

Smith-Magenis Syndrome Family Day

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1. Genetic Support Network of Victoria
2. Genetic Health Services Victoria
3. Smith-Magenis Syndrome Family Group

Smith-Magenis Syndrome Family Day

On Saturday 20th April 2002, 12 families met at the Melbourne Museum - their common bond was that one of their family members had **Smith-Magenis Syndrome (SMS)**. Families had travelled from all over Victoria and several from NSW. The day was co-ordinated by the Genetic Support Network of Victoria, in collaboration with Dr George McGillivray, Genetics Fellow, Margaret Sahhar, Senior Social Worker both from Genetic Health Services Victoria and Craig and Katrina Simpson, parents of a child with SMS.

What Is Smith-Magenis Syndrome?

SMS is caused by a deletion of 17p11.2 and can be detected by FISH.

Features of SMS include:

- developmental delay;
- intellectual disability;
- low muscle tone and feeding problems in infancy;
- a characteristic facial appearance;
- sleeping difficulties;
- behaviours such as hyperactivity, head banging, skin-picking, loud outbursts, excitability.

A Dad's Bright Idea

The idea for this family day was born a long time ago. In 1999, at the Association for Children with a Disability's expo, a parent, Craig Simpson, who had a child with a rare genetic condition called Smith Magenis Syndrome approached the GSNV coordinator. He expressed his keen interest in establishing a group for families who had a child with SMS. After three years of talking about it, it finally came to fruition.

How Did We Find The Families?

Families were found and contacted via a teamwork approach between known SMS families, PRISMS (the USA support group), the GSNV co-ordinators and the Genetic Health staff.

- Dr McGillivray searched the Genetic Health Services Victoria database, checked files to confirm the SMS diagnosis and sent invitations confidentially to all families found this way.
- The Simpson family contacted all SMS families they had met personally or had contact with over the past ten years.
- PRISMS co-operated by sending out our invitation to Australian families on their mailing list.

On the invitation, families were given the option to respond to Dr McGillivray, the Simpson family or the GSNV co-ordinators – depending on whom they felt most comfortable speaking to.

A Momentous Occasion

This day was momentous for a number of reasons:

- For most of the families it was the **first time** that they'd ever met another family who had a child with SMS.
- It was a day set up **just for the families**. It had **no clinical or research focus** at all, however there was a geneticist and a social worker present on the day.
- The day was **highly supported** by the Melbourne Museum who provided the meeting room, complimentary passes and staff to conduct a guided tour of the museum with children, siblings and others - leaving parents to discuss the real issues whilst knowing their children were being entertained and cared for. The Museum was chosen because it provided a **neutral space** and one that was full of activities.
- The **value of a support network** such as the GSNV was highlighted, when affordable accommodation was able to be sourced for one of the interstate families through another support group (Dialysis and Transplant Association), who have accommodation available for families visiting Melbourne.

Parents Are The Experts

The discussion which the parents conducted was friendly and spontaneous and required little facilitation by the professionals present. Resources and ideas were shared, including:

- **Empowerment** – parents reminding each other that they are the experts in SMS, and that they can be assertive in managing their child's care and education.
- **Personal stories** were told, which were helpful for parents of younger children to envisage the potential for their child's future.
- The **names of useful books**, programs, and government benefits were shared among families.
- Ideas for **support for siblings** were shared.
- **Options for education** were discussed, including the decision between integration into mainstream schools and special schools.

Where To From Here

The actions to be taken as a result of this day were:

- A list of **contact details** (given with permission) has been produced and distributed among SMS families.
- GSNV to **contact genetic counsellors** nationally – starting with a poster at the HGSA conference.
- Families to join the USA-based SMS **email listserv**.
- A **webpage** will be written and hosted by the GSNV website.
- A get-together for families will be run annually, giving careful consideration to cost, location and respite care for the children.

The next get-together has been planned for early February 2003.

Contact Us

The GSNV is keen to provide ongoing support to the SMS Family Group and would be very happy to put families and professionals from around Australia and New Zealand in contact with the group.

Please contact the GSNV on info@gsnv.org.au or (03) 8341-6315.