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The Gathered View

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

Report from Conference 2002

The Many Angels Among Us

By Janalee Heinemann, Executive Director

Angels come in many sizes, and with many faces. In Salt Lake City, as I watched our beautiful little children all sitting on the floor in front of the room laughing at the magician, I thought of how the theme Angels Among Us fit this year's conference so well.

From the precious 5-month-old babies to the little girls in their party dresses, you wanted to go up and hug each and every one of them.

Since my own children are grown and my youngest grandchildren now live far away, I got down on the floor with the little ones just to feel their delight. One little girl in a princess dress sat on my lap and leaned back against me, bringing back that indescribably tender feeling you can only get with a child in your arms.

There were other Angels in Salt Lake City this year. Pam Tobler, who gave up her part-time job for the last six months to organize this conference, certainly fits in the "Archangel" category. No matter how many ways she was being stretched at once, Pam was always kind and available.

The volunteer angels, who ranged in age from teenagers to 70 plus, all pitched in to do whatever was needed with smiles on their faces.

The hotel staff was the friendliest group of employees I have ever worked with at a conference, and there were also a few grandparent angels helping out.

As always, our three boards (governing, scientific, and clinical) and officer angels gave freely of their expertise and time.

Our parent angels supported each other, and Helena, our Brazilian angel, shared her dreams of a PWS organization in her country.

The decision to go to a smaller conference with a focus on the young child was a very difficult one. But watching this large group of little ones singing a song they had practiced and then throwing the teddy bears they had personally made up into the air…we all knew it was the right decision.

Typically, the programming for the young child is an afterthought in our conference planning because we have so many complex issues to resolve. Also, the parents of the very young child often are overwhelmed by what they see and what they hear. But this year, they were uplifted partially because with so many of our children on growth hormone and with early intervention, it was difficult, if not impossible, to tell our siblings from our children with Prader-Willi syndrome.

Kerrigan Mehner of Santa Clara, California, age 2½, who has PWS, was one of the little angels attending Conference 2002 with parents Bill and Wendy Mehner.

As for we parents of older children with PWS, I personally felt, and also heard from other parents of older children that the conference ended up being an unexpected delight for us to attend. The sessions for the parents of the older child were excellent, and to be

Angels continued on page 9

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

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

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

Five elected to PWSA (USA) Board of Directors

Two incumbents and three newcomers were elected to the PWSA (USA) Board of Directors at the July 2002 annual membership meeting in Salt Lake City.

Carolyn Loker, of Plainwell, Michigan, was first elected to the Board in 1999 and is currently vice president. She is the PWSA (USA) Young Parent Mentoring Coordinator. and has also served as co-president of the Michigan chapter since 1997. Husband Jim is a pediatric cardiologist and serves on the PWSA (USA) Clinical Advisory Board. Their daughter Anna, age 7, has PWS.

Pamela Tobler, who joined the Board of Directors three years ago, most recently co-chaired the 2002 National Conference in Salt Lake City, Utah. She lives in Orem, Utah with her husband Brent and three children, Sarah, 4, Jacob, 2, and Nathan, 6, who has PWS.

The three newest board members are not new to the PWSA (USA) organization.

Janice Agarwal, mother of Samuel, 2, and Alexander, 3, who has PWS, is active in the PWSA (USA) Parent Mentoring Program. A physical therapist, she lives with children and husband David, a physician, in Zionsville, Indiana.

Lisa Graziano is also active in the Parent Mentoring Program. A licensed marriage and family therapist, she lives with her husband TJ and son Cameron, 3, who has PWS, in Redondo Beach, California.

Carol Hearn of Plymouth, Minnesota, is currently president of the Minnesota Chapter. Both she and her husband Tim are attorneys and have three children, including son David, age 10, who has PWS; Jessica, 15; and Maryellen, 13.

Members in the News

- **Dr. Marilyn Dumont-Driscoll**, wife of Dr. Dan Driscoll, chairperson of our Clinical Advisory Board, is listed in the May edition of the *Ladies Home Journal* as one of the "The Best Doctors For Families - Coast To Coast."

Dr. Marilyn Dumont-Driscoll

Dr. Marilyn has also had published in the January 2002 edition of *Current Problems in Pediatrics* an article titled "Genetics And The General Pediatrician: Where Do We Belong In This Exploding Field Of Medicine?" In the article, she writes about PWS.

- President of PWSA(USA) **Lota Mitchell** had an article about her daughter, Julie, now 32, growing up in their township outside Pittsburgh, Pa. published in the December 2001 issue of *Mt. Lebanon Magazine*. Unbeknownst to Lota, the magazine submitted her article, titled "For Some, Food Can Kill", along with others to two journalistic competitions.

Lota won a second place in her category for the article both from Matrix and from the Golden Quill. Judges for Matrix were from all over the country, and judges for the Golden Quill were from Connecticut. As a result, more than the 33,000-plus people who live in Mt. Lebanon were educated about Prader-Willi syndrome.

- Executive Director **Janalee Heinemann** recently received the Volunteer of the Year award from the Victim Assistance Program of the Sarasota County, Florida Sheriff's Office, for her years of volunteer leadership with the Homicide Bereavement Program there.

Praise for PWSA (USA)

I just received the crisis packet in the mail today. Thank you so much for your support. I will try to keep you posted on anything that happens and will most definitely refer anyone that has questions about the syndrome to your 800 number. I was surprised to see all of the information that was sent. It's so nice to know that there are people that understand the difficulties of raising a child with this unique syndrome. Thank you again.

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The newsletter is informative and entertaining. As grandparents of a 7 year old with Prader-Willi syndrome we are grateful for the excellent job you do.

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Thank you very much. Great service and consultation. More of this is needed. PWSA has its act together. I'll be letting ARC know.

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Thank you so very much for everything that you have done. It is so nice to know that there truly are people out there who care.

Chapter Leaders E-mail Group

NOTICE

Chapter leaders, officers, board members, newsletter editors

If you are not getting e-mail from the CLE (**C**hapter **L**eaders **E**-mail group), please call national and ask for Diane to get on the list and/or to check your e-mail address

Questions About Testosterone and PWS

By Phillip D.K. Lee, MD

Can testosterone be used in an adult male to increase the length of the penis?

Testosterone will not significantly affect penile length in a sexually-mature male, e.g. a male who has been previously exposed to full testosterone levels either naturally or via medication for an extended period of time.

However, a male with hypogonadism (abnormally low natural testosterone production) who has not received full medical replacement therapy will have a response to testosterone therapy.

Does it have beneficial effect on bone density?

Yes, testosterone is thought to increase bone density and bone strength. It is not known whether this is a direct or indirect effect.

However, it is interesting that even though women have very low levels of testosterone compared to men, these low natural levels of testosterone appear to have similar bone effects in women.

Can aggressiveness be avoided by dosage?

There is no scientific evidence that physiologic (e.g. normal adult or even supraphysiologic) levels of testosterone cause aggressive (i.e. violent) behavior in humans.

Most of the reported associations of testosterone and violent behavior have been anecdotal, scientifically uncontrolled and/or statistically biased. A well performed study published this year [1] scientifically measured a number of behaviors in both normal and hypogonadal men who received 200 mg of depot testosterone by injection every other week.

Interestingly, in this study, the hypogonadal group self-reported increased levels of verbal aggression, hostility, anger and irritability during testosterone therapy, although the scientific measures of aggressive behavior did not change.

Moreover, the normal group who actually had much higher levels testosterone did not have changes in either measured or self-reported aggression. This indicates that the self-perception of increased aggressiveness during therapy might be more related to preceding hormonal status and behavior patterns than to testosterone levels per se. Here is the last paragraph from that study:

"In conclusion, we have found that supraphysiologic levels of T (testosterone) do not lead to significantly increased aggression or mood disturbances. Instead, the inability to control one's behavior when such control is required by a particular situation was found to significantly predict levels of aggression over and above age and T level."

For males with PWS, I recommend normal replacement levels of testosterone using daily patches or gels, combined with specific psychosexual and behavioral counseling as clinically indicated.

Reference:

1. O'Connor DB, Archer J, Hair WM, Wu FCW: Exogenous testosterone, aggression, and mood in eugonadal and hypogonadal men. Physiology and Behavior 75: 557-566, 2002.

Dr. Phillip D. K. Lee is Professor of Pediatrics, David Geffen School of Medicine at UCLA, and Clinical Director, Division of Pediatric Endocrinology at Mattel Children's Hospital at UCLA. He is a member of the PWSA (USA) Scientific Advisory Board.

Rehab Therapy Series to Start, Questions Requested

By Janice Agarwal, P.T.

I thoroughly enjoyed speaking to the many parents of infants and young children at our recent Utah Conference. We are seeing hypotonic babies diagnosed with PWS at earlier ages. Having a diagnosis of PWS earlier allows us to look to the future, to conquer potential weaknesses and to emphasize preventative care. We have the unprecedented opportunity to be proactive in our therapies.

I have been asked to write several columns for *The Gathered View*. To more effectively address individual therapy needs, I will be taking questions directly from readers, combining similar questions into "topics."

Over time, I will address the following areas: motor development and therapeutic activities to reach milestones, sensory integration and activities to learn the sensation of movement, balance and righting reactions, orthotics and bracing and special equipment, and alternative therapies.

I hope to help parents understand the needs of their children and help supporting clinicians understand how to better assess and treat our children. I will provide resources for you to do your own research. Please email me with questions or topics you would like to see addressed. My address is: jagarwal@indy.rr.com

Janice M. Agarwal is a physical therapist specializing in the needs of young children. Her son Alexander, age 3, has PWS. Janice is also newly elected to the PWSA (USA) Board of Directors and volunteers in the Parent Mentoring Program.

Prader-Willi Sndrome: A Study of the Face

By Judith Allanson, MB ChB FRCP FRCP© FABMG FCCMG

In Prader-Willi Syndrome, a characteristic facial appearance has been described, and was originally considered an important diagnostic clue. Key features include almond-shaped eyes, a short upturned nose, a small mouth with down-turned corners and thin lips, and an oval shaped face. However, a recent study found facial appearance to be the least consistent of all the key features.

In 70 percent of individuals with Prader-Willi syndrome, deletion of the paternal copy of chromosome 15q11-13 is found, while maternal uniparental disomy (UPD) is seen in most of the remainder.

Over the last few years, with your help, I have examined the faces of many individuals with PWS, most with deletion of chromosome 15 and some with UPD. This study has been conducted with the help of two colleagues – Dr. Suzanne Cassidy in Cleveland and Dr. Carol Clericuzio in Albuquerque.

I have examined 109 individuals with Prader-Willi Syndrome, 57 females and 52 males. Forty-four are known to have a deletion of the critical region of chromosome 15q; 18 have UPD; in the remainder a clinical diagnosis was made by a physician with extensive experience with PWS.

In addition to a thorough examination of the face, I also carried out a series of measurements of the head and face using calipers and a paper metric tape measure. These dimensions were chosen to represent craniofacial widths, lengths, depths and circumferences, plus details of ear, eye, nose and mouth structure. For each dimension, age- and sex-matched normal standards are available for comparison. Many families were kind enough to share photographs, too.

My results are as follows:

Children with PWS due to deletion have a small head, and a long face with prominent forehead and narrowing at the temples. Eyes are close-set, upslanting and almond-shaped. The nose is small, with an upturned sharp tip and narrow bridge. The mouth has thin lips and down-turned corners. The chin is small. With age, the fine, angular features persist.

Children with PWS due to uniparental disomy have slightly different features and a squarer face. The nose, in particular, is different, being more prominent and fleshy over the bridge, and longer with a narrow base. Eyes are a little wider apart and lids may be more horizontal. In the older person, the nose is longer and broader/fleshier at the root (between the eyes) and bridge.

Detailed measurement confirms the subjective impression mentioned above. The head is small and relatively long and narrow. Eyelids are small. At 3 to 8 years, individuals with UPD have a longer face, greater protrusion at the tip of the nose but a narrower base to the nose, and a smaller mouth. At 8 to 12 years, persons with UPD have a longer face and nose, increased nasal protrusion and average eye spacing (in deletion, spacing is reduced).

These findings persist in adults. I must emphasize that these differences are very subtle and most doctors would not pick them up without the special training which geneticists have.

This study confirms that facial appearance in Prader-Willi due to UPD is less what we would consider "typical" for PWS, and loss of characteristic facial features might lead to delay in diagnosis. Awareness of the variation in PWS, particularly when the cause is UPD, may help recognition of this syndrome.

Acknowledgements

I am very grateful to the individuals and families who allowed me to measure heads and faces and review photographs. Some data were gathered at the Annual Meeting of the Prader-Will Syndrome Association (USA). I would like to thank the Board and organizers who made this possible. Several staff at the New Mexico PWS Project were kind enough to shuttle me around the state to meet families. I am very grateful to them and my colleagues, Drs. Cassidy and Clericuzio, and their staff, especially Shauna Heegan in Cleveland.

Dr. Judith Allanson is Professor of Pediatrics at Children's Hospital of Eastern Ontario, Department of Genetics, Otawa, Canada.

PWSA (USA) Publications Available

New educational products made available in the last six months are:

- A CD version of our new "Medical Overview" video
- Two new Spanish brochures: "Q & A" and "Medical Alert for Parents and Providers"
- A Spanish version of A Guide for Families & Professionals (Thanks to Dr. Moris Angulo)
- A Supportive Living Care Plan for an Adult with PWS in placement. (Thanks to Jerri DiCosimo) Available in both a notebook format and changeable CD format (thanks to Barb McManus) that can be adapted to meet individual needs

Contemplating Independence Day

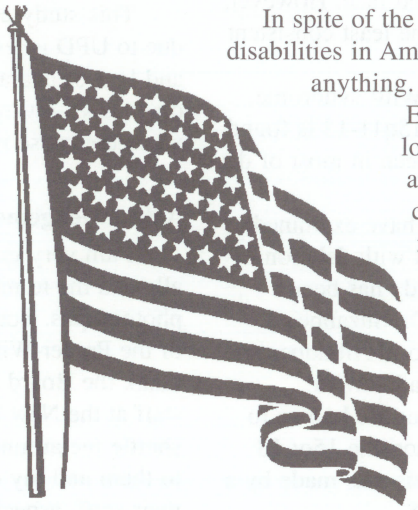
By Teresa Kellerman

We hold these truths to be self-evident, that all men are created equal, that they are endowed by their Creator with certain unalienable Rights, that among these are Life, Liberty, and the pursuit of Happiness.

—The Declaration of Independence of the Thirteen Colonies, July 4, 1776

Well, we all know that all persons are NOT created equal. Some are born with genetic defects, like my Karie who has Prader-Willi syndrome. Many are born with Fetal Alcoho Disorder (FAS), like my John. Although life is not fair or equal for them, and although others see them as "less than," they see themselves as the wonderful human beings that they are.

My third child was not created equal, in that he is gifted with looks, brains and musical talent far beyond that of his peers. And yet he is saddled with responsibilities a emotional burdens far heavier than his equa



Independence Day usually makes me feel sad and glad all at the same time. I'm happy to live in a country where I can speak up and be heard regarding my children's rights, where I can change the system, change the laws, move my legislators to support services needed for my kids, to be able to help them achieve their potential of that Happiness that we strive to provide for our children.

I feel sad too, because the 4th of July is a celebration of Independence. Freedom is a precious and abundant commodity to most in America. But for our kids in their legal coming of age, freedom is not so easily won. I have not seen any documented accounts of individuals with Prader-Willi syndrome being able to live independently. In fact, the only way to ensure our kids will enjoy safety and happiness is through restrictions of the freedom they want so badly.

As I watched the fireworks display tonight, I thought of how colorful and exciting my life has been as a parent of these wonderful kids. The explosions and outbursts, not knowing what is going to come next, waiting for the grand finale to subside and for quiet to return. I think of how life must be like the 4th of July every day for my kids when they experience sensory overload from everyday life that doesn't bother the rest of us but sets them off again and again.

When I watched the lightning build up in the clouds in the sky after the fireworks show, I thought of the storms we weather as parents, in awe of the power of nature that is mostly beyond our control, like the emotions and behavior of kids with FAS or PWS, as we scurry for a place of safety, protection for ourselves and our children, from their disability and from a society that does not understand.

In spite of the struggles we have faced living with mental disabilities in America, I wouldn't trade this country for anything.

Except maybe an island somewhere that has lots of chocolate and coffee, and 24/7 respite, and computer cable access, where our kids can't get out and predators can't get in. Then maybe I would trade.

But that doesn't exist. So I'm happy to stay here. Hope you had a happy and safe July 4th, and appreciate your own freedom!

Teresa Kellerman of Tucson, Arizona is the mother of Karie, 27, who has PWS.

The Chuckle Corner

Hot Hot Hot!

My son Daniel, age 4, was left one evening in the care of a babysitter who ordered a pizza with the works and ate all but the hot stuff on it, which was left behind.

The next morning I discovered Daniel eating the hot peppers, and I asked him if they were good.

He said, "NO!" and made an awful face.

Then I asked him if he wanted any more, and his answer was

"YES!"

Cathy Scibiur, Ravenna, Ohio

Do you have a joke or funny story to share with readers about Prader-Willi syndrome? Send it to the PWSA (USA) office. Be sure to include your name, phone number and address in case we have any questions.

PWSA (USA) NEEDS YOU!

WHAT DO WE NEED?

We need you, our PWSA (USA) "family" to:

- Volunteer to spread the word about PWSA (USA) in your local community.
- Volunteer your talents to assist with special projects.
- Volunteer to do a fund-raiser in your community. We have resource people to assist you.

We are a family of more than 2,600 members
Together we are strong and powerful
Together we do make a difference

Maria Christine Vucci, age 2

WHY SHOULD YOU HELP?

PWSA (USA) has credibility and clout

We know the difference between noisy activism and quiet, long-term accomplishment. We are not a start-up organization. Our money goes to research and member support. PWSA (USA) has a 27-year history of providing services to families dealing with Prader-Willi syndrome.

We value your time and money

PWSA (USA) has a strong and ethical not-for-profit accounting system that assures our organization has the appropriate checks and balances required by law and good charitable operation standards recommended by the National Association of Non-Profit Boards and Council of Better Business Bureaus.

We are recognized in the research community

The professionals on our Medical and Scientific Advisory Boards are recognized by their peers worldwide. They have access to the latest scientific data and guide us through the complex world of research.

We offer membership support

While we continue our fight for a cure for our children, PWSA (USA) will not forget your loved one's other needs for support, education and community awareness. No other organization in the world has the extensive education and support programs provided by PWSA (USA).
PWSA (USA) is a relatively small group of committed people trying to serve an ever-expanding population—without federal or state aid. We need your active support.

WHAT YOU CAN DO RIGHT NOW

- Donate frequent flyer miles
- Volunteer for the Orlando Conference
- Volunteer to organize a tabletop display of PWS milestones
- Do you have expertise in insurance or legal matters of endowments, estates and trusts? Volunteer to consult w/ the National office* (*A retired person is preferred so we can avoid conflict of interest issues)

Together we will make the sun shine brighter on our children... and together we will find the CURE!

Remembering To Be Grateful

By Lota Mitchell, PWSA (USA) President

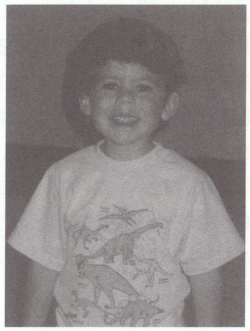
We laughed a lot and we cried a little listening to Conference 2002 keynote speaker Jason Hall. A young man of 32 and a quadriplegic speaking from a wheel chair, he said something which was very memorable to me: "You can't be grateful and depressed at the same time."

And he described how he had learned to be grateful that he still had the use of his wrists even though he couldn't move his hands after a diving accident when he was 15.

Mulling this over on the plane back to Pittsburgh from the conference, I thought about what I was grateful for at that moment:

- Our beautiful little ones, most of whom in the Teddy Bear parade in the closing ceremonies were hard to distinguish from their siblings who didn't have PWS

- The research and researchers who are contributing so much to the hope we have for our children's future



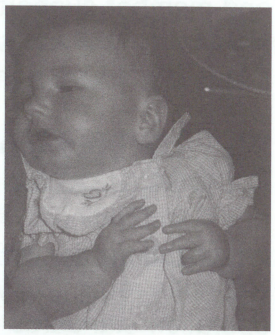
- Conference Chair Pam Tobler and the small army of volunteers it took to put on this wonderful conference

- The dedicated group of officers and board who give of their time, talents and treasure to steer the course of PWSA(USA)
- Another equally dedicated group — our Chapter presidents, who are out in the trenches and do more than anyone realizes
- PWSA(USA), which has provided help, support, information and many deep friendships over the years to so many, including me
- And I am grateful that my daughter Julie, 32, is able to be enjoying two weeks at Camp Sky Ranch in NC.

> Hope is much more than a mood. It involves a commitment to action.... What we hope for should be what we are prepared to work for and so bring about, as far as that power lies in us."
>
> *John Polkinghorne*

Hope shimmered and glimmered and glowed all around us these past few days. As we go to our homes, we might well remember the words of John Polkinghorne, physicist, Anglican priest and author, in his new book *The God of Hope and the End of the World:* "Hope is much more than a mood. It involves a commitment to action.... What we hope for should be what we are prepared to work for and so bring about, as far as that power lies in us."

So I took two more messages home with me in addition to the dirty clothes and mountain of papers in my suitcase. PWSA(USA) needs each and every one of us to help it to accomplish its missions. And Jason, who in spite of paralysis from the neck down went to college, married and is successful in his field, vividly demonstrates that life can be good even in the most difficult of circumstances.



Conference 2002

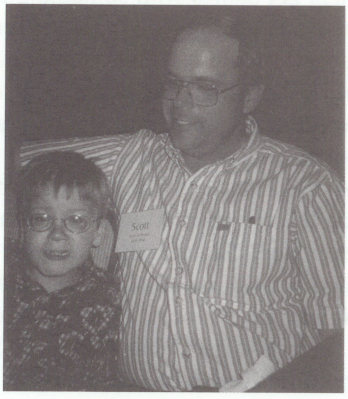
A note of thanks to everyone involved in approving our conference grant. We enjoyed the conference very much and feel revitalized in our efforts to help our son, Carson. The information we received on growth hormone therapy helped us make the decision to put Carson on that course. Again, thank you and know that your efforts are appreciated.
Kyle and Suzette Garrett

PWSA (USA) Conference Grants

Funding Sources

PW Foundation, Inc.	$ 5,770.00
Michigan State Chapter	1,498.86
Indiana State Chapter	561.00
Private Donation – Bill Capraro	1,517.00
Total Special Funding	9,346.86
Grants from PWS (USA)	$ 6,223.83
Total Grants Awarded	$15,570.69
Total Families Funded 2002	18

An outstanding scientific research panel made a presentation at the Salt Lake City Conference. An audio tape of the entire presentation is available *for members only* at a cost of $10.00. To order, call our national office.



Angels -- *continued from page 1*

able to spend time with the parents of the babies and little children was a real joy.

Having lived long enough to witness this new generation of children with PWS was one of the most rewarding experiences I have ever had. We thought we were attending to help out, not knowing how much we would get in return.

Next year we will have the big conference again in Orlando, and we will all be delighted to see our older children there. In fact, at the 2003 conference, we will have our first PWS Advocacy Advisory Board meeting. Six people with PWS will be chosen as board members, with our governing board member Mary Kay Ziccardi as facilitator/chair.

Although my son Matt will be happy to see his friends again next year, he was easily pacified about missing this year's conference by an alternative trip with us to visit relatives in Iowa. I heard from several parents that providing alternative trips for their older children also worked out well.

Next year, Matt will again dance every dance after the banquet, and we will all beam with pride over our young adults. But Matt, as another of the angels among us, understood that this was the year for our little ones to shine... and he was glad.

Ordinary mothers who do more:

Saluting the mother of a child with a disability

By Lori Borgman

Expectant mothers waiting for a newborn's arrival say they don't care what sex the baby is. They just want it to have 10 fingers and 10 toes.

Mothers lie.

Every mother wants so much more. She wants a perfectly healthy baby with a round head, rosebud lips, button nose, beautiful eyes and satin skin.

She wants a baby so gorgeous that people will pity the Gerber baby for being flat-out ugly.

She wants a baby that will roll over, sit up and take those first steps right on schedule (according to the baby development chart on page 57, column two).

Every mother wants a baby that can see, hear, run, jump and fire neurons by the billions. She wants a kid who can smack the ball out of the park and do toe points that are the envy of the entire ballet class. Call it greed if you want, but a mother wants what a mother wants.

Some mothers get babies with something more.

Maybe you're one who got a baby with a condition you couldn't pronounce, a spine that didn't fuse, a missing chromosome or a palate that didn't close. The doctor's words took your breath away. It was just like the time at recess in the fourth grade when you didn't see the kick ball coming and it knocked the wind right out of you.

Some of you left the hospital with a healthy bundle, then, months, even years later, took him in for a routine visit, or scheduled her for a well-check and crashed head first into a brick wall as you bore the brunt of devastating news. It didn't seem possible. That didn't run in your family. Could this really be happening in your lifetime?

I watch the Olympics for the sheer thrill of seeing finely sculpted bodies. It's not a lust thing, it's a wondrous thing. They appear as specimens without flaw — muscles, strength and coordination-ordination all working in perfect harmony. Then an athlete walks over to a tote bag, rustles through the contents and pulls out an inhaler.

There's no such thing as a perfect body. Everybody will bear something at some time or another. Maybe the affliction will be apparent to curious eyes or maybe it will be unseen, quietly treated with trips to the doctor, therapy or surgery.

Mothers of children with disabilities live their limitations with them. Frankly, I don't know how you do it. Sometimes you mothers scare me. How you lift that kid in and out of the wheelchair 20 times a day. How you monitor tests, track medications and serve as the gatekeeper to a hundred specialists yammering in your ear.

I wonder how you endure the clichés and the platitudes, the well-intentioned souls explaining how God is at work when you've occasionally questioned if God is on strike.

I even wonder how you endure shmaltzy columns like this one — saluting you, painting you as hero and saint, when you know you're ordinary. You snap, you bark, you bite. You didn't volunteer for this, you didn't jump up and down in the motherhood line yelling, "Choose me, God. Choose me! I've got what it takes."

You're a woman who doesn't have time to step back and put things in perspective, so let me do it for you. From where I sit, you're way ahead of the pack. You've developed the strength of a draft horse while holding onto the delicacy of a daffodil. You have a heart that melts like chocolate in a glove box in July, counter-balanced against the stubbornness of an Ozark mule.

You are the mother, advocate and protector of a child with a disability. You're a neighbor, a friend, a woman I pass at church and my sister-in-law. You're a wonder.

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You know you have a child with special needs when...

- You compare ER's instead of grocery stores.
- The clothes your infant wore last fall still fit her this fall.
- Everything is an educational opportunity instead of just having plain old fun.
- You cheer instead of scold when they blow bubbles in their juice whilesitting at the dinner table (that's speech therapy), smear ketchup all over their high chair (that's OT), or throw their toys (that's PT).
- You fired at least three pediatricians and can teach your family doctor a thing or two.
- You have been told you are "in denial" by at least 3 medical or therapy professionals. This makes you laugh!
- You get irritated when friends with healthy kids complain about ONE sleepless night when their children are ill.
- Your vocabulary consists of all the letters OT, PT, SP, ASD, VSD, IFSP, etc.
- You keep your appointment at the specialist even though a tropical storm is raging because you just want to get this one over with, you waited 8 months to get it, and besides, no one else will be there!
- Fighting and wrestling with siblings is PT.
- Doctors/specialists/hospitals etc. all know you by your name without referring to your chart.
- You keep a daily growth chart.
- You phone all your friends when your child sits up for the first time, at age 2.
- You have a new belief: that angels live with us on earth.

Little Mikey Is Now a Big Brother and Lovin' Life

By Nicole Henshaw

Michael Bryan Henshaw (Mikey) was born July 6, 1999, weighing only 4 lb. 9 oz. Even though he was so tiny, the hospital released him after three days, on a Friday, still weighing less than 5 lb. The hospital pediatrician wanted to see him the following Monday. Once she examined him in her office, she immediately sent him to Children's Hospital in Pittsburgh. He spent almost three weeks in the hospital, with a diagnosis after two weeks.

During the time we spent with him in the hospital (staying day and night), we witnessed many tragedies of the babies who were in the Neonatal Intensive Care Unit with Mikey. While the PWS diagnosis was frightening, in some ways it was a relief compared to what other parents had to face. We were not totally ignorant of PWS — we have a cousin who has a son with PWS (age 5 at the time of Mikey's birth). We knew that we would have a loving, cheerful, happy little boy. We also knew that there would be many challenges in the years ahead.

Big brother Mikey, who has PWS, loves his little brother Tommy

At 3 years old Mikey is definitely that happy, loving, caring little guy. He is very protective of his baby brother Tommy, born May 23, 2002. When someone he is not familiar with holds the baby, he cries, and points to one of his parents — he wants that person to give the baby back. He loves to shower his little brother with hugs and kisses.

> We find that attending the conferences... has helped us immensely. The caring and sharing are very important.

Right now we're teaching Mikey that Tommy has no teeth, so he can't eat the Cheerios that Mikey so wants to feed him. Mikey seems to compromise by feeding his teddy bear. There was also the time Mikey thought the baby was a sticker book...

Mikey has been to three PWS conferences in his young life. In 2000 he was the "Baby of the Future" at the Pittsburgh Conference. Last year he attended the Minnesota Conference, and this year he attended the Pittsburgh mini conference. He loves being with all of the kids (especially the girls — he's quite the ladies' man — and adults. While he does not know the significance of the Conferences, or that he has PWS, he seems to connect with everyone involved.

We find that attending the conferences (parents and grandparents) has helped us immensely. The caring and sharing are very important. We are very grateful to the parents of the older persons with PWS — they have done so much of the ground work and investigating, etc., so that we as parents and grandparents can follow in their footsteps, and possibly make it better for those to come.

While he was delayed in all of the milestones, he has always tried very hard. His biggest challenge now is his speech. He does receive speech therapy once a week, and in the fall will attend preschool and continue his speech therapy. Most of his words have the same sound — "Atta." He does say "thank you,"' "bye" and "hello." He comprehends everything that we say to him, and when we ask him what he is trying to say, he will let us know if we are right or wrong.

The school he will be attending will have typically developing children as well as children with various challenges. He will attend four days a week, ride the school bus (he is very excited about that), and have an aid during snack time.

Mikey loves to watch television. The Three Stooges top the list, although he loves "Mr. Rogers," "Blue's Clues," and "The Wiggles" (sort of Beatles meet the Teletubbies). His favorite movies include "The Wizard of Oz" and "Lady and the Tramp."

Any time he hears music, Mikey will get up and dance, and he's starting to sing along. All of the lyrics are "ba, ba, ba," but *he* knows what he is singing. He also enjoys books, telephones, musical instruments, and hats (does he like hats!). His favorite place to go is the mall. Not to shop, or even to eat — the mall is where the playground is. He always manages to make at least one friend (usually a girl), and he runs all over the place.

Although the eating problem has not affected Mikey yet, we do keep an eye on his food intake, since he is developing a fondness for bread. However he eats a wide variety of foods, and his favorites include cheese, carrots and mushrooms. He also

Mikey continued on page 13

Locking the Refrigerator and Cabinets for Prader-Willi Syndrome

By Allen Heinemann

One of the questions often asked as a child with Prader-Willi syndrome gets older is, How can we keep our child from sneaking into the refrigerator or cupboards and getting at food?

It's hard enough to keep food off the counter and put away, but it can be very stressful to have to keep an eye on the kitchen to catch someone before he or she gets into food. So it becomes necessary for reducing everyone's stress level to have the food locked up.

Through the years, I have seen many approaches. I've seen plastic chains draped around the entire body of the refrigerator, bars dropped across the front, like you would see on a Pepsi machine, and even a cement block put in front of the door, making it hard to open.

Here are some of the more common solutions.

1. If your house lends itself structurally to it, consider putting lockable doors in the kitchen. However, more and more homes are designed in an open format (with the kitchen the center of activity!), and it is not practical to enclose the kitchen.

2. When we needed to lock up the kitchen cabinets, rather than put locks on every door, we took the area that was normally used for a small breakfast table, purchased a full-sized armoire (clothes cabinet) and used it to store all our food. It had a double door that one simple hasp and padlock kept secure.

3. Kitchen cabinets are kept locked easily with a hasp and padlock arrangement that can be purchased at a hardware store. Flush-mounted key locks look better, but you may need a carpenter to install them.

4. I could find no manufacturer of home refrigerators that could furnish a factory-equipped lock. The only things I could find that were lockable were small hotel refrigerators, chest style freezers or big commercial units that were either freezer or refrigerator only.

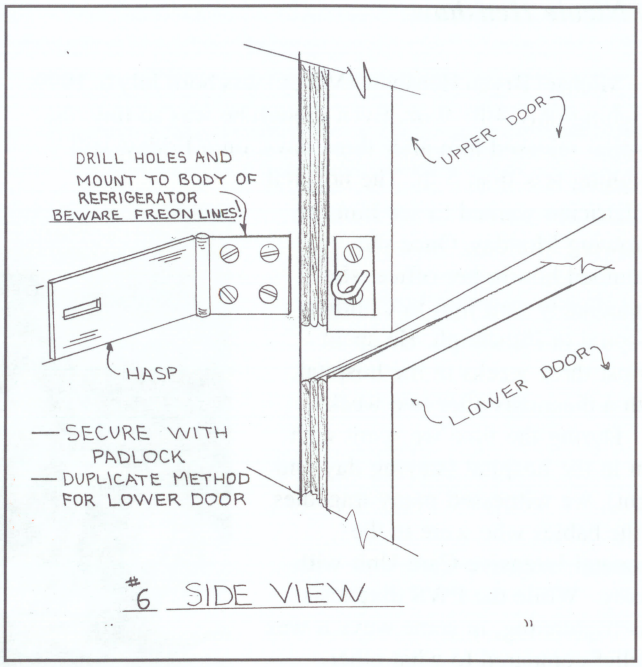
5. A side-by-side refrigerator is the easiest to put a chain and padlock on. Plastic coated bicycle chain with a combination lock works the best.

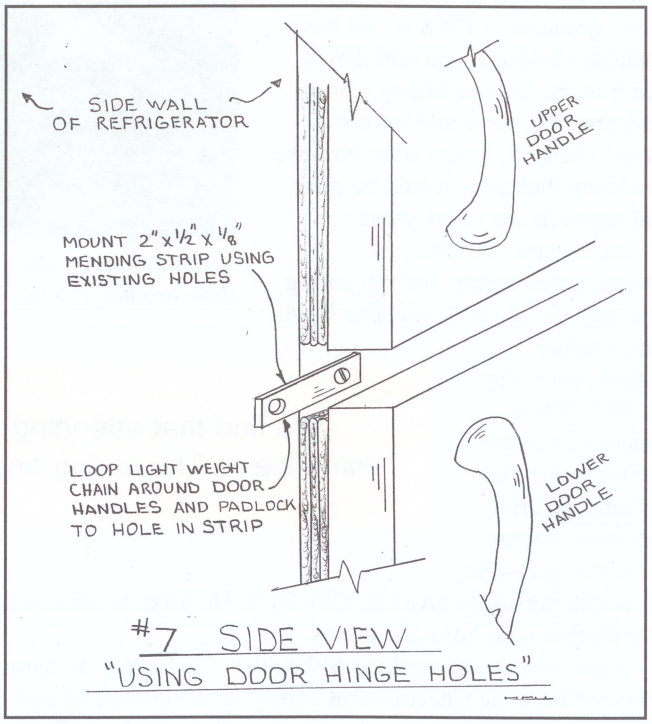
6. Standard refrigerators can also be locked with two hasps and padlocks, one for the upper piece and one for the lower. The hasp is basically a latch that swings over another looped piece on the door that the padlock then slips over to secure.

The problem that you run into is that on some refrigerators the Freon lines can run close to the surface. ***Putting screws into the side can pierce the line and ruin the refrigerator!***

A safer approach is to simply epoxy the hasps to the side of the refrigerator.

Both of these methods can work, but are not the prettiest to look at, and do deface the refrigerator. (See Illustration "Using Hasp and Padlock")





7. There is another method that doesn't do any damage to the refrigerator and can be done with standard hardware parts. It sounds more complicated than it actually is.

It involves using the extra screw holes that reverse the doors on most newer units. If you look near the door handles between the upper and lower compartments, you will see on the body of the refrigerator unused screw holes.

Locking the Refrigerator continued on page 11

Thank you's for 'We Remember'

Thank you for remembering Michael in *The Gathered View.* Please accept this donation his memory. I wish it could be more.

Marie Mackay
Riverton, Utah

I want to express my appreciation to Janalee for taking over and handling Lindsay's wish of donating her brain and tissue; to the people who donate their valuable time and energy to the PWS Association.

The "In Memory of Lindsay" plaque was a total surprise to our family.

What a nice way to remember our daughter by.

Thank you all for your thoughtfulness.

Lori Rich and Lou, Brad and Kevin
Las Vegas, Nevada

I was so pleased to see the "We Remember" page that I want to send a memorial to both Lindsay Rich and Kenneth Ayotte. I think this page is so very important. Thank you.

Marilyn Bintz
National City, California

Locking the Refrigerator - *continued from page 10*

At a hardware store you can purchase a small, flat metal strip called a mending plate (a long strip with holes on each end, 1/8 inch thick by 1/2 inch wide by 2 inches). You can mount it to the refrigerator using one of the screw holes, leaving one end of the strip sticking out. Then take a short length of lightweight, plastic-coated swing set chain and loop it around the handles, and lock the chain with a padlock through the hole at the end of the metal strip.

If you followed me this far in the explanation, you won't have any trouble installing this system. Its main advantage is that it doesn't deface the refrigerator and is relatively discreet. (See Illustration "Using Door Hinge Holes")

I'm sure there are other methods out there, and if you've got one that works that you think others might want to try, send it to the national office, and they'll get it published in an upcoming newsletter.

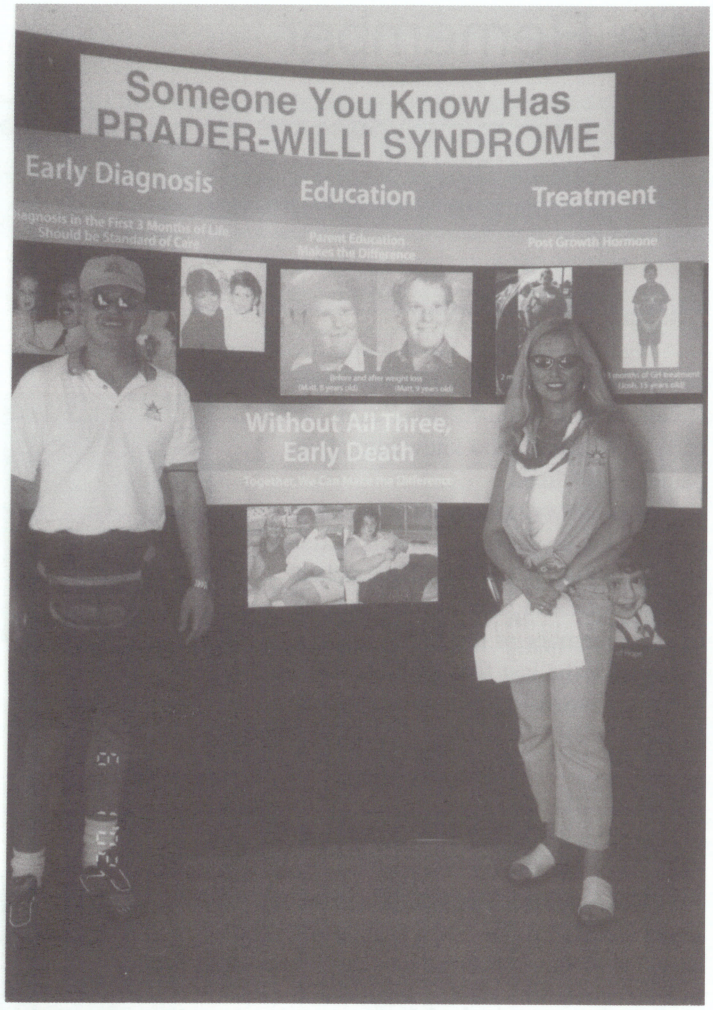
My son Matt, who has Prader-Willi, was actually relieved after we installed locks. He said, "Before, my hand would go in the refrigerator and I couldn't stop it."

Now it's one less thing that he has to worry about.

Al Heinemann of Sarasota is the father of Matt, age 29, and husband of PWSA (USA) Executive Director Janalee Heinemann.

Some people's kids' problems with Prader-Willi are dramatic, ours are more like Chinese water torture

- Stewart Maurer, Lexington, South Carolina



Putting for PWS

Al and Janalee Heinemann worked at the PWS display booth at this spring's Siesta Key Chamber of Commerce Golf Tournament. Funds raised from the putting contest and auction benefited PWSA (USA).

Mikey - *continued from page 11*

likes "exotic" foods like artichokes and calamari, but not steak or hamburger.

We are very involved in our local chapter, and are hopeful for Mikey's future. We have the support of our extended family, who not only contribute financially to our chapter by donating for our annual golf outing (sponsorships, door prizes, a week at a Hilton Head condo), but also by volunteering at the conferences. At the 2000 Pittsburgh Conference, we had 19 volunteers — friends and family, including Mikey's grandparents, great grandmother, great aunts, and cousins. We all explain PWS to anyone who will listen. Our neighbors, friends and church family all know about the syndrome. It is never too early to educate those with whom he will come in contact during his life.

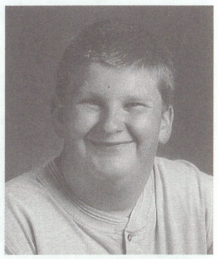
Nicole and Bryan Henshaw live with sons Mikey and Tommy in Pittsburgh, Pennsylvania.

We Remember

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

Michael Seth Mackay

Michael, 18, died Jan 4, 2002, from injuries sustained in a Trax train accident. His mother Maria, of Riverton, Utah, said Michael came to this earth to teach all who knew him about patience and love.



Michael was dearly loved by his parents, his brothers and sisters, extended family and many friends. He touched many lives during his sojourn here on earth. A member of the Latter Day Saints Church for the last five years, it was Michael's privilege to bring the bread for Sacrament Meeting.

Steven Jutras

Steven, 23, was raised by Tanya Pittser of Anaheim, California. He choked to death on food.

Tanya wrote, "Having been born on December 25th made Steve special from the start. He had a wonderful sense of humor and looked forward to playing jokes on all of us daily. He was loved by all of us and we were truly blessed to be a part of his life.

"There were frustrating moments with Steven. I can't count how many times he said, 'I'm sorry. It will never happen again.'

"I never thought I would miss hearing those words, but I do because they were always followed by a big loving hug. There is not a day that goes by that I don't think about Steven. He was, and always will be my brother."

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

Melanie Clubb

Melanie Lynn Clubb, 27, of Collinsville, Illinois, was the daughter of Stanley and Donna. She died Sept. 14, 2001 of unknown causes.

Melanie participated in the Girls Auxiliary Groups (Gas), the Girl Scouts and Special Olympics.

Her mother said "Melanie was a joy. She taught me so many things about life. She loved everyone and showed it. She was born with a smile on her face and she never stopped smiling. She never ever complained no matter how bad she felt. She always thought of the other person. She never cursed and she would get upset if someone else did, because she was afraid they wouldn't go to heaven.

"She loved to sing, and she was always singing. She loved mom and daughter days out. Melanie was my best friend and always will be. She was in the church choir and she helped with Bible School in the music and the kids loved her."

Her older brother Shawn said, "Her differences didn't matter. She had a great sense of humor and she loved all the music we loved."

Her younger brother Aaron said, "She got excited about your birthday or Christmas and her excitement made you feel very special."

All felt that Melanie was the hub of their family.

Robert R. Jones

Robert, 56, from Ohio, died of unknown causes. His parents, Virgil and Beulah Jones, are both deceased.

His sister Sharon Kerr said Bob, as he preferred to be called, loved life.

Sharon wrote, "A man by age a child by nature. He never changed from child to adult mentally. He believed in Santa Claus, and hung his stocking every Christmas Eve. Bob was always the first one up on Christmas morning with excitement as to what would be in his stocking. There better be a deck of playing cards. If Bob didn't get another gift at Christmas besides his cards, that was fine with him.

"Easter and his birthday too, he loved the candy and eggs, but the deck of playing cards were his treasure. When he died he had better than 350 decks. He usually took the ace of spades out because it was the 'sign of death.' They have a card collage hanging on the wall at Wood Lane as a memorial to him."

We Remember continued on page 15

Angel Fund Contributions

April - May 2002

Seraphim ($1,000 or more)

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Mike & Susan Trogan *(in honor of Seth Rutherford)*

About PWSA (USA)

We have gone from 2,407 members to 2,709 members in the last 12 months, more than a 12.5 percent increase.

Our web site daily hit average in May was 24,373 (increased from 7,966 over 11 months). Daily visits on our web site were 1,169 (an increase in 11 months from 613).

We currently have 82 children under the age of one, 78 one-year-olds, 63 age two, 67 age three, 85 age four and 68 age five, for a total of 443 children with PWS who are five and under.

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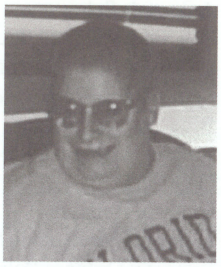
We Remember

Jonathan Langewisch



Jonathan was 23 years old when he died of unexplained causes. Jonathan's parents, Irwin and Roberta, of Milford, Connecticut, said that when he was born, they were told he would never walk, talk or sit up alone. They were also told he would never learn to read. Jonathan not only learned to walk and talk, he read daily and kept his own journal. He was an avid horseback rider, was on the swim team and graduated from high school.

Jonathan loved people and always saw the good in everyone. He always wanted to do something for someone else. He taught his best friend, who was withdrawn and non-verbal, to speak and to read. He would read to her every day and quiz her.

Following is an excerpt from one of Jonathan's letters: "Every night when I go to sleep I think of you Mom and I have nothing but good dreams. When I was thinking in my sleep last night you were so beautiful when you were a little girl. When I went to sleep I try to think of Mom and Dad and how much you love me and how proud you are of me. I will hug Molly really tight and you will have good happy thoughts. I promise."

Jonathan has an identical twin who also has Prader-Willi syndrome.

Acknowledgements

Our Sincere Thanks for Contributions Received in April and May 2002

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Annie Durell
Tom and Lorrie Russo
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Chris & Michele Reimer
Theodore K. Rice *(Greater Twin Cities United Way)*
Barbara S. Gerber Trust *(for Young Parent Mentoring Program in memory of Dr. & Mrs. Benjamin Schulman)*
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Robert & Wauneta Lehman

Mission Benefactors continued on page 15

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.