



# The *Gathered View*

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National Newsletter of the Prader-Willi Syndrome Association (USA)

## Report from IPWSO

# Reaching Out to Help Each Other Around the World

By Pam Eisen

PWSA (USA) IPWSO delegate

I want to bring you up to date on the latest developments with IPWSO and the exciting role that we (PWSA-USA) have been asked to perform.

At the end of January, Janalee Heinemann and I had the pleasure of meeting with David Gordon, treasurer of IPWSO, and Giorgio Fornasier, IPWSO's president. How fortunate we are to have these very special individuals working on behalf of our children and people with PWS everywhere! David is a warm, generous, capable and humorous man with an abundance of knowledge and resources. Giorgio, as many of you may know from the 2001 International Conference, has a presence as big as life itself. His passion for IPWSO radiates from his heart and touches all who meet him.

Our meeting was intense and dynamic, particularly because of the great expansion of IPWSO within a short time. Trying to meet the urgent needs of people from so many countries presents immense challenges.

As I reported at the USA board meeting, IPWSO is now comprised of 44 countries, with about half of our membership consisting of underdeveloped and poor countries. These families, who love their children no less than we love ours, face huge hurdles that we cannot even imagine.

In many countries there is a paucity of information and resources. They may lack facilities where a diagnosis can be made. Many of the doctors may never have heard about PWS. Additionally, they may be facing huge financial and political restraints. Because of lack of information and government non-concern for handicapped people, children with PWS may even be abandoned.

In many of these parts of the world, it takes tremendous courage and tenacity for a member organization to develop and exist. Many of the families are desperate for help, with IPWSO as their only contact to other families and professionals. Cognizant



*Celebrating PWSA (Brazil). In the foreground from left: Attorney Solange Kobage, Helena Portugal, Dr. Jack Yung Kuo (professional delegate). IPWSO President Giorgio Fornasier is at the center rear.*

of these facts, at the IPWSO board meeting, we resolved that fundamental to our international organization should be a system of mutual support and help among member countries.

Giorgio proposed that the 50 percent of IPWSO membership, which consists of countries with higher economic standing and more advanced medical care, would take the responsibility of "twinning" with an underdeveloped country.

This pairing of countries would be a cooperative effort of providing assistance and encouragement to countries that have so little knowledge of the syndrome. This support can be given in many ways, from simply pairing families (via e-mail) to sharing printed material, connecting families and professionals to available resources, sending volunteers to lend experience and manpower, housing families who come to our country for a diagnosis, or by helping the country for a family to attend a regional conference. Carolyn Locker's new support and information e-group would be a perfect example. The possibilities are limitless!

*IPWSO Report continued on page 7*

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### NEWSLETTER

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\$30 Individual

\$35 Family

\$40 Agencies/Professionals

For members outside the United States, dues are \$40 Individual, \$45 Family and \$50 Agencies/Professionals (US Funds).

We never deny parents membership for any reason.



*IPWSO Delegate Pam Eisen (left) is pictured with IPWSO President Giorgio Fornasier and PWSA (USA) Executive Director Janalee Heinemann (right) at a reception for Giorgio held in Sarasota, Florida.*

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Opinions expressed in *The Gathered View* are those of the authors or editors and do not necessarily reflect the views of the officers and board of directors of PWSA (USA) unless so stated. Medical information published in *The Gathered View* should not be considered a substitute for individualized care by a licensed medical professional.

*The Gathered View* welcomes articles, letters, personal stories and photographs and news of interest to those concerned with Prader-Willi syndrome.

Communications regarding *The Gathered View* or PWSA membership and services should be directed to the national office of PWSA (USA) in Sarasota, Florida.





# Register Now for National Conference July 11-13

"Angels Among Us" is the theme of the PWSA (USA) National Conference, to be held in Salt Lake City, Utah July 11-13. The 24th annual event will be held at the

Salt Lake City Marriott Downtown, hosted by the Prader-Willi Utah Association.

## General Conference

Topics as diverse as behavior management, sibling issues, teaching social skills and how PWS affects the digestive system will be offered by a variety of presenters, many world-renowned.

Special topics for providers and health care professionals will also be offered, including an overview for health care professionals and a physician-led question and answer session.

**Keynote Speaker is Jason Hall, who became a quadriplegic as the result of a diving accident at age 15. A life-threatening automobile collision in 1997 kept him hospitalized for months.**

Jason's tenacity and determination are inspiring. Today Jason speaks professionally, presenting in the business, educational and civic arenas. His life has taught him a great deal of what it means to persevere, to dream and to be a champion.

See [www.pwsausa.org](http://www.pwsausa.org) for more presentation topics.

## Scientific Conference

These sessions are designed for researchers and clinicians in the field of Prader-Willi syndrome. Scientists, medical specialists and other professionals will make presentations. Those registering for the Scientific Conference will also automatically be registered for the General Conference; however the meal package must be purchased separately.

A limited number of parents will be admitted to the Scientific Conference as observers only.

## Professional Care Givers and Providers Program

This program is designed for all who work in homes, residential facilities, vocational and educational programs, health and human service agencies and other community programs that provide assistance and education to those with PWS and their families. Certificates of attendance will be given.

## Youth and Infants Program (YIP)

**This recreation program for babies and children age 0 to 8 who have Prader-Willi syndrome and their siblings is offered only during the General Conference sessions.** For many of the attendees and their families, YIP is the highlight of their year. Please register your YIP participant(s) as early as possible.

Each participant must be individually registered and accompanied to the conference by a parent/guardian, who will remain at the conference whenever YIP is in session. When YIP is not in session, each YIP participant is the responsibility of his or her parent/guardian.

## Registration

Please register as soon as possible. This year, online registration is available, with forms to be posted at

[www.pwsausa.org](http://www.pwsausa.org), so that you can register and pay by credit card from your computer. If you wish to have registration forms e-mailed to you, please send an e-mail to [registrar@pwsausa.org](mailto:registrar@pwsausa.org). To have forms mailed to you, call PWSA (USA) at (800) 926-4797.

## Conference Site and Hotel

Nestled at the foot of the rugged Wasatch Mountains to the south shore of the lake for which it is named, Salt Lake City features one of the most scenic backdrops in the country. It was recently the site of the 2002 Winter Olympics. The capital of Utah, the city is emerging as a prominent population and economic center of the Rocky Mountains.

Despite dramatic growth, Salt Lake maintains the charm of a small, personable city. It is still an easy place to get around, and its residents are friendly and down to earth.

The Salt Lake City Marriott Downtown is a newly renovated, premier convention hotel featuring meeting space and ballrooms and including an indoor pool, health club, restaurants, gift shop and 24-hour business center. It is one of a select group of hotels to receive the AAA four-diamond rating.

## Tourist and Lodging Information

The Salt Lake City Marriott Downtown, 75 South West Temple, Salt Lake City, Utah, 84101, (801) 531-0800 or (800) 228-9290. Conference Rate is \$89.00 per night. Web address: [www.marriott-hotels.com](http://www.marriott-hotels.com)

For additional information, contact the Salt Lake Convention & Visitors Bureau, 90 South West Temple, Salt Lake City, Utah, 84101, (801) 521-2822 or (800) 541-4955. Web address: [www.visitsaltlake.com](http://www.visitsaltlake.com).

## Conference Grant Requests

The following are criteria for obtaining a conference grant:

- Names of family planning to attend and person with PWS.
- The financial and emotional needs of you family should be detailed in a letter to PWSA (USA) Please state whether you have ever received a grant before. Are you seeking local funding also?
- Reason for wanting to go to the conference – hopes for conference, to learn what, possible benefits to person with PWS and to family.
- Specific request: Your budget for going to conference and what you need – registration, hotel, travel, etc.

All grants are reviewed and decisions made with the intent of assisting as many families as possible; therefore, some grants may be only partial grants.

**Submission deadline is May 10, 2002.** You will receive a response from PWSA (USA) by May 24, 2002.

Grant requests should be mailed, emailed or faxed.

FAX: (941) 312-0142

Email [national@pwsausa.org](mailto:national@pwsausa.org) Re: Grant Committee

Mail: Prader-Willi Syndrome Association (USA)

5700 Midnight Pass Rd.

Suite 6

Sarasota, FL 34242



# PRADER-WILLI SYNDROME ASSOCIATION (USA) ANNUAL REPORT TO THE MEMBERSHIP FOR THE YEAR 2001

*By Janalee Heinemann, Executive Director*

*Lota Mitchell, President*

*Ken Smith, Board Chair*

## OUR MISSION STATEMENT

**Through the teamwork of families and professionals, PWSA (USA) will improve and enhance the lives of everyone impacted by Prader-Willi syndrome (PWS) and related conditions.**

## Looking Toward the Future

In 2001, a major effort was put toward creating a 5-year Strategic Plan. In expanding our horizons, we expanded our mission statement to include a statement of vision that reflects our current, broader scope of services.

## Research

Over its 25-year history, PWSA-USA has been an energetic, constant and productive player in the world of Prader-Willi syndrome research. Its contributions to the identification of and management of those people with the syndrome are legend. However, the association with all its resources – including clinical and scientific professionals, lay parents and volunteers and funding – can make more progress in the area of PWS research support.

Prader-Willi syndrome, with its unique genetic, epidemiological and clinical features, should provide fertile ground for the investigation of some of the most pressing health issues of today, e.g. obesity, obsessive-compulsive behavior, depression, osteoporosis, etc. The solution to the key problems of PWS would relieve families and the health care system of extraordinary human and financial costs.

## Research Strategy

We plan to stimulate research about Prader-Willi syndrome and help set priorities and direction of that research.

*Research Fellowships* – Encourage this prime pipeline of professional talent (e.g., MDs and PhDs) to become interested in PWS – and dedicate themselves to our cause.

*Awareness* – Increase awareness of PWS and its needs at the Federal government and its agencies such as NIH, as well as major foundations.

*PWS Center* – Investigate the possibility of establishing a national center of excellence dedicated to PWS research.

*Obesity Connection* – Increase the connection of PWS with the global obesity issue.

*Cooperation* – Facilitate communication and cooperation within the scientific community.

*Education* – Provide mechanisms for the dissemination of information among the scientific community and to the lay community. Conduct the annual Scientific Conference.

*Scientific and Clinical Advisory Boards* — Maintain the high caliber of members and services provided from the SAB and CAB of PWSA (USA).

*Database* – Investigate the feasibility of a database of research projects relating to PWS. Establish a registry of all those individuals with the syndrome.

*Funding* – Generate private and public funding for research. Assist in the funding of “seed projects” that are the precursors of major studies. Conduct fund-raising for the PWSA research fund and other special projects. Increase the awareness within PWSA of government and private funding opportunities.

## OUR VISION STATEMENT

Through the teamwork of families and professionals, PWSA (USA) will improve and enhance the lives of everyone impacted by PWS and related conditions.

- We will provide education and resources in order to improve the quality of life for everyone with the syndrome as well as the people who support them.
- We will instill a sense of compassion and understanding through our dedication to providing awareness and enlightened knowledge about the syndrome.
- We will secure the resources necessary to accomplish our goals. PWSA (USA) will take a leadership role in supporting and stimulating research, which will ultimately lead to a cure.
- Furthermore, we believe the research findings related to PWS will significantly impact the understanding of obesity and appetite regulation in the general population.

*Annual Report continued on page 5*





#### Fund-raising

Activity by Year	1997	1998	1999	2000	2001
Contributions (includes donations, \$82,235 \$126,568 \$209,075 \$276,654 \$400,014 Angel Fund, & grants)					
Percent Increase	35%	39%	24%	31%	

#### Resource and Fund Development

The table above illustrates the significant increase we have accomplished over the past four years in funding — excluding conference, membership dues, merchandise sales and interest/investment income.

To further enhance our funding, we plan to center our attention on the following objectives:

- Establish a Foundation in order to provide a financial base
- Emphasize designated funding for an endowment and for research
- Encourage fund-raisers by members across the nation
- Focus on nurturing major donors and planned giving

#### Awareness & Education

The year 2001 has been our most significant regarding awareness — and 2002 is expected to be even more dramatic. In early 2002, we will distribute without charge to approximately 2,500 health providers and others, our three new educational products that we created in 2001:

- *PWS: The Early Years* (a video targeted for families of younger children)
- *PWS: An Overview Video For Health Care Professionals*
- *Growth Hormone And Prader-Willi Syndrome: A Reference for Families and Care Providers*

A Public Service Announcement (PSA) with Senator Bob Dole has been distributed to 250 television stations around the nation. PR information has gone to all chapter presidents, and nine major cities have received media packets and been contacted as targeted areas for media coverage.

We have hosted awareness booths/tables at three conferences, and plan to host such booths at three major conferences in 2002.

We also have sent out more than 9,000 free educational mailings, 700 orders for educational materials and approximately 1,000 free specialized awareness packets: 1) for health care providers; 2) on general awareness; 3) for parents of newly diagnosed children.

Thanks to earlier diagnosis and education, we are entering a new era for PWS, with much brighter horizons. *The number of parents of young children contacting PWSA (USA) dramatically increased in the year 2001.*

Our web site is a major resource for information on PWS, increasing from an average of 2,600 pages of requests in February 2001 to an average of 5,000+ pages each month for the last four months of 2001. The number of "hits" for the year was 3,615,873. A significant number of new calls come from people who first found us on our web site.

PWSA (USA) responds to educational and crisis calls through our toll-free, 800 telephone number. There are more than 1,000 calls each month — at a cost to the association of \$1,650.00 a month. We also respond to inquiries by mailing free educational information requested at an average of \$920.00 per month in postage. Availability around the world has been significantly increased through e-mail and Web site.

#### PWS statistics: People with PWS known to PWSA (USA)

Range	Count
0-5	299
6-11	524
12-17	666
Over 18	2,327
Total number	3,816

We produced, published and offered 15 brochures, 27 booklets, 9 videos (3 in European/PAL format) and 4 comprehensive books. *All were written by professional volunteers and edited, designed and published primarily by volunteer efforts.*

#### Technology

We made exceptional progress in 2001 mainly due to the generosity of time and equipment from two volunteer grandparents. Who said our older generation is technologically impaired?

Numerous equipment upgrades were made, which included adding another phone line, upgrading all computers, improving anti-virus and back-up systems, converting the membership database to ACCESS 2000, adding a server and adding a label printer.

#### Programming Enhancements

We modified the membership database to accept auxiliary memberships, thus allowing families to add relatives and care providers at a reduced fee.

We began three new e-mail support programs.

We increased and enhanced pages on our web site.

#### MEMBERSHIPS

Family memberships	1882
Professional memberships	321
Memberships provided free of charge*	350
International Members	96
New members in 2001	310

\*No parent is denied membership due to inability to pay

Annual Report continued on page 6



### EXPANDING OUR FRONTIER—INTERNATIONAL SUPPORT

Thanks to awareness and e-mails, the world of Prader-Willi is getting bigger in numbers and smaller in distance. Solidarity, co-operation, mutual support and sharing are fundamental. There are no “greater than” or “lesser than” nations, only nations that have been more fortunate than others. Knowledge is not ours to hoard, and information and support should be given as freely as the air we breathe – it is essential to all children with PWS.

#### Hosted the 2001 IPWSO (international) conference

**The 2001 International Conference in St. Paul, MN was a great success.** This was the fourth World Conference, the first to be held in the USA. There is truly no way to thank Jim and Joan Gardner enough for hosting the world conference, and their entire chapter and committee chairs for their outstanding work. Total cost of the conference was more than \$300,000 – of which \$205,813 was raised in charitable income, which made this extraordinary event possible.

#### INTERNATIONAL CONFERENCE STATISTICS

Total number of people registered	1380
International Scientists	125
Professional Community Service Providers	195
Volunteers	355
Number of YAAP registrants	280
*200 of whom have PWS	

*Although our languages sometimes keep us apart, our hearts are one.*

*-- Giorgio Fornasier*

#### CONFERENCE GRANTS PROVIDED

Families	36
Scientists (from 7 countries)	16
Service Providers	14
IPWSO Representatives	3
Total Number of Grants Provided	69

#### IPWSO – Shining a Light in the Darkness

Although our nation has great needs concerning PWS, we believe that each candle we light makes our own way brighter. Thanks to the leadership of our International President, Giorgio Fornasier, and the governing members of IPWSO, 44 countries are now represented in this PWS international organization – of which we are proud members.

Spanish is spoken in 14 of the 44 nations. This and the many requests for materials in Spanish from our own country led us to reproduce our “Weight & Behavior” brochure in Spanish and add a *Management of PWS* book/CD, thanks to the PWS organization in Spain. Working with the California foundation, we will translate two more brochures into Spanish – the “Q & A” brochure and the “Medical Alert for Parents and Care Providers.”

PWSA (USA) is striving to cross the language barrier that our hearts have already crossed. In cooperation with IPWSO, we are able to get support in translating all languages. We also have Spanish and Portuguese translation software to assist us with the vast array of international e-mails we receive.

During the year 2001, volunteers donated more than 8,000 hours to PWSA (USA)

### PROGRAMS THAT MAKE A DIFFERENCE

#### New Parent Mentoring Program

Through this program we believe that we can have the greatest impact on early intervention and prevention. Early diagnosis, education and awareness are the keys to prevention of life-threatening obesity and years of isolation and emotional trauma for the family of the child with Prader-Willi syndrome.

Early intervention can also save thousands of dollars in medical expenses and greatly reduce emotional turmoil on families.

*Eighty-six families of newly-diagnosed infants and toddlers became involved with this program in 2001.* It is the most exciting service we offer regarding prevention. How these parents are first introduced to Prader-Willi syndrome has a lifelong impact.

One of our volunteer board members, Carolyn Loker, is parent coordinator. She is a pediatric cardiology echosonographer, co-President of PWSA Michigan State Chapter and the parent of a young child with PWS. She has trained eight volunteers to provide one-to-one mentoring and support services through phone and e-mail to parents of newly-diagnosed infants and toddlers.

*Thanks to the Pharmacia grants,* we are also sending all parents in this program the new video and growth hormone book free of charge. We will also send their physicians the video for health providers and the growth hormone book at no charge.

#### Medical Intervention Support

Calls and e-mails on acute and serious medical crises have increased. Hospitals, physicians and parents worldwide consult with PWSA (USA) with medical emergencies and questions daily. Using phone, fax and e-mail, PWSA (USA) consults with our volunteer *Clinical Advisory Board and Scientific Advisory Board members* to respond to all through our Triage Support System.

#### Bereavement

Norma Rupe, our volunteer coordinator for this program, continues to do an outstanding job. She had 37 new bereaved families in 2001, and sent out 67 holiday bereavement packets. The holiday packets are sent for the first 2 years. Norma now individualizes each packet and also contacts each family personally by phone.

As a follow-up, we are investigating the causes of death with PWS through a committee that will provide a comprehensive review of each death. Studying the sudden deaths of individuals with PWS is of special interest and concern.

*Annual Report continued on page 7*



**Prader-Willi Syndrome Assoc. (USA)**

**Major Donors**

**January 1 – December 31, 2001**

Pharmacia Corporation

F. R. Bigelow Foundation

Katherine B. Andersen Fund

The Saint Paul Foundation

Chippie Alterman Trust

PWSA of Michigan

Jim and Joan Gardner

Denver Security Traders

Torbert Produce, Inc.

The Sam P. Alterman Family Foundation

Hugh J. Andersen Foundation

**Crisis Intervention & Prevention Program**

A significant role of the national office is to assist with crisis situations. This is done through the support of a qualified crisis counselor via phone consults and networking, e-mail, our publications and individualized crisis packets, each containing very specialized letters. We consult with attorneys, legislators and physicians, and teleconference with schools and courts.

**CRISIS CASES**

<b>Total Year 2000</b>	<b>231</b>
<b>Total Year 2001</b>	<b>391</b>

**Our Alterman Crisis Counselor**

David Wyatt plans to focus on the following areas in this next year:

1) **Supportive Placement** – Our case

statistics demonstrated that 30 percent of our crises were those of the need for appropriate placement. It is important to enhance our relationship with care providers and keep an updated list of placement option. We are working on a user-friendly care provider form and database to introduce into our web site.

2) **School Advocacy** – The combination of zero tolerance and mainstreaming has been the cause for many of our children who get suspended and even arrested for behavior that would be considered “typical” for PWS. A policy statement needs to be developed that could easily be placed in an IEP contract.

3) **Psychosexuality** – Incidents of sexual activity and/or abuse have been on the increase. Our children are getting older and their sexual needs appear to be getting them into situations fraught with ignorance and the lack of sexual understanding. We are researching how other disability groups are dealing with sexual education, and plan to develop policies and resources that may be adopted by PWSA (USA) that will be relevant to those caring for teens and adults with PWS.

In his personal comments to the Board of Directors, David stated: “This is a position that is privy to the pain, stress and struggles of the parents of children and adults with Prader-Willi syndrome. Just as one hears the worst of scenarios, another comes to take its place. I have also been impressed and renewed in spirit by the resiliency, strength, ingenuity and humor of those who have shared their stories with me. In each crisis instance, it seems that those involved come up with new ideas, personal strength and a strategy to manage the incident.”

## Bylaws Amendment to Provide Greater Board Representation

The Board of Directors has unanimously decided to bring to the membership a vote to amend the Bylaws, which would eliminate floor nominations for seats on the Board beginning either this year or in 2003.

The Board wants to assure a greater representation of the entire membership in the election process. Analysis of the attendance figures shows that in our larger conferences only about 1/8 to 1/6 of PWSA members attend any given conference, where the elections take place. Floor nominations prevent the total membership from knowing and being able to vote for the whole slate of candidates.

We encourage proxy voting so that a greater number of the whole organization chooses their representatives, not mainly those at conference. Now that we are having alternate year, smaller conferences, the issue is of even greater importance.

In order to have a strong Board and therefore a strong organization, it is essential that the Nominating Committee identify the needs of the Board and recruit individuals with the skills to meet those needs. Also considered, of course, is the mix of parent/professional, age of children represented and geographical location. The Nominating Committee and Board are committed to an active recruitment process so that there will be more candidates than positions that are open. This will provide the membership with choices.

This edition of *The Gathered View* is featuring Board candidates with pictures and bios on pages 8 and 9. **VOTING MEMBERS, PLEASE READ THESE CAREFULLY, MAKE YOUR CHOICES, AND SEND IN YOUR PROXY IF YOU ARE NOT ATTENDING CONFERENCE. YOUR VOTE COUNTS.**

## IPWSO REPORT - continued from page 1

IPWSO would like us at PWSA(USA) to open our hearts and lead the way by considering accepting Brazil as our “twin” country. All who have read my article in the January-February 2002 issue of *The Gathered View* will already be familiar with the courageous mom, Maria Helena, who has started an organization in her country.

Since the article was published Helena has made great strides. She is sending information on PWS to all pediatricians throughout Brazil.

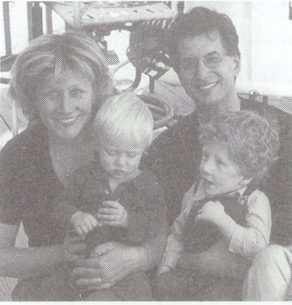
Another well-informed mother (previously from the U.K.) has accepted the position of secretary of the newly founded organization. In hope of spreading PWS awareness and reaching more family and professional contacts, Helena will soon be a guest on a famous Brazilian TV talk show. Her determination and hard work is so admirable!

Helena wrote, “I would like our logo to show people holding hands around the world (people with no color but transparent in their heart and with a neutral nationality) who form all together a Brazilian heart. Help, love, and respect toward our children.”

If there are any members who would like to help with this project, please contact me by phone at 717-737-5555 or by e-mail: [pamel1@bellatlantic.net](mailto:pamel1@bellatlantic.net).



# Candidates for the PWSA (USA)



## Janice M. Agarwal, Zionsville, Indiana

I am the mother of Alexander (diagnosed with PWS when 8 days old) and his younger brother Samuel. Before beginning my full-time career as a mother 2 years ago, I was a pediatric/neonatal Physical Therapist at a children's hospital in New York. I trained pediatric physical, occupation and speech therapists as well as nurses in developmental aspects of children, with emphasis on children under 3 years old.

I currently mentor parents of children newly diagnosed with PWS and am developing a handbook to help parents understand physical, occupational and speech therapy, and equipment available for our children. I brainstorm with families to create home environments that enhance cognitive and motor growth through play with parents and siblings. My strengths are working with children and their

parents and participating in team care of children with special needs. I look forward to bringing a therapist's and young mother's perspective to the Board.



## David Bogazyck, Gross Point Park, Michigan

My son Zachary is now 15 months old and was diagnosed with PWS at seven weeks of age. Although our medical caregivers had heard of the syndrome, none had treated any infant patients with this diagnosis. Fortunately, we were able to receive immediate information and support from PWSA (USA). Two weeks later, we were able to attend a Michigan chapter meeting and discuss our many questions and concerns with other families.

I am an attorney, currently the corporate secretary and general counsel of Fiberlink Solutions, a telecommunications corporation. I specialize in advising corporations and organizations in the areas of corporate, contract and government compliance issues. Using my background, I have provided ongoing

advice to both the National and Michigan chapters on several issues confronting both organizations. More important than providing advice to the PWSA (USA), my role as an aggressive patient advocate is to provide increased opportunities for our children and adults with PWS. Along with my wife Edie, who is expecting our second child in July 2002, we look forward to raising awareness and funding for all PWS organizations so that no opportunity is compromised, diminished or overlooked.



## Edmund Funai, Eastchester, New York

I am the husband of Maryanne, and father to 6-month-old twins Peter (with PWS) and Phoebe.

I am also a physician, on the full-time faculty at New York University School of Medicine. I'm a Maternal-Fetal Medicine specialist, taking care of high-risk patients. I currently have funding from the National Institutes of Health to investigate pre-eclampsia, or high blood pressure in pregnancy. I'm very interested in learning more about the experiences of PWS parents from a research perspective, and working with the NIH and PWSA to encourage federal funding of research into diseases like PWS.



## Lisa Graziano, Redondo Beach, California

I appreciate the opportunity to run for a seat on the Board, and share with you some of my life skills and experiences that may assist PWSA (USA) and the families of children and adults with Prader-Willi syndrome.

I have a masters degree in clinical psychology and am a licensed marriage and family therapist. I served 5 years as executive director of the largest non-profit psychiatric association in California before resigning to establish my private psychotherapy practice.

I am an active volunteer for PWSA (USA) and have attended every annual educational meeting since the birth of our son Cameron 3 years ago. I am an active member of the Prader-Willi California Foundation. Last year, with the help of my husband T.J. and the California Foundation, we formed a

family support group for the Southern California area. I am most fortunate to have been married 15 years to an extraordinary man, and I am prouder than words can express of our son Cameron, who is the soul in my life. I commit my energy, enthusiasm, focus, eternal hope and optimism to PWSA (USA) as they assist individuals with PWS and their families.

*Research continued on page 9*



# Board of Directors Election

## Carol Hearn, Plymouth, Minnesota

My husband Tim and I have three children (daughters ages 15 and 13, and a son age 9), the youngest of whom has PWS.

A 1983 graduate of Harvard Law School, I practice law part time, specializing in contract law. My husband is also an attorney.

In 2000-01, I served as the chairperson of the volunteer recruitment program for the PWSA (USA) and IPWSO international conference, and as chairperson of the Parent Special Education Advisory Council for our school district. I have served in the capacity of vice president of PWSA-MN, and am now the current president of PWSA-MN.

David is on growth hormone and grew 5 inches in the last year. He is slim, happy, and full of energy. In the scheme of what we thought the future might bring, and in light of living with a sister who had a stroke at age 18 and lost all of her voluntary muscle movement, David is a "dream child."

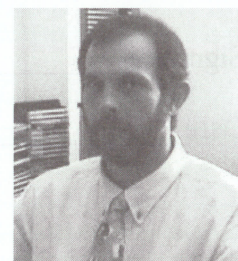


## Henry Lee, Morgantown, West Virginia

When Sam was born, we already knew something was wrong, he had hardly moved during pregnancy. Marge and I actively sought a diagnosis for over 5 years, and all we were ever told was that Sam would "grow out of it." So we kept looking and were finally diagnosed with PWS in 1996.

Because there were only five diagnoses (that I know of) in West Virginia, we had to look elsewhere for a support network. When some people in Pennsylvania were trying to reform their state chapter for PWSA, we joined up with them. In 1998, during the organizational meeting, I was elected as vice-president for PA. When the PA chapter hosted the 2000 conference, I was facility and technology chair. While that week was probably the hardest I have ever worked, it was also the most rewarding experience of my life.

I've been the computer network manager for West Virginia University – College of Business and Economics for the past 6 years. Before this, I worked in computer field service for 15 years and am a 4-year veteran of the US Air Force. My education includes a Bachelor of Arts from West Virginia University, 1999. It took me 18 years to finish my bachelor degree, but I finally did!



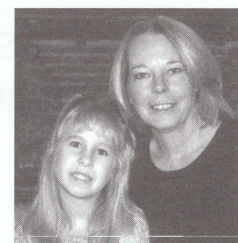
## Carolyn Loker, Plainwell, Michigan

I've been a member of the board of directors of PWSA (USA) since 1999, and in 2001 was elected to serve as vice president of PWSA (USA). At the chapter level, I've served as co-president of the Prader-Willi Association of Michigan since 1997.

Recognizing the unique needs of parents with newly diagnosed infants, I coordinate the Young Parent Mentoring Program, and am also involved with the PWSA (USA) support and information e-mail programs. I was also a parent consultant for the Growth Hormone Booklet, Nutrition Booklet for Infants and Toddlers, the Handbook for Parents and the new video "The Early Years."

My husband Jim is a Pediatric Cardiologist and serves on the Clinical Advisory Board. We reside in Kalamazoo, Michigan and are the parents of four daughters. Our youngest daughter Anna, 7 years old, has Prader-Willi syndrome.

I spent 14 years as a Pediatric Cardiac Echocardiographer at Riley Children's Hospital at Indiana University Medical Center. In addition to my work for PWSA, I'm a co-founder of the Parent-to-Parent Organization of Michigan and serve as an advisor.



## Pamela Tobler, Orem, Utah

I'm sure many of you have seen those toy globes filled with water, the ones with the village scene and when you shake it, it "snows" in the village. On September 14, 1995, it snowed in our village when Nathan joined our family. Shock was my first reaction, but not for long. We soon recognized that snow doesn't ruin things, it makes them look different, and usually more beautiful. We decided to do everything we could to make our son's life as rewarding and fulfilling as possible.

The past 3 years have been filled with many opportunities to learn and grow. Thank you for the opportunity to serve on the board of directors. I now seek your vote again to continue serving on the board.

My background includes a bachelor's degree in public relations. I have developed strong communication skills that will assist in more awareness activities. I have served as the past president of the PWSA Utah chapter, coordinated a state-wide awareness campaign, and am co-chair of the 2002 National Conference.

With our son only 6, we are dealing with many issues that parents of younger children with PWS are encountering. I see this opportunity of serving on the board as an opportunity to represent those families and individuals and to improve the quality of your lives. I want to assist my son, and in the process I want to assist your sons and daughters (and grandchildren) to have as rewarding and fulfilling a life as you and I enjoy.



*Research continued on page 11*



**Prader-Willi Syndrome Association (USA) 2002 Official Proxy**  
**Must be received at PWSA (USA) office by June 28, 2002**

I hereby appoint \_\_\_\_\_ of \_\_\_\_\_ to  
(print name of your designated proxy voter) (state of residence)  
vote as my proxy at the PWSA (USA) Annual Membership Meeting in Salt Lake City, Utah, July 2002.

**Instructions to proxy voter:**

☐ **Please cast my vote as you see fit**

**OR**

☐ Please cast my vote for the Board of Directors  
candidates I have marked below: (VOTE FOR 5)

I am a member in good standing of PWSA (USA)

Name \_\_\_\_\_  
(please print)

Signature \_\_\_\_\_

Date \_\_\_\_\_

☐ Janice K. Agarwal

☐ David Bogazyck

☐ Edmund Funai

☐ Lisa Graziano

☐ Carol Hearn

☐ Henry Lee

☐ Carolyn Loker

☐ Pamela Tobler

☐

(This space provided for a write-in candidate)

Vote for one: (See page 7 for details)

☐ Floor nominations should be eliminated at the Annual Membership Meeting starting in 2002.

☐ Floor nominations should be eliminated at the Annual Membership Meeting starting in 2003.

☐ Floor nominations should NOT be eliminated at the Annual Membership Meeting.

**Prader-Willi Syndrome Association (USA)**  
**2002 Official Proxy for Second Family Member**

This ballot to be used by  
Family Memberships only

I hereby appoint \_\_\_\_\_ of \_\_\_\_\_ to  
(print name of your designated proxy voter) (state of residence)  
vote as my proxy at the PWSA (USA) Annual Membership Meeting in Salt Lake City, Utah, July 2002.

**Instructions to proxy voter:**

☐ **Please cast my vote as you see fit**

**OR**

☐ Please cast my vote for the Board of Directors  
candidates I have marked below: (VOTE FOR 5)

I am a member in good standing of PWSA (USA)

Name \_\_\_\_\_  
(please print)

Signature \_\_\_\_\_

Date \_\_\_\_\_

☐ Janice K. Agarwal

☐ David Bogazyck

☐ Edmund Funai

☐ Lisa Graziano

☐ Carol Hearn

☐ Henry Lee

☐ Carolyn Loker

☐ Pamela Tobler

☐

(This space provided for a write-in candidate)

Vote for one: (See page 7 for details)

☐ Floor nominations should be eliminated at the Annual Membership Meeting starting in 2002.

☐ Floor nominations should be eliminated at the Annual Membership Meeting starting in 2003.

☐ Floor nominations should NOT be eliminated at the Annual Membership Meeting.



# Beware of Medical Advice Over the Internet

By Daniel J. Driscoll, Ph.D., M.D.  
Co-Chair, Clinical Advisory Board and  
Merlin G. Butler, M.D., Ph.D.  
Chair, Scientific Advisory Board

There is now a wealth of medical information available at our fingertips over the Internet. But how good is this information really? Well, some of it is accurate, but much of it reflects unsubstantiated claims. In general, anyone can post information without it being verified. There is a real danger that families will accept as gospel information available on the Web and spread this potential misinformation to friends and others over the Internet.

Any information on the web needs to be carefully evaluated. First, assess whether the "source" of this information is reliable. An initial screen should investigate the source of the information (i.e., whether it is a "non-profit" organization such as PWSA (USA), the National Institutes of Health, an academic institution such as a university, or a "for profit" organization.) Also, assess the motivation for the posting of the information.

If it is for a new treatment, the reader needs to ask several questions: Have clinical trials been done and published? Was it published in a respected medical journal? Were the results significant? Did other groups obtain the same results? What are the possible side effects of the treatment? Is it better than the usual treatment? Are the suggested medications approved (and therefore regulated) by the Food and Drug Administration (FDA)?

An example of a successful medical treatment for PWS fulfilling all of the above criteria would be growth hormone therapy for our children with PWS.

For most parents, medical research does not move fast enough. However, this is not because researchers are not working hard searching for solutions. In the last 20 years there

Any information on the web needs to be carefully evaluated. First, assess whether the "source" of this information is reliable. Also assess the motivation for posting the information.

has been remarkable progress in our understanding of PWS. Our children are being diagnosed and treated much earlier. Parents with adult-aged children with PWS can identify significant differences in diagnosis and clinical management of today's children with PWS versus what they went through years ago.

The first rule in Medicine is to "*Do no harm.*" We should all remember the "thalidomide story" in the 1950s, where babies exposed to this medication during pregnancy were born with terrible birth defects. We all want cures as quickly as possible, but we need to ensure that before using new medicines that they have been appropriately tested. This is not the easy route, but it is the safest.

Remember, ask your health professional and do your own "research" before accepting or starting new treatments. We all want the best for our children. Sometimes "the best" involves waiting for reliable data! The Web can be a good starting point to gather information, but don't let it be your last point.

## How Are Bears And PWS Alike?

Several months ago I received a call from a Ralph A. Nelson, M.D., Ph.D., FACP. He is head of the Department of Internal Medicine for the University of Illinois College of Medicine at Urbana-Champaign, as well as director of research at Carle Foundation Hospital in Urbana, Illinois.

Dr. Nelson is a world-renowned expert on the subject of metabolism in bears and in the area of clinical nutrition. Twenty years ago he wrote a chapter in our first *Management of PWS* book. He has never forgotten PWS, and recently, PWSA-USA has been collaborating with him on a research project.

Due to a non-disclosure agreement, I cannot go into detail, but would like to at least give you some basics.

For some time Dr. Nelson has been studying the control of appetite in bears. Bears are remarkable since they are able to go many months without eating or drinking. They prepare for this "denning" period with several weeks of ravenous foraging and feeding. There are several substances that may control this process.

Every parent of a child with Prader-Willi knows that in the first two years of life, getting your child to eat is a problem because the appetite is usually poor and sucking difficult. But by the age of 4 to 5, most children with PWS begin a period of runaway appetite.

Dr. Nelson's research team is comparing substances that control the process of feeding/fasting in the blood of both the child/adult with PWS and the bears. Our hope is that the studies of bears will be helpful in finding a way to control appetite in those with PWS. We will keep you updated.

For more information, you can contact Jim Kane at 410-321-9788.

— Janalee Heinemann, Executive Director

## The Chuckle Corner

My son Anthony is 6 years old and although his speech is pretty good, he sometimes does say some funny things.

One day after he got off the school bus, I asked him how his day was. He was very excited, and jumping up and down he said, "We had a prostitute on the bus today."

I said, "She's a SUBSTITUTE driver honey."

Driving in our van one day, Anthony said out of the blue, "My daddy is a liar."

I asked him if he was promised something and didn't get it.

He said, "NO, no he's a liar, a liar, you know, he went to school and now he's a liar."

I told him his daddy is a LAWYER.

Johanna Costello, Uniontown, OH





## Parent Discusses PWS and Hypothyroidism

On August 27, 2001, my 19-month-old daughter Isabel, who has PWS, was diagnosed with hypothyroidism, meaning her thyroid, a gland in the throat, was not producing sufficient levels of hormones as it was supposed to.

These thyroid hormones help to regulate a number of metabolic functions in the body, and it is very important to have

**I am not a doctor, but I would encourage everybody to consult their doctors about hypothyroidism testing.**

sufficient level of thyroid activity, especially in infants and toddlers.

Hypothyroidism occurs in approximately 5-6 percent of the population (from the research I've done as a parent), and PWS is not known to cause any increase in hypothyroidism.

The problem is that PWS may mask an underlying hypothyroidism. If I went to my doctor and said that a child or adult with PWS had low energy, weight gain and irritability, the doctor might assume this was due to PWS and would never check for hypothyroidism. Since hypothyroidism is tested via a simple blood test, I believe that all PWS children and adults should be tested periodically.

I am not a doctor, but I would encourage everybody to consult their doctors about hypothyroidism testing.

Everyone should be on the lookout for hypothyroidism (with PWS or not). Hypothyroidism produces some of the following symptoms (according to [www.Endocrineweb.com](http://www.Endocrineweb.com)):

- Fatigue
- Weakness
- Weight gain or increased difficulty losing weight
- Coarse, dry hair
- Dry, rough pale skin
- Hair loss
- Cold intolerance (can't tolerate the cold like those around you)
- Muscle cramps and frequent muscle aches
- Constipation
- Depression
- Irritability
- Memory loss

Our doctors had not ordered a hypothyroid test, but we were fortunate. At the PWSA conference in Minneapolis at the Young Parent Mom's discussion group, there was discussion of hypothyroidism. My wife Debra picked up on the discussion and we spoke with our endocrinologist about it. Since my daughter was giving blood for another reason anyway, our doctor agreed

to add the hypothyroid test. The test results indicated that she had hypothyroidism.

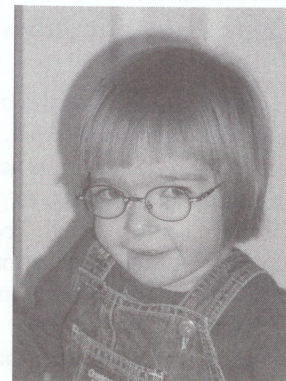
We detected an increase in Isabel's energy levels after beginning treatment (although at her age it is hard to differentiate a change in energy due to the treatment from general growth). This illustrates why it is important to seek out the latest information and to question and do research for your doctors.

Luckily, once detected, hypothyroidism is very easy to treat – Isabel is given a “secret special desert” of yogurt every night, which contains one crushed pill of synthetic thyroid hormone. As any child with PWS would, she loves her treat.

Once on the medication, her thyroid hormone levels increased to the normal range.

If you discover that your child has hypothyroidism, or you have any questions that I (a non-medical expert) can help with, please e-mail me at [lutzer@fuse.net](mailto:lutzer@fuse.net).

*Robert Lutz  
Cincinnati, Ohio*



Isabel Lutz, age 2

## Another Parent Comments on Hypothyroidism

In my conversations with parents from the Young Parent Mentoring Program and the PWSA(USA) e-mail support/information group, it has become apparent that hypothyroidism may occur more than we realize.

The hypothalamus causes the pituitary gland to release a chemical that stimulates the thyroid to produce thyroid hormone. The causes of secondary hypothyroidism (hypothalamic hypothyroidism) are failure of the pituitary gland to secrete the chemical to stimulate the thyroid gland, or failure of the hypothalamus.

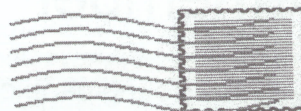
All states are mandated to test thyroid levels (blood draw) during the newborn screening process, but not all states perform a complete thyroid profile (free T4, T3, TSH). Some states only check TSH level. Testing only for TSH can miss hypothalamic hypothyroidism.

Children may not respond as well with growth hormone therapy until thyroid levels are normalized. You may want to ask your endocrinologist to check a complete thyroid profile prior to and after starting growth hormone.

If your child has a diagnosis of hypothyroidism, please contact me at [carolynloker@yahoo.com](mailto:carolynloker@yahoo.com) or 12534 Anson, Plainwell, MI 49080.

*Carolyn Loker  
Plainwell, Michigan*





## College Student Says Dare to Dream and Never Let Go

Hi, my name is Robin MacGillivray. I am a 20-year-old woman with PWS. Just like you, I have dreams. I decided the first step I needed to take to acquire my dreams was to attend college. A Community College wouldn't cut it. I had to be a student at a challenging college.

I decided on the University of St. Thomas in St. Paul, Minnesota. UST happens to have a very high reputation. They prepare their students for success and offer many places to study. Perfect!

Whatever I did paid off because after many weeks of waiting I finally received the confetti-filled acceptance card. Yes, I was going to college.



*Robin feeds pigeons at the Piazza San Marco, Venice, Italy*

Not only was I a freshman in college, I lived on campus! Even though it was challenging, the year had its rewards too. I had formed friendships, lost 20 pounds, developed study habits and had fun!

I want to inform you that I am now in my second year at UST. I am still living on campus and striving. I have a cumulative GPA of 2.8.

During the last few weeks, I have received a letter from the Dean of UST informing me that I made the Dean's Honor List last semester. So I am succeeding in something that was thought to be impossible! I am living proof the individuals with the PWS label CAN go to college. They can even live on campus!

My next dream/goal is to receive my licensure for Elementary Special Education. It will be tough but I can manage. I cannot wait!

I hope reading this letter has been a source of inspiration for you. Dare to dream and never let go! Then and only then you can make anything possible. Good Luck!

**Robin MacGillivray**  
**St. Paul, Minnesota**

## School Personnel Team Up to Help Cameron Do His Best

We have a phone system set up with the cafeteria at my 7-year-old son Cameron's school. I call them if he is having breakfast at school OR if he is bringing his lunch with him from home. If I don't call, they assume he's had breakfast at home and is eating lunch in the cafeteria.

Cameron knows that he can't just walk up into the line and go through and get breakfast. He knows that I call the cafeteria manager and that she knows who he is.

So one day he decided to go the sneaky route. He went up to his softhearted para-professional and told her that he was hungry and had not eaten. He was trying to get *her* to get him some breakfast.

The para had already been informed about his diagnosis and that he could not be given treats without permission and that food must be kept out of his sight. When Cameron approached her, she wasn't sure what to do, so she went to another para for advice. This particular para is the mother of his teacher and she also is aware of Cameron's diagnosis. She called the teacher on the cell phone and was advised to not feed him, she'd deal with it when she arrived, and his teacher began speeding her way to the school.

In the meantime, they also spoke with the cafeteria manager, who called me. The problem was that I didn't actually *watch* Cameron eat breakfast. I unlocked the freezer and saw him remove the sausage biscuit and I swear I heard the microwave, but I never actually saw him eat the food because I left the room to lay out his clothes and to get dressed.

They put Cameron on the phone so I could determine if he

had breakfast or not. I asked Cameron if he ate his breakfast. He of course declared no.

I then asked, "Did you eat the sausage biscuit?"

His response again was "NO."

Playing detective, I said, "I see the empty wrapper right here."

His response was, "I burned it (the sausage biscuit)."

I then asked, "Where's the burnt food?"

His response: "In the trash."

Me: "What trash?"

Cameron, "Oh, I gave it to the dog."

Needless to say, Cameron Jones did not get a second breakfast, but the school did get their first taste of the lengths he will go to. So by the time the teacher got there, the issue had been resolved. Everyone is impressed with how smart and clever Cameron is. I got to see that our phone call system is a great one, and that the school really is dedicated to doing their very best for him. Everyone was right on target and did everything that was necessary to protect him from himself. I LOVE this school!

Now I get to sit back and relax and enjoy my son's elementary education because I know these people are dedicated to educating him and keeping him safe. They make me feel that my son is important and worth their time and effort. They make me feel like my son is just as valuable and worthy as every other child at Riverside. What a good feeling!

**Velma Jones**  
**Shreveport, Louisiana**



# We Remember

Each of our young people with PWS had something special to offer this world — and we, along with their families, want to share who they were and what they meant to the people who loved them.

— Janalee Heinemann

## Lindsay Rich

Lindsay, who lived in Las Vegas, Nevada with her parents, Louis and Lori Rich, died on December 20, 2001 at age 22 of weight-related congestive heart failure. That was the day, her mother said, that Lindsay “became God’s angel.”

Since she was a sophomore in high school, Lindsay was adamant that she wanted to donate her hypothalamus when she died, because “it might help other kids with PWS.”

A beautiful young woman, Lindsay graduated from Green Valley High School in 1998. During her high school years, she was student of the month, went to school dances and her senior prom. She loved being in the high school choir, English



classes and her child development class. Lindsay was the first learning-disabled student to ever complete and pass with B’s and C’s in that class.

With her winning personality and million-dollar smile, Lindsay was high-spirited and competitive. She was a lifetime Girl Scout, earning her Gold Award, the highest accomplishment in Girl Scouts, and was the highest Girl Scout cookie seller both in Las Vegas and in the State of Nevada. She also loved all animals, especially desert tortoises, and was an avid Disney and Barbie doll collector.

“We all have our challenges in life, some bigger than others and some sooner than others,” her mother Lori Rich said. “Lindsay never let her challenges get in her way. Her theme was to climb every mountain, follow your dreams and be all you can be.”

## Kenneth Ayotte

He brought humor and inspiration to everyone whose life he touched. The son of Ron and Eileen Ayotte, Kenny, as he was known by all, died October 2001 at the age of 36, in Concord, New Hampshire. Just prior to his death from leukemia, cirrhosis of the liver and complications of PWS, Kenny had been working at a local Wal-Mart.

Kenny was remembered by many in the community for his dedication to the athletic teams at Concord High School, where he was a special needs student. Kenny managed the football, baseball, tennis and basketball teams in the 1980s.

When word spread that Kenny had died, sportswriter Ray Duckler, wrote a touching profile about him in the Concord *Sunday Monitor*, in which coaches and friends recalled Kenny’s high school days. “Mention Ayotte’s name to the coaches who worked with him and admiration and affection spill out,” Duckler wrote.

“Kenny was the heart and soul of this high school... he was everybody’s manager.... Everybody had a piece of Kenny,”



Concord boys’ tennis coach Harvey Smith recalled.

“Ken’s mother, sister, brother and I are very proud of what Ken was able to accomplish,” said his father Ron. “We were also very pleased that a number of athletes that Ken associated with during these years attended a memorial service for Ken,” he added.

Editor’s Note: *As most of you are aware, PWSA (USA) has a bereavement follow-up program coordinated by Volunteer Norma Rupe, who lost her own daughter. We also have articles that we send to our members free of charge, along with envelopes for memorial contributions. For more information about these and other resource materials, contact the PWSA office, 5700 Midnight Pass Road, Suite 6, Sarasota, FL 34242; phone (800) 926-4797, Fax (941) 312-0142.*

## Remembering Howard Merritt Christman, a loving grandfather

Dear PWSA (USA),

Enclosed is a small envelope in which you will find checks totaling \$2,000 in memory of my father-in-law, Howard Merritt Christman.

I have also added a list of all those people who donated directly to PWSA (USA) or wrote checks to us requesting that those donations be sent to the national office.

Dad Christman was a wonderful man who loved his family more than anything. He was Andy’s biggest supporter, always encouraging him and giving him strength. He lived life to the fullest every day, savoring it, taking it all in.

We would like this money used to help families in crisis. The

office and staff, especially Norma and David and Janalee, have been there for us during several emergency situations.

The crisis packets that you sent out on Andy’s behalf helped to “turn the tide” to get the services he needed. We hope that the enclosed funds can do the same for other families who are seeking help for their children with PWS.

Andy is doing well at Oconomowoc Developmental Training Center in Wisconsin. We hope that, finally, we have found a place where he can flourish.

*Sharon Christman, Grand Blanc, MI*



# Contributions In Memory Of

## Kenneth Artrip

Gifford Dental Laboratory

## Kenneth Ayotte

Jeanne Balog

James A. & Carol A. Komara

Kaaren E. Westlund

## James H. Bebrin, Sr.

William & Rhonda Earle

Warren & Dorothy Ramsdell

## Denise Capitani

John D. & Lynn A. Steben

## William A. Capraro, Sr.

Brook Forest Teachers

Karen A. Kolschowsky

## Duke Lee

(Dr. Phillip Lee's father)

Allen & Janalee Heinemann

## Frank Moss

Lota & Dave Mitchell

## Mindy Osthoff

Allen & Janalee Heinemann

## Timothy B. O'Leary

Lota & Dave Mitchell

## Jack & Lucille Wehner

Al and Linda Kennett

## Ora Marguerite Lee

Max W. & Marjorie M. Ankney

Kathryn C. Beamer

Christian Bias

A.R. Blethen

Sara T. Blethen

Cecil F. & Hazel L. Casteel

Jay & Cynthia Coats

Sarah & Sal Davoren

Thomas & Carolyn Keech, Jr.

Evelyn & Dan Kimble

Barbara & Richard Lee

Harold Lee

Mary Ann Miller

Odell C. & Mary Miller

Lota & Dave Mitchell

James & Margaret Montgomery

Laureate Alpha Nu

William H. Ringler

Harriet Romans

Rick & Linda Seime

Darlene R. Simmons

Spruce Street United Methodist Church

Kathy Stowasser

Margaret Tucker

Joan M. & Marvin L. Vest., Jr.

Margaret & Robert Wisinski

Catherine & Thomas Wright

## Mary Rica

Kenny Vctor

## Mary Richter

Donald & Glenda Grimm

## Lindsay Rich

Berkley & Karen Alexander

Cathy Ameling

W.T. Dugan

William & Judith Eichenseer

Jere & Janice Francis

Jacob & Betty Garehime

Donald & Charlene Lee

Doreen B. Lee

Roe & Hermoine Magness

Dava McCoig

Duane & Marjorie Olivier

Frank & Donna Plasso

Rose E. Ricci

David & Lois Ritner

Joan & David Sailon

M.M. & M.T. Schumacher

Lorraine Schur

Dominick & Toni Sgarlata

Mary Carol Sharp

Carmen Star

Susan & Gay Utley

Sally & Joe Vazzana

## Stephen Singer

Gloria & Marvin Barsky

## Jacob Soncarty

Mark & Robyn Johnson

## Grant Young

Fred & Alberta Beguhl

## ANGEL FUND CONTRIBUTIONS

Seraphim (\$1,000 or more)	Heavenly Angel (\$500 - \$999)	Heavenly Angel (\$500 - \$999)	Arch Angel (\$250-\$499)
<b>2001</b>	<b>2001</b>		
William A. Capraro, Jr.	Kevin Boehl	Dr. & Mrs. D. Ernest Ward, Jr.,	Camperships for Retarded
Gregory & Sandra Deaton	Mary J. Culver	Dr. Ozmer L. Henry, Jr., Mr. &	Children ( <i>in memory of</i>
James E & Suzanne L. Fuller	Bill & Cathy Evans	Mrs. J. Harvey Oliver, Jr., Dr.	<i>David Means</i> )
R.B. "Old Dog" Galloway	Fieldstone Foundation	& Mrs. Demming Ward, Mr.	Barrett Heywood ( <i>in honor of</i>
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Prader-Willi syndrome (PWS) is a birth defect first identified in 1956 by Swiss doctors A. Prader, H. Willi, and A. Labhart. There are no known reasons for the genetic accident that causes this lifelong condition, which affects appetite, growth, metabolism, cognitive functioning and behavior. The Prader-Willi Syndrome Association (USA) was organized in 1975 to provide a resource for education and information about PWS and support for families and caregivers. PWSA (USA) is supported solely by memberships and tax-deductible contributions.

