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The Gathered View

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

In this issue

From Despairing to Believing

'Angel' Sandy Heien FostersTeamwork

By Susan George

I believe there are angels among us and, if we are fortunate enough, we will occasionally recognize them.

A young woman by the name of Sandy Heien has truly become an angel to our family, but most especially to our daughter. Shannon is 26 years old and has a life threatening disability called Prader-Willi syndrome. This syndrome is unique and offers many obstacles to be met and overcome on a daily basis.

The most serious aspect of this syndrome is that Shannon never feels full and is always hungry. Her mind is constantly devising a way to get more food (foraging) whether it is out of the trash, the neighbor's house or just overindulging. To compound things, she gains weight on 1,200 calories a day and she has very little muscle tone. The only way to help her is to control her environment through constant supervision, locked cabinets and too little independence.

Shannon Armour, who has PWS, with her special angel Sandy Heien

Understandably, Shannon has felt imprisoned by her disease. Even though she is cognitively limited, she knows how different she is and she longs to be normal. She knows she will never be able to have children, drive a car or live on her own, and she knows how others look at her. Her days were often marked by loneliness and sadness.

Two years ago Sandy became Shannon's job coach at the day program she attends here in Big Bear. Shannon's life experience began to improve immediately. Sandy has become Shannon's friend. She has just the right mix of tenderness and toughness. In her gentle and compassionate manner, Sandy diffuses the many meltdowns Shannon endures and redirects her into constructive behavior. She knows when to tell Shannon no, and she protects her from the ignorance and insensitivity of others.

Shannon is so much happier now. She feels accepted. Sandy truly loves her unconditionally. She feels cool. Sandy and Shannon sing to the radio together and do cool girl things together. She feels loved. Sandy hugs her, encourages her and doesn't let her give up. The young woman has helped transform my daughter from despairing to believing.

Sandy has given me a gift as well. Watching her interact with my daughter has shown me how to better love Shannon. I no longer get so caught up with the everyday burdens of raising a disabled child. I am more forgiving, gentle and accepting.

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Prader-Willi Syndrome Association (USA)

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

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Janalee Heinemann

Executive Director's View

Concerns About Addressing Deaths and the Relationship to Growth Hormone

I have been getting e-mails and calls of concern about a report of seven deaths worldwide of children who were on growth hormone. In the interest of our membership, I want to keep all parents and care providers updated with the latest facts on this issue.

As always, I am committed to sharing with you honest and straight-forward information. Having been very involved with this issue, I want to assure you that while there is reason for concern, I believe there is no reason to panic.

We have been sending information on deaths known to us at PWSA (USA) to our medical boards and to Dr. Martin Ritzen of Sweden. (For our newer members, Dr. Ritzen is one of the most renowned researchers in the world on growth hormone and PWS.)

At PWSA (USA) we have followed 58 deaths from 2001 to March 2003. Of those, there is conjecture that one MAY be related to growth hormone treatment which is included in the two deaths reported from the U.S. The other five deaths we have heard about were not from the U.S. To keep this in perspective, we also know hundreds of children with PWS who have been placed on growth hormone (GH) without adverse effects and are doing well.

The following is a summary of the issues as I know them. Please keep in mind that I am not a medical physician, and PWSA (USA) is not making a formal statement. I have, however, asked four key physicians to review what I have written, and all agree that I have included all of the information available at this time. Dr. Martin Ritzen responded: "It is well written and brings up the important note to all parents that respiratory problems may be a serious concern, with or without GH treatment."

- While it is unclear what relationship growth hormone had, if any, with the seven deaths worldwide, keep in mind that almost all of the other deaths reported to us were of children and adults with PWS who were *not* on GH. These events have heightened our awareness that our children are at risk in general due to respiratory issues.

- Respiratory issues combined with obesity appear to be a major risk factor for our children with PWS (See our article on this topic from the March-April 2003 edition of *The Gathered View*) and the main risk factor identified in starting growth hormone (GH). It has recently come to light that there *may* be a very slight risk in starting a child on growth hormone who is very obese and already having apnea problems (the deaths were early in the start of the treatment), with the possibility of slightly increasing the tonsils to the point of obstruction and apnea.

- The safest course would be to perform a sleep study test prior to receiving growth hormone if there are ANY respiratory concerns — and then repeating the study after a few months of being on growth hormone. (This advisory/ indication will come out officially in the near future.) Of course, many of our children should have a sleep study test with or without GH, since we are finding that many have some form of obstructive respiratory problem.

If obstructive apnea problems are added to the lack of central hypoventilation /apnea response, then many of our children and adults are at risk with or without GH treatment. (Central hypoventilation is a disorder of decreased breathing rate or depth, particularly during sleep.) In the case of a child who is obese with apnea, he or she should not only have a sleep study test, but also see an ENT to consider having tonsils and adenoids removed.

- A child with PWS should begin a weight loss program *prior* to starting GH, since obesity is a risk factor. The dilemma is that weight loss is easier while on GH treatment, so waiting to start GH delays the success of a weight loss program. It is important for parents to understand that GH is only an adjunct to diet and other external controls.

Based on the above, Pfizer Inc. (formally Pharmacia) changed the labeling to include the following contra indication and warning:

"CONTRAINDICATIONS: Growth hormone is contraindicated in patients with Prader-Willi syndrome who are severely obese or have severe respiratory impairment.

WARNINGS: There have been reports of fatalities with the use of growth hormone in pediatric patients with Prader-Willi syndrome who had one or more of the following risk factors: severe obesity, history of respiratory impairment or sleep apnea, or unidentified respiratory infection. Male patients with one or more of these risk factors may be at increased risk. Patients with Prader-Willi syndrome should be evaluated for upper airway obstruction before initiation of treatment with growth hormone. If during treatment with growth hormone patients show signs of upper airway obstruction (including onset of or increased snoring), treatment should be interrupted. All patients with Prader-Willi syndrome

Growth Hormone continued on page 15

Diagnosing and Treating Sleep Apnea in Children and Adults with Prader-Willi Syndrome

By Barb Dorn, RN, BSN

More information is being learned about apnea and Prader-Willi syndrome (PWS). Apnea is a condition in which a person stops breathing for a prolonged period of time while sleeping. Over time, this can result in high blood pressure, heart attack and/or stroke.

There are two types of apnea: central apnea and obstructive apnea. The problem in central apnea arises in the brain. The cause for this is often unclear; however, the message to breathe is altered, resulting in the stopping or interruption of breathing. In obstructive apnea, a person's throat or airway passage becomes blocked; air can't flow to the lungs.

Many people with PWS have been found to experience obstructive apnea. Risk factors for obstructive apnea include obesity and poor muscle tone. The symptoms of obstructive apnea include snoring, daytime sleepiness, waking up feeling tired and unrested, morning headaches, difficulty concentrating and, irritability and/or agitation. Ninety percent of people with PWS experience daytime sleepiness. Previously, obesity was believed to be the primary reason for this breathing problem. However, this problem is being documented in those with PWS who are not obese.

Researchers have found that people with PWS show other breathing and sleep abnormalities. Sleep studies have shown delayed sleep onset, frequent arousal in sleep, an increase in total waking after sleep onset and rapid eye movement (REM) abnormalities (Vela-Bueno, Kales & Soldatos, 1984; Harris & Allen, 1985; Hertz & Cataletto, 1992).

Other breathing problems in those with PWS have been noted, including mild obstructive apnea, lowered oxygen levels during sleep, and abnormal responses when oxygen and carbon dioxide levels were altered.

Tony Dorn patiently waits as sensors and electrodes are applied as part of his sleep study.

When a person's breathing is too shallow or if the throat is obstructed, the oxygen level falls and the carbon dioxide level rises. Normally, our body responds by either increasing the rate of breathing or by causing a person to move or arouse (which then makes he or she breathe deeper). It has been found that people with PWS do not increase their breathing or arouse when these levels are abnormal during sleep (Mendez, 1990).

Sleep apnea is diagnosed from a sleep study. Various sensors and electrodes are attached to monitor airflow, heart rate, leg movements, oxygen levels and brain waves. Sleep studies are done at night and can be done in a hospital or at home.

The application of the sensors and the need for cooperation for a prolonged period of time can often be challenging for the person with PWS. Because of their tenuous emotional control, this process may lead to anxiety and/or emotional escalation in some people. Some people with PWS are also sensory-defensive and become very anxious when devices are attached to them.

In order to decrease family stress and to maximize cooperation, in-patient testing is often recommended. People with PWS are often "people pleasers," and cooperate more with technicians than they do with family members. Admission to the sleep laboratory is typically late in the evening, with discharge in the early morning.

If the person with PWS is found to have sleep apnea, measures to correct this must be started. Obesity is the number one correlate to sleep-related lowered oxygen levels. Weight management must be instituted. A nutrition referral and/or evaluation of environmental supports may be needed. Exercise should also be a part of this program.

To treat obstructive sleep apnea, the physician may recommend an air pressure device called CPAP (Continuous Positive Airway Pressure). This treatment device delivers gentle, steady airflow through a soft mask that is placed over the nose. This helps to keep the throat structures from blocking the airway. The physician will determine the amount of pressure that is needed. It is often difficult to adjust to wearing this mask while sleeping. The most successful approach is to be helpful and encouraging – not adversarial.

Surgery may also be suggested to remove excess or enlarged tissue that may be causing obstruction of the throat.

In summary, people with PWS are at increased risk of developing obstructive sleep apnea. Because of behavior challenges, diagnosing and treating this disorder can be problematic for these individuals, as well as for those who support them. Treating sleep-related breathing problems can help the person with PWS awake feeling alert and refreshed. It may help prevent daytime sleepiness and other serious health problems.

An Informational Handout

Sleep Apnea and People with Prader-Willi Syndrome

It has been found that people with Prader-Willi syndrome are at higher risk for developing obstructive sleep apnea. This is a condition in which a person's throat or airway passage becomes blocked; air can't flow to the lungs. Risk factors for obstructive apnea include obesity and poor muscle tone. It is being documented in those with Prader-Willi syndrome who are not obese.

Symptoms of obstructive apnea include

- **Snoring**
- **Daytime sleepiness**
- **Waking up feeling tired and unrested**
- **Morning headaches,**
- **Difficulty concentrating**
- **Irritability and/or agitation**

90% of people with PWS experience daytime sleepiness.

Treatment of Obstructive Apnea

- Get weight under control. Consult nutritionist. Limit food access. Exercise.
- If indicated, Continuous Positive Airway Pressure (CPAP) therapy will be needed. This is the delivery of forced air through a mask that covers the nose while the person is sleeping. This keeps throat structures from blocking the throat/ airway.
- Surgery to remove excess or enlarged tissue from the throat may be needed.

Diagnosing Sleep Apnea

The primary way this disorder is diagnosed is through a sleep study. It can be done at home or in a sleep laboratory.

Numerous sensors and electrodes are attached to a person. Various factors are monitored while sleeping, including oxygen level, airflow, body movements and brain waves. This procedure is often difficult for the person with Prader-Willi syndrome.

Practices for A Successful Sleep Study

- Foreshadow what to expect.
- Sleep technician may need to allow extra time for breaks. Apply electrodes – take a break – have a stretch – verbal praise – apply more.
- Use diversion while applying sensors. Watching a video may be helpful.
- Provide lots of praise!
- Celebrate success; reward when completed. If possible, take a photo after all electrodes are applied. It is a big hit for "show and tell."
- For those who are sensory defensive, have person wear some electrodes a day or two before test. It may decrease sensitivity and anxiety.
- Inform physician of problem. Priorities may need to be set in what is to be assessed.
- Apply electrodes to most sensitive area last.

Tips for Using CPAP for the Person with Prader-Willi Syndrome

- Work on increasing wearing time of the mask, gradually. Start with wearing the mask 5-10 minutes before bedtime. Slowly increase time – 10 minutes the first few nights, 15 minutes the second night. It may take a month before wearing it all night.
- If having problems with compliance, discuss with physician. May require change in mask and/or added humidification.
- Celebrate success. Use lots of verbal praise. Use an incentive chart if needed.
- If person refuses to wear, do not argue or force. Point out positive outcomes – fewer headaches, more rested, etc.
- Have weekly "check-ins" with the nurse and the person with PWS; the nurse can offer support and encouragement.

Treating sleep-related breathing problems can help the person with Prader-Willi syndrome feel alert and refreshed. It may help prevent daytime sleepiness and other serious health problems.

(PWSA of WI, Inc. 2003)

Advanced Bone Age and Early Signs of Puberty

By Lota Mitchell, Associate Editor

A discussion of this topic on the PWSA(USA) 6-12 years e-mail group went something like this, with mothers describing their children and bringing up questions.

Mom#1

Is anyone dealing with advanced bone age and/or treatments delaying puberty? Our daughter (disomy), 11, had a normal or even early start on puberty. Concern now is that while she has been on GH successfully for the past 1 ½ years, she is no longer responding and has not grown in the past three months and menarche seems eminent.

Mom #2

My son (imprinting), 7, started genotropin in October 2000, 1.7 mg per day, reduced to 1.4 mg. in April of 2002. He has pubic hair and some hair under his arms and has to wear deodorant. In September 2002 he had the second bone age X-ray, which was 12 years 6 months. Since his first bone age X-ray he has aged one year. His doctor is very worried about his linear growth because he feels that the genotropin will stop working if his bone age doesn't slow down. He started in September taking 10mg. of Tamoxifen twice daily.

Mom #3

About 2 years ago my son (now 11) had a bone age of 11.5 years. He was and still is taking Nutropin AQ; the GH we began on. The endo and I felt it was unnecessary to change to Genotropin as he was doing well. When the advanced bone age was discovered, dosage was cut to half in hopes that the cutback would still maintain the lean muscle tissue but slow bone growth down. He has still grown following the normal growth curve, but bone age basically stood still for the past 2 years. Yet he maintained most of the lean muscle tissue and stamina. He is gradually moving back to a full "normal" dosage over the next year, with close monitoring of bone age. My son had underarm hair and leg hair immediately after beginning GH treatment (no public hair development at this time). We were told by the endo that underarm body odor is a common side effect with GH usage; he has used deodorant since he was 6.

Mom #4

My son, 11, has been on Genotropin for 2 years. At age 10 his bone growth was 13 years. He was retested in the spring and it was still 13 years. His height is still in the 10% percentile; I'm concerned that his advanced bone age will limit the time he has for growth. (He also has severe scoliosis so the curve may 'shorten him' to an extent.) After starting GH, I noticed the growth of underarm and pubic hair. The Dr. didn't seem to think it had anything to do with GH. At my request a test was taken that showed early adrenal activation for puberty. The link to GH and increased bone age/early puberty needs to be investigated.

Mom #5

My son, 9 years 7 months, was at 12 to 12 ½ at his last bone age, a few months ago. He is 130 lbs and 4' 11". He has had pubic hair for at least six months (enough to notice) and is starting to get underarm hair. Hormone testing indicates he is not in or starting puberty.

Mom #6

Daughter started GH at age 3 years. At 5 years started developing pubic hair and underarm odor. At 8 years considerable amount of pubic hair, no breast budding.

We sent these descriptions to Phillip D.K. Lee, M.D., Professor and Clinical Director of Pediatric Endocrinology at the David Geffen School of Medicine at UCLA and a member of the PWSA (USA) Scientific Advisory Board. Here are Dr. Lee's comments on the causes of advanced bone age and early signs of puberty.

All of these cases pertain to a common, somewhat complex problem in obese individuals, which is further compounded in PWS by the GH/IGF deficiency. Here are the basic points:

In normal puberty, there are 2 separate events. One is adrenal androgen (male-type hormone) production, which causes secondary sexual hair in girls and, to a lesser extent, in boys. This is called adrenarche. The other is gonadal steroid production; ovarian estrogens in girls, testosterone in boys, which causes the other changes of puberty. If the only signs of puberty are pubic or underarm hair growth and increased bone growth/maturation, then a child probably only has adrenarche. If a girl has breast development and/or menarche or a boy has genital enlargement, then these are signs of gonadal maturation.

Gonadal maturation is controlled by gonadotropins (LH and FSH) from the pituitary gland. The control of adrenarche has not been completely defined.

Each of these events (adrenarche and gonadal steroids) contribute to advancement in bone age, accelerated growth ("growth spurt") and eventual closure

continued on next page

Dr. Lee's Response continues...

of the growth plates. If these events start too early and bone maturation advances more rapidly than bone (height) growth, the final adult height will be less than expected.

In otherwise normal obese children *without PWS*, the adrenarche part of puberty can occur earlier than normal. This typically occurs in a subset of children who have a tendency toward insulin resistance. These children develop high insulin levels in response to obesity. The high insulin and related effects are thought to stimulate adrenal androgen production, resulting in adrenarche, and increased rates of bone growth and maturation. In this situation, both bone growth and adrenarche are stimulated proportionately; the children are generally tall for age, can have full puberty a little bit earlier than expected, and stop growing earlier than usual. However, they usually achieve a normal adult height since both bone growth and bone maturation are proportionately hyper-stimulated over a sufficient time period to achieve full height potential. The hyper-stimulation of bone growth is due to a combined effect of pubertal hormones and growth hormone.

A certain subset of children with PWS will also have a tendency toward this type of insulin resistance phenomenon and early adrenarche. This is not due to PWS itself, but is just a frequent tendency in obese children. Often, there is a family history of type 2 diabetes, obesity, polycystic ovary syndrome and related conditions; all associated with insulin resistance. When these children with PWS become increasingly obese, the insulin resistance can worsen, causing early adrenarche. The adrenal androgens cause the bones to grow and mature faster. However, since children with PWS also have a type of GH deficiency, their bone growth is not adequately hyper-stimulated by the adrenarche. Therefore, the bone maturation and closure occurs at a faster rate than the bone (height) growth. These children can temporarily have a normal height due to stimulation of bone growth by adrenal androgens. However, since GH is lacking, they do not have an adequate growth spurt. As a result, their bone growth plates close too early and they end up finishing their growth far too early, ending up as very short adults. Unfortunately, many of these children do not appear to meet usual criteria for GH use in PWS (i.e., growth failure), until it is much too late. I have always felt that these are the PWS children who need GH treatment the most in terms of optimizing height.

The gonadal part of puberty, which is important for bone closure in children without PWS, seems not to be a primary concern in most children with PWS. Even in the first case, in which a girl with PWS is described as being close to menarche, it is likely that the child's adrenarche is the primary factor causing the rapid advance in bone age. Most children with PWS have a relative or absolute deficiency in gonadotropin secretion; therefore, the timing of gonadal puberty is not usually a factor in determining final height. However, if menstrual cycles do occur, the gonadal steroids associated with this occurrence can further accelerate bone maturation and closure.

There are medical ways to stop the progression of gonadal steroid production. The typical method is to use a medication called leuprolide, which stops gonadotropin secretion. This medication is not usually useful in PWS since most children with PWS already have a gonadotropin deficiency. However, in the case of a child with PWS who has evidence of gonadal puberty, such as menarche, leuprolide therapy may be a consideration.

Unfortunately, there is no known way to safely stop adrenarche once it starts. One could theoretically take out the adrenal glands or turn off the adrenal steroid production. However, the most important steroid made by the adrenal gland, cortisol, is necessary for normal metabolism. Loss of cortisol can be life threatening. Unfortunately, there isn't a good way to turn off the adrenal androgen secretion without also turning off cortisol secretion. Controlling weight and reducing insulin may help to prevent or slow the progression of early adrenarche, but it does not stop it completely.

It is thought that androgens cause accelerated bone growth and maturation by first being converted in the body to estrogens. Therefore, estrogen inhibitors, such as tamoxifen and other drugs, could theoretically counteract the effects of adrenal androgens on bone maturation. This has not been studied in children with PWS.

Finally, in reference to #3, although GH promotes bone growth, there is no evidence that it directly affects bone maturation and closure. However, GH can raise insulin levels, and the increased insulin could then be associated with increased adrenal androgen production.

Therefore, in children with PWS, it is best to prevent early-onset of adrenarche by (1) weight control and (2) reduction of insulin levels if they are high, e.g. by diet, exercise and, in some cases, medication. In cases in which early adrenarche and accelerated bone maturation has already started, GH therapy should be given even if the current height is normal height at the moment. Anti-estrogen drugs may also be useful in slowing down the rate of bone maturation; however, this has not been studied in children with PWS.

The control and timing of puberty and the interaction of puberty with growth hormone are very complex topics. I have tried to cover the major points in this brief discussion. However, each individual child has his/her unique combination of factors controlling growth and maturation. Therefore, if an abnormality of puberty or growth is suspected or diagnosed, full evaluation and careful follow-up by an experienced pediatric endocrinologist is recommended.

Lota Mitchell

President's View

Connection by E-mail; Connection by Love

Ah computers! Can't live with 'em and can't live without 'em (to use an old cliché usually applied elsewhere). The occasional times when my computer has been down, I suddenly find myself with some free time for other things. Nice! But sometimes, in addition to all the routine chores they handle for us, they provide some unexpected benefits.

In early May after many months of trying to get everything in place, the computer we bought for our daughter Julie finally got hooked up to an Internet provider. And she got hooked up with a computer expert who will come every other week to give her an hour's instruction — and, of course, fix whatever snafus may have occurred. Personal experience demonstrates that snafus are just about a given, Murphy's Law alive and well.

Julie, 33, lives in a residential placement run by Keystone Community Resources outside Scranton, Pennsylvania, 300 miles from home in Pittsburgh. I get there once or twice annually, she comes home three, four times a year, and of course we talk on the phone. It is a good program, she is happy there, and I would not bring her back to Pittsburgh if something opened up here. I believe in "If it ain't broke, don't fix it." But never in the six years she's been there have I had the view of her day-to-day life that I do now.

As soon as she had her first lesson, I immediately started receiving an e-mail a day. After the first one, which said tersely, "This is my first letter," they have not been short. For example, I know about what she is doing at work and what her chores in her house are. I not only know when she goes to the library, I know what books she takes out — piles of them. I'm not sure she ever gets them read. I learned long ago that people with PWS like lots of "stuff," whatever "stuff" may be. Of course, I send her an e-mail every day, too.

As soon as Julie had her first lesson, I immediately started receiving an e-mail a day. After the first one, which said tersely, "This is my first letter," they have not been short.

The end of May I took Julie to North Carolina to visit her brother and his family who live out in the country near Chapel Hill, plus a cousin in Virginia on the drive home. She had never seen her little nephew, Joe Henry, who is almost two. It was a good trip. I'd like to share what she had to say about it via e-mail (unedited):

> "Your right it was a really nice weekend together. It was really nice to spend time with each other.It was a really fun Weekend.Spending time with each other,Visiting Doug Shannon Colleen Katherine Joe Henry their family & friends & spending time wIth them.Going in the pool which was to cold.going in the hot tub. Playing games with you & them & stuff arround their house.Getting to see thiier cows again., Going to see the horss show with Doug & Colleen.Which Is what Colleen does in Horseback Riding lessons, & Going to see Missy my cousin & her to kids. And cousin Charlie there too. Visiting all of them & Getting a tour arrond their house. Pluss traveling with you in car & listening to story tapes. But the best things were spending time with you,Getting to see my Nephew Joe Henry for the first time.And visiting his Mother DAD & Sister,& visiting cosin Missy her 2 kids which are my little cousins.And cousin Charlie which was at thier house."

Isn't this what we want for all of our children, with or without PWS, little or grown up — that we enjoy being with them, that they enjoy being with us, and that they are happy in what they are doing?

Peace, Lota

2003 PWSA (USA) Conference Grants

Thanks to the help of the Capraro fund-raiser, our state chapters and individual support, we have been able to assist 45 families with conference grants this year.

State chapters providing grant funds are: California • Colorado • Florida • Georgia • Maryland/Virginia/DC • Michigan • Minnesota • North Carolina • Northwest • Oklahoma • Pennsylvania • Texas

Ann Coyne, PWSA (USA) Financial Manager

By Lota Mitchell, Associate Editor

Ann Coyne, PWSA (USA)'s financial manager, can be a great help with chapter administration.

Ever wonder about any of our national office staff?

Meet Ann Coyne, PWSA(USA)'s friendly financial manager, who says she is "happy to help anyone who needs it. I can look things up, research questions, whatever."

Ann can be a great help with chapter administration. "While the national office can't answer legal questions regarding a chapter's decision to file for tax exemption," Ann says, "we can answer any questions that might help with the process, what information is necessary, how often they have to report to the IRS and other questions that might come up."

So when you're not sure about your chapter's state registration, or 501c3, or other financial questions, Ann is the person to ask.

Her career included a 10-year membership in the American Society of Association Executives. When she saw the ad in the paper for the job at PWSA(USA), also an association, it seemed just right. At the time she wanted a part time job — which initially it was — and she had taken classes in bookkeeping and business management. It fit then and has ever since.

In her job at the national office, she handles money from the time checks arrive until they get to the bank to the right accounts. She works with the auditor and does anything and everything that is financial. She says, "Since I've been doing the state registrations for charitable solicitations, I have learned quite a bit about the laws regarding nonprofits and fund raising.

"There are several good websites that have helpful information: http://members.aol.com/irsform/1023/misc and www.nonprofits.org/npofaq. A book that has been recommended on several of the nonprofit websites is *Prepare Your Own 501(c)3.* No other book has this much information about completing IRS Form 1023, the application for tax exempt status."

Ann notes that "for those chapters deciding not to seek tax exemption, it is important to note that they can't call themselves tax-exempt organizations. If they seek contributions, they must let the donor know that it can't be claimed as a tax-exempt contribution. They can use the national office tax exemption, but they will need to follow the guidelines set down by the Board of Directors."

She adds, "It's a relief for small organizations to learn that the IRS Form 990, the annual return of organizations exempt from tax, is not required when gross receipts are less than $25,000. *However*, it might be a better idea to file a "blank" form 990 than to not file at all. First, in some cases the IRS deletes organizations that do not file from their annual list of qualified charities. Second, the annual 990 is a very good way to notify the IRS of changes in your organization's address, etc. And third, filing a blank form 990 gives your organization a "paper trail" so that when a new president or treasurer takes office; he or she will be able to tell at a glance that the IRS filings are all up to date.

"To file a blank return, complete all the identifying information at the top of the return, check the box indicating that gross receipts are normally less than $15,000, sign and date the return, and send it to the IRS, Ogden, Utah 84201. Be sure to make a copy for your own records."

Ann's administrative experience makes her one of PWSA (USA)'s most valuable resources.

Born and raised in Chicago with a B.S. in Psychology from Roosevelt University there, Ann came to PWSA(USA) from the Virgin Islands where she had lived for 25 years. She moved to the islands with five of her seven children (two were in college) to be close to her family after her dentist ex-husband was killed during a robbery at his office. Her brother taught at the U. of the Virgin Islands, and her mother, sister and brother-in-law lived in Venezuela, a short plane ride from the V.I. A few years after her move, she lost her oldest son to pancreatic cancer.

Once in the Virgin Islands, Ann went to work for a large hotel on St. Thomas as reservations manager and bookkeeper. Three years later she became Executive Director of the St. Thomas-St. John Hotel Association, a job she held for more than 10 years. Bookkeeping was of great importance, since all financial records were in cardboard boxes and shopping bags! Her other responsibilities included lobbying with local government, developing membership programs, increasing membership, introducing

Ann Coyne continued on page 15

PWSA Research Request for Proposals:

Capraro Research Grant To Advance the Psychological Health of Those With PWS

Prader-Willi Syndrome Association (USA) is dedicated to serving individuals affected by Prader-Willi syndrome (PWS), their families, and interested professionals.

Currently, known behavioral and psychiatric illnesses in PWS individuals are treated in a multitude of ways, using pharmacologic and behavioral approaches. Because treatment regimens are diverse, relative efficacy is difficult to establish.

PWSA (USA) seeks to facilitate a better understanding of the effectiveness of the various methods of treatment of behavioral and psychiatric illness in individuals with PWS. We invite proposals to describe current modalities employed, as well as their relative effectiveness.

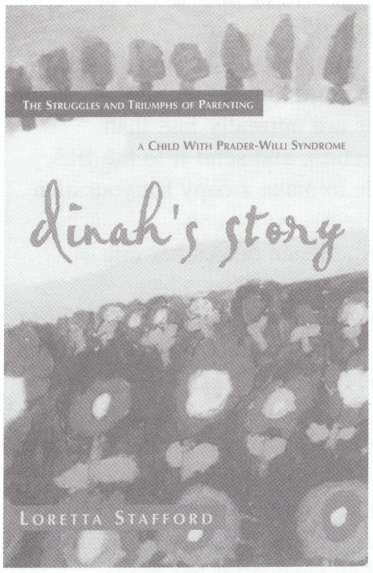
Funds Available: Up to $ 20,000 for one year of support. Awards cover direct costs only.

Eligibility: The candidate must have a full-time faculty appointment at an institution with a well-established research and/or PWS program. Investigators at all phases of their career are welcome to apply, but should show evidence of ability to work independently.

Review: Each application will be assessed for scientific merit by two or more reviewers. While the candidate is not expected to have an extensive publication record in PWS, past productivity is a consideration. Previous abstracts, publications, honors, and awards will be assessed, with priority given to publications either directly or indirectly related to PWS. Investigators with epidemiologic and/or behavioral research experience are preferred, as well as a design that employs a patient/family questionnaire.

Deadline: Guidelines for grant proposals can be obtained by calling PWSA (USA) at (800) 926-4797. Deadline for submission is September 15, 2003.

Dinah's Story: The Triumphs of a Child with PWS



Author Loretta Stafford documents the life of her daughter born with PWS, a birth defect not yet identified at the time of her birth, in *Dinah's Story.* The story is one of family, faith, hope and despair, tragedies and triumphs. It's the story of a baby who was not supposed to survive, but who, at age 48, continues to celebrate life through her love of family and friends, her gift of painting, and her trust in God.

While *Dinah's Story* focuses on the unique – and sometimes bizarre – characteristics of PWS, it could benefit any parent, extended family member, or educator who lives with, loves or interacts with a child or adult with special needs.

Loretta retired after teaching second grade for more than 30 years. She is also a never-to-be retired mother of two extraordinary children: her son, a university president; and her daughter, who has PWS.

Loretta's faith in God never allowed her to give up on the child that doctors said would neither live nor thrive. Again and again, Loretta found ways to not only keep her daughter alive, but also to ensure that she had a meaningful life, filled with purpose, friends and accomplishments.

All proceeds from the sale of *Dinah's Story* go to the Dinah Stafford Scholarship Fund at Grand Canyon University in Phoenix, Arizona.

"Dinah's Story is an exploration of the impact on one individual and one family of having a child with Prader-Willi syndrome. In contrast to the many writings of professionals about this condition, this book is full of insight into how Prader-Willi syndrome can alter both positively and negatively the daily lives of family members. This family's religious beliefs served as a source of comfort and strength, and the story is written from that perspective. But it touches and teaches us all — parent, sibling, and professional alike, regardless of our own religious beliefs — about how lives are altered by the unexpected birth and future course of a person with Prader-Willi syndrome."

Suzanne B. Cassidy, M.D., Professor of Pediatrics
Chief, Division of Human Genetics, University of California, Irvine

Ed. Note: Dr. Cassidy is a member of the PWSA (USA) Scientific Advisory Board.

PWSA (USA) Scientific Advisory Board - Grants Awarded

AWARDED	RECIPIENT/LOCATION	PWS RESEARCH TOPIC
June 1983	Oakwood Residence Minnesota	Behavior Management Study
June 1986	Dr. Pool, et al University of Connecticut	Orofacial & Dermatolglyphic Characteristics in Patients with PWS
June 1987	Drs. Favus and Walzak University of Chicago	Bone Disease Study
June 1988	Drs. Costiff & Ruvalcabra University of Washington	12-Hour Study of Nocturnal Growth Hormone Secretion of PWS
July 1989	Drs. Moores and Nostrom Minnesota	Exercise Program for PWS
Dec.1989	Drs. Greenswag and Whitman Univ. Iowa & St. Louis Univ.	Psychotropic Medication Drug Study
July 1990	Dr. Vanja Holm University of Washington	Diagnostic Criteria
Jan.1991	Dr. Susan Cassidy University of Arizona	Classification Study
July 1991	Drs. Greenswag and Whitman Univ. Iowa & St. Louis Univ.	Psychotropic Medication Drug Study
July 1992	Dr. Cloutier University of Connecticut	Pulmonary Function and Exercise in PWS
July 1994	Dr. Coppes University of Calgary	PWS Cancer Research
Jan. 1995	Dr. DeMario University of Connecticut	Central Autonomic System Study
June 1996	Dr. Wevrick University of Alberta	Imprinted Genes in PWS
Aug. 1997	Anastasia Dimitropoulos Vanderbilt University	The Development of Behavioral Problems and Eating Disorders in Children with PWS
Oct. 1997	Dr. Gila Hertz	Assessment of Excessive Daytime Sleepiness in Patients with PWS
July 1998	Dr. Susan Sell University of Alabama	Relationship Between Obesity & Risk for Diabetes in PWS
July 2000	Dr. Nathan Shapira University of Florida	Open Pilot Study of Topiramate in Adults with PWS
July 2000	Dr. R. Tracy Ballock Univ. Hospitals of Cleveland	Orthopaedic Manifestations of Prader-Willi Syndrome
Oct. 2000	Dr. Susan Sell University of Alabama	Extension of Neuroanatomical Correlates of Hunger Satiation in Subjects with PWS
Aug. 2001	Dr. R. Nathan Shapira University of Florida	Neuroanatomical Correlates of Hunger & Satiation in Patients with PWS
Jan. 2002	Dr. R. Nathan Shapira University of Florida	Continuation of Neuroanatomical Correlates of Hunger & Satiation in Patients with PWS

View From The Home Front

Thank you, PWSA, for Bringing Hope and Support

Last Nov 20, my tiniest angel turned 2. The last two years have been nothing short of a chaotic blur. Brayden by the grace of GOD has come a long way! While trying to get a box of photos and mementos organized for scrap booking, I came across a poem that I remember writing in the NICU room-in unit before we were released. I wrote it as I watched my tiny 5 lb. angel sleep among a vast array of tubes and noisy machines. I still get emotional looking at the pictures, and remember vividly the potpourri of emotions that consumed me.

Though I get upset every now and then, I am blessed to have Brayden in my life. I am thankful for all you guys do to help bring the light of hope to us parents in need of not only literature, but emotional support. So I thought I'd write to say thanks, and send a letter w/a hug and lots of love for all you do!

Tracy and Brian Mittasch live with Brayden in Edmond, Okhaloma.

Brayden Mittasch, who has PWS, will turn 3 in November

The Dreams of a Prader Willi Parent

I dream about what it would be like to have my son be "normal." Would he be an excellent student, an outstanding athlete or just the best-liked kid in his class.

I dream about going to a restaurant as a family, and not having to grab my son's hands away from the others' food, and not being stared at by the other patrons.

I dream about telling my son that we are going to do something out of the norm and he doesn't get upset about it.

I dream about my son riding a bike without training wheels, running up the steps of a slide and swinging as high as a bird.

I dream about my son wearing clothes like the other boys in his class, the same size would be a bonus.

I dream about what it would be like to talk about PW or think about PW and not feeling sad and wanting to cry.

I dream about leaving the dishes and good on the table after a meal to run outside to see the rainbow that I know will soon disappear.

I dream about being able to reason with my son.

I dream about how my son's twin sister really feels about her brother and how her life would be different if he didn't have PW.

I dream about how I would feel if I was hungry all of the time.

I dream about my son playing with his toys and not having to worry about putting them in his mouth.

I dream about being able to eat a meal and not hearing "I am still hungry" when we are done.

I dream about what it would be like if everyone would really know what it is like to be a PW parent.

I dream about being able to some day tell my son that there was been a cure for PW.

I dream my son doesn't have PW, and then I wake up.

Susan Selehi of Michigan is the wife of Lee and mother of 15-year-old Matthew, who has PWS, and his twin sister Jenny.

The Chuckle Corner

While going about my daily duties, I found this note that my 22-year-old daughter had quietly (she's very quiet when she needs to be!) placed on the counter behind me. Written on one side of a paper napkin in large letters: Mommy Dearest Please Read.

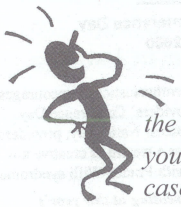
On the opposite side was written:

Dear Mommy Dearest:

I wanted to ask you about if you Remember when I felt like sneaking you told me to tell you and you said you would give me a little something to munch. I Feel Like sneaking some hotdogs and Buns, and some baked beans 5 bites. So what do you say? I know It is 25 minutes till snack But I am gong nuts.

Love the Trouble Maker RJL

Christie Loomis, LaPine, Oregon



Please send your joke or funny story to the PWSA (USA) office. Be sure to include your name, phone number and address in case we have any questions.

Shannon - *continued from page 1*

Once again, I have been able to see my daughter as the precious gift from God she truly is.

One of Shannon's favorite questions is, "How come I am doing so good?"

I tell her it's because "We don't give up," and "You, Sandy and I make a good team." She just smiles.

There are angels out there. May we all learn to open our hearts and see.

Susan George lives in Sugarloaf,California.

Fund-raising for the love of Patty

Prader-Willi English Channel Challenge

Five brothers plan to swim across the English Channel this summer to bring attention to Prader-Willi syndrome. They plan to swim the 22-mile distance in August 2003 in tribute to their sister, Patty, who was diagnosed with Prader-Willi syndrome (PWS) 10 years ago. It took 34 years of searching for a diagnosis and struggling with the syndrome before they had an explanation for her insatiable appetite and medical problems.

Andy, Matt, Courtney, Michael, and Jim Roberts came up with their plan to swim the English Channel during a family gathering. The grueling event will take place some time in August, depending on weather conditions.

The Channel is just less than 22 miles across, but tidal movement can dramatically increase this distance. There are numerous hazards that could slow the team, including oil slicks, untreated sewage, jellyfish and the fact that it is the busiest shipping channel in the world.

The English Channel was first swum in 1875 by Captain Matthew Webb, a Victorian army officer. Since then, more than 6,000 attempts have been made, but less than one in 10 has been successful. The Roberts brothers' swim will be the first time a family of five brothers will have ever attempted this feat.

"We want to experience the challenge of swimming this ultimate open-water swimming event, to enjoy the fellowship and camaraderie of sharing this experience, and, most importantly, to recognize and honor Patty, who has struggled and achieved so much and continues to do so in a way we will never fully understand," Andy Roberts said. "Our lives have been made better, our experiences richer, our memories sweeter because of Patty."

Today, Patty lives in a Prader-Willi supportive living home with three other ladies who also have PWS. Patty now weighs 150 lbs. — down from the 420 lbs. she weighed 10 years ago — and has every right to feel proud of her own achievement.

How You Can Help

The Roberts brothers' goal is to bring attention to PWSA (USA) and our international organization, IPWSO. Positive benefits for sponsoring this event include recognition, visibility and international exposure for a business.

The swim will cost the team $7,000 to $10,000 — which includes registration, travel and hiring a pilot to accompany them across the Channel in order for their attempt to be recognized. The Roberts Brothers are looking for sponsors to help raise money for the event and to support the endowment fund for the Prader Willi Syndrome Association (USA).

If you know of a potential sponsor and/or media contact, please call Bill Vucci at (301) 570-9131 or Janalee Heinemann at (800) 926-4797.

About the brothers

- **Andrew J. Roberts**

Andy, 43, lives in Grand Rapids, Michigan with his wife Kim and their four children. Andy graduated from Ohio State University in 1983 and received his Master of Business Administration from Ohio State University in 1991. He is employed as a financial advisor at Financial Advisory Corporation in Grand Rapids. He swam for the Cincinnati Marlins and Moeller High School, where he was co-captain of the team in 1978.

- **Matthew J. Roberts**

Matt, 42, lives in the Chicago area with his wife Sharon and their three children. He graduated from the University of Arizona before receiving his Master of Divinity from Trinity Evangelical Divinity School, where he is now a Ph.D. candidate in Intercultural Studies. After serving as a missionary in Romania from 1996 to 2000, he began his current position as head of school at Westlake Christian Academy in Grayslake, Illinois. Matt is also a swim coach for the Grayslake Stingrays. He swam for the Cincinnati Marlins and St. Xavier High School, where he was co-captain of the state championship team in 1979. Matt also swam and played water polo at the University of Arizona.

- **T. Courtney Roberts**

Courtney, 41, lives in Cincinnati, Ohio and is engaged to be married in October 2003. He graduated from Harvard University in 1984 and received his Doctor in Medicine from Ohio State University in 1990. He is a family physician at Mount Carmel Family Medicine and Crossroad Health Center. He swam for the Cincinnati Marlins and St. Xavier High School, where he was captain of the state championship team in 1980. He also swam for Harvard University, participated in the Manhattan Island Swim and competes in master swimming events.

- **Michael A. Roberts**

Mike, 39, lives in Cincinnati, Ohio with his wife Melanie and their two children. Mike graduated from the University of Notre Dame in 1986 and Notre Dame's Law School in 1990. He is a partner with the law firm of Graydon Head & Richey LLP. Mike has previously served on the United States Swimming Counselors Committee. He swam for the Cincinnati Marlins and St. Xavier High School, and swam and played water polo at Notre Dame.

- **Jim Roberts**

Jim, 38, lives in Worthington, Ohio with his wife, Cindy, and their three children. A 1987 business graduate of Ohio State University, he received his Juris Doctor degree in 1991 from Capital University Law School. He is employed as corporate counsel with Wendy's International, Inc. in Dublin, Ohio. He swam for the Cincinnati Pepsi Marlins and St. Xavier High School and was captain and assistant coach of water polo for Ohio State University.

I Want the World To See The Brother I Know

By Jamais White

"I'm pregnant," said my mother. Those were the first words ever spoken pertaining to my little brother. At that time, I only had two sisters, one older, and one younger; three years apart from each of them, and I was stuck in the middle. I was 12 at the time and extremely excited because I was finally going to have the little brother that I always wanted. Now I know how wrong I was.

Michael White, who has PWS, celebrates his 5th birthday with cake.

The pregnancy seemed normal enough. Until the due date, that is. My brother was due on the 16th of September, so when the 18th rolled around, we all got a little worried. My mother went to the hospital that day, to put everyone's worries at ease and to find out what was wrong. I sat at home, wondering, worrying, not knowing what to do, when my father called, and told me it was a boy.

Michael Baron Howie White, my new little brother. Something was wrong with him, though. The doctors said he could not come home because he was very sick and they did not know why.

Michael spent the first month of his life in the ICU at Meadowcrest Hospital. That entire month was filled with lonely nights because my parents would go to visit him every night while I would sometimes stay at home, worrying about this little person who was too sick to leave the hospital. On the occasions that I would get to see him or hold him, I was always afraid that I would break him.

The love was undeniable. Sometimes, he would open his eyes, and look up at me from his tiny big blue eyes, and it would hurt to know that I couldn't protect him from this horrible thing, this thing that made him so small and helpless.

Michael was finally released from the hospital; however, he did not come home alone. He had to constantly be attached to a heart and respiration monitor. The drive home from the hospital was a nightmare because the machine's alarms kept going off. The slightest movement in the wrong direction would affect the monitor's sensitivity. It was very stressful.

After many tests and a year later, the doctors diagnosed Michael with Prader-Willi syndrome. Like many others, I had no idea what this was. My mom, being the incredible person she is, researched everything she could about Prader-Willi (to this day, she's still researching). She made it her job to explain to everyone, in terms we could all understand, what this syndrome really was.

Eventually Michael grew out of that monitor, and the next 5½ years were an adventure. I have experienced things that some people may never see, hear, or know in their lifetimes.

I thought living in a house where the refrigerator and cabinets were under lock and key would be hard. I became accustomed to it. I thought it would be hard to deal with giving Michael shots of growth hormone every night. I became accustomed to it. It is still sometimes frustrating at night, not being able to only tuck him in bed, but also having to put his bi-pap machine on him in order for him to breathe while he sleeps. I am still getting used to it.

The one thing that upsets me the most about his condition is the way some close-minded people can and will judge him, not for who he is, but for what he looks like. It is difficult knowing that my little brother weighs 20 pounds more than I do, and he is 12 years younger than I am.

As far as the people who do know him, they adore him. I never thought it was possible for someone to have more friends than I do. Michael brings joy to anyone's life that will allow him.

I wish I could change things. I would never change him, just the world around him. I want the world to see the same wonderful, beautiful, and amazing life that I see every time I look into those big blue eyes. I could never love someone or something as much as I love him. He is always comforting when I'm sad. It hurts more than anything to see him cry, and when he smiles, the sun shines brighter, and the heavens sing. You see, I was wrong about getting the little brother I always wanted, I got something better: I got my Michael Bear.

Jamais White, 17, lives with her family in Luling, Louisiana.

We welcome writings from siblings for *The Sibling View:* good experiences, bad experiences, we want to hear what you think. They can be signed or anonymous, whichever you prefer. Send them to the attention of Lota Mitchell at the PWSA (USA) national office, or e-mail to her at ljecholsm@juno.com.

Growth Hormone - *continued from page 3*

should be evaluated for sleep apnea and monitored if sleep apnea is suspected. All patients with Prader-Willi syndrome should have effective weight control and be monitored for signs of respiratory infections, which should be diagnosed as early as possible and treated aggressively."

Recent data indicate that GH actually improves respiratory function in PWS. One study result states: "Peak flow rate, percentage vital capacity, and forced expiratory flow rate improved and number of hypopnea and apnea events and duration of apnea events trended toward improvement after GH intervention. "Effects of Growth Hormone on Pulmonary Function, Sleep Quality, Behavior, Cognition, Growth Velocity, Body Composition, and Resting Energy Expenditure in Prader-Willi Syndrome." (2003) Haqq AM, Stadler DD, Jackson RH, Rosenfeld RG, Purnell JQ, Lafranchi SH - Portland, Oregon. *The Journal of Clinical Endocrinology & Metabolism* 88(5):2206-2212.

In addition, Dr. Martin Ritzen recently wrote to me: "I might add that we did a similar study in Sweden before and after GH, and found improved respiratory response (with GH) (Lindgren AC, Hellström LG, Ritzén EM, Milerad J 1999 "Growth hormone treatment increases CO(2)-response, ventilation and central respiratory drive in children with Prader-Willi syndrome." *Eur J Pediatr* 158:936-940.

PWSA (USA) would like to perform a more comprehensive study of deaths of those with PWS who are reported to us. Our goal would be to apply for funding and hire a medical student or fellow to help us analyze data, including the study of autopsies, and get more detailed information on the medical history of the child or adult with PWS who died. As the only national membership organization for Prader-Willi syndrome, and with a bereavement program in place, we have the data on deaths — but do not have the time to perform an adequate review.

My greatest concern is that we may go back to the days when endocrinologists were reluctant to put a child with PWS on GH. So much positive about GH has occurred beyond height — such as improved body composition, increased muscle function and increased energy.

The fact that we have recently put our 30-year-old son Matt on the PWS adult growth hormone study is the best example of my continuing confidence in the important role that growth hormone has in providing quality of life and improved health in our children and adults with PWS. (Matt was on GH from age 14 to 19 and then off for 10 years prior to the current adult study.)

As I write, Matt has lost approximately 30 pounds in three months! Is this all due to initiating small doses of GH? We think it is due to a combination of GH and a new exercise routine of walking a school track four to six laps daily. But we know from experience that prior to the growth hormone, Matt could walk the track all day and not have that kind of success.

At this time, there is no recommendation to discontinue GH therapy in PWS. The multiple beneficial effects of GH therapy in children with PWS are well documented. The company which has approved labeling for GH therapy in children in PWS, Pfizer (Pharmacia), and the Lawson-Wilkins Pediatric Endocrine Society, the major pediatric endocrine group in the U.S., have both reviewed the available information and are expected to issue summary statements. PWSA (USA) will keep our membership informed of this progress.

We will keep our members updated with as much objective information as we can for the health and well-being of all of our children with Prader-Willi syndrome.

Meanwhile, those who have specific questions regarding GH therapy in PWS are advised to discuss them with their physician. If your physician has additional questions, he or she can contact Pfizer Medical Information at 1-800-323-4204.

Ann Coyne - *continued from page 9*

travel agents and travel writers to the Virgin Islands, and traveling all over the Caribbean, Mexico, Venezuela, Argentina and Europe on sales trips.

At a time when the Virgin Islands was becoming very popular, Ann was asked by one of the condominium resorts on St. Croix to become general manager of the condominium association and try and turn the property around. A few years later it was written up by *Travel and Leisure* magazine as the best condominium on St. Croix. Then hurricane Hugo hit.

Returning to the states after Hugo and then another hurricane destroyed her home, she moved to Sarasota four years ago to be close to her aging mother, also a rather remarkable woman. (Her mother was one of the first female executive directors for the Federal Housing Authority in the U.S., and at 91 does her own bookkeeping on the computer.)

Ann is a lover of reading and theater (her brother had a play on Broadway), volunteer at the symphony, and grandmother of seven. She says, "The present staff of professionals in the national office has the best interests of all members at heart. I believe that I not only speak for myself, but for the rest of the staff as well. We want to help."

PWSA (USA) gratefully acknowledges the printing and mailing of this newsletter is made possible by a grant from CIBC World Markets Corp./ Miracle Day USA.

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April - May 2003

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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.