



The *Gathered View*

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

Michigan Families Run, Golf for Research *Over \$10,000 Raised in Two Special Events*

PWSA's Michigan chapter has fast become one of our bright "points of light," as the efforts of individual families and the chapter leadership are setting new standards for local involvement in the fight for those with PWS.

5K Run/Walk for Nicholas

Laurie Baskin, the mother of 2-year-old Nicholas, undertook her own fall fundraiser for "PWS appetite-related research." Her "Run/Walk for Nicholas," which was held September 11 in West Bloomfield, drew a crowd of more than 100 and raised over \$8,500 for research! Dr. Jim and Carolyn Loker were kind enough to change their schedule to represent PWSA (USA) at the Walk for Nicholas. Jim is on our Medical Advisory Board, Carolyn is on our governing board, and they share the Michigan chapter presidency.

When asked why and how a busy, young mother, who had no specific experience in fundraising, ever decided to take on such a task, Laurie said:

"When Nicholas was diagnosed at birth with Prader-Willi syndrome, I immediately asked: Why?—Why us? What could we do about it? Being in the profession I was in (print production), I knew



Nicholas Baskin (second child from left, held by his mom, Laurie) was the star of the "Run/Walk for Nicholas." Other "stars" of the day included, from left: Anna Loker, 5 (with her dad, Michigan co-president Dr. Jim Loker); Samuel Malott, 15 weeks; Carrie Mellesmoen, 15 years; and Andrew Willson, 4.

what my strengths and resources were, so holding a fundraiser seemed a bit overwhelming, but taking it one step at a time, relying on the help of many, it came together. The results were immeasurable as well as satisfying my drive to 'do something.' I feel we have helped others along the way in our quest for help with the insatiable appetite."

Second Annual Golf Outing

Another Michigan member, Tom Kopietz, coordinated a second annual golf outing for PWSA, in honor of his nephew Shaun Kopietz. The proceeds of

the golf event—\$2,345—were donated to PWSA of Michigan, with his permission to add this donation to the Baskin family's funds for appetite research.

As a result of the efforts of two families, more than \$10,000 has now gone to the PWSA (USA) Research Fund, earmarked for studies relating to the disordered appetite characteristic of PWS, and one grant has already been approved.

We cannot thank Laurie, her family and friends, Tom Kopietz, the Lokers, and the Michigan chapter enough. (The Michigan chapter also had donated \$3,450 to PWSA

earlier in 1999 from its Awareness Week Walkalong.)

Laurie plans to make the Run/Walk for Nicholas a yearly event and is willing to guide others who would like to consider doing a similar fundraiser. Call PWSA (USA) at 800-926-4797 for more information.

NOTE: PWSA (USA) does not receive government funding, nor does it hire professional fund-raisers. Money raised by members *does* go directly to meeting the needs of our families. You *can* make a difference!

—Janalee

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Hold these dates—

PWSA's 22nd National Conference

July 20-22, 2000

Pittsburgh, Pennsylvania



July 19, 2000

Pre-conference Events:

The 15th Annual Scientific Conference **of the Prader-Willi Syndrome Association (USA)**

The 2000 PWSA Scientific Conference will include papers on genetics, medical problems, growth, and behavior.

If you are interested in presenting a paper at this meeting and would like to receive further information, please contact:

Dr. Jeanne Hanchett
Scientific Conference Chair
Telephone: 412-420-2328
Fax: 412-681-1061

Annual Service Providers' Workshop

Meeting announcements will be mailed to service providers in January. If you have not received the announcement by February 1, please contact Ken Smith at 412-420-2420, or e-mail him at this address: KenSmith@attglobal.net to receive workshop information.

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

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Opening Our Hearts This Holiday Season

by Barb Dorn

As we celebrate the holiday season, many of us open our hearts by giving or helping others in need. It has been part of the mission of PWSA (USA) to open our hearts to *all* people who are affected by Prader-Willi syndrome, including persons with "acquired PWS" as well as those with "PWS-like disorder." I don't believe that the medical community necessarily utilizes or endorses these last two diagnoses. However, the more awareness we create, the more we are faced with people who have the same characteristics and needs as persons with genetically proven PWS. They too need our help and support.

So what is the difference? First of all, I want to say that these definitions or descriptions are basically my descriptions. As I travel the State of Wisconsin as well as the nation, I have had to explain these terms frequently. Once again, we are talking about people. And people do not often fit nicely into definitions and descriptions. My hope is to help you gain a better understanding of some of our similarities and needs that these individuals face.

People who have "acquired PWS" are not born with it. They do not have any abnormalities with their chromosomes. They typically develop the characteristics of PWS as a result of a brain tumor or damage in the area of the brain called the hypothalamus. Most have lived normal lives until either a brain tumor occurs or they suffer some sort of brain injury. They typically then begin a lifelong battle with food-seeking as well as behavior challenges. The book *For the Love of Christie* (which is available through PWSA-USA) clearly shares one family's experiences with this situation. It is truly a moving story.

People who have PWS-like disorder also exhibit most of the characteristics and challenges of genetically proven

PWS. They too do not have abnormal chromosome studies. These people often face problems with life-threatening obesity, learning challenges (mostly mental retardation) as well as temper outbursts and behavior concerns. In order to help them with these concerns, they also need the same approaches and strategies that many of our children and adults with PWS need. Oftentimes, however, because they do not have the chromosome abnormality, they are left with little or no support or resources.

The national organization as well as our chapters respond to these individuals

in the same way we respond to someone with a genetic confirmation of PWS. It is sad to think that many of these people are not referred to our organization. No one should ever feel alone. In the past, we did not have the sophisticated diagnostic services available that we have today. Many were diagnosed by the characteristics they were exhibiting. We began this organization supporting most people with PWS who were not genetically proven to have this disability. We are seeing an increasing number of individuals with PWS-like disorder. We have an obligation to open our hearts and reach out all those in need.

As we celebrate the holiday season and the start of a new year and a new millenium, may we all keep our hearts and our minds open to all those who need our help and support. On behalf of the officers, board of directors and staff of PWSA (USA), I would like to extend to you best wishes for a happy and safe holiday season.

Take care ...



Single Parents Needed

One of PWSA's new projects will be a collection of articles for parents on coping with having a child or adult with PWS. We want to include a section specifically for single parents. Barbara Whitman, Ph.D., a behavior specialist, will be in charge of that section and would like to contact as many single parents as she can to identify issues and solutions for parents in this situation.

If you are a single parent and would be willing to be interviewed to help develop material for this project, please contact Dr.

Whitman by telephone (314-577-5609, days) or e-mail (WhitmanB@SLU.EDU), giving your name, address, and phone number.

Looking at the Bigger Picture

by Janalee Heinemann

Most of our members know that PWSA (USA) creates, publishes, and distributes more free literature than anyone else in the world on the subject of Prader-Willi syndrome. They also know that we have an 800 information and crisis line, where we respond to hundreds of calls a week, and a Web site from which 6,400+ pages of information are tapped each day. My last article dealt with the amount of international support we give through mail and e-mail. But, in spite of all of we do, it is not enough. No one is more painfully aware of this fact than myself.

Although there are many success stories (including that of my own son, with whom we are having a delightful holiday visit), we still receive far too many calls about tragic situations where a child or teen is in a life-threatening situation because of their morbid obesity. Examples from cases I was working on last week are: a 14-year-old youth in Texas who weighs 430 pounds; a 20-year-old young man from

North Carolina who is over 400 pounds; an 11-year-old girl from Illinois who weighs 360 pounds; a 36-year-old young man from Alabama who is 4 foot 10 inches and 515

pounds; and a 7-year-old girl from Pennsylvania who is so obese that she needs a wheelchair and must crawl up the stairs. *Each of these young persons with PWS is in serious medical crisis—and we had never had a referral on them until now!*

Prader-Willi syndrome is the most common known genetic cause of life-

threatening obesity in children that has been identified. It has been estimated that one in 12,000–15,000 people have the syndrome, which equates to 350,000–400,000 people worldwide. PWSA (USA) knows of 4,085 persons with PWS in the United States out of an estimated 17,000–22,000. This leaves approximately 80 percent of those dealing with PWS without diagnosis and/or education and support services in the USA!

Experience has shown that early diagnosis and education can prevent obesity-related deaths and years of isolation and emotional trauma to the family and child. It can also save thousands of dollars a year in medical costs for each child. So, we must continue to strive for more awareness, education, support, and answers.

As Executive Director, I am aware that although I *love* working directly with the families, to spend all of my time assisting families in crisis on an individual basis is not the most effective use of my time. So I typically handle only the most complex situations and those needing specialized crisis information packets. We are working hard to get a grant to fund a **Crisis**

Intervention and Prevention Counselor. This person will be able to spend the time to give ongoing support to our families. It usually takes more than a call or a crisis packet to effectively support a family. There is so much we could do to prevent the problems if we have a person to: 1) work with the school system when problems are just beginning,

instead of waiting until a child is suspended or expelled; 2) educate a family before their child is in medical crisis; 3) advocate for a family before they are in desperate need of placement; and 4) educate professionals who are working with a child.

“Awareness has always been and must continue to be our major goal.”

Awareness has always been and must continue to be our major goal. One cost-effective method of obtaining awareness is through media exposure, so I attempt to be in frequent touch with the media. Thanks to the help of many parents throughout the nation, we are constantly working on getting media exposure and frequently sending information packets. You may not hear about all of our attempts, but *someday* we will get a great celebrity spokesperson. I can't tell you how hard we have tried!

Another role I play in looking at “the bigger picture” is to connect needs with interest. As the “PWS clearinghouse,” we often are the first to get the call on something that might be an unknown link that will someday give us the “cure” to PWS—or at least a medication or procedure that will alleviate some of the problems associated with the syndrome. We are fortunate to have so many professionals who are renowned for their work with PWS on our **Scientific Advisory Board** and our new **Clinical Advisory Board**. (In an upcoming *Gathered View*, we will give you some background on the members of these two boards and the work they are doing.) When I see potential trends develop or hear of any-

“We still receive far too many calls about tragic situations where a child or teen is in a life-threatening situation because of their morbid obesity.”

Executive Director's Report—contd.

thing that might be a piece in the puzzle, I share this information with members of our two medical boards and network the appropriate parties.

Thanks to the "tag-teaming" of parents, I have addressed several questions to the Scientific and Clinic Advisory Boards with the hope that they pique an interest in the pursuit of intriguing cases for a possible clue to aiding PWS. Whether it is advocating for more research on young children with PWS and growth hormone, or looking at a class action suit (see article in this edition) to reduce the number of young adults with PWS waiting for appropriate placement—it is thanks to this tag-teaming effort that we make progress.

One example is an interesting connection I noticed in the fact we have a few young children with a dual diagnosis of **mitochondrial disease and PWS**. The most interesting news is that these children are doing "shockingly better" than predicted. We're intrigued with the possibility that the medication prescribed for the mitochondrial disease may have a positive effect on PWS symptoms. Two physicians have taken an interest and are following up on these cases.

Another example of tag-teaming is regarding news about **Vagus Nerve Stimulation**, wherein a type of "brain pacemaker" will be implanted into the chest area to increase cerebral blood flow to the hypothalamus to curb appetite. It has been proven to be effective on animals. One parent e-mailed an article on the topic. Another got the name and number of the director of technology development for the project, and I called him to discuss the potential of this treatment option for PWS. In this case, he was able to state that although there will be a study beginning on obese adults, no one with other psychological or other health problems will be admitted into the study at this time. We did agree to share information and he said to be in touch next summer or fall for an update.

Another role I need significant assistance with is in raising funds to support our many outreach

causes. Two wonderful examples of how this is beginning to happen are:

1) We just received word that we were awarded a grant for \$17,000 from Ronald McDonald Charities for our awareness efforts. This is partly because we wrote a good grant—but also probably because a parent and board member, Pauline Haller, (and her husband, Eric, who owns a McDonald's franchise) wrote a letter of support and made calls.

*"We are all a part
of creating
the tapestry of hope for
a quality life
for our children with
Prader-Willi syndrome."*

2) A new parent in Michigan, Laurie Baskin, and the Michigan uncle of a young child, just completed fundraisers for "PWS appetite-related research." Thanks to such support for research PWSA (USA) is able to award research grants such as the one just approved for Susan Sell, Ph.D., on "Neuroanatomical Correlates of Hunger and Satiation in Subjects with PWS using Positron Emission Tomography."

Never one to be shortsighted on seeing needs—or short on ideas regarding initiating new programs—is a blessing and a curse for me. My undying gratitude goes to the many volunteers who assist in the follow-up. Two current examples that come to mind are:

1) Thanks to our board member and volunteer from Minnesota, Jim Gardner, we have had tremendous response from our questionnaire to grandparents for the booklet on grandparents and PWS, which is the

kickoff to our new grandparent program. With that feedback has come offers from grandparents to volunteer in a variety of projects.

2) Thanks to a very special office volunteer, Norma Rupe, a bereaved parent herself, the bereavement program continues to support people on a regular basis.

There is not a Michelangelo who will create for us "the bigger picture" nor one scientist with "the cure" for PWS. We are all a part of creating the tapestry of hope for a quality life for our children with Prader-Willi syndrome. It will be the teamwork of the members of our Scientific Advisory Board and our Clinical Advisory Board, combined with the tag-teaming of our parent members that will give us the answers.

When we are working late in the national office, we often push ourselves a little bit longer by asking, "*If there was not PWSA (USA) to pull the pieces together—who?*"

Before you give to the Angel Fund Drive this year, please ask yourself the same question. —JH



Wish List

We are in great need of a new office fax machine!

We need a heavy-duty, plain-paper model that can handle multiple pages and recipient lists.

If you or your business could donate such a machine or the funding to buy one, please call the PWSA (USA) office in Sarasota:
1-800-926-4797.



✧ A Child is Born ...

As we work toward universal early diagnosis of Prader-Willi syndrome, we must never forget that early diagnosis brings pain as well as hope, and requires rising to challenges that once were unknown, such as finding a way to tell family and friends that your newborn is affected forever by something called PWS. In their children's birth announcements, two of our new families offer remarkable examples of courage, openness, and willingness to begin fighting the battle—by educating themselves and others and asking for support. May all of our recently diagnosed families take strength from the words that Shanin and Gage Haverfield and Bob and Suzanne Brice sent to those nearest and dearest to them this year.

We are elated by God's gift of Claudia to our family. We felt it would be best to explain in her birth announcement the genetic disorder Claudia was born with. The genetic disorder is called Prader-Willi syndrome (pronounced "prod-der willy"). There are several symptoms of PWS. At this early stage in Claudia's life we have only seen one symptom, hypotonia (low muscle tone). Some of the symptoms do not appear until age one or later. Fortunately some of the symptoms are treatable with medicine and family intervention. There is a web site that is dedicated to the education and support of parents of kids with PWS. If you would like to find out more about PWS, we invite you to visit this web site: www.pwsausa.org. You can also utilize several search engines to get you to this site and other related sites. Please be warned that not all information on the web is good information. Some is very dated and some very biased to show the extremes of this disorder. If you do not have access to the Internet please call and we will mail you the information we have researched on PWS.

We are asking that you pray for successful research for PWS and its symptoms. At this point, we do not know if there are any studies to alter genes to correct this disorder, but we do know there is research in combatting the symptoms.

If you were planning to welcome Claudia with a gift, we ask that you consider making a donation to the Prader-Willi Syndrome Association. Your donation can be directed to research or to support families. Many employers will match contributions to nonprofit organizations (like PWSA) dollar for dollar. Novartis is matching our contributions. If you do not have the ability to receive company match, you can send your contribution to us and we will see that your gift is maximized.

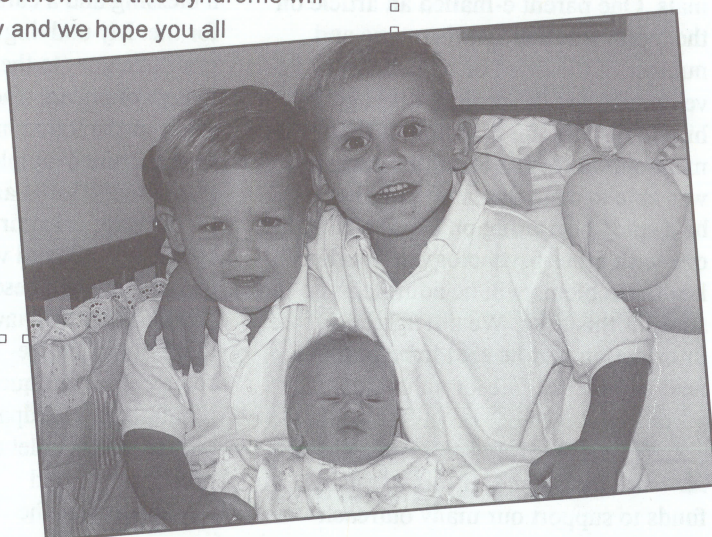
We are not sure what the future holds for Claudia. We do know that this syndrome will only be a small part of Claudia. She is such a pleasant baby and we hope you all get a chance to enjoy her like we do!

We are also enclosing some thoughts that were passed on to us from another family with a child that has PWS. These thoughts have helped us to put this into perspective.

Yours truly,

Shanin & Gage

Big brothers Camden and Clay with their new sister, Claudia



Note: The Haverfields' letter included a copy of Emily Perl Kingsley's well known essay "Welcome to Holland," which was published in The Gathered View, February 1997. This essay, and many parent articles are included in a PWSA collection entitled "The Early Years," recommended for parents of young children.

Greetings! There is so much to say. Our letter is to inform those who may be unaware of our daughter's birth and condition, as well as to follow up with those who are aware.

Savannah was born Saturday, March 13th at 10 p.m. ... kicking and crying as any healthy newborn would. I remember Bob saying in surprise, "It's a girl, Suzy!" Then he cut the umbilical cord and Savannah was whisked away by the neonatologist and nurses because of the aspiration of meconium. They assisted her in our labor room. The neonatologist argued that it was unnecessary for me to hold our baby since there were more procedures to follow.

Savannah was handed over reluctantly and I was able to hold her for a mere 15 minutes, and once again she was taken away.

On Sunday Lil' George came to see his new baby sister. What joy it was to see his face light up and to watch him gently and lovingly handle her. The hospital would not release us on Sunday evening as expected because of Savannah's positional problems at birth and weak feedings. Savannah would not nurse at all but would swallow the formula they made us force down her. Late Sunday night her temperature dropped considerably and she was lethargic. She was taken away and placed under heat lamps for hours as the doctors scratched their heads in wonder. I cried for hours. I was scared and confused. Late Monday night the neurologist said they could not find anything wrong with her and we could go home. Little did we know all of her symptoms were something very serious.

Within 12 hours of discharge from the hospital, Savannah had fallen into a coma-like state. It was then that our lactation consultant, who was making a home visit to help with feedings, noted Savannah's unusual condition (i.e., weakness, lethargy, squealing when touched) and urged us to see the pediatrician immediately. By 4 p.m. Tuesday we were in the pediatrician's office. We were told that we needed to admit Savannah to the Neonatal Intensive Care Unit (N.I.C.U.). By 6 p.m. Bob and I tearfully surrendered our little girl who had only been with us less than 72 hours.

Every test imaginable was run: cranial ultrasound, EEG, MPI and a multitude of blood work. Everything came back negative and normal. Savannah improved every day while in N.I.C.U. She was released 8 days later without a diagnosis. Shortly after, we received a call from Savannah's geneticist wanting to see us regarding the results of her DNA test. Instantly we knew something was wrong.

We made the trip to Miami Children's Hospital where we were given the diagnosis. I remember those grim words all too well: "Mr. and Mrs. Brice, your daughter has been diagnosed with a rare, spontaneous genetic disorder called Prader-Willi syndrome." She went on to say that Savannah has a deletion (a missing piece) in chromosome #15. ... I remember feeling numb. Any hope we had that Savannah's problems were temporary or curable had been lost. Further DNA testing was done to confirm her actual diagnosis. ...

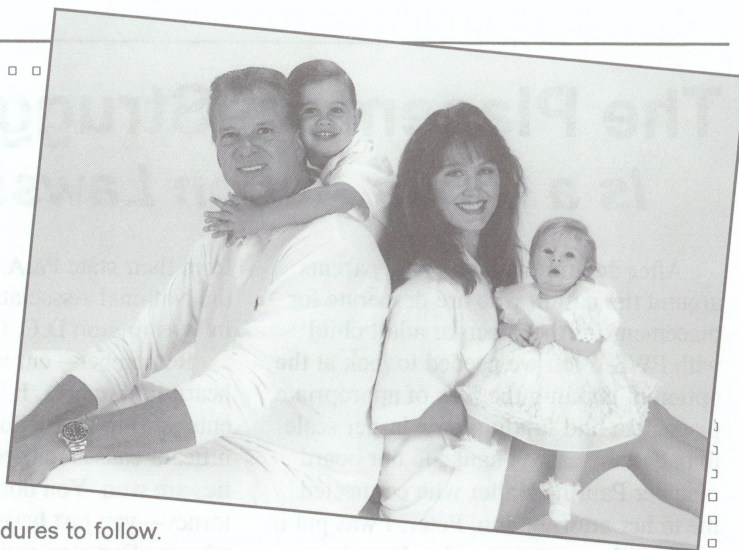
This is why we did not send out a birth announcement right away, with the exception of a very brief, simple letter to our family members. We wanted confirmation of Savannah's syndrome so that we could share, as well as educate, our family and friends. It is our hope that the enclosed brochure [PWSA's "Questions and Answers About Prader-Willi Syndrome"] will not only help you to understand our daughter's condition but also to help you pray for us.

Savannah just started speech therapy and physical therapy at home. We are currently awaiting occupational therapy. Because she suffers from hypotonia (low body muscle tone), she will need these to help with strength—just to do what comes naturally for other babies (i.e., sit up, crawl, walk and talk). Because of her hypotonia, Savannah is unable to nurse, so she receives Mommy's milk in a bottle. Speech therapy will help strengthen the muscles in her mouth, cheeks and tongue. We hope to be nursing soon. Her overall strength is our primary concern. Currently, we need to focus on several things: we need to take care of ourselves and our marriage, to learn all we can about nutrition and to take each day as it comes.

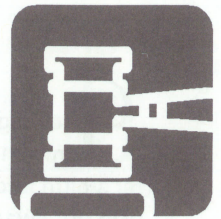
... Thank you to all who have diligently prayed for us. ... to all who called, wrote letters, sent gifts and provided meals for our family. We have never seen such an outpouring of love and affection. ... Thanks to our parents and family for all of their support. Most of all we would like to thank God for giving us our "Special" little girl and to praise Him for who He is: Almighty God, Creator of all, Ruler of all and the Great Physician and Healer!

With all of our love,

Bob, Suzanne, Lil' George and Savannah



The Placement Struggle: *Is a Class Action Lawsuit an Option?*



After dealing with so many parents around the nation who are desperate for placement for their teen or adult child with PWS, I felt we needed to look at the option of tackling the lack of appropriate placement and funding on a larger scale than case by case. Thanks to our board member Pauline Haller who connected me to her attorney son, Peter, I was put in touch with an attorney who does class action suits in New York. I spoke to Kim Sweet, an attorney with New York Lawyers for the Public Interest, a Protection & Advocacy subcontractor. After discussing the issues with Kim, it became clear that a national lawsuit would not be possible, due to the fact that the responsibility for providing services is a state level issue. *She did, however, have some excellent advice on approaching the problem on a state level.*

In Florida, due to the class action lawsuit of *Doe v. Chiles*, the court ordered the Department of Children and Family Services to provide housing and other services to a waiting list of developmentally disabled people. The judge ruled that if the state receives Medicaid money, it has an obligation to provide placement with "reasonable promptness," which was defined as *90 days*. Recently, U. S. District Judge Wilkie Ferguson, Jr., held the state in contempt and imposed a \$10,000-a-day fine. He faulted inadequate funding by the state legislature.

While the Florida decision could be overturned on appeal, Kim sees this case as potentially precedent setting for other states. In New York, for example, advocates threatened to recreate the Florida case. To avoid such a suit, the state agreed to provide the services! A number of suits have been filed in other states as well, challenging either the criteria or the waiting lists for "home and community-based waiver" services provided by states under the Medicaid Act.

Each state has free legal services for people with disabilities through a designated Protection and Advocacy Services agency. (See page 9.) If a family does not feel they received adequate assistance

from their state P&A, they can contact the National Association of P&A Systems in Washington D.C. (202-408-9514).

Remember—our voices will only be heard in numbers. It is only through parents uniting their efforts that most significant causes for people with disabilities are won. You don't have to be an attorney—you just have to be willing to take the first step and make the call. I remember when we decided to look at placement options in Missouri. Our state

chapter group was so ignorant that it took two visits by a very patient local agency person before we could even grasp what a group home was! It wasn't our wealth of knowledge that got the homes open—it was our persistence. Now there are *nine* supportive living homes open in Missouri. There would still be none if it weren't for "parent power."

—Janalee

Protection and Advocacy Agencies for Persons With Developmental Disabilities

The Protection and Advocacy for Persons with Developmental Disabilities (PADD) Program was created by the Developmental Disabilities Assistance and Bill of Rights (DD) Act of 1975. The governor in each state designated an agency to be the P&A system, and provided assurance that the system was and would remain independent of any service provider. P&As are required by the DD Act to pursue legal, administrative and other appropriate remedies to protect and advocate for the rights of individuals with developmental disabilities under all applicable federal and state laws.

The DD Act requires that PADD clients meet the definition of developmental disabilities as defined in the Act — chronic and attributable to mental and/or physical impairments which must be evident prior to the age of 22. These disabilities tend to be life-long and result in substantial limitations in three or more major life areas: self-care, receptive and expressive language, learning, mobility, self-direction, capacity for independent living and economic self-sufficiency.

P&As develop priorities, after receiving public comment, which establish case selection criteria. Priorities must insure that the most vulnerable populations or those with complex advocacy needs are served before less vulnerable populations. P&As must reach out to unserved or underserved populations. The need to prioritize is necessary as the demand for representation often exceeds the resources of the P&A system.

Activities of a P&A System include:

- investigating, negotiating or mediating solutions to problems expressed by persons with disabilities eligible for P&A services;
- providing information and technical assistance to individuals, attorneys, governmental agencies, services providers and other advocacy organizations;
- providing legal counsel and litigation services to eligible persons and groups who satisfy the established priorities for the provision of services; and
- providing education and training for their staff, governing boards, advisory councils, volunteers, service delivery professionals, constituency groups and the community.

In addition, P&A systems interact with elected and appointed officials to share information which will assist policy makers in making legislative and administrative changes which benefit persons with disabilities.

Editor's Note: The information above is taken from the Web site of the **National Association of Protection and Advocacy Systems** (www.protectionandadvocacy.com). This site features a summary of the docket of P&A cases challenging Medicaid Waiver waiting lists and eligibility criteria and a detailed list of P&A agencies.

State Protection and Advocacy Agencies

State P&A agencies go by various names, but their functions are the same, as spelled out in the federal Developmental Disabilities Act. Below, listed alphabetically by state, are the names and phone numbers of these agencies, as listed on the National Association of Protection and Advocacy Systems Web site (www.advocacyandprotection.com). This site includes address and Internet contact information, as well as P&As for the U.S. territories and for Native Americans.

Alabama Disabilities Advocacy Program
205-348-4928, 800-826-1675

Disability Law Center of Alaska
907-565-1002, 800-478-1234

Arizona Center for Disability Law
520-327-9547

Arkansas: Disability Rights Center, Inc.
501-296-1775, 800-482-1174

California: Protection & Advocacy, Inc.
916-488-9950, 800-776-5746

Colorado: The Legal Center
303-722-0300, 800-288-1376

Connecticut: Office of P&A for Persons with Disabilities—860-297-4300,
800-842-7303

Delaware: Disabilities Law Program
302-575-0660

District Of Columbia: University Legal Services—202-547-0198

Florida: Advocacy Center for Persons with Disabilities
850-488-9071, 800-342-0823

Georgia Advocacy Office, Inc.
404-885-1234, 800-537-2329

Hawaii: Protection & Advocacy Agency
808-949-2922

Idaho: Co-Ad, Inc.
208-336-5353, 800-632-5125

Illinois: Equip for Equality, Inc.
312-341-0022, 800-537-2632

Indiana Protection and Advocacy Services
317-722-5555, 800-622-4845

Iowa P&A Service, Inc.
515-278-2502, 800-779-2502

Kansas Advocacy & Protection Services
785-273-9661

Kentucky: Office for Public Advocacy
502-564-2967, 800-372-2988

Louisiana: Advocacy Center for the Elderly and Disabled
504-522-2337, 800-960-7705

Maine: Disability Rights Center
207-626-2774, 800-452-1948

Maryland Disability Law Center
410-234-2791, 800-233-7201

Massachusetts: Disability Law Center, Inc.—617-723-8455

Michigan P&A Service
517-487-1755

Minnesota Disability Law Center
612-332-1441, 800-292-4150

Mississippi P&A System for DD, Inc.
601-981-8207

Missouri P&A Services
573-893-3333, 800-392-8667

Montana Advocacy Program
406-444-3889, 800-245-4743

Nebraska Advocacy Services, Inc.
402-474-3183

Nevada Advocacy & Law Center, Inc.
702-257-8150, 888-349-3843

New Hampshire: Disabilities Rights Center—603-228-0432

New Jersey P&A, Inc.
609-292-9742, 800-922-7233

New Mexico: Protection & Advocacy, Inc.
505-256-3100, 800-432-4682

New York Commission on Quality of Care for the Mentally Disabled
518-381-7098, 800-624-4143

North Carolina: Governor's Advocacy Council for Persons with Disabilities
919-733-9250, 800-821-6922

The North Dakota Protection & Advocacy Project—701-328-2950, 800-472-2670,
800-642-6694 (24 hr. Line)

Ohio Legal Rights Service
614-466-7264, 800-282-9181

Oklahoma Disability Law Center, Inc.
405-525-7755, 800-880-7755

Oregon Advocacy Center
503-243-2081, 800-452-1694

Pennsylvania P&A, Inc.
717-236-8110, 800-692-7443

Rhode Island Disability Law Center Inc.
401-831-3150, 800-733-5332

South Carolina: Protection & Advocacy for People with Disabilities, Inc.
803-782-0639, 800-922-5225

South Dakota Advocacy Services
605-224-8294, 800-658-4782

Tennessee P&A, Inc.
615-298-1080, 800-342-1660

Texas: Advocacy, Inc.
512-454-4816, 800-252-9108

Utah: Disability Law Center
801-363-1347, 800-662-9080

Vermont Protection & Advocacy
802-229-1355, 800-834-7890

Dept. for Rights of Virginians w/Disabilities
804-225-2042, 800-552-3962

Washington P&A System
425-776-1199, 800-562-2702

West Virginia Advocates, Inc.
304-346-0847, 800-950-5250

Wisconsin Coalition for Advocacy
608-267-0214

Wyoming P&A System
307-638-7668, 307-632-3496,
800-821-3091, 800-624-7648



Camp Grants

The Prader-Willi Foundation is now accepting applications for grants of up to \$500 for summer 2000 camperships.

The purpose of the camperships is to assist families in sending their children with PWS to summer camp programs. Eligible summer camp programs can be residential or day camps. Families are encouraged to apply for these grants, even for small amounts.

To qualify for a campership, the applicant must provide the Foundation with:

1. A letter stating that they are in financial need and that they are sending their child with PWS to a summer camp program. (No documentation of financial need is necessary; a simple statement will suffice.)
2. A copy of the bill or other documentation on the camp program's letterhead, confirming enrollment.

Once the application is approved, the Foundation will award 50 percent of the camp tuition, up to a maximum of \$500 per family, per year. The check will be sent directly to the applicant, not the summer camp, and only after receipt of a copy of the paid tuition bill.

While there is no application deadline, the grants are made on a first-come, first-served basis, so families are urged to make camp decisions and apply as soon as possible.

Applications for camperships should be sent to:

The Prader Willi Foundation
c/o Meg Comeau
13 Oak Knoll Road
Burlington, MA 01803

If you need help in locating a residential camp that has served individuals with PWS—or if you know of a camp to recommend—please contact PWSA (USA): 1-800-926-4797.

Words of Thanks and Praise ...

for Janalee and Our National PWSA Office Team

"Thank you so much for your help and support. Even though our [daughter] is without a diagnosis, your prompt interest and oodles of information have changed our lives. We can now understand and help our daughter instead of try to 'fix' her. You and the PWS Association alone have given us the courage and knowledge to move beyond the syndrome."

"Thanks a million for taking the time to talk to me and writing the letter. You showed so much kindness and compassion. It took away the pain and sorrow with a few kind words."

"I wanted to send you a quick note for putting the packet together for the sake of Castlewood Group Home in Kentucky. Your quick help sure did make a difference for the struggle to keep Castlewood open. ... It is nice to know we have your experience and expertise on our side."

"I'd like to officially and personally thank you for attending and speaking at our Iowa conference. Your message was enlightening and comforting to both parents and caregivers."

"Just was thinking of you and your staff at the PWSA Association. How thankful I am that this association exists. I have called many times and you all helped with my tears and fears with PWS. ... I thank you for the commitment you have made toward families like mine. I pray that God will give you three times more than the hope you all have given us this holiday season."

"This is a small note to thank you deeply for calling me last week. To be honest, I was both surprised and impressed to you would take time from your busy schedule to call."

"You really have the gift of humor. I think if anyone can help it's you. You know how to see the bright side of everything. When the tough gets overwhelming, you know how to handle it. I'm sure I am not only speaking for myself, but anyone dealing with Prader-Willi syndrome: You are WONDERFUL. Thank you."

"Recently, we spoke regarding my daughter ... I just want to report to you that I am seeing very nice results. ... It was the perfect Christmas gift. I know that it's not a cure, but it is relief from a very difficult situation. Thanks for your support and concern."

"I would like to thank everyone there at the national office for the help I have received this past couple of months. I called and talked with Janalee about my 21 year old daughter. ... the surgeon was refusing to operate [to remove her gallstones] because she was not vomiting or complaining of pain. This was even after our family doctor explained why she wasn't in pain. I was given the names of two doctors to contact by Janalee ... and they were both willing to talk to [the surgeon]. ... Everything went great with no problems."

"I am so thankful for you and the others at PWSA and for all you do to improve the quality of our lives."

"My heartfelt thanks go to you for all your efforts on behalf of our kids who have Prader-Willi syndrome. The world is a better place, thanks to you."

"Thank you so much for your help from the Crisis Fund. It took a lot of worry off our shoulders during the holidays. ... How can you just say thank you. No words can say it, so I wrote a poem."



All About Angels

Some may have glistening wings or
Enchanting voices that sing.

Some may have halos that gleam or
Hearts that seem to burst with glee.

Some may blow trumpets or
Bake crumpets (???)

Some may be older or
Much, much younger.

Some may be seen or could be heard.

Then there are others
That do not need these things.

They simply do a remarkable thing or
Say some words that surpass
What is expected.

—by Sherry Kirk



The Chuckle Corner

Helen Murphy of Eastchester, New York, shares the following chuckle about her son Matt and says she wishes she'd kept a book of "all his funny sayings."

When Matt was 12 years old, he had a Harrington Rod inserted in his back (to correct scoliosis).

Telling a neighbor about it, I said, "I guess it was named after the doctor who invented it." Matt joined in and said, "Oh, yes, his name was Rodney."



PARENT SURVEY:

HOW CAN GRANDPARENTS HELP BEST?

At the last PWSA national conference, we announced that we are developing a booklet to help grandparents deal with the challenges of having a grandchild with PWS, and we invited grandparents to help us. We have had a tremendous response to the survey we developed—*Grandparents have been more than willing to share their feelings and experiences.*

Equally important, however, is the parents' perspective of how their parents and/or in-laws could give meaningful help and understanding. Parents' answers to the following questions will help us round out the viewpoints in our booklet and develop a guidebook that will truly help this and future generations of grandparents. Please rest assured that your answers will be anonymous.

Parents: Please help us help grandparents by answering these questions. Use a separate sheet of paper, if needed, and number your answers to match the question numbers below.

1. How old is your child with PWS? _____
2. Could your child's grandparents have been more supportive at the time of diagnosis? How?
3. How can grandparents best help with food control?
4. What do your child's grandparents typically misunderstand about PWS?
5. What do your child's grandparents typically do wrong?
6. How are your child's grandparents most helpful?
7. What are the fears/concerns of your child's grandparents?
8. How could your child's grandparents be more supportive at the present time?
9. Do the grandparents seem to have the same rapport with all of your children — or do they have favorites?
10. Do you think the grandparents spend enough time with your child with PWS? If not, why?
11. Do you accept the grandparents' advice, when it's offered? Do they accept your advice on how to care for your child with PWS?
12. Do you share your concerns about your child with the child's grandparents?
13. Is there anything else you feel would be particularly important to share in this grandparent booklet?

PLEASE SEND YOUR SURVEY RESPONSES AS SOON AS POSSIBLE TO:

PWSA (USA), 5700 Midnight Pass Road, Suite 6, Sarasota, FL 34242

Acknowledgements

OUR GRATITUDE FOR CONTRIBUTIONS RECEIVED IN SEPTEMBER AND OCTOBER

1998-99 Angel Fund

Gabriel
(\$1,000 or more)
The Durst Family

Heavenly Angel
(\$500 to \$999)
Allen & Janalee Heinemann

Angel
(\$100-\$249)
Norman D. Kenney, Jr.
Chris & Leslie Miller (*In honor of Claudia Haverfield*)
George Tribett
(*In honor of Claudia Haverfield*)
Roger & Ronda West

Cherub
(Up to \$99)
John & Karen Black (*In honor of Claudia Haverfield*)
Beverly Jonas
Bryant & Marilyn Jones
William & Delores Schleppey



Other Donations

Patron Memberships
(\$100+)

Ole Dam
Joyce Shepard
John & Sue Hruska
Stewart & Bronnie Maurer
Thomas & Patricia McRae
Jonathan & Louise Pye

Contributing Memberships
(\$50-\$99)

Bernard & Carol Charles
Rajiv Gujral
Bob Harrison
Robert & DJ Miller
Maia Sybrina Nadal
Marty Paaren
Robert Redmond III
Akio Shimura
Henry & Suzanne Singer

Research Fund
Stuart R. Boyd

Operating Fund

Anthony L. & Jean Antin
Shirley Burnett (*In honor of Jerry Spero's 75th birthday*)
Shirley Burnett (*In honor of Mike Feigelson's special birthday*)
Mathew & Carrie Driscoll (*In honor of Claudia Haverfield*)
Jeri Farris
Ray & Tony Hall
(*In honor of Claudia Haverfield*)
Opal Wilson
(*In honor of Claudia Haverfield*)
Yoshiaki Harada
Cindy & Kasey Kelley
Dale Kramer (*In honor of Izhak Livny's 50th Birthday*)
Lane & Phyllis Loyko (*In honor of Amanda Diaz*)
Reader's Digest Foundation (matching Antin donation)
Morrey L. Rotenberg (*In honor of Shirley Lehman, for her speedy recovery*)
Akio Shimura
United Way of Los Angeles
Cliff & Wanda Strassenburg
Bryon E. Wise (*In honor of Lorrie Prettyman*)



Special Events

Our thanks to the many contributors and participants in the following special events to benefit PWSA (USA).

Awareness Week
PWSA of Minnesota

Children's Garden Day Care
Mini Walk-a-Thon
Organizer: Robin Stuckey-Gaskin

Run/Walk for Nicholas
Organizer: Laurie Baskin

Second Michigan Golf Outing
Organizer: Tom Kopietz

MEMORIALS

HAL BURNETT
American National Bank

ANN M. DURST
Marshall R. Bird
The Durst Family
Bryant & Marilyn Jones

GENEVIEVE HONDEL
Lota & Dave Mitchell

DONNA HUENNEKENS
Lota & Dave Mitchell

DONALD V. KANE
Central Brace & Prosthetics, Inc
Robert & Rebecca Baummer
Jim and Joan Gardner
Jack Lowry
Lota E. Mitchell
Michael Murphy
Catherine Rykowski
Donna Weisner

LEONARD LEVINE
Gary & Karen Hirsh

STUART PIKE
Richard Roth

NANCY ANDERSON TALBOT
James Alaback
Virginia Anderson
Allen and Velda Cook, Jr.
David & Susan Groff
Tyrus John
Marilyn and Tom Miller
Carolyn V. Shotwell
Cecile M. Thorpe
Marianne E. Talbot
Carolyn Wolff
Norman & Dorothy Lord
Billie M. Ward

LESLIE TORBERT
Nancy and Luke Lynn

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.

