



RESOURCES:

- NIH Office of Rare Diseases (ORD)
http://rarediseases.info.nih.gov/asp/resources/rardis_info.asp
- National Organization for Rare Disorders (NORD) <http://www.rarediseases.org>
- National Human Genome Research Institute: "Undiagnosed Condition in a Child"
<http://www.genome.gov/17515951>
- Genetics Education Center: University of Kansas Medical Ctr. "Unknown Conditions"
<http://www.kumc.edu/gec/prof/genecntr.html>
- National Library of Medicine/Medline Plus
<http://www.nlm.nih.gov/medlineplus>
- National Society of Genetic Counselors
<http://www.nsgc.org/resourcelink.cfm>
- Syndromes Without a Name (UK)
<http://www.undiagnosed.org.uk>
- S.W.A.N. in Australia
<http://www.swanaus.bigpondhosting.com>

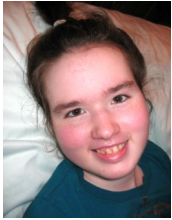


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Syndromes
Without
A
Name
USA

SWAN-USA,
providing support, information,
and connections to families of
children with undiagnosed
medical conditions



What is a Syndrome?

- A **Syndrome** is a group of signs, symptoms, or features that occur together and create a picture which may suggest the presence of a particular medical condition or disorder.
- **Symptoms** are subjective evidence of a medical condition that are experienced by a patient and reported in the medical history such as pain, nausea, or dizziness.
- **Signs** are objective evidence of a disorder that a physician, or nurse can recognize during a physical examination such as wheezing, visual impairment, or a seizure.
- Signs and symptoms are important tools that can help a physician make a diagnosis.
- Some children have only a single symptom, while other children may have a number of symptoms affecting multiple body systems.
- Medical researchers have identified over 6000 rare medical conditions.
- Many disorders have similar signs and symptoms, making diagnosis difficult.
- Specific symptoms of some disorders may not appear until a child is older.
- Some children have signs and symptoms that are so unique, physicians are unable to make a diagnosis.



Why is a Diagnosis Important?

- Information
- Support
- Services
- Treatment Options
- Planning

Without a name or “label” for your child’s condition, you may have difficulty obtaining reliable information to help you understand your child’s medical condition, finding qualified medical professionals, gaining access to healthcare supports, or even making plans for the school programs your child may need. Finding ways around the “system” to obtain services, or insurance coverage can be confusing, overwhelming, or provoke feelings of anger. You may feel isolated or alone as your child is referred from one specialist to another in the search for a diagnosis. Dealing with physicians or medical professionals can be frustrating due to the long waits, limited appointment time, and difficulty finding a specialist who may be able to offer helpful advice on treatment options, testing, or clinical trials. You may feel like you are living in “limbo;” unsure what the future holds for your child and the rest of the family.

SWAN-USA is there to help by offering your family a place to talk, and gain information, advice, ideas, and even encouragement for managing your child’s unique medical condition. Although our members children may not have the same exact symptoms as your child, there are many families in a similar situation—living with a child who has an undiagnosed rare disorder. Medical researchers estimate that about 33% of children with special healthcare needs lack a specific diagnosis.

Who is SWAN-USA?

SWAN-USA is a non-profit organization dedicated to providing support to the families of children living with an undiagnosed medical condition. Our goal is to be a resource for patients, their families and the medical community. We try to help families with similar conditions connect for mutual support, help understanding medical information, and exchange ideas, advice, or information through our website and our online support group. Our mission is to :

- Promote policies that will improve the quality of life, health, and welfare of those lacking a diagnosis.
- Provide educational information, programs and support through our newsletter, emails, online support group, and website.
- Help patients and their families obtain benefits, support services, insurance coverage, and medical programs.
- Create a database of undiagnosed syndromes that can be used by physicians as a tool for identifying “unique” conditions.
- Connect with international groups to raise public awareness and understanding of children living with undiagnosed disorders.
- Create a network of medical professionals who can offer advice, support, or help.

For more information, or to join SWAN-USA, please visit our website: www.undiagnosed-usa.org

Or contact:

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