



2005 Annual Report

P.R.I.S.M.S., Inc.
Parents and Researchers Interested in Smith-Magenis Syndrome
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Mission

PRISMS is dedicated to providing information and support to families of persons with Smith-Magenis Syndrome (SMS) and foster partnerships with professionals to increase awareness and understanding of SMS. PRISMS is also committed to the support and promotion of research in the causes, optimal management and treatment of SMS.

About SMS

Smith-Magenis syndrome is clinically recognizable chromosome microdeletion syndrome. It is caused by a missing piece (deletion) of part of number 17 chromosome (del 17p11.2). Ann C.M. Smith, M.A., D.Sc. (hon), a genetic counselor, and Ellen Magenis, M.D., a cytogeneticist first described SMS in the early 1980's.

Although the exact incidence is not known, it is estimated that SMS occurs in 1 out of 25,000 births. SMS is extremely under-diagnosed, but as awareness of it increases, the number of people identified grows every year.

Programs & Services

Since 1993, PRISMS has served as a central clearinghouse for information about SMS, providing a range of educational and support services. Today we provide programs and services for hundreds of families each year in the US and abroad. Our services include:

- Telephone and email support
- Web site: <http://www.prisms.org>
- Database of registered families
- Official newsletter – [*Spectrum*](#)

- Information packet for newly diagnosed families
- [SMS brochure](#) (622KB)* and video for families, caregivers & medical professionals
- [Parent-to-Parent Program](#)
- [International Conferences on SMS every 2-3 years](#)
- A multidisciplinary [Professional Advisory Board](#) whose members serve as a resource to families and professionals.

2005 Highlights

- The 4th International SMS Conference "Building Bridges of Hope" was held on April 29 - May 1, 2005 in Cincinnati, OH. The International SMS Conference is an important program where families and professionals come together to learn and support each other. Over 300 families and professionals from all over the world attended the conference.
- The International SMS Conference was preceded by a Research Roundtable held on April 28th, 2005. The Research Roundtable was co-moderated by PRISMS Professional Advisory Board members, Ann Smith, MA, and Sarah Elsea, Ph.D.
- Produced the SMS awareness silicone bracelets embossed with "Smith-Magenis Syndrome"; the bracelets supported both awareness and fund-raising.
- Supported publishing of Shirley Dechaine's book about her own experiences raising a son with SMS. The book is called "*It's All About Me! One Family's Experience with SMS*" with forewords by Ann C.M. Smith, M.A., D.Sc. (Hon.) and Ellen Magenis, M.D.
- Supported the local TV programming on SMS (Texas) to increase public awareness on Smith-Magenis Syndrome; a video of this programming was produced for distribution.
- Central Michigan University charity dance to spread the words about SMS and support PRISMS was organized by a sophomore who was acquainted with an SMS child in her area on February 19, 2005.
- 2005 Great Lakes Region golf outing took place at the Valleywood Golf Course in Swanton, Ohio, on Saturday June 25th, 2005, to raise awareness of Smith-Magenis Syndrome and raise fund for PRISMS.
- Regional SMS family gatherings spread to more areas, including the 4th Annual Pennsylvania SMS picnic on Saturday July 30, the Rocky Mountain SMS picnic on August 21, and the Northern California SMS family picnic on September 18, 2005. These events are great venues to facilitate family networking and sharing.

Governance and Finances

PRISMS, Inc. is a nonprofit corporation organized under 501(c)(3) of the Internal Revenue Code and incorporated in the State of Virginia. PRISMS is supported by membership dues, charitable contributions, and volunteer work. An 8 member [Board of Directors](#) governs PRISMS. In addition, PRISMS works closely with a multidisciplinary [Professional Advisory Board](#), which provides medical guidance and reviews research proposals. **Ann C.M. Smith, M.A., D.Sc.(hon)**, the co-discoverer of SMS, with National Human Genome Research Institute, National Institutes of Health (NIH), Bethesda, MD serves as chair of the Professional Advisory Board.

Board of Directors

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Ann C.M. Smith, MA, DSc (hon)
Reston, VA

P.R.I.S.M.S., Inc.
Statement of Financial Position
December 31, 2005
(With Comparative Totals for 2004)

	2005	2004
ASSETS:		
Petty Cash and Cash on Hand	\$ 100	\$ 100
Cash in Checking	63,979	16,186
Cash in Savings	19,491	19,243
Cash in CD	53,044	101,415
Total Cash	136,614	136,944
 Prepaid Insurance	 1,120	 825
 TOTAL ASSETS	 \$ 137,734	 \$ 137,769
 LIABILITIES:		
Accounts Payable	\$ 13	\$ 670
 TOTAL LIABILITIES	 13	 670
 NET ASSETS:		
Unrestricted-General	126,755	126,133
Unrestricted-Designated	10,966	10,966
 TOTAL NET ASSETS	 137,721	 137,099
 TOTAL LIABILITIES AND NET ASSETS	 \$ 137,734	 \$ 137,769

P.R.I.S.M.S., Inc.
Statement of Activities
For The Year Ended December 31, 2005
(With Comparative Totals for 2004)

SUPPORT AND REVENUE:	2005	2004
Conference Registration	\$ 46,153	\$
Contributions-United Way	2,222	2,921
Contributions-Other	37,495	13,451
Contribution-In-Kind-NIH	13,500	
Contribution-In-Kind-Other	1,510	3,210
Memberships	2,250	240
Miscellaneous		371
Interest Income	1,878	1,544
Fund-Raising -		
Golf Tournament	22,780	25,671
Product Sales	5,446	369
	<u>133,234</u>	<u>47,777</u>
Total Support and Revenue		
 EXPENSES:		
Program Services	98,775	36,113
Management & General	15,743	1,990
Fund-Raising	18,094	12,608
	<u>132,612</u>	<u>50,711</u>
Total Expenses		
Change In Net Assets	\$ 622	\$ (2,934)
Beginning Net Assets	<u>137,099</u>	<u>140,033</u>
Ending Net Assets	<u>\$ 137,721</u>	<u>\$ 137,099</u>

This financial report is abstracted from audited financial statements prepared by Sonnenberg & Company, CPAs, San Diego, CA. A complete copy of our financial statements along with the auditor's opinion and the accompanying notes is available from our office upon request.