

2006 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 <u>Professional Advisory Board</u> whose members serve as a resource to families and professionals.

2006 Highlights

- PRISMS-sponsored new SMS Discussion Forum or Bulletin Board was online. This great new resource is designed to build a "knowledge base" for SMS – created by parents, professionals and people affected with SMS – to help and support each other. Information is well-organized by category and topics to facilitate participation in online discussion and/or finding entries posted before.
- Started to send out monthly information e-mails to keep everyone up to date on fundraising, conference information, membership drive, and other business reminders.
- Designated July as the Smith-Magenis Syndrome Awareness Months and introduced the SMS Awareness Photo Contest.
- PRISMS participated in a workshop called "Genetics in the Classroom: Behavior and Interventions for Student with Genetic Syndromes by setting up a table display to increase awareness of SMS. This workshop in Maryland was well attended by special education professionals, educators, behavior specialists, nurses, social workers, parents and others.

PRISMS Board Members and other parents gave speeches about Smith-Magenis Syndrome to medical school faculty, post-doctoral fellows, students and staffs at University of California, Los Angeles, and to 7th-grade students/teachers of Shiloh Middle School in Hampstead,

- Maryland. The PowerPoint presentations generated awareness and understanding of SMS.

 Actively engaged in planning for the 2007 International SMS Conference to be held in Reston, VA, May 11-13th, 2007. Planning activities included additional fund-raisings, organizing meeting sessions and materials, inviting speakers and workshop leaders, developing online registration tools, negotiations for on-site childcares, facility visit and other
- logistics preparations.
 Initiated or participated in several new fund-raising activities, including "Pennies in the Pickle Jar for PRISMS", "Good Search", "Birdies for Charity", while continue with the annual "Holiday SMileS" fund-raising drive.

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 <u>Board of Directors</u> governs PRISMS. In addition, PRISMS works closely with a multidisciplinary <u>Professional Advisory Board</u>, 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, D.Sc (hon)

Reston, VA

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Charlene Liao, Ph.D.

Palo Alto, CA

P.R.I.S.M.S., Inc.

Statement of Financial Position December 31, 2006 (With Comparative Totals for 2005)

ASSETS:		2006		2005
Cash in Checking	\$	74,835	\$	64,079
Cash in Savings		19,763		19,491
Cash in CD	-	55,309		53,044
Total Cash	_	149,907		136,614
Prepaid Expenses-Conference		14,583		
Prepaid Insurance	-	1,130	_	1,120
TOTAL ASSETS	\$	165,620	\$	137,734
	=		=	
LIABILITIES:				10
LIABILITIES: Accounts Payable	\$_		\$_	13
Accounts Payable	\$_	0	\$_	
	\$_	0	\$_	13
Accounts Payable TOTAL LIABILITIES	\$_	0	\$_	
Accounts Payable	\$_	0	\$_	
Accounts Payable TOTAL LIABILITIES NET ASSETS:	\$_		\$_	13
Accounts Payable TOTAL LIABILITIES NET ASSETS: Unrestricted-General	\$_ -	154,654	\$_	13 126,755
Accounts Payable TOTAL LIABILITIES NET ASSETS: Unrestricted-General	\$_ -	154,654	\$_	13 126,755

\$ 165,620 \$

137,734

TOTAL LIABILITIES AND NET ASSETS

P.R.I.S.M.S., Inc. Statement of Activities For The Year Ended December 31, 2006 (With Comparative Totals for 2005)

SUPPORT AND REVENUE: Conference Registration Contributions-United Way	\$	6,055	\$	2005 46,268 2,222
Contributions-Other		31,985		37,495
Contribution-In-Kind-NIH Contribution-In-Kind-Other		1,375		13,500 1,510
Memberships		8,765		2,250
Interest Income		2,536		1,878
Fund-Raising -		4.005		20.700
Special Events Product Sales		4,085 2,387		22,780 5,446
Floutict Sales	-	2,301	-	3,440
Total Support and Revenue	***	57,188		133,349
EXPENSES:				
Program Services		20,056		109,509
Management & General		7,321		15,743
Fund-Raising	-	1,912	_	18,094
Total Expenses	_	29,289		143,346
Change In Net Assets	\$	27,899	\$	(9,997)
Beginning Net Assets	_	137,721	_	147,718
Ending Net Assets	\$ _	165,620	\$ _	137,721