PRISMS Mission, Vision, Values

MISSION

PRISMS is dedicated to providing information and support to families of persons with Smith-Magenis Syndrome (SMS), sponsoring research and fostering partnerships with professionals to increase awareness and understanding of SMS.

The organization places critical focus on providing programs/services and support in areas of education, awareness, and research.

VISION

PRISMS is the leader of the worldwide Smith-Magenis Syndrome community and engages, inspires, and empowers families, physicians, educators, researchers, and others so they can support and improve the lives of everyone affected by SMS

VALUES

Compassionate - We are a compassionate organization that cares deeply about the well-being and the needs of each and every individual within the SMS community.

Empowering - We empower families with the knowledge they need to make the best decisions for their family's needs.

Conscientious - We are conscientious in ensuring that all of our actions and practices serve the needs of the SMS community.

Inclusive - We encourage and seek participation from all those interested in advocating for and creating a positive impact for the SMS community.

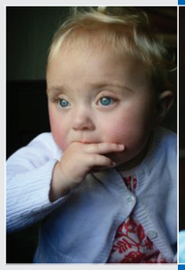
Excellence - We focus on quality, conducting our work to the highest ethical and professional standards, and striving for excellence in all that we do.

Common Features

A specific pattern of physical, developmental, and behavioral characteristics has been found in individuals with SMS. Common features include:

- Developmental delay / intellectual disability
- Hypotonia (low muscle tone)
- Poor gross motor and fine motor skills
- Feeding problems in infancy (poor suck/swallow); failure to thrive or difficulty gaining weight (< 3 years)
- Speech delay
- Characteristic facial appearance
- Short fingers and toes
- Distinct, broad-based gait (style of walking)
- Scoliosis (abnormal curvature of the spine)
- Vision problems (strabismus; nearsightedness)
- Middle ear abnormalities, chronic ear infections
- Hearing impairment
- Hoarse, deep, sometimes nasal voice
- Decreased sensitivity to pain, hypersensitivity
- Constipation
- Sleep disturbance (frequent nighttime awakenings; daytime sleepiness)
- Self-injurious behaviors
- Prolonged tantrums, explosive outbursts, impulsivity
- Arm hugging/hand squeezing
- Endearing and engaging personalities
- Excellent long-term memory for names, places, events
- Great sense of humor
- Eagerness to please and sensitivity towards others

It is important to remember, however, that SMS is a variable disorder, and not every individual with SMS will have all the features listed above. Some may have just a few, whereas others may have many.



Become a PRISMS member today! Membership is open to all interested in supporting and engaging with the SMS community.

Visit **www.prisms.org/us/how-to-help/become-a-member** to sign up and learn why your membership is important.

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Your donation, no matter how small, helps PRISMS achieve its mission.

Contributions can be made online through our website or mailed to:

PRISMS, Inc.
PO Box 206528
Dallas, TX 75320-6528

UNDERSTANDING SMITH-MAGENIS SYNDROME

prisms

Parents and Researchers Interested in Smith-Magenis Syndrome

EDUCATION | AWARENESS | RESEARCH

prisms.org

What is Smith-Magenis Syndrome (SMS)?

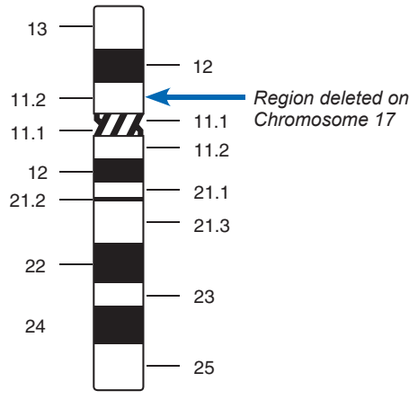
Smith-Magenis syndrome (SMS) is a neurobehavioral disorder caused by particular genetic changes on chromosomal region 17p11.2, which contains the gene *RAI1*. In most cases, SMS is due to a missing copy of the 17p11.2 region. This is called a deletion. Less commonly, SMS is caused by particular genetic changes, called mutations, in the *RAI1* gene itself.

SMS is a rare disorder that occurs in about 1/15,000 to 1/25,000 births. Although the number of individuals diagnosed with SMS has increased in recent years due to better diagnostic tools, the syndrome likely remains underdiagnosed.

Diagnosis

The diagnosis of SMS is usually made using a genetic test called a chromosomal microarray analysis (CMA), or more commonly, a microarray. A microarray can detect extra or missing pieces of genetic material. This test is typically ordered as part of the standard genetic work-up for children with developmental and behavioral symptoms.

When SMS is specifically suspected, targeted genetic tests, such as FISH (fluorescence in situ hybridization) or *RAI1* mutation analysis can be ordered instead of a microarray to look for a 17p11.2 deletion or an *RAI1* mutation, respectively. Although SMS is genetic, it usually does not run in families.



PRISMS Education, Awareness, Research

Parents and Researchers Interested in Smith-Magenis Syndrome (PRISMS) is a support organization for families and professionals involved in the care of people with SMS.

PRISMS serves as a central clearinghouse for information about SMS, providing a range of educational and support services, including:

EDUCATION

- PRISMS website www.prisms.org: a comprehensive resource with information and support for individuals and families living with SMS. The website is updated regularly and contains the most recent data, research articles, newsletters, and more!
- Telephone and email support – including eblasts with updated news and events
- International Building Bridges of Hope Conference – a multi-day educational family support event
- Official Quarterly Journal – PRISMS Spectrum
- Regional Representative Program – a support and mentoring program for parents/families around the world
- Publications including “On the Road to Success with SMS: A Guidebook for Schools” and “A Smith-Magenis Guidebook: Exploring Adult Residential Living”

AWARENESS

- International Partnership Program
- Awareness materials – SMS brochure, bookmarks, wristbands, awareness and compassion cards
- Social networking – Facebook, Twitter, Instagram

RESEARCH

- Professional Advisory Board – leading medical and scientific experts in SMS
- International SMS Research Symposium
- Database of registered families
- Research support and funding

PRISMS is primarily a volunteer organization that serves families around the world! PRISMS Board of Directors and volunteers raise SMS awareness and funding through a variety of events and campaigns, including World SMS Awareness Day (November 17th).

PRISMS maintains its mission of service to our members in order to enhance the lives of persons with Smith-Magenis Syndrome.