genetic Terms](#): NIH vocabulary with read aloud capability and images

[Wheel of feelings](#) (document)

[NSGC Genetic Counselor Awareness Day 2019 graphics](#) (document)

# PRENATAL GENETICS

[Prenatal Genetic Tests - Merck](#) (website)

- Test available and procedures

[CVS](#) (video)

[Prenatal Genetic Tests - Medline](#) (website)

[Hydrocephalus](#) (document)

[Prenatal Genetic Counseling](#) (website & video)

[Prenatal Ultrasounds](#) (video)

- For patients that consider genetic testing

[Cell-free DNA](#) (video)

[Assisted reproductive technology](#) (document)

Deciding to have [Prenatal Testing Questions](#) (document)

[Amniocentesis](#) (video)

# CARDIOGENETICS

[HCM](#) (website)

[Long QT syndrome](#) (website)

[Dilated Cardiomyopathy](#) (website)

[Atrial fibrillation](#) (document)

[Brugada syndrome - Mayo Clinic](#) (website)

[Familial hypercholesterolaemia](#) (website)

[Brugada syndrome - Texas Heart Institute](#) (website)

# PEDIATRIC GENETICS

- [Hemophilia](#) (website & document)
- [Ichthyosis](#) (website)
- [Tuberous sclerosis](#) (video & documents)
- [Prader-Willi Syndrome](#) (website)
- [Noonan Syndrome](#) (website)
- [Marfan Syndrome](#) (website)
- [Kabuki Syndrome](#) (website)
- [Neurofibromatosis](#) (website & documents)
- [Angelman Syndrome](#) (website)
- [Osteogenesis Imperfecta](#) (website)
- [Down syndrome](#) (documents)
  - Overview of what is down syndrome
  - What causes down syndrome
  - How it is diagnosed
  - Signs to pay attention to when aging
  - Guide for future parents
- [Fragile X syndrome](#) (website)
- [Cystic Fibrosis](#) (website)
- [Albinism](#) (website)
- [Deaf and Blindness](#) (website)
  - Other patient resources (documents)
- [CHARGE syndrome](#) (document)
- [Congenital Adrenal Hyperplasia](#) (website)
- [Craniosynostosis](#) (website)
  - Apert Syndrome
  - Crouzon Syndrome
  - Pfeiffer Syndrome
  - Saethre-Chotzen Syndrome
  - Muenke syndrome
- [Carpenter syndrome](#) (website & video)
- [Skeletal Dysplasias](#) (documents)
  - Achondroplasia
  - Campomelic dysplasia
  - Hypochondroplasia
  - Morquio Syndrome
  - Pseudoachondroplasia
  - Multiple epiphyseal dysplasia

# BIOCHEMICAL GENETICS

- [PKU](#) (website)
- [Lysosomal storage disease](#) (website)
  - Gaucher Disease
  - Tay-Sachs
  - Niemann-Pick
- [Fabry disease](#) (website)
- [Mucopolysaccharidoses](#) (website)

# NEUROGENETICS

[Huntington's Disease](#) (documents)

- Juvenile Huntington's Disease
- Guide for predictive testing
- Information on long term care
- Nutrition and Therapy guide

[Muscular Dystrophies](#) (documents)

- Amyotrophic Lateral Sclerosis
- Charcot-Marie-Tooth & Related Diseases
- Duchenne & Becker Muscular Dystrophies (DMD and BMD)
- Facioscapulohumeral Muscular Dystrophy (FSHD)
- Friedreich's Ataxia (FA)
- Facts About Genetics and Neuromuscular Diseases
- Inflammatory Myopathies (Myositis)
- Limb-Girdle Muscular Dystrophies (LGMD)
- Myotonic Muscular Dystrophy (DM, or MMD)
- Spinal Muscular Atrophy (SMA)

[Neurogenetic conditions](#) (website)

- Creutzfeldt-Jakob disease
- Guillain Barre syndrome
- Rett syndrome
- Batten Disease
- Febrile Seizure

[Seizures](#) (website)

[Amyotrophic lateral sclerosis -ALS](#) (website)

[Alzheimer's disease](#) (website)

## LABORATORY AND BILLING

[Buccal swab collection instructions](#) (document)

[Insurance authorization instructions](#) (document)

## RARE CONDITIONS

[Guide for patients with rare conditions](#) (website)

[Advice for families not diagnosed](#) (website)

# CANCER GENETICS

## [UTSW Hereditary Cancer Syndromes](#) (documents)

- APC
- ATM
- AXIN2 - associated cancers
- BAP1 - associated cancers
- Birt Hogg Dube Syndrome
- BRIP1 - associated cancers
- CHEK2 - associated cancers
- Constitutional Mismatch Repair Deficiency
- Cowden Syndrome
- DICER1-Associated Cancer
- Familial Adenomatous Polyposis
- Familial Atypical Mole and Malignant Melanoma
- Fanconi Anemia
- Gorlin Syndrome/Nevoid basal cell carcinoma
- GREM1 - associated cancers
- Hereditary breast and ovarian cancer
- Hereditary leiomyomatosis and renal cell cancer
- Hereditary leukemia
- Hereditary papillary renal cell cancer
- Hereditary pheochromocytoma/paranglioma
- Hereditary retinoblastoma
- HOXB13-Associated cancers
- Juvenile Polyposis syndrome
- KIT-Associated cancers
- Li-Fraumeni syndrome
- Lynch Syndrome
- MC1R- associated cancers
- MRE11A-associated cancers
- Von Hippel Lindau
- Tuberous sclerosis
- Rhabdoid tumor predisposition type 2

## [St. Judes Hereditary Cancer List](#) (website)

- Ataxia-Telangiectasia
- Beckwith-Wiedemann Spectrum
- Constitutional Mismatch Repair Deficiency Syndrome
- Diamond Blackfan Anemia (DBA)
- DICER1 Syndrome
- Familial Adenomatous Polyposis
- Familial Hemophagocytic Lymphohistiocytosis
- Hereditary Leiomyomatosis
- Hereditary Neuroblastoma
- Hereditary Paraganglioma-Pheochromocytoma
- Hereditary Retinoblastoma
- Juvenile Polyposis Syndrome
- Li-Fraumeni Syndrome
- Multiple Endocrine Neoplasia Type 1
- Multiple Endocrine Neoplasia Type 2
- Neurofibromatosis Type 1
- Neurofibromatosis Type 2
- Nevoid Basal Cell Carcinoma Syndrome
- Noonan Syndrome
- Peutz-Jeghers Syndrome
- PTEN Hamartoma Tumor Syndrome
- Rhabdoid Tumor Predisposition Syndrome
- Von Hippel Lindau Syndrome
- WT1-Related Syndromes
- X-linked Lymphoproliferative Syndrome

[BRCA1/2 - NIH](#) (website)

[BRCA1/2 - Basser](#) (website)

[Lynch syndrome](#) (document)

[Li-Fraumeni syndrome](#) (website)

[Cowden syndrome](#) (website)

[Familial adenomatous polyposis syndrome](#) (website)