

Helpful Resources

Gene Reviews (CFC entry): <http://www.ncbi.nlm.nih.gov/books/NBK1186/>

GeneTests

<https://www.genetests.org/>

Find laboratories that test for CFC syndrome. GeneTests is a medical genetics information resource developed for physicians, genetic counselors, other healthcare providers and researchers. Their goal is to improve and simplify searches for tests, clinics, and related information from external links, while maintaining the excellence you have come to expect from GeneTests.

Genetic Alliance

<http://www.geneticalliance.org/>

Genetic Alliance is one of the world's leading nonprofit health advocacy organizations. We engage individuals, families, and communities to transform health. Trying to find information and interventions for disease, searching for health information, and/or trying to find ways to participate in research is difficult. We create ways to make it easier to find or build solutions in health services and research.

Our network includes more than 1,200 disease-specific advocacy organizations, as well as thousands of universities, private companies, government agencies, and public policy organizations. The network is a dynamic and growing open space for shared resources, creative tools, and innovative programs.

Global Genes

<http://globalgenes.org>

Global Genes™ is one of the leading rare disease patient advocacy organizations in the world. The non-profit organization promotes the needs of the rare disease community under a unifying symbol of hope – the [Blue Denim Genes Ribbon™](#). What began as a grassroots movement in 2009, with just a few rare disease parent advocates and foundations, has since grown to over 500 global organizations.

National Organization for Rare Disorders (NORD)

<http://www.rarediseases.org>

The National Organization for Rare Disorders (NORD), a 501©(3) organization, is a unique federation of voluntary health organizations dedicated to helping people with rare “orphan” diseases and assisting the organizations that serve them. NORD is committed to the identification, treatment, and cure of rare disorders through programs of education, advocacy, research, and service.

RASopathies Network

<http://rasopathiesnet.org>

Rasopathies are a group of genetic syndromes that are as common as 1:1000. The RASopathy syndromes include: cardio-facio-cutaneous (CFC), Costello (CS), Leopard/NSML, Neurofibromatosis type 1 (NF1), and Noonan (NS).