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The *Gathered View*

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



Abby Heathman, Nevada

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This Boston Marathon Was for Ashlyn

By Janet Berg

I am proud to inform you that for the benefit of Prader-Willi syndrome on behalf of Ashlyn Ricardo, I completed the 109th running of the Boston Marathon in April 2005.

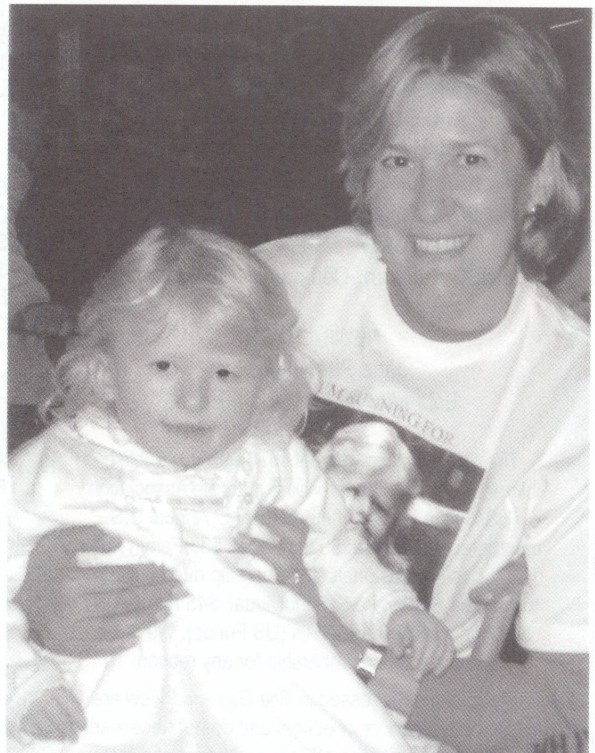
The effects of Prader Willi are hunger and muscle pain. The effects of the Boston Marathon, for me this time, were the same. After this long week my effects are dissipating. For Ashlyn, and many like her, they are just beginning. With financial assistance from people like you, there may be a way to help her and others with this syndrome to feel better, too.

New Year's Day this year I was offered a number for the Boston Marathon by the Marshfield Road Runners. For reasons unknown to me at that time I accepted. I actually considered backing out until Ashlyn's Uncle Dave stopped by my office at Brewer Plymouth Marine.

Dave asked me why I was running. I went into my usual self-serving stuff — "it makes my three sons proud, there are lessons to be learned, it keeps you in shape, it is a great sense of accomplishment, because it is there." After a few moments Dave politely stopped me; he wanted to know if I was running for charity. It seems he had one in mind, a very special 2½ year old.

Race day comes and I'm at its start in Hopkinton preparing for the race (napping on the green and singing along with the guitar players). I proudly wear the T-shirt Ashlyn gave me with her picture on it captioned "I'm running for PWSA".

I start 18,198 deep in a pack of more than 20,000 runners. It takes a half hour to walk to my starting coral and then back to the start after the gun goes off. The hot noon sun takes its toll but the crowds along the way fan my spirits.



Marathoner Janet Berg raised \$5,000 on behalf of Ashlyn Ricardo, who has PWS

About the 6 mile mark I can see my "style" in mirrors along the side. I don't look so well. The occasional rock band gives me rhythm that the continuous water stops take away. My feet begin to ache and breathing becomes trying. As I approach Wellesley College I start to hear a loud thunder, which turns out to be the students screaming as if I were the first runner past — high fives abound. The front runners have long since finished and are looking forward to the award ceremony.

Miles ahead is the infamous Heartbreak Hill, which is now stuck solid with empty Gatorade cups. My sneakers are drenched by

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Jan/Feb: Dec 1; Mar/Apr: Feb 1; May/Jun: Apr 1;
Jul/Aug: Jun 1; Sep/Oct: Aug 1; Nov/Dec: Oct 1

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If asked for Domain Name it is CIMCO



Media Mania: Awareness Comes At A Price

Janalee Heinemann

The amount of recent media coverage about PWS has created both excitement and concerns, along with questions about the role of our PWSA (USA) national office. I want to share with our full membership what I wrote to our e-mail groups.

Those who have been willing to open their families to public viewing and possible criticism to bring about awareness of PWS deserve our thanks. Each family risks how it will be portrayed — and no one gets paid for their efforts. Thanks to this coverage, many children who were not diagnosed in infancy are identified. Many, many families and professionals have contacted us to say, “I think my child has...” or “I am working with a child who has PWS and I need help.”

Good or Bad - We can't control the media

Some have said that PWSA (USA) should somehow be able to control what the media chooses to do or how a story is portrayed. I am frequently contacted by the media and often send awareness packages and names of professionals in the field to approach for comment. Sometimes, with a family's permission, I give media people their names — but media have many other ways to get names, and they almost never choose the family whose child is doing well. Currently, the most popular way for media to recruit is to put something on their web sites asking families to respond and tell their stories. PWSA (USA) has no control over this, or over what facts are given or not given. Although it does not please us, media people want to show a dramatic situation.

I was very involved with the *20/20* and *Discovery Channel* stories, giving producers information and contacts, but again, having no control over the outcome. Many felt the *Insider* piece, an example where the producers never contacted me for any information, was poorly done. The *Insider* had every opportunity to include a professional — in fact, did film Dr. Moris Angulo — but used none of that footage. In another disturbing situation, a writer from *The National Inquirer* misrepresented what magazine she was writing for. Fortunately, in spite of their reputation, she did a fairly sensitive article. There have been shows with which I would not cooperate — some much worse than the *Insider*.

On the other hand, both *Money* magazine (July edition) and *People* magazine contacted me, and said they plan to portray a more positive image of PWS and the families I connected them with. I've had contacts with the *Dr. Phil Show*, which is now pursuing several families and working with a few physicians from our medical boards. I don't know where this show will go — but it is fairly major exposure, so worth

the effort. Several of our families have recently been in their local news. So media mania — good and bad — continues!

Before you judge families portrayed in the media, consider the many variables in PWS due to genetic variances, early intervention, and management; thus there are many families in much, much worse situations. Remember, we deal with many crisis situations daily. Most of you do not know the worst of the worst — I hope you will never need to know. We have a new generation of children doing great, and we want to keep it that way. My own son Matt with PWS is 32, slim, happy, and very well behaved. But we cannot turn our backs on the families with children and adults with PWS who have tremendous struggles. If your child is doing well, please be grateful rather than point fingers.

Who or What is “National”?

During the media flurry there was a lot of comment about what “National” should or should not do. Who or what is “National” in your mind? Reality is that “National” is not a huge corporation, but a very small dedicated staff and a lot of wonderful volunteers like you from around the nation.

“National” is...

- **Me (Janalee Heinemann)** who married into the syndrome and raised Matt since he was 7 yrs old. I've dedicated my life to this cause both as a volunteer and professional for 25 years.

- **David Wyatt**, 73, retired minister and chaplain supervisor who lost his daughter at age 4 to cancer, has had major medical issues, yet dedicates his life to PWSA (USA) as Crisis Counselor.

- **Carolyn Loker**, a PWS mother and doctor's wife, who could be enjoying spas and playing tennis, but instead spends almost every day volunteering for the cause of PWS. Her husband **Jim** spends many nights and weekends volunteering for PWSA (USA) in spite of his busy schedule as a pediatric cardiologist and medical director of a hospital.

- **Barb McManus**, a retired PWS grandma who could be playing golf and bridge, but instead spends almost all day every day volunteering her extensive computer expertise to PWSA (USA). Just recently has she begun receiving a small stipend for her database work.

- **Our two wonderful medical boards** of physicians who devote countless volunteer hours to PWSA (USA) to consult, write, present on the latest in research, and SAVE LIVES!

- **Norma Rupe**, an 81-year-old volunteer who lost her daughter and has coordinated our bereavement program for many years and is now coordinating our Study of Death grant.

Media Mania continued on page 12



President's View

Our Parent Mentors Offer Solutions and Hope

Carolyn Loker

Since our Parent Mentoring Program originated 4 years ago, it has served 676 families. It has blossomed into a Parent Mentoring Program II program, reaching families of children 3-5 years old, coordinated by Vicki Knopf, along with Grandparent Mentoring Programs I & II, coordinated by grandparents Michele Leightman and Kay Goldberger.

Our thanks and gratitude go to Diane Spencer and Cindy Beles at the PWSA (USA) national office, who receive the first call from anxious and sometimes very emotional families. The Parent Mentoring Program has expanded to 62 trained parent mentors in the U.S. and Canada.

The letter below followed an e-mail posting to the parents of children 0-5 e-mail support group after the "20/20" television segment about PWS was aired. We share it with you as an illustration of how this program is assisting families of children who have PWS.



To our precious children with PWS we offer love and support

such as yourselves and Anna, we were able to start GH 4 months after her diagnosis, and this has enabled her to grow taller and stronger. She is so precious and pleasant, at least as much as any typical 3-year-old.

So I join you in celebration, to celebrate the love I have come to feel for my special Emily, to celebrate the successes big and small she continues to make every day, and to celebrate this e-support group that shares ideas and support across

the country and the world. Finally, let me personally celebrate these moments when your experience, compassion and understanding of PWS teach me as a relatively inexperienced mom new coping skills and strategies, and help me to continue to see the beauty of my precious daughter. Thanks so

much, you are an inspiration and great asset to all of us.

Bev Folmer, Wilmington, Delaware,
mom to Emily, 3 yrs., UPD

Dear Carolyn,

Thank you for taking the time to write such a beautiful post to our 0-5 e-mail group. It brought tears to my eyes. Just over a year ago when we got Emily's diagnosis (at 22 months, a "late" diagnosis these days), my husband and I absorbed all the PW info on the web, and believed our sweet baby was going to be nothing but temper tantrums from sun up to sun down.

A few days after the diagnosis I was giving her a bath, and she was laughing, happy, playing in the bathtub, typical bath-time fun for her. I said to her with tears in my eyes, "I'm going to miss you," completely believing that the days of her being happy, smiling, and laughing were near an end.

The next day you called as a New Parent Mentor, and I'll never forget you telling me that Anna was sweet, all who knew her loved her and she was a happy child. It was as if the sun came out. You (and other generous caring moms and dads after you) helped me realize that although Emily will have her struggles and we will have struggles as well, there is no reason to believe we won't hear that precious laugh any more.

As she turns 3 in two weeks, she is still so sweet, and has the greatest laugh you can imagine. She recently has developed a fondness for singing, and although the words are not always clear, we so love listening to her songs and cheer with her when she reaches the end. Thanks to the pioneers

Praise and Thanks for our Parent Mentors

Janice Agarwal	Kathy Funk	Anina Pfeiffer
Chris Appel	Kay Goldberger	Sherri Planton
Ann Baird	Colleen Goodall	Kari Porter
Carroll Beeson	Lisa Graziano	Pamela Rauch
Theresa Bender	Mark Greenburg	Lisa Ranieri
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Johanna Costello	Jim Loker	Heather Valeo
Tammy Davis	Raquel Lopez	Anne Vucci
Teri Douglas	Tina Miller	Holly Warner
Debbie Fender	Tracy Mittasch	Jeff Warner
Jeff Fender	Sara Oetjens	Christy Watson
Maryanne Funai	Tammie Penta	Susie Wood

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Eight Research Proposals Are Now Under Review

By Robert Lutz, PWSA (USA) Research Committee Chairman

PWSA (USA) announced two months ago that it intended to fund up to \$300,000 worth of scientific research. The first step in the process of deciding how to spend the funds was for researchers to submit Letters of Intent by June 1 summarizing their proposals; PWSA (USA) would then invite the authors of the most meritorious proposals to submit full grant requests.

Now PWSA (USA) is pleased to announce that eight Letters of Intent were submitted by qualified researchers on a range of topics. While we can't reveal the specific nature of the proposals at this time, they can be categorized as follows:

- 2 Genetic (hyperphagia/hunger)
- 2 Gastrointestinal
- 1 Endocrinology (hyperphagia/hunger)
- 1 Respiratory/sleep
- 1 Psychiatry
- 1 Exercise

By July, PWSA (USA) will have informed researchers of its choices, asking finalists for full grant proposals.

While this process is likely to absorb a good portion of our research funding, we continually strive to raise more money for research. We assure both the membership and the scientific community that we are always open to receipt of requests for research funding and will always attempt to fund valuable projects.

Research that we have previously funded continues to advance:

- Dr. David Stevenson of the University Of Utah, who is leading the project on the "Causes of Death in PWS," will share some initial findings at the Scientific Conference in Orlando in July.
- Dr. Jean-Pierre Chanoine and his fellow researchers at British Columbia's Children's Hospital in Vancouver, Canada, who are leading the study of the "Effect of Somatostatin on Ghrelin Concentrations, Food Seeking Behaviour and Weight in Patients with Prader-Willi Syndrome" report the following:

"We are presently investigating whether inhibition of ghrelin by an analogue of somatostatin could represent a safe and efficient approach to decrease appetite and weight gain in children and adolescents with PWS. Concentrations of ghrelin, a ... hormone that stimulates appetite, are high in subjects with PWS.

"Analogues of somatostatin have been shown to decrease ghrelin concentrations both in subjects with and without PWS. The study involves 2 periods of 4 months each, separated by a 6-month 'washout period.'

"All subjects are receiving, in random order, placebo and somatostatin. The first subjects who entered the study are presently entering the second period of the study.

"The study is blinded and placebo-controlled, meaning that neither the subject (or his/her family) or the investigator know when placebo or somatostatin analogue is injected. So far, no serious side effects were reported. Analysis of the data will be performed after the last patient has finished the study. Results will be available in 2006."

Lastly, PWSA (USA) will be publishing the abstracts from the PWSA (USA) Scientific Conference in July, and we encourage all those interested in research to read these latest studies and activities. The Scientific Conference provides an important forum for discussion of advances in PWS research.

PWS and Problems with Brown Fat Cells

By Bryan E. Hainline, M.D., Ph.D.

Obesity and body temperature regulation problems have been well known in individuals with PWS for many years. Physicians and family members have often suspected that the symptoms are related to altered ability to burn fat but have had little biological evidence to confirm that impression.

Recent research by a team at Children's Hospital in Boston has begun to point in the direction of altered fat cell metabolism in PWS. This new study reported in the journal *Nature Cell Biology* was part of ongoing research to understand which genes are involved in changing immature ("stem cells") into mature brown fat adipocytes (fat cells that burn fat and make heat).

Normal vs. abnormal cells

This paper examined expression of multiple genes in preadipocytes (cells that can be turned into normal brown fat cells) and mature adipocytes that were obtained from normal and abnormal mice who had had specific genes deactivated (knockouts).

The abnormal mouse cells lacked specific genes needed for insulin signaling, the process by which insulin pro-

duces action inside a cell, and can not turn into normal mature brown adipocytes. The researchers found that several genes were expressed differently in the knockout cells in addition to changed genes that produce insulin action.

The role of the *neclin* gene

The most interesting finding was that the *neclin* gene was inappropriately and highly expressed in the abnormal preadipocytes. Prior research has shown that *neclin* may be involved in the process of turning immature nerve cells into mature neurons. In 2001, researchers in Germany found that *neclin* was highly expressed only in brown preadipocytes and not in white. Recently, another study showed that *neclin* worked with another protein needed to help young muscle cells mature.

The *neclin* gene is located in the critical area on chromosome 15 that is deleted or made nonfunctional in patients with PWS. The conclusion from these research findings is that *neclin* gene product is an important

Brown cells continued on page 13

Adults With PWS Have High Levels of Ghrelin

By Dr. Tony Goldstone, MRCP, Ph.D.

Adults with PWS but not adults with obesity due to hypothalamic damage from craniopharyngioma have high levels of the appetite-enhancing hormone ghrelin.

Ghrelin is a hormone produced principally by the stomach that increases appetite. Levels of ghrelin in the blood are high when fasting and before meals, and fall after eating food. This suggests that changes in ghrelin may normally contribute to the hunger felt before meals and feelings in fullness after eating. People who are obese usually have low levels of ghrelin in the blood. Another hormone produced by the gut called PYY has the opposite effect. PYY reduces appetite and also ghrelin levels in the blood. Levels of PYY in the blood are low when fasting and before meals, and increase after meals.

People with Prader-Willi syndrome (PWS) develop an uncontrollable appetite from early childhood, which persists through the rest of their lives, and can lead to extreme obesity at an early age. Prevention and management of obesity is vital to avoid complications of obesity, such as sugar diabetes, heart and lung problems. There are no effective treatments currently available for the insatiable hunger.

Ghrelin and the brain

It was recently found that, despite being obese, patients with PWS have unexpectedly very high levels of ghrelin in their blood. The cause for this is unclear. It has been suggested that this may cause or contribute to their increased appetite, raising the possibility of developing a drug treatment to reduce their hunger.

Ghrelin and other hormones produced by the intestine, like PYY, which control appetite, are thought to work through a part of the brain called the hypothalamus. Defects in the hypothalamus of patients with PWS are thought to prevent the normal action of hormones and signals that reduce appetite.

Patients who have tumors that involve the hypothalamus, such as craniopharyngioma, are also at risk of

developing obesity and increased hunger as a result of damage to the hypothalamus. This may result from the tumor itself or damage from surgery to remove or radiotherapy used to shrink the tumor.

We wondered if the levels of ghrelin in the blood are still high after eating in people with PWS. We wondered if people with obesity and hypothalamic damage from craniopharyngioma tumors might also have high levels of the hunger hormone ghrelin which might contribute to their obesity. We also wondered whether any of these patients might have low levels of the appetite-reducing hormone PYY that could also contribute to high ghrelin levels. We studied healthy adults who were slim or obese, and adults with PWS and craniopharyngioma tumors. Blood was taken when they had fasted and in some subjects blood was also taken regularly after they ate a standard breakfast.

We found that levels of ghrelin fell normally after eating food in everyone, including those with craniopharyngioma and PWS. However, the otherwise healthy subjects with obesity ***always had lower levels of the hunger hormone ghrelin compared to healthy slim subjects.***

Patients with craniopharyngioma who were slim had ghrelin levels similar to healthy subjects who were slim. Patients with craniopharyngioma who were obese had similar ghrelin levels to otherwise healthy subjects who were obese. By contrast, obese ***subjects with PWS had much higher ghrelin levels than otherwise healthy subjects who were obese.***

Ghrelin and insulin

The high level of ghrelin in obese people with PWS but not with craniopharyngioma tumors appears to be at least partly due to people with PWS having lower levels of another

hormone, insulin, that regulates blood sugar levels. The obesity and hunger seen in some patients with craniopharyngioma is not therefore due to high levels of ghrelin. It remains to be determined what contribution, if any, the high level of ghrelin in people with PWS makes to their hunger and obesity.

Research continues

Research studies are being carried out to determine the effect of lowering ghrelin levels, and if drugs become available, of blocking the action of ghrelin in people with PWS.

All groups had similar blood levels of the appetite-reducing hormone PYY. Low PYY levels do not therefore explain the high levels of ghrelin in people with PWS.

The results of this study were published in April 2005: "Fasting and postprandial hyperghrelinemia in Prader-Willi syndrome is partially explained by hypoinsulinemia, and is not due to peptide YY3-36 deficiency or seen in hypothalamic obesity due to craniopharyngioma," A.P.Goldstone, M. Patterson, N.Kalingag, M.A.Ghatei, A.E.Brynes, S.R.Bloom, A.B.Grossman & M.Korbonits; *J Clin Endocrinol Metab* 90:2681-2690, 2005.

We would like to thank all the individuals, carers and their families for taking part in our study, and also the United Kingdom Prader-Willi Syndrome Association and the UK Medical Research Council for their financial support.



High Incidence of Hip Dysplasia in Patients With PWS

Summary by David Agarwal, M.D., Indiana University Medical Center

Slipped capital femoral epiphysis (SCFE) is the sliding of the rounded head of the thigh bone on the growth plate at the top of the shaft of the thigh bone, and is usually seen in obese adolescent males in whom over-activity causes excessive shear stress on the growth plate, leading to hip and knee pain.

Because obesity, hypogonadism, and growth hormone therapy are associated with SCFE and are also common in PWS, PWSA (USA) funded research (reference below) to determine whether children with PWS are at greater risk for SCFE than other children. Five hundred sixty-five surveyed members (63%) of PWSA(USA) research list submitted information on 279 males and 286 females, 58% indicated low activity level, 37% medium activity level, 5% high activity level. Of those, 38% had prior growth hormone therapy.

The prevalence of specific orthopedic conditions was: flat feet 47%; scoliosis 41%; knock-knees 19%; hip dysplasia 10%; osteoporosis 9%; patellofemoral instability 7%; bow legs 3%; clubfeet, nursemaid's elbow, and leg-length inequality each 2%; and SCFE only 0.2%. Although the prevalence of SCFE in the PWSA (USA) database was not shown to be lower than the prevalence in the normal population, the authors concluded that the prevalence was lower than they anticipated, perhaps due to the protective effects of a relatively inactive lifestyles, delayed puberty (SCFE often occurs during growth spurts), or possibly by a decreased tendency to develop the type of stress needed to cause this kind of growth plate injury.

The study did find, however, that the prevalence of hip dysplasia in people with PWS is 10 times greater than in the normal population. Hip dysplasia is abnormal ligamentous laxity allowing the rounded head of the thigh bone to slip out of its hip socket, causing hip instability (weakness), subluxation (hip partially out of the socket), or dislocation (hip completely out of the socket), is usually seen in the left hips of firstborn female breech infants, and can cause a loss of the blood supply to the head of the thigh bone (avascular necrosis).

The authors believe the high prevalence of hip dysplasia in PWS might be due to the combination of hypotonia with ligamentous laxity or to fetal inactivity that could prevent proper development of the hip socket. They concluded that because delays in diagnosis of hip dysplasia often cause chronic subluxation and degenerative joint disease later in life, hip x-ray monitoring for children with PWS may be warranted.

Dr. David Agarwal comments: With earlier diagnosis, improved dietary management, and growth hormone therapy, I expect fewer children with PWS to show obesity (decreased risk of SCFE), and more children to show higher activity levels (increased risk of SCFE). The hip dysplasia prevalence will likely remain high.

Because children with PWS are often unable to show signs of hip or knee pain, and because delays in lower extremity motor development (crawling, cruising, walking, running) in children with PWS may simply be attributed to hypotonicity instead of to a musculoskeletal skeletal hip disorder, parents, pediatricians, and therapists need to maintain a high index of suspicion for hip dysplasia and SCFE.

Reference: West, L.A. and Ballock, R.T. "High incidence of hip dysplasia but not slipped capital femoral epiphysis in patients with Prader-Willi Syndrome," *Journal of Pediatric Orthopedics*. September/October 2004; 24(5):1-3. PMID 15308908.

Parent Mentors - continued from page 4

I was very moved by Beth's response; it warmed my heart and helped remind me of the importance of the PWSA (USA) Young Parent Mentor Program. Wonderful things are happening because of this program, one of which is healthier, happier families resulting in a more optimistic path to start our journey. It brought to mind a poem I wrote at the beginning of our own family's journey:

Promises

*My precious child,
As I take your hand in mine,
And we walk this journey together,
I promise...
To be your comforter and guide,
To laugh with you,
To love you,
And hold you close to my heart,
To encourage you and give you hope.
These are my promises to you, my precious one.*

Parent Mentors, we celebrate your love and care for our new families, and thank you with all our hearts!
Hugs from Carolyn, Mom to Sweet Anna

Surveys and Commentary Sought for Sibling Booklet

Regardless of where they live, those who have a sibling with PWS have a lot of feelings about their experience. We are planning a booklet for siblings made up of your writings and the sibling survey information.

*Please e-mail a contribution for the Sibling View to ssurvey@pwsausa.org or mail it to the national office. You can ask for a copy of the survey from the national office or do it online at www.pwsausa.org/sibling.asp.
Deadline is September 30, 2005.*

The online completed surveys are starting to come in! Please do one yourself!

— Lota Mitchell, Associate Editor

Intelligence Testing: What You Need To Know

By Amy McDougall, M.S.

Intelligence testing is a topic that tends to generate strong responses in us as parents: anxiety about our child's abilities and what services he/ she will receive, disbelief that these numbers could give us anything meaningful, frustration that someone could give a rigid test and then expect to understand our child's abilities better than we could. As a parent and practitioner, I understand these emotions, which can be one more concern associated with the PWS "journey".

I hope that all parents can use this information to feel informed with both preschool and school-age special education systems.

Cognitive Assessment

Various instruments are used to measure what is commonly known as "IQ". At the time of this writing, most states require a cognitive (often called "psychological") portion of a psycho-educational evaluation, so any child receiving services via the special education system would have one completed. However, the role of cognitive assessment may be changing, given the reauthorization of IDEA.

At young ages, it is very difficult to differentiate between speech/ language, muscle tone and cognitive ability, since the primary means of conveying ability rely on the abilities to speak or move items. Some will even contend that it is not possible to truly test "intelligence" until a child is around 7 years old. In a sense I agree with this, as the young mind is so moldable that skills can be taught which will impact a child's performance on intelligence testing (such as the skills learned via occupational, physical and speech therapies).

As children get older, we can teach skills, but they are not as likely to impact performance on cognitive assessment. So up until that point, is intelligence testing not reliable? I believe the best way to look at it is that the tests can give us information about a child's abilities *at that time*.

Seeing Beyond the Scores

It is impossible for one test to assess every area of strength and weakness. There is some wonderful discussion out there about multiple intelligences: emotional, musical, athletic, being good with directions, and so on. IQ tests tend to look primarily at the skills that are often associated with a traditional view of learning within a classroom. Motivation, perseverance and work ethic cannot be measured on a test (though observations can give a clue about these traits). So we should always look beyond the scores. Bear in mind that any assessment is basically a "snapshot" of a child's performance on a given day, and might vary a little from day to day based on the factors discussed above.

When we talk about standardized tests, we are referring to instruments that have been administered to thousands of children in the same way (evaluators actually get manuals telling how to ask the questions, and even how to question responses and prompt!) The scores that children receive are based on how other children of the same age are able to do on the exact same items.

Say your child is able to give the right answer if a question is reworded: does this automatically mean your little one is not as "smart" as the other kids who could get the item with the way it was originally asked? No.

Perhaps you tend to always ask questions in the same way and your little one was confused by how the question was asked. Maybe there are some language issues, and he/ she did not understand what was being asked. Maybe it was the first subtest given and your little one was still in the "Who is this person asking me questions?" stage. The point is, why did your child struggle with a task that other kids did not find difficult and what can you do about it? Maybe you aren't concerned because your little one could do that task on another day with a familiar person, so what is the sense in worrying about it? Maybe you start to vary the way you ask

Some Commonly Used Tests

- Differential Abilities Scales (DAS)
- Stanford-Binet Intelligence Scale-Fifth edition (SB-V)
- Wechsler Intelligence Scale for Children- Fourth edition (WISC-IV)
- Wechsler Preschool and Primary Scales of Intelligence- Third edition (WPPSI-III)
- Woodcock-Johnson Tests of Cognitive Ability

The more reliable and comprehensive tests start at age 2½. "Infant tests" can be given before this (such as the Hawaii Early Learning Profile and the Bayley Scales of Infant Development-2nd edition). Brief tests, such as the Slosson and the K-BIT (Kaufman Brief Intelligence Test) take very little time, but because there are few subtests, they may "test high" if the subtests tap into a child's particular areas of strength. The longer tests obviously require more time, but look at a broader range of abilities.

your little one questions. Or maybe you say, "OK, here's an area of weakness, where do we go from here?"

Time can also be an issue, as many of our children will need additional time to work through a task. As an evaluator, I often allow children to go beyond the time limits allowed on the test merely because I want to see if they can get the right response. When I score these items, I am required to score them based on the time limit of the test (since the majority of children that age could accurately complete the item within the time allowed). I will, however, note whether or not each child can do the task given extra time, or if the task was beyond his/ her capabilities.

Issues Affecting Results

Many diverse factors beyond innate ability influence how well a child does on these tests. Did the child understand what was being asked? Able to pay attention long enough? Had the opportunity to be exposed to this sort of information?

Did the child care to do what was asked, or was it more appealing to play with the toys or go outside?

The evaluator's approach can either draw children in or make them very wary. If an evaluator is "new" to your child, he/she may be uncertain how to respond to this unfamiliar person. The setting of the evaluation can influence how a child performs. Are there numerous distractions in the room or is it quiet? I have tested in my own office, where a child may be overwhelmed by the new setting, and I have tested in the child's home, where the child may be more comfortable, but might have more distractions. (For example, there may be older siblings present who are very interested in what is in the test kit who stay in the room answering the questions, rather than allowing the child being evaluated to truly show what he/she is capable of.)

Another factor that might be easy to overlook when scheduling a testing session is time of day. If your child has significant fluctuations in his/ her blood sugar levels, or usually naps at a certain time of day, planning around these can have a dramatic impact. Some children reach a point of "information overload" and may need to have a break, or even be tested on separate days. When scheduling an evaluation, think of the things you know about your child, so that you are better able to discuss the time and place that you feel would be the setting in which your child can perform best.

An evaluation can also bring up ideas that might not have been thought of from everyday experience. For example, I recently evaluated a student who was struggling academically. Both the parents and classroom teacher indicated that the child could not follow multiple-step directions and was often "zoned out" in class. The question of an attention deficit had been raised. On evaluation, the student's overall cognitive ability was within the average range. However, very weak verbal comprehension skills were demonstrated in contrast to average non-verbal, problem-solving skills. In short, the student does not have an attention deficit, but a weakness

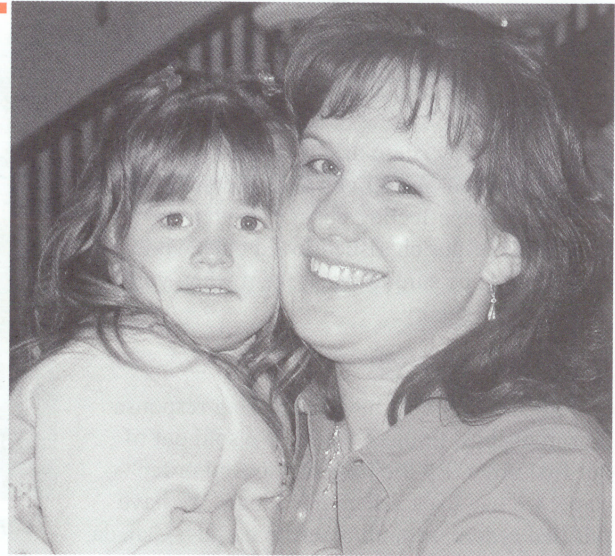
in the area of language. Because the student did not fully understand the abstract language that was being used, it was difficult to attend to lectures and work through multi-step directions. Now the child will be receiving speech therapy rather than medication.

Use Results to Focus

Take advantage of the information that comes from an evaluation to look at the areas you want to focus on, either through therapies or how you do things on a daily basis. With areas of weakness you should be thinking remediation ("can I fix it?") and compensation ("how do I work around it?"). For example, suppose your child has weak memory skills and cannot memorize math facts. Of course you try to work with flash cards and speed drills at first (remediation), but do you push the child to the point of total frustration or do you say, "Well, using a calculator is more efficient and it's better to have the real life skill" (compensation)? Personal experience and maturation can have a very positive effect on how a child learns to deal with personal areas of weakness. We all have areas of weakness we've learned to compensate for and are more successful, healthy adults knowing that we cannot be perfect in every area, but let's build on our strengths. The earlier this process is started in a child's life, the better.

As an "overview" example, I've summarized our family's experience with preschool cognitive testing. I requested that evaluators wait to schedule the testing date until after my daughter Noelle, who has PWS, turned 2 years 6 months so that the evaluator (other than me) could use the DAS.

Prior to the evaluation, I knew that Noelle had very little language that she used to speak (expressive language), but felt that she understood everything we said to her (receptive language). Based



on the way she "works" situations, I suspected that she had good problem-solving skills.

Noelle is also the type of kid who typically only does things when it suits her. At the early preschool level, the DAS has four subtests, two of which rely on non-verbal skills and two that rely on verbal skills. On the first subtest, when asked to build a tower of blocks, Noelle smiled and refused to complete this fine motor task. The next subtest involved pointing to named items or placing items in certain positions based on direction (no spoken language needed). Noelle scored in the average range on this subtest. On a subtest where she was asked to match a picture on a card with one of several pictures on the page based on a similar concept, Noelle scored in the average range. The last subtest involves verbally identifying a presented picture. Noelle has minimal spoken vocabulary, so she was unable to answer any of these correctly.

When scored, Noelle's performance on the overall test would be quite low, but the subtest scores paint a clear picture of her current abilities. Her refusal to complete the first subtest was reflective of her personality, rather than an inability to do the task, so I am not concerned about this low score (though I did test the limits and gave her the task the next day: average range performance with no hesitation or

Intelligence continued on page 13

Fund-raising and Awareness: We Salute Your Efforts!

By Jodi O'Sullivan

As Director of Community Development, I'm pleased to list some of the activities accomplished by some of our membership and friends for fund-raising and awareness. These individuals are effecting change for the betterment of our cherished loved ones with PWS. Please be sure to thank them when you have an opportunity.

PWS Wristbands

PWSA (USA) is having amazing response for wristbands. In three weeks, we sold out of our first order. By the time our second order came, we had back orders piled high. We have fulfilled orders from all over the world—Canada, England, Germany, Mexico, Spain and more. Again, we SOLD OUT of youth sized bands. We hope you wear your bands with pride. Here is what some members shared with us about their wristbands.



Teaming Up With PWS Wristbands

In the white T-shirt, Caroline Knopf, 4, with PWS. In the red T-shirts, Ben Knopf, 6, with PWS (center) and David Knopf, 10, with PWS (right). These siblings are with some team mates from the East Lyme Vikings Jr. Varsity Baseball Team, on which their big brother, Ryan Knopf (3rd from left), plays. These guys not only wear their orange bracelets every single day, they are Awesome with David, Ben and Caroline!

It is time for us all to stand and cheer for the doer, the achiever — the one who recognizes the challenge and does something about it. — Coach Vincent Lombardi

Robyn Jones (mom to Ryan, 17 months, with PWS) Kansas City, Missouri

Robyn went to a garage sale looking for an Exersaucer. When she found one and was paying for it, the woman grabbed her PWS wristband and said "Prader Willi, that's a great cause — my sister has it!"

Robyn learned that the woman's sister is 32, was diagnosed at age 17, and not only has PWS, but also Autism and Down syndrome and lives in her own apartment in a group setting.

Robyn was happy to know that this woman's sister is living relatively independently. The woman was amazed that Robyn already had a PWS diagnosis for her son.

Diane Seely (mom to Reagan, 2, with PWS), Columbus, Ohio

The Seely family sold about 70 wristbands and did a skip-a-meal fund-raiser that raised more than \$700. Each member of the family did something different. Diane's husband printed all of the flyers for the skip-a-meal effort and helped stuff the envelopes. Her two youngest girls and the respite care provider helped make posters to hang at school.

Diane said she had always been a very quiet and shy person, yet these days when someone opens "that door," she talks about PWS without shame, and as long they are interested, she'll keep talking. The Seelys plan to do another fund-raiser this fall.

PWS Awareness

Christina Smallwood (mom to Payton, 8, with PWS) Loves Park, IL

In May, Chris organized an awareness assembly at the school her daughter will be attending next year. She also sent flyers, donated by the school district, home with the school children, inviting them to march with Payton during their town's Memorial Day parade. Representatives from the school district's disability program joined in the parade with them. There were 37,000 people at the parade. Chris and her husband led their float with a borrowed PWSA (USA) banner. Payton rode in a Corvette, donated by a local dealership for the day, wearing a crown. Almost 40 people walked with Payton. The local paper mentioned their float.

The parade passed by The Fashion Bug, a clothing retailer, where Chris and Payton had been earlier that week looking for a bathing suit. Because of Payton's large size, finding a swim suit to fit her is difficult; they found one at this store, but could not afford it and left without it. The store manager was watching the parade and recognized Payton. Later that weekend, the manager and her employee made a special trip to the Smallwood home, where they presented Payton the swim suit in a beautifully wrapped box. When Payton realized she could keep it, she cried with happiness.

Payton also made new friends as a result of the awareness campaign. Some older kids told Payton not to be scared to be going to their school next year because they would

Awareness continued next page

More Awareness Activities

watch out for her. Also, two little girls on bikes stopped at Payton's house, explained they had seen her in the parade, and wanted to know if Payton could play. Go Payton!

Nina Roberto (mom to Niyani, 12; Sonny, 3, with PWS; and Lennon, 2), Richmond Hill, New York

Nina educated approximately 800-1,000 people with a poster she made. At a family party she visited every table to discuss PWS and left brochures. She asked people to take a flyer and post it at work and or talk to a friend about it. Her cousin asked if she would speak at his college. He is getting his Master's Degree next year in counseling and took a great interest in PWS. Nina's aunt was very thankful for the flyer because now she can explain PWS to her friends. Her brother-in-law is leaving copies of the flyer and will display the poster at the library where he works. Her other cousin plans to order wristbands for her co-workers. Nina asked each person to tell one other to help spread awareness.

Her son's teacher made a poster for classroom door with information from the PWSA (USA) web site. After her poster was displayed at her church for a week, Nina posted it at her friend's job, where the workers were asking questions like wildfire, and at daughter Nivani's school. Her son's speech therapist and special instructor have also spread the news. Nina said her experience "was such a wonderful opportunity to tell as many people as I could," adding, "I didn't know it would be this easy."

Angela Krambeer (mom to Ryan, 5, and Dylan, 3 with PWS), Crystal Lake, IL

Always trying to spread awareness, Angela gave a presentation to the local hospital about PWS, and now, when she walks in, they know who her family is. She wrote an article for the May/June issue of a local woman's publication, the *McHenry County Woman*, which has an estimated readership of 75,000 people, with free distribution to businesses and doctors' offices. Angela says, "I love to educate people, and to share our story. So much positive has happened in my life as a result of this path we are traveling, and I want to help people to focus on that, and not dwell on the bad."

Becky Loupe (mom to Austin, 9 months with PWS, and Caleb, 5), Lockport, LA

When Becky went to the ball park to watch her older son practice for T-ball, a little boy and his mother approached. They had seen her on the front page of the local paper. The mom thanked Becky and pointed out her other child, a little 5-year-old boy who played on Becky's son's team. The woman said they finally might know what's wrong with her son. He has all the signs of Prader-Willi, but the doctors never tested him for that. He didn't talk until about 4, was slower with his milestones, and has a constant desire to eat, going to bed some nights crying for food. She will be taking him to the doctor to have him tested for PWS. Becky said of her efforts, "This was why I sent the PSA to the newspaper. I was so excited that it actually helped someone else out. I felt I made a difference to someone else's life, and I can't even begin to explain how good that feels."

Raising Funds for PWS Research

Josilyn's Faith Foundation, Palm Beach, Florida

Josilyn's Faith Foundation held the 2nd Annual Prader-Willi Golf Classic in honor of Josilyn Faith Levine in Palm Beach Gardens, Florida at the PGA National Golf Course. About 100 people attended, including staff from the PWSA (USA) national office who volunteered — Executive Director Janalee Heinemann, who also spoke;

Business Manager Steve Dudrow; and me, along with Josi's aunt. PWSA (USA) President Carolyn Loker and Anna, her 10-year-old daughter with PWS, who were on vacation in Florida that week, took time to attend also. Ronnie and Ira Levine, Josi's grandparents and event organizers, made a donation of more than \$11,000 for research to PWSA (USA) on behalf of the Foundation.

Jay Headley (dad to J.R., 6, with PWS) Dublin, OH

Jay raised more than \$4,200 for PWSA (USA) running the Columbus, Ohio Half Marathon on April 2. It was a very cold (20 degrees), wind-chilled, early April day with driving snow for the entire race. It was difficult, but whenever Jay got tired or cold he would think of J.R. and the other children to keep him going. He did beat his goal time of two hours and felt great to be able to make a contribution.

Paul Ralston Memorial Golf Tournament, Siesta Key, FL

The Siesta Key Chamber of Commerce held a golf fundraiser June 5 and named PWSA (USA) a beneficiary. Staff from the PWSA (USA) national office worked the event, which to date has earned PWSA (USA) more than \$1,000. Thanks to our staff and wonderful volunteers for making the event a success, and to the Torbert Family and Colorado Rockies for providing silent auction/raffle items.



On the links at the 2nd Annual Prader-Willi Classic Golf Tournament are Rachel, 5, with her sister Josilyn, 2, who has PWS

We never said it would be easy, we only said it would be worth it!

- **Diane Spencer**, who could be retired, but instead puts in long days as our support coordinator.

- **Ann Coyne**, our financial manager, also of retirement age, who lost a child to cancer. Ann has chosen to delay the hip replacement she needs because she feels the association cannot afford to have her off for any period of time before conference.

- **Cindy Beles**, who answers the phone when you call. Cindy's son is severely disabled due to a brain tumor, but she is always cheerful with those who call. Her son now volunteers for us.

I could go on and on, but please try to remember that "National" is no more than a group of dedicated people around the nation, who have sacrificed nights and weekends and offer talent and time to make the life of your child a better one.

Comments from our members...

• I WISH that there WERE "nice" ways to portray the trials of a family dealing with PWS, but I know that there really aren't a lot AND (to paraphrase the old saying): "Nice doesn't sell newspapers".... I think "National" does great work and my wife and myself very much appreciate your efforts. We ALL have tremendous battles and day-to-day, one-foot-in-front-of-the-other existences, and anyone who thinks it's NOT a constant battle is either incredibly blessed or incredibly (perhaps willingly?) blind.....we appreciate you and we BEG you: Keep up the GREAT work! Thank YOU.

• ...if anything, the media attention has benefited us personally. My daughter Safiya is 6 years old and attends kindergarten. We had a hard time convincing the school district as part of her IEP that anything significant was wrong with her. They knew she had PWS but could not comprehend the seriousness of the syndrome, as Safiya comes across fairly "normal" during any interaction. We even provided them with all the literature, but still it did not have the desired effect. It was only after watching the 20/20 segment that the school resource specialist grasped the seriousness of this syndrome, especially without proper intervention.

Marathon - continued from page 1

well wishers hosing me down. As I approach Boston, the Citgo sign finally comes into sight with only a few spectators and runners left. I feel quite alone and it is hard to focus. My thoughts turn to Ashlyn.

As I come close to the finish I save up my energy for the turn onto Boylston Street and pose for the camera. Volunteers rush in with blankets and food. I'm too proud to sit in the wheelchair but too weak to raise my foot to remove the timing chip. The medal slips on my neck as I trudge to a side street and collapse on a bench.

My 13th, most difficult and most memorable Marathon ended safely. It feels great to have run for PWS, and not dwell on the reality that 10 years ago I was in the top 10% of the

If There Were No National...

We've received both positive and negative feedback regarding recent media coverage. One very disturbing response was: *"I think the reason why people do not subscribe to National is because of things like this."* In all of the discussion about "National's" role, have you considered **what would happen if there were no "National"?**

- Our e-mail support groups are only available thanks to "National." Most new parents' early education and connections are probably due to "National's" New Parent Mentoring program.

- Most of the positive educational materials, and medical alert articles and booklets that SAVE LIVES are only available thanks to "National."

- Our web site, www.pwsausa.org, which gets more than 2,000 visits a day, and also SAVES LIVES because of the excellent medical alert section used daily by ERs and ICUs, exists thanks to "National". (One parent whose child was just diagnosed told me his physician instructed him to go to our web site – and only our web site.)

- Much progress in PWS research is due to the many ways "National" supports research (see our web's research section). There is not a day that we are not dealing with researchers.

- If your child is in medical or any other kind of crisis, you know that you can always turn to "National" for help. And we will be there for you.

- Words are unable to describe the gratitude I feel for the work you all do at National! It was the first place I turned after learning about my daughter Roxy's condition; and your package of hope, as well as your website really launched me onto a path of better understanding — even allowing me to see a glimmer of hope for Roxy's future.

Boston Marathon and this year I was almost last. I am glad to be safe and that I finished the race.

On behalf of all of the Ricardos and me, I thank everyone for their contributions to the Prader-Willi Syndrome Association (USA). Our pledges so far have surpassed the \$5,000 mark. It would have been worth it just for the single sweet thank you that Ashlyn gave me last weekend and the gratitude I have felt from her family.

Boston Marathon Runner Janet Berg lives in Scituate, Mass. She ran on behalf of Ashlyn Ricardo, who has PWS and lives with her family in Carver, Mass. Janet Berg will forever be a World Class runner to the PWSA(USA) Family.

The Chuckle Corner

Can You Hear Me Now?

After years of yelling from the second floor for someone located in the basement to pick up the phone, we finally installed an intercom system in our home.

Our son, David (age 12, with PWS) made good use of it at about 10:00 am one weekend morning when he pressed the button and said, "Can someone please wake me up, 'cause I'm really hungry!"

Carol Hearn, Plymouth, Minnesota



Do you have a joke or funny story to share? Please send it to the PWSA(USA) office. Be sure to include your name, telephone and address in case we have questions.

Check Out MEMBERS ONLY On the PWSA(USA) Website

Be sure you get into the habit of visiting a relatively new option on the website, **Members Only**, which is going to become increasingly important.

Many new items are now in this area, and more will continue to be added: research abstracts from the 2004 Scientific meeting, 2004 IPWSO abstracts, preview of the new homepage prior to being published on the main site, Handouts and Brochures, current news on PWS, Research search Abstracts from the web, and a new thing like eBay where you can put new or almost new items for sale.

The Ratings column will eventually warn the viewer about its content (like the movies). A "Q" rating means "Recommended for parents of teens and adults." A "Q + 6" would mean "Recommended for parents of children age 6 and up."

You must be a member of PWSA (USA) to enter Members Only. Password and User names are on page 2 of *The Gathered View* and are changed each issue. — **Lota Mitchell, Associate Editor**

Brown Fat Cells - continued from page 5

The *neclin* gene is located in the critical area on chromosome 15 that is deleted or made nonfunctional in patients with PWS. The conclusion from these research findings is that *neclin* gene product is an important regulatory protein involved in changing early cells destined to form final tissues including brain, muscle and fat. Abnormal changes in its level in immature fetal cells (either amount or timing) may be part of the cause of the symptoms of PWS infants and older individuals. PWS patients have small muscles and biopsies show changes that have been thought to be due to atrophy (loss of tissue mass) but may be immature or poorly formed muscle.

The lack of formation of normal brown fat cells and resulting increase in white fat cells which store fat may lead to obesity. Incomplete or altered maturation of brain cells may explain problems such as mental retardation, behavior problems or other neurologic problems.

Much research remains to be done in the area of insulin action and how the various genes regulate the process of maturation of cells and metabolism in normal cells, but this finding brings hope for explaining the changes in PWS and possibility for some form of treatment.

Reference: Yu-Hua Tseng, Atul J. Butte, Efi Kokkotou, Vijay K. Yechoor, Cullen M. Taniguchi, Kristina M. Kriauciunas, Aaron M. Cypess, Michio Niinobe, Kazuaki Yoshikawa, Mary Elizabeth Patti & C. Ronald Kahn; "Prediction of preadipocyte differentiation by gene expression reveals role of insulin receptor substrates and *neclin*" *Nature Cell Biology* Volume 7, June 2005 pp 601-611.

Dr. Hainline is a member of the PWSA (USA) Clinical Advisory Board.

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encouragement from Mom). Her evidenced abilities to understand language and problem solve were what I had expected.

In her specific area of weakness, our speech therapist is focusing on both remediation and compensation. We are working at increasing Noelle's spoken vocabulary and language usage, but knowing that she can become frustrated at times, she is learning some sign language. When Noelle is better able to use language, I suspect that her overall IQ will rise quite a bit, based on the potential that I see in other areas.

The bottom line is that while I do not believe that test scores are all-encompassing of who a child is or what his/ her abilities are, I think there is a great deal of information to be gained from this testing if the results are put in perspective and used properly.

I have outlined much of my perspective as a parent and practitioner, but please be aware that there may be other professionals who have contrasting opinions. My hope is that you will be able to use this knowledge to be strong, informed advocates for your child. I encourage you to ask anyone who evaluates your child to describe what your child's personal strengths and weaknesses are. I rarely evaluate a child who is not strong in at least one skill area, and weaker in another. The key is being able to identify both, so that educational programs and therapies can be tailored to build on your child's individual learning style.

Amy McDougall is a school psychologist in New York who also performs pre-school evaluations. She and husband Harry and their children, Steven, 9; Noelle, 3, with PWS; and Logan, 17 months, live Fulton, N.Y.

We Remember...

Every person has something special to offer this world — and we, along with their families, want to share who they were and what they meant to the people who loved them.



Andrew J. Hill

Andrew passed away just 2 weeks before his 16th birthday from seizures that were caused by a viral infection of the brain. He had survived 2 brain surgeries for Craniopharyngioma in 1999 and 2000 and 6 weeks of radiation treatments in 2001. He was diagnosed with Acquired Prader-Willi syndrome* just over a year

ago. The surgeries rendered Andrew without any hormones; in effect, his pituitary gland was non-functional. Before the family found out about PWS, Andrew had reached 228 pounds and was just over 4 feet tall. At the time of his death he was just 10 pounds shy of reaching his goal weight of 135 pounds and was very proud of this accomplishment.

Andrew's mother Kristen Nix said the family finally found hope from an article that ran in the Flint Journal about the Christman children titled "Hungry for Help."

She wrote, "Andrew was a very brave and sweet boy who never asked why this happened to him, never got angry that he was sick and was a joy to the nurses, doctors and surgeons that worked with us to keep things going over the past 7 years."

With a donation to PWSA (USA) Kristen asked that the money be used "to further your good work on behalf of children like Andrew and to help raise awareness that children with brain tumors CAN have **Acquired** PWS. I fear that many are slipping thru the cracks because doctors do not recognize that the symptoms can be aligned and treated the same as a child born with the syndrome. My son was proof of this; he responded wonderfully to the PWS program that the Children's Institute developed for him, and was doing very well before he contracted the virus that caused the seizures which took his life. Thank you for all the support, information and assistance that you gave us and for helping us find the Children's Institute where we learned how to live with PWS in a much more positive and productive way. Andrew enjoyed a much better quality of life due to the tools that we received through his stay there and was doing so much better; we were (are) all proud of him."

* *Hypothalamic obesity is the official medical term for what we call "Acquired PWS." It is from head trauma affecting the hypothalamus. This condition is thought to arise from overeating due to poor regulation of satiety and hunger. Besides obesity, hypothalamic insult can lead to other endocrine abnormalities including growth hormone deficiency and hypothyroidism, both of which exacerbate obesity. Hypothalamic obesity can be seen in children with brain tumors, those who have undergone surgery, or those who have had radiation.* — Bryan E. Hainline, M.D., Ph.D.



James M. Bennington

Born Nov 3, 2001, James died March 17, 2005. He was the son of Paul and Hairani Bennington and elder brother of Haris. "James meant so much to us and we loved him dearly. He was a lovely, smiling boy and we are blessed to have known him during his short stay in this world.... We felt that we had

more love to give him and him to us," his mother Hairani wrote. "We would like to thank PWSA-US for sending us the booklet in memory of James.... PWSA-US had been a source of information for both Paul and I and we thank you for the latest information to cope with PWS and we are eternally grateful," she stated.

Sadly, James died suddenly just two days after his brother Haris was born. James's father wrote the following poem, which he read at his son's memorial service.

Four, for One Day

*We are not lost, but we cannot see the way,
Should we sing or should we grieve?
One life given, another snatched away,
No-one can tell us what caused you to leave.*

*A special care, a special need,
You touched everyone you knew,
Who knows what chance a normal life to lead?
So much love to give, so much more to do.*

*To a better place, they say,
You lost your fight to live,
Now your new brother joins the fray,
To him all your love we'll give.*

We were four, for one day.

The PWSA (USA) Bereavement Program is coordinated by Volunteer Norma Rupe. We offer free bereavement support materials for our members, along with envelopes for memorial donations. For more information about these and other materials, contact the PWSA (USA) National Office.

Our Deepest Sympathy

CAMERON MAC ARTHUR
9/19/1967-1/1/2005
Son of June MacArthur, CA

TIFFANY BLANKENSHIP
1/1/1991 - 2/12/2005
Daughter of Diane and
Tom Blankenship, GA

THOMAS J. GRAESSLE
4/23/1975 - 2/14/2005
Son of Shirley Dingley, CA

ANDREW J. HILL
1/1/1999 - 2/26/2005
Son of Mr. & Mrs. Kevin Nix
and Mr. & Mrs. Mike Hill, MI

MICHAEL GORMAN
8/11/1952 - 2/28/2005
Son of Robert & Barbara
Gorman, CT

SUSAN PARRISH
8/17/1958 - 3/1/2005
Daughter of Tom & Muriel
Parrish, CA

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11/3/2001 - 3/17/2005
Son of Paul & Hairani
Bennington, The Netherlands

LAWTON MILLER
8/20/1985 - 4/1/2005
Son of Lawrence & Rankin
Miller, SC

PATRICIA MC CALL
5/1/1960 - 4/21/2005
Daughter of Bill & Jean
McCall, TX

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10/30/1962 - 4/26/2005
Son of Ardel Lesti, SD

ISAIHA FLORES
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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.

