Smith-Magenis Syndrome Australia

Information Brochure

You are not alone. We are a dedicated team of volunteers, representing a local community of families, carers and professionals; supporting loved ones diagnosed with Smith-Magenis Syndrome.

About us

AT SMITH-MAGENIS SYNDROME AUSTRALIA, WE ARE COMMITTED TO DRIVING LOCAL AWARENESS, ASSISTING WITH FAMILY COLLABORATION AND FACILITATING EDUCATION OF THE BROADER COMMUNITY.

Smith-Magenis Syndrome Australia is comprised of a small team of Australian parents, who have children diagnosed with Smith-Magenis Syndrome (SMS). We have come together with a common desire to drive a greater local Australian awareness, support and a sense of community. Smith-Magenis Syndrome Australia is a registered not-for-profit organisation. Our work includes awareness campaigning, interfacing with the specialist and educational community, facilitating respite camps, disseminating the latest research and guidance, helping families navigate the National Disability Insurance Scheme (NDIS) and building a strong network of families and support professionals.

PRISMS International Partner Program

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Smith-Magenis Syndrome Australia is a member of the PRISMS International Partnership Program. As a member, Smith-Magenis Syndrome Australia along with PRISMS, recognise that SMS is a global public health challenge that affects families around the globe. Together our organisations want to raise awareness of the common issues that people living with SMS and their families face, irrespective of where they live in the world. Global cooperation benefits the entire Smith-Magenis Syndrome community. This partnership lays the groundwork for future joint initiatives and increased transpacific collaboration for the entire SMS community.

10 Quick Smith-Magenis Syndrome (SMS) Facts

- SMS is a rare chromosomal disorder caused by a deletion or mutation of genetic material from chromosome 17, referred to as deletion 17p11.2.
- It is estimated that SMS occurs in as many as 1 out of 25,000 people, however it is highly underdiagnosed – with approximately 100 individuals documented in Australia.
- It is characterised by an identifiable pattern of distinctive physical features, developmental delays, mild to moderate intellectual impairment and behavioural challenges.
- Diagnosis is normally made through chromosomal analysis via clinical blood testing methods such as a cytogenetic test, FISH or microarray analysis.
- Although SMS is a genetic syndrome, it rarely is inherited from a family member.
- Individuals with SMS are often given dual/multiple parallel diagnosis of attention deficit/hyperactivity disorder (ADHD), attention deficit disorder (ADD), obsessive compulsive disorder (OCD), oppositional defiant disorder (ODD), and autism spectrum disorder (ASD).
- Behaviour challenges include sensory processing disorders (SPD), inattention, hyperactivity, impulsivity, anxiety, explosive outbursts/tantrums, attention-seeking and self-injurious behaviours (SIB).
- The majority of individuals diagnosed with SMS experience significant sleep disturbance due to an inverted circadian rhythm of melatonin.
- Affected individuals can benefit strongly from early childhood intervention programs, special education, speech therapy, occupational and physical therapy, and sensory integration assistance. Families and carers are encouraged to leverage respite services and psychosocial support.
- Despite behavioural, intellectual and physical challenges, people with SMS are generally engaging, affectionate, perceptive, sympathetic, eager to please and have a fantastic sense of humour.

Our Activities

Awareness. Throughout the year, we run a variety of social media awareness and fundraising campaigns in alignment with events such as Rare Disease Day and Smith-Magenis Syndrome Day (held on the 17th of November). We also join campaign efforts with bodies such as the Genetic Support Network Victoria (e.g. Facing Forward Campaign). We raise funds for awareness through sales of merchandise and local community events.

Support. A portion of the funds raised by Smith-Magenis Syndrome Australia are used to assist organisations, such as Camp Breakaway, who provide SMS-specific programs and services. We also provide a comprehensive listing of support resources on our website.

Information and Education. A range of articles, literature, and blog posts are regularly communicated and accessible via Facebook and the 'About' and 'Community' sections of our website. Additionally, we provide every newly diagnosed Australian family with the PRISMS "On the Road to Success with SMS" guidebook.

Community. Smith-Magenis Syndrome Australia represents a local community of families and their support network. We work with state representatives to encourage networking activities and family connections. We facilitate a collaborative platform for families to share their experiences, insights and requests for support.