

2008 Annual Report



*Parents and Researchers Interested
in Smith-Magenis Syndrome*

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

PRISMS is dedicated to providing information and support to families of persons with Smith-Magenis Syndrome (SMS) and fostering 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 a 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 United States and abroad. Our services include:

- Telephone and email support
- Website: www.prisms.org
- SMS Bulletin Board
- Database of registered families
- Information packet for newly diagnosed families
- SMS brochure and bookmarks 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
- Quarterly Newsletter, *The Spectrum*



2008 Highlights

PRISMS, Inc. reached the 15 year milestone this year and celebrated with an updated logo and Spectrum banner. Looking back over the years, we have made huge strides in our ability to reach out to all persons interested in Smith-Magenis Syndrome.

We continue to be supported through donations. Many individuals and organizations contribute, with each donation being appreciated. The 2nd annual 5K road race was held in Ohio. PRISMS also sought and received a significant grant from The Aetna Foundation, an independent charitable and philanthropic arm of Aetna Inc. Grant funds, combined with local donations, helped PRISMS provide a service dog which is helping a young lady manage the behavioral characteristics of SMS and become a role model for others. In addition, a portion of the grant funds were used to support the Smith-Magenis Research study at NHGRI-DIR at the National Institutes of Health (NIH). This research study is currently ongoing at the NIH campus in Bethesda, MD under two IRB-approved protocols.

PRISMS was able to provide a research contribution to Ann Smith's program at NIH. NIH started the first controlled treatment trial targeting sleep in the SMS individual.

Mary Beall and Gail Kopp joined Ann Smith in August at Camp Breakaway in Australia. They were able to share PRISMS information and experience, as well as gain information to bring back to the states.

Planning for the 2009 Conference, Building Bridges, was ongoing throughout 2008. This conference will take place in September 2009 in Reston, VA.

Spectrum, the newsletter for PRISMS, continues to be published quarterly. Please view the 2008 newsletters, found at www.prisms.org for details on all of the above, plus much more!

Governance & 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. A 7 member, non-compensated 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 Genome Research Institute, National Institutes of Health, Bethesda, MD, serves as chair of the Professional Advisory Board.

Board of Directors

President—Randy Beall, Richardson, TX

Vice President—Margaret Miller, Herndon, VA

Secretary—Lindsay Warman, Loveland, OH

Treasurer—Jeri Gawlowski, South Lyon, Michigan

Board Member and Fundraising Chair—Percy Huston, Cape Girardeau, MO

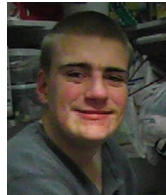
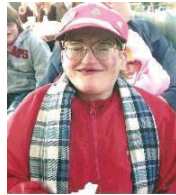
Board Member and Public Relations Chair—Charlene Liao, Palo Alto, CA

Board Member and Spectrum Editor—Julia Hetherington, Beaufort, SC



Pictured from left to right:
Margaret Miller, Jeri Gawlowski, Lindsay Warman, Randy Beall, Ann Smith, Percy Huston, Charlene Liao
Not Pictured: Julia Hetherington

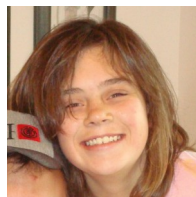
2008 Annual Report



P.R.I.S.M.S., Inc.
Statement of Financial Position
December 31, 2008
(With Comparative Totals for 2007)

	2008	2007
ASSETS:		
Cash in Checking	\$ 36,496	\$ 28,848
Cash in Savings	97,576	79,618
Cash in CDs	69,427	67,541
Total Cash	<u>203,499</u>	<u>176,007</u>
Contributions Receivable		15,000
Prepaid Insurance	<u>850</u>	<u>1,130</u>
TOTAL ASSETS	<u>\$ 204,349</u>	<u>\$ 192,137</u>
NET ASSETS:		
Unrestricted-General	193,383	163,171
Unrestricted-Designated	10,966	10,966
Temporarily Restricted	<u>18,000</u>	<u>18,000</u>
TOTAL NET ASSETS	<u>204,349</u>	<u>192,137</u>
TOTAL LIABILITIES AND NET ASSETS	<u>\$ 204,349</u>	<u>\$ 192,137</u>

2008 Annual Report



P.R.I.S.M.S., Inc.
Statement of Activities
For The Year Ended December 31, 2008
(With Comparative Totals for 2007)

CHANGE IN UNRESTRICTED NET ASSETS	2008	2007
SUPPORT AND REVENUE:		
Conference	\$	\$ 65,531
Contributions-United Way	12,086	5,390
Contributions-Other	34,550	53,329
Contributions-In-Kind	400	1,407
Memberships	6,993	6,396
Interest Income	4,843	1,921
Fund-Raising -		
Special Events	7,121	18,262
Product Sales	985	1,831
Total Fundraising	<u>8,106</u>	<u>20,093</u>
Net Assets Released from Restrictions	18,000	
Total Support and Revenue	<u>84,978</u>	<u>154,067</u>
EXPENSES:		
Program Services	47,020	133,252
Management & General	5,648	10,915
Fund-Raising	2,098	1,383
Total Expenses	<u>54,766</u>	<u>145,550</u>
Increase In Unrestricted Net Assets	\$ 30,212	\$ 8,517
CHANGE IN TEMPORARILY RESTRICTED NET ASSETS		
Restricted Contributions		18,000
Net Assets Released from Restrictions	<u>(18,000)</u>	
Decrease in Temporarily Restricted Net Assets	\$ <u>(18,000)</u>	\$ <u>18,000</u>
INCREASE IN NET ASSETS	12,212	26,517
BEGINNING NET ASSETS	<u>192,137</u>	<u>165,620</u>
ENDING NET ASSETS	<u>\$ 204,349</u>	<u>\$ 192,137</u>

This financial report is abstracted from audited financial statements prepared by Sonnenberg & Co, 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.