



Surrounding the Question for Children Undiagnosed

Why is a Diagnosis Important?

- Information
- Support
- Services
- Treatment Options
- Planning

Who is SWAN-USA?

We are an organization that advocates for children and young adults who have syndromes without a name. We offer support, advice and information on the challenges that families face when there is no diagnosis. We also advocate for changes in the medical community that will benefit undiagnosed individuals.

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

We **advocate** for

- awareness/recognition by medical community, education system, social services, general public
- more dialogue within the medical community with respect to undiagnosed cases
- increased continuity of care among/between specialists and primary care physicians
- improving the diagnostic process by attempting to participate in/create a database in order to make diagnostic connections
- potentially new programs to protect children/families without a diagnosis from "falling through the cracks" and to allow them to access appropriate services

For more information, or to join SWAN-USA,

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We **provide support** to parents/children/families in order to

- address the lack of information families have without a diagnosis
- offer empathy/understanding/connections to other families
- motivate and empower parents/families to advocate for the best healthcare/services for their child
- we help to address psychosocial concerns such as feelings of isolation, guilt, helplessness, frustration, emotional distress, etc.

