Resources for Patients and Families

**Genetic Alliance** ([http://geneticalliance.org](http://geneticalliance.org))
- This Web site is useful for health care providers as well as families.
- This well-organized Web site includes a directory of genetic support groups that can be found by clicking on specific genetic disorders, which are listed alphabetically.
- Links to the support groups, as well as contact information are provided.
- Parent information on newborn screening tests, similar to the ACMG ACT sheets, can be found at [www.babysfirsttest.org](http://www.babysfirsttest.org).

**Unique Rare Chromosome Group** ([www.rarechromo.org](http://www.rarechromo.org))
- This family-friendly Web site includes information only about rare chromosomal disorders.
- Specific cytogenetic variation leaflets written in English, German, Spanish, French and Italian can be found on this Web site.

**National Organization of Rare Disorders** ([www.rarediseases.org](http://www.rarediseases.org))
- This Web site for medical providers and families contains descriptions, symptoms, causes and treatments for rare disorders, as well as links to support groups.