

SMITH-MAGENIS SYNDROME: SEE ME SHINE

A Film by Katie Aarons

FILM SYNOPSIS

Smith-Magenis Syndrome (SMS) is a rare chromosomal disorder caused by a deletion or mutation of genetic material from chromosome 17, characterised by an identifiable pattern of distinctive physical features, developmental delays, mild to moderate intellectual impairment and behavioural challenges. It is estimated that SMS occurs in as many as 1 out of 25,000 people, however it is highly underdiagnosed – with under 100 individuals documented in Australia.

Smith-Magenis Syndrome: See Me Shine introduces us to Indiana and Amélie, two young girls who have been diagnosed with the rare condition. In speaking with their parents and medical experts, we can get an understanding of the syndrome, the challenges faced by the children, the SMS support network and the abilities sufferers show as they grow older.

The short documentary features a number of speakers with various exposure to children with Smith-Magenis Syndrome:

Associate Professor David Armstrong MD, FRACP

Respiratory and Sleep Paediatrician at Monash Medical Centre

Dr Armstrong is currently monitoring Indiana's sleeping patterns, which are heavily affected by the syndrome. Indiana is the second child with SMS that Dr Armstrong has treated, with an older patient showing positive growth over time.

Katie Aarons

Mother of Indiana and filmmaker

Katie is the mother of 2½ year old Indiana, who was diagnosed with SMS at 9 weeks of age. Katie gives her perspective of a mother of a young child with Smith-Magenis Syndrome, the symptoms suffered by Indiana and her growth over time.

Penny Green B. Physio (Hons) M. Physio (Paediatrics)

Paediatric Physiotherapist at Physiotherapy Jr.

Penny has been Indiana's physiotherapist for the past two years. Penny provides insight to her role as a physio working with a child with SMS and details Indiana's growth since beginning treatment.

Cally Bauman

Mother of Amélie and Victorian Representative of SMS Australia

Cally's daughter Amélie is 11 years old and was diagnosed with SMS when she was 4 years old. Cally provides further information about being the mother of a child with Smith-Magenis Syndrome, as well as talking about SMS Australia, which is a non-for-profit support group for families affected by Smith-Magenis Syndrome.

The conclusion to *Smith-Magenis Syndrome: See Me Shine* is that despite being faced with a serious disability, the children that are diagnosed with SMS can achieve a variety of milestones, including participating at the Special Olympics. The strength of character displayed by children with SMS is a testament to the work of their families, medical experts and support groups.

FILM INTENT

The main objective of this short documentary is to generate awareness about the little-known syndrome, detailing the various symptoms and problems faced by diagnosed children and their families and to show children with SMS overcoming adversity to live happy and fulfilling lives. The film also serve to promote SMS Australia, a support network for families affected by Smith-Magenis Syndrome.

FILMMAKER BIOGRAPHY

Coming from a family with a background in television production, Katie Aarons has followed in the footsteps of her father Brian and brother Steve with a love for video production.

Having obtained her Diploma of Screen and Media, Katie began working alongside her brother and father, producing content for their music television channel, Red Sky Music. Katie has helped to produce a variety of studio-based television programs, artist interviews, music event coverage and live concerts.

Moving forward, Katie intends to further develop her skills as a producer to provide more support with Red Sky Music productions.

