



2004 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

2004 Highlights

- The new web site <http://www.PRISMS.org> became on line with improved features such as easier navigation, more contents on SMS, more photos and foreign language translations.
- Developed and offered to members a short DVD about Smith-Magenis Syndrome and PRISMS for use in fund-raising activities.
- Collaborated with “Positive Exposure”, a non-profit organization with innovative programs, to bring positive images of children with Smith-Magenis Syndrome to a gallery in the Times Square of New York City from February to May 2004. The program challenges the stigma associated with differences and celebrates the richness of genetic variations with positive images and powerful life stories.
- Supported a key member’s initiative to print public announcement message about Smith-Magenis Syndrome in products. The [Paladini seafood sauces](#) became the first merchandise carrying information about SMS in its product labels. A portion of the profit is donated to PRISMS.
- Signed on with <http://eScrip.com> to raise fund for PRISMS through members’ everyday purchases at eScrip merchants. The PRISMS group ID number is 150239751.
- 2004 Great Lakes Region golf outing took place at the Valleywood Golf Course in Swanton, Ohio, on Saturday June 26th, 2004, to raise awareness of Smith-Magenis Syndrome and raise funds for PRISMS.
- The 3rd Annual Pennsylvania SMS picnic was held on Saturday June 12th, 2004, to facilitate networking and sharing among SMS families.

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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Richardson, TX

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Board Member

Michael Singleton
Jamieson, OR

Immediate Past President

Board Advisor

Connie Bessette
[Francetown, NH](#)

P.R.I.S.M.S., Inc.
Statement of Financial Position
December 31, 2004
(With Comparative Totals for 2003)

ASSETS:	2004	2003
Petty Cash and Cash on Hand	\$ 100	\$ 100
Cash in Checking	16,186	18,984
Cash in Savings	19,243	19,114
Cash in CD	101,415	100,000
Total Cash	<u>136,944</u>	<u>138,198</u>
 Prepaid Insurance	 <u>825</u>	 <u>1,835</u>
 TOTAL ASSETS	 <u>\$ 137,769</u>	 <u>\$ 140,033</u>
 LIABILITIES:		
Accounts Payable	\$ <u>670</u>	\$ <u> </u>
 TOTAL LIABILITIES	 670	 0
 NET ASSETS:		
Unrestricted	126,133	129,067
Unrestricted-Designated	<u>10,966</u>	<u>10,966</u>
 TOTAL NET ASSETS	 <u>137,099</u>	 <u>140,033</u>
 TOTAL LIABILITIES AND NET ASSETS	 <u>\$ 137,769</u>	 <u>\$ 140,033</u>

P.R.I.S.M.S., Inc.
Statement of Activities
For The Year Ended December 31, 2004
(With Comparative Totals for 2003)

SUPPORT AND REVENUE:	2004	2003
Contributions-Pfizer	\$ 2,921	\$ 20,000
Contributions-United Way	13,451	1,994
Contributions-Other	3,210	17,500
Contributions-In-Kind	240	650
Memberships	371	860
Miscellaneous	1,544	62
Interest Income		
Fund-Raising -		
Garden Tour		12,375
Golf Tournament	25,671	24,485
Other	369	650
Total Support and Revenue	47,777	78,576
 EXPENSES:		
Program Services	36,113	20,664
Management & General	1,990	5,381
Fund-Raising	12,608	6,659
Total Expenses	50,711	32,704
Change In Net Assets	\$ (2,934)	\$ 45,872
Beginning Net Assets	140,033	94,161
Ending Net Assets	\$ 137,099	\$ 140,033