



YOU ARE NOT ALONE

Support Networks for Genetic Conditions

Community Research Education Advocacy Resources

What is a Genetics Network?

Genetics networks strive to make life easier for people affected by genetic conditions. They offer a sense of community, and provide information and resources. Many support research. Each network has its own personality, priorities and activities. Most networks focus on a particular genetic condition or group of conditions.

Genetics networks may call themselves lay advocacy groups, support groups, networks, etc. A network may be local, regional or national in scope. Some have paid staff and others are volunteer organizations. Depending on the condition, size of the organization and history of the network, various services and resources are provided which may include:

- educational conferences
- regular meetings
- a web site
- a toll-free phone line
- printed materials
- research incentives and support
- scholarships for family education
- matching services for: individuals, families, or professionals

Services are usually free of charge.

What Can a Genetics Network Provide?

Genetics conditions often have a profound influence on our lives, but finding information and resources can be challenging. Genetics networks can help you find what you need.

Community

One important role of a genetics support network is emotional support. Participants share their experiences through group meetings, matching families, one-to-one contact, social activities, or sponsoring an Internet web site with stories and photographs.

Individuals and families are experts on living day-to-day with their condition. They are most likely to have to have practical information about:

- equipment,
- behavior management strategies, and
- lifestyle suggestions.

Resources

In addition to being a rich source of information, networks can also link individuals to other helpful resources. For example:

- health care professionals,
- legal aid,
- recreation opportunities, or
- social services.

Education

People with a specific condition and their loved ones are motivated to learn about their condition. Medical information for individuals, families and their health care providers is shared in the form of:

- conferences,
- newsletters,
- pamphlets,
- fact sheets, and
- web sites.

Some networks focus on educating the public or policy makers.

Advocacy

Networks can help you advocate for the things you need from:

- schools
- workplaces, or
- insurance companies.

Some genetics networks are strong political advocates.

Research

Networks stay up-to-date on the latest research on their condition and are often the first to hear of new treatments or breakthroughs. Networks offer their members the opportunity to:

- keep up with recent advances,
- participate in research, and
- fund research.

Why Contact a Genetics Network?

It is often helpful to learn from others. Whether you are looking for support or information, there is likely a network that can help. Networks keep information about people who contact them confidential.

You may:

- choose to take a leadership role or even start your own network;
- become active in a group and reach out to others;
- take only the information that you find useful; or
- not contact a network at all, but have the assurance that it is there if you need it.

Many find that contact is most important when they first learn of their diagnosis, or when facing a new life stage (school age, adolescence, etc.). You can choose what works for you.

How do I find a Genetics Network?

A genetics specialist can often direct you to local services, or contact one of the following organizations:

Genetic Alliance ,Inc.
800-336 GENE (4363)
www.geneticalliance.org

Family Village
www.familyvillage.wisc.edu

Family Voices
1-888-835-5669
www.familyvoices.org

NORD
800-999-6673
www.rarediseases.org

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Regional Genetics Group. PacNoRGG
maintains a directory of genetics networks
based in Alaska, Idaho, Oregon &
Washington on its web site:

<http://www.pacnorgg.org/publications.htm>

Copies of this booklet can be obtained
from the PacNoRGG web site.

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