



2003 Annual Report

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

(Parents and Researchers Interested in Smith-Magenis Syndrome)

P.O. Box 741914

Dallas, TX 75374-1914

Tel: 972-231-0035; Fax: 413-826-6539

Website: <http://www.prisms.org/>

Email: info@prisms.org

Federal Tax ID Number: 54-1652029



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 micro deletion 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.

Common features of SMS include: characteristic, yet subtle, facial appearance, infant feeding problems, low muscle tone, developmental delay, sleep disturbance, self-injurious behaviors, prolonged tantrums, explosive outbursts, speech/language delay, ear infections, arm hugging/hand squeezing and decreased sensitivity to pain.

Although the exact incidence is not known, it is estimated that SMS occurs in 1 out of 25,000 births. However, 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 packets and brochures for families, caregivers & medical professionals
- Parent-to-Parent network
- Educational conferences on SMS
- Professional Advisory Board members serve as a resource to families and professionals.

2003 Highlights

- Continued to provide telephone and email support for SMS families.
- Produce and distribute *Spectrum*, our membership newsletter.
- Produced a 7 minute SMS video that highlights SMS characteristics, research centers and PRISMS programs. Plans are underway to distribute this video to SMS families.
- Improved existing website by creating a parent corner, improved links, online newsletters, online brochure, and online donation. We plan to introduce a new web site in 2004. Expanded features for our new site will include easier access, instant translation to different languages and more information about dealing with SMS.
- Worked with SMS families on major fundraising/awareness events: Great Lakes golf tournament, Northern California garden tour, Entertainment book, United Way and Paladini sauce labels.
- Provided educational materials that were distributed at fundraisers.
- Provided support to sister groups: the SMS Foundation, UK, ASM 17 (France) and the new Australia SMS Foundation.
- Visited the Michigan State University campus and toured Dr. Sara Elsea's research laboratories to learn about her exciting new SMS research findings (see Spring/Fall 2003 edition of *Spectrum* newsletter)
- Expanded PRISMS volunteer positions: Parent-To-Parent regional coordinators and additional Spanish translators.
- Began planning the next SMS conference scheduled for April 28 – May 1, 2005. We have selected the Cincinnati Westin as our site and have a signed contract. A program committee has also been formed.

Governance and Finances

P.R.I.S.M.S., 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, contributions, and volunteer work. An eight 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, serves as chair of the Professional Advisory Board. Dr. Smith is currently the principal investigator of the first Natural History Study of SMS at National Human Genome Research Institute at the National Institutes of Health (NIH), Bethesda, MD.

Board of Directors

President

Randy Beall
Richardson, TX
rmbeall@comcast.net

Treasurer

Janet Forbes Reeder
San Diego, CA

Immediate Past President

Board Advisor
Connie Bessette
Francestown, NH
cbessette@prexar.com

Vice President/ Secretary

Rochelle Wright
Springboro, OH
rochelle.wright@ncr.com

Board Member

Margaret Miller
Herndon, VA
trellims@aol.com

Board Member

Michael Singleton
Jamieson, OR
hammackf@monkeyworx.com

Board Member

Charlene Liao, Ph.D.
Palo Alto, CA
xcliao@yahoo.com

Professional Advisory Chair

Ann C.M. Smith, MA, D.Sc (hon.)
Reston, VA
acmsmith@mail.nih.gov

P.R.I.S.M.S., Inc.
Statement of Financial Position
December 31, 2003
(With Comparative Totals for 2002)

ASSETS:	2003	2002
Petty Cash and Cash on Hand	\$ 100	\$ 100
Cash in Checking	18,984	11,448
Cash in Savings	19,114	82,660
Cash in CD	100,000	
Total Cash	138,198	94,208
Prepaid Insurance	1,835	
TOTAL ASSETS	\$ 140,033	\$ 94,208
LIABILITIES:		
Accounts Payable	\$	\$ 47
TOTAL LIABILITIES	0	47
NET ASSETS:		
Unrestricted	129,067	83,195
Unrestricted-Designated	10,966	10,966
TOTAL NET ASSETS	140,033	94,161
TOTAL LIABILITIES AND NET ASSETS	\$ 140,033	\$ 94,208

Statement of Activities
For The Year Ended December 31, 2003
(With Comparative Totals for 2002)

SUPPORT AND REVENUE:	2003	2002
Contributions-Pfizer	\$ 20,000	\$
Contributions-United Way	1,994	608
Contributions-Other	17,500	18,496
Conference - Registration		21,263
Conference - Video / Audio Sales		545
Memberships	650	2,147
Miscellaneous	860	363
Interest Income	62	107
Fund-Raising -		
Garden Tour	12,375	
Golf Tournament	24,485	17,605
Silent Auction		2,030
Other	650	
Total Support and Revenue	78,576	63,164
EXPENSES:		
Program Services	20,664	70,979
Management & General	5,381	3,152
Fund-Raising	6,659	5,104
Total Expenses	32,704	79,235
Change In Net Assets	\$ 45,872	\$ (16,071)
Beginning Net Assets	94,161	110,232
Ending Net Assets	\$ 140,033	\$ 94,161

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.