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The Gathered View

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

Grant Whiting, New York

In this issue

Clint Hurdle Goes to Bat for PWS Awareness

By Jane Phelan, Editor

As manager of the Colorado Rockies major league baseball team, Clint Hurdle has always liked to win. As spokesman for PWSA (USA) Awareness Week, he's helping to create wins for PWS.

Clint and his wife Karla are the parents of son Christian, 18 months, and daughter Madison, almost 4, who has PWS. When Madison was diagnosed, the Hurdles didn't waste any time getting involved to help their daughter. Clint believes education and attitude can make all the difference. He and Karla have always been generous with their time and support; this year they've gotten even more active for PWS.

Clint has a whole team behind the effort. The Colorado Rockies sponsored the taping of PSAs (public service announcements) about PWS that includes footage of Madison. During Awareness Week, the ball club also arranged to set up a special display booth about PWS at the stadium.

Clint and Karla announced they will donate $100 for every Rockies win this season with the Win for Kids program. Their donation will be split between PWSA (USA) and The Children's Hospital of Denver. The Rockies and FSN Rocky Mountain are encouraging fans to support the effort and pledge at least $1 per Rockies win this season. All proceeds will go directly to the non-profits, and the Rockies Foundation will match all pledges.

The Hurdles have involved friends and family on behalf of PWS, raising thousands of dollars at golf tournaments and more. His sister, Bobbi Martello, raised more than $3,500 for PWSA (USA) with the Madison Hurdle Softball Tournament which was featured in Baseball The Magazine. She and her volunteers plan to make it an annual event. And thanks to Clint, the Polis-Schutz Family Foundation donated $70,000 to PWSA (USA) for research!

Clint and Karla Hurdle with son Christian, 18 mos., and daughter Madison, almost 4, who has PWS

Photo: Expressions by Sandy Puc'

Both professionally and personally, Clint Hurdle likes to dream big and stay optimistic. "We have as good a chance as anybody in our division," he says of the ball club. He's focused on making people aware of the challenge of PWS and the importance of research. He gave students information when he spoke at Metropolitan State College of Denver's Intercollegiate Athletics annual Scholarship Auction in April. The students then distributed the information and collected donations at men's and women's basketball games and raised more than $400 to benefit PWSA (USA). "Adversity is something you learn to deal with and overcome," he says.

See Clint's PSA about PWS on our web site, www.pwsausa.org

See page 8 for more awareness stories

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Deadlines to submit items to *The Gathered View* are:
December 1; February 1; April 1; June 1; August 1; October 1

Our Mission: PWSA (USA) is an organization of families and professionals working together to promote and fund research, provide education, and offer support to enhance the quality of life of those impacted by Prader-Willi syndrome.

Members Only: Check our website www.pwsausa.org for downloadable publications, current news, current research and much, much more limited to members only!
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Support Groups: We sponsor seven support groups to share information. You'll find them listed on the web at http://www.pwsausa.org/support

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Executive Director's View

The Symbiotic World of PWS Programs and Research

Janalee Heinemann

The word "***symbiotic***" means a cooperative, mutually beneficial relationship between two people or groups. All Prader-Willi syndrome programs have a symbiotic relationship with research. We hope someday that research will make some of our programs less needed, but meanwhile researchers need our programs to identify the issues and educate researchers on the true needs of our children and families. Between research and programs, and collaboration throughout the world, the progress we have made in the quality of our children's lives due to this symbiosis would make Dr. Prader very proud.

The following are examples of how our programming interacts with and positively affects research on Prader-Willi syndrome.

• **Awareness booth staffing and presentations at medical conferences both nationally and internationally** keep me updated on research being done and gives me the opportunity to discuss collaboration on both medical care and research with these physicians and researchers.

• **Incoming medical crises to the PWSA (USA) office** give me a sense of what the real medical issues are. I can then communicate with our medical and research boards plus contact international researchers about the issues I see that are of concern and are potentially intriguing for research.

This also keeps us in touch with the information we need to publish to reduce our children's medical risks. From this, we developed the concept of supporting a medical survey and creating our new medical database that has been of great interest and incentive to researchers and helpful for medical situations.

The GI medical crises and sudden deaths we have been seeing were incentives for sponsoring the research project "Impact of Dietary Content upon Gastrointestinal Motility in Individuals with PWS."

• **Our bereavement program** was the impetus and natural transition for initiating our Study of Death research project. If we were not involved with families while their child was alive by supporting them medically and emotionally, we would not know how to contact these families after their child's death and they would not be as willing to cooperate with the follow-up surveys.

• **Our New Parent Mentoring and Crisis Intervention Programs** help us keep up to date on problems and needs of our children and adults with PWS. Thus we can direct researchers to focus on our areas of concern, and not just what intrigues them.

For example, we've restructured our research grant funding process to begin with a Request for Proposal written by PWSA (USA) that asks for project ideas specifically targeted to our needs, defined in conjunction with our Scientific Advisory Board and Clinical Advisory Board.

• **Publications** such as our new 3rd edition of the PWS Management book, our Medical Alert booklet, *The Gathered View*, our website, and Dr. Bassel's new section on the web site that reviews research — all are examples of how our many publications help to educate researchers and direct their potential focus of research into needed areas.

• **International Support** and international travel support our goal of aiding and educating PWS families and professionals in other countries. But good ideas and research projects are not contained solely in the USA. We bring back reports on interesting research going on in other countries and personally connect researchers around the world. One of PWSA (USA)'s advantages is we're not exclusively connected with any university or hospital so we can share with all.

• **Our PWSA (USA) National Conference** is the only yearly interdisciplinary scientific program focused entirely on PWS research in the world. The reports on research and the informal collaboration that take place during these meetings spark ideas for new research – and this has continued for 27 years.

View What's New, Check Our Web Site

You can download and print a new PWSA (USA) brochure, "PWSA (USA) Helping Families and Professionals," at www.pwsausa.org or you can obtain it by calling the national office.

You can also download and print a new hand-out from the Members Only section of our web site, "For the Student with Prader-Willi Syndrome Food is Never OK in the Classroom." This hand-out is needed by every parent of a pre-school and school age child to help the school system understand the complexity of food issues and PWS.

— Carolyn Loker, PWSA (USA) President

Carolyn Loker

President's View

Our PWSA (USA) Crisis Team Is Here For You

Many of you know that for years, **David Wyatt** has literally held down the fort for all of our families in crisis. David is 74 years old and a retired chaplain supervisor who volunteered for us for a few years until, thanks to the Alterman Foundation, we were able to get an ongoing grant to pay him a salary. He has often worked full-time in his half-time position for a long time.

Now, thanks to the increase in donations from so many of our families doing fundraisers, along with a CIBC World Markets Miracle Day grant donation, we have been able to establish a Crisis Team to further serve your needs and allow us to be more proactive with crisis situations.

We now have two part- time crisis counselors, and David will continue 10 hours a week as our Crisis Counselor Consultant. Other members of this awesome team are:

Barb Dorn has a 21-year-old son with PWS. She is a licensed registered nurse, has been a nurse educator, and has experience in teaching people with disabilities as well as parents and professionals. She served for 8 ½ years as executive director/outreach program director for PWSA of Wisconsin, Inc. and as a statewide consultant and educator on Prader-Willi syndrome.

Barb is also a past PWSA (USA) president, has created numerous educational handouts and co-authored a book, *The Student with Prader-Willi Syndrome – A Resource for Educators.*

Kate Beaver, whom we introduced last edition, has a 19-year-old daughter with PWS. Kate has a master's degree in social work and worked for 10 years with phone crisis counseling in another field. Her husband is an ER physician.

We are really blessed to be able to hire such dedicated and knowledgeable people (in both their professions and PWS).

David can now focus on training and establishing outreach programs. Both Barb and Kate will cover all areas of crises as needed; however, Barb will focus more on the educational issues and being a back up for Executive Director Janalee Heinemann on medical crises, while Kate will focus more on the issues of adults with PWS. Both will be working with younger child issues such as SSI, insurance and therapy denials. As part of our virtual office crew, Barb and Kate live close enough in Madison, WI to meet face-to-face when needed.

Working For A Cure Tomorrow – Helping Our Families Today

In future editions, we'll be telling you more about plans the team has, not only for handling crises, but programming and educational materials to help prevent future crises. Each issue of our newsletter is so packed with new information that we rarely have space to discuss our crisis work. But each week we get thank you notes like the following:

"Thank you so very much for writing the crisis letter for my daughter. I am hopeful that your help cuts through some of the pre-set ideas held by the Division of Developmental Disabilities personnel. David, also many thanks for listening to me express my frustration and for affirming my convictions about PWS and my daughter's situation."

The September-October issue will feature an expanded Chapter View with news of their activities and events!

Medical Alert

Watch for Poison Ivy, Oak and Sumac

Dr. Moris Angulo of our Clinical Advisory Board suggests that parents and caregivers of people with PWS be particularly alert as we enter the season for poison ivy, poison oak and poison sumac.

People with PWS are known to scratch and pick at places on their body. This often causes large sores that can and do get infected.

Exposure to poison ivy, poison oak and poison sumac causes the skin to become very itchy. When scratched it will not only inflame the affected area but can also spread to other parts of the body. For people with PWS, who have a high tolerance for pain, the lesions can cause serious skin infections if not caught and treated early by a dermatologist.

Remember that prevention is the best cure. A walk through the woods or even an open field without protective clothing is an invitation to disaster.

The above is NOT medical advice; for that you must consult your medical professional.

Medical View

Hunger and Satiety in Prader-Will Syndrome

By Angelo Del Parigi, M.D

Hyperphagia in Prader-Willi syndrome is generally thought to be due to impaired satiation/satiety rather than exaggerated hunger.

However, the exact nature and extent of the neural defects resulting in the abnormal eating behavior of PWS are unknown. We have previously observed increased activity in the ventral prefrontal cortex in response to early satiety in normal weight and obese subjects and have hypothesized that, if the defect is predominantly a lack of satiation, subjects with PWS may have a blunted activation in this region of the brain in response to the consumption of a meal.

To test this hypothesis, we used an imaging technique called PET (positron emission tomography), to measure changes in regional brain activity in response to hunger (after an overnight fast) and early satiety (after a liquid meal) in 10 genetically confirmed PWS subjects and in 8 control subjects.

Satiety was associated with a smaller activation of the ventral prefrontal cortex in PWS compared to control subjects. Conversely, hunger was associated with a greater activation in several subcortical brain regions in PWS compared to control subjects.

Consistent with our hypothesis, the reduced activation of the ventral prefrontal cortex reveals a possible neurofunctional marker of the lack of satiation in this syndrome. Our findings also suggest the existence of functional impairments in the brain's representation of both satiety and hunger in PWS subjects.

Dr. Del Parigi is associate director/early clinical leader for Pfizer Global Research and Development in Groton, Connecticut. He has presented his findings at the PWSA (USA) National Conference Scientific Day.

Participants Sought for Three Research Studies

Learning Profiles of Children with PWS

Researchers at the Clinical Center for Development and Learning (CDL) at the University of North Carolina at Chapel Hill are conducting a study on learning profiles of children with PWS. The results of this study will be used to develop a tool for developing learning plans specific for children with PWS.

They are seeking 100 families of children ages 3-17 with PWS to participate in a questionnaire study. This will involve parents and teachers completing a questionnaire designed to explore the educational and cognitive strengths and needs of children with PWS.

Parents will also be asked to complete three additional short questionnaires about their child's behavior and food preferences. Participation in this portion of the study is optional and will take approximately 30 minutes for teachers and 1 hour for parents. Parents will receive a letter outlining their child's strengths and needs, with recommendations based on their child's profile. In addition their child could participate in an assessment of neuropsycho-logical and educational abilities. The assessment at the CDL will take approximately 3 hours. Families will receive a thank you gift and a full report of their child's neuropsycho-logical and educational strengths and needs, with recommen-dations based on their child's profile.

Participation is completely voluntary; you may choose not to participate in any portion of the study or withdraw from the study at any time.

For more information contact Dr. Anne Wheeler at 919-843-7049 or 919-966-5171 or at anne.wheeler@cdl.unc.edu.

PWS Sibling Study

Melissa Maxwell, a graduate student from the lab of Elisabeth Dykens and Elizabeth Roof at the Vanderbilt Kennedy Center in Nashville, Tennessee, has received a small pilot grant to conduct a study on the sibling relationship.

She is seeking participation in this IRB (Internal Review Board)-approved project, which is a survey of the siblings of those with PWS. The goal is to identify the range and correlates of outcomes that siblings experience — both the challenging and rewarding aspects of the sibling relationship — and how these effects might differ from siblings of those with other types of developmental disabilities.

Maxwell hopes that this study can lead to more effective supports for siblings, especially for siblings who will become caretakers when parents can no longer serve this role.

The study involves a one-time, 30-minute telephone interaction with a parent, a 30-minute telephone interaction with a sibling of the child with PWS, and a few short follow-up questionnaires that will be sent via mail.

Telephone interviews can be scheduled at participants' convenience (including evenings and weekends). Both the sibling and parent will receive a $10.00 gift card for participating.

For more information please e-mail Melissa Maxwell at m.maxwell@vanderbilt.edu or telephone (574) 261-6937.

Editor's Note: This study is separate from and not affiliated with the PWSA (USA) Sibling Survey and booklet currently being compiled.

Research continued on page 8

Integrated Versus Self-Contained:
Making the Right Classroom Choice For Your Child

By Nancy Finegold

All parents of a child with special needs must make difficult placement decisions regarding their child's education. After all, our children will spend at least 7 hours daily at school away from us with designated adults that we entrust to care for and educate them. We all want them to be placed in the best hands possible.

In my experience as a parent of a child with PWS, and as a school psychologist for 14 years, I believe it is essential to try to look ahead. Choosing the best school and classroom program for our children is not always simple. Sometimes it seems as if we have to persevere tirelessly, weeding through tall fields of confusing rhetoric, unfamiliar abbreviations, and "psychology-speak" that is often difficult to understand at those mandatory special education planning meetings that we all must attend for our children.

My daughter was in an integrated class for kindergarten and first grade. She is now finishing the second grade in a special self-contained class. Because I live in a small school district, there are only six other children in the class. It took many meetings, a child advocate, an attorney, and a long and tedious impartial hearing with my school district to finally get my daughter into the small, structured, self-contained 12-month classroom setting that she needed. So far, it is working out well.

Early successes with integration

Most young children with PWS who start in a special education preschool are placed in an integrated class setting. Our children seem to love other children and interact well with them while they are young. They are very affectionate and like to help care for their less independent classmates.

My daughter Dina was named "the little mayor" by her preschool director because of how well she maneuvered around the school building, greeting everyone she met with a wave and a big smile. Our children tend to be quite savvy, alert, and bright in many ways. They sometimes appear to be ahead of their years in their ability to pay attention to their environment, to learn their schedules, and to know their classmates. All of these attributes make them perfect candidates for the integrated class model in preschool.

The downside is that this can foster false hopes. We start to believe that, maybe with enough exposure to "typically functioning" peers of the same age group, our children will grow to be "typically functioning" as well.

Unfortunately, life does not usually work this way. People with disabilities such as PWS have specific challenges and deficits that warrant structure, attention, and services that set them apart from their peers in many ways.

Needs change as children age

The problem with an integrated class does not become apparent until our children become somewhat older. After kindergarten (5-6 years of age), the gap between children with PWS and their typically developing classmates begins to widen. Of course, each child is different. Some have more cognitive potential, fewer behavioral difficulties, fewer social problems, and less of a hunger drive than others. However, we have to be realistic about our children's needs and pending difficulties. Their need for more structure, supervision, specialized learning, and one-to-one attention increases as the academic and social demands of school become greater.

When our children leave preschool and enter the school system, choosing a kindergarten placement wisely is important. Many school districts do not readily move children into a more restrictive program once they are settled in school and the IEP (Individualized Education Plan) has been written. As a result, you may need to wait (often 2 or 3 years) to be able to prove to your school district that your child either has significant academic delays or has enough of a social/emotional deficit to warrant a smaller, self-contained classroom setting.

10 months versus 12 months

Your child may need the same structure, attention, and services in the summer as from September to June. Many school districts do not place children in 12-month programs easily, but the younger you can get them in, the easier it will be to keep them in this type of setting as they grow. Knowing that your child is set for six weeks out of the summer in the same educational program he/she attends through the school year can give you a tremendous peace of mind.

Integrated classes are always 10 months. You then must find an appropriate summer program and negotiate related services (such as speech, OT and PT) with your school district for these months. You will also have to prove that not being in school for the summer will cause considerable academic regression for your child, which can be very difficult. You may need an attorney and have to invest a lot of money, time and energy before you can hope to accomplish this goal.

Teachers, students and classroom sizes

Depending where you live, integrated classes are typically quite larger than self-contained special education classes, with 18 to 24 students. Self-contained classes usually have no more than 12 to 15 students (sometimes much fewer).

In self-contained programs the teachers are always certified in special education and typically much more experienced and in a better position to educate children with special needs. The integrated classroom usually has a special education teacher in the room for only part of the school day (usually a half day). A general education teacher is in the room for the rest of the day.

Education continued on page 13

We Salute Our Hardworking Medical Advisors

PWSA (USA) is privileged to have some of the world's most accomplished medical professionals working on our behalf. These generous people not only volunteer their time to serve on our PWSA medical advisory boards, they also make themselves available for consultation about medical and research issues and in crisis cases. We'll be sharing information about them with our readers, beginning with the two physicians who chair our boards, Dr. Daniel Driscoll and Dr. Merlin Butler. Both have devoted hundreds of hours to PWSA, and we sincerely thank them.

Dr. Merlin Butler

Dr. Merlin Butler, M.D., Ph.D., chief of medical genetics at Children's Mercy Hospitals and Clinics, Kansas City, Kansas, runs a very busy medical clinic. Dr. Butler also chairs our Scientific Advisory Board. Dr. Butler and his colleagues were the first to begin unraveling the genetic puzzle of PWS when they discovered and reported that the chromosome 15 deletion in PWS was contributed by the father.

But that's not all. In 2005 alone, Dr. Butler also accomplished the following: wrote 14 journal articles, seven book chapters and gave 11 scientific presentations. He also edited two books: *Management of Prader-Willi Syndrome, 3rd edition* (publisher Springer-Verlag) and *Genetics of Developmental Disabilities, 1st edition* (publisher Taylor & Francis). In his humble way, Dr. Butler is quick to acknowledge the dedication and assistance of his co-workers and colleagues.

Dr. Butler earned his medical degree at the University of Nebraska College of Medicine. He earned his Ph.D. at Indiana University, where his dissertation was on Prader-Willi syndrome, and completed postdoctoral work at Indiana University, University of Notre Dame and Jackson Laboratory, Maine.

Dr. Daniel Driscoll

Daniel J. Driscoll, Ph.D., M.D., professor of pediatrics and the Hayward Professor of Genetics Research at the University of Florida, Gainesville, was one of 15 scientists recently named to the prestigious Johns Hopkins University Society of Scholars.

Dr. Driscoll, who chairs the PWSA (USA) Clinical Advisory Board, is considered one of the world's leading researchers on PWS. His meticulous studies of individuals with Angelman and Prader-Willi syndromes are considered milestones in the burgeoning field of epigenetics.

"I am very honored and humbled to have received this award from such an outstanding university," Dr. Driscoll said. "I have had wonderful collaborators, colleagues, students and families along the way, which has made all the difference. In my mind, they deserve most of the credit."

After earning his doctorate at the Indiana University School of Medicine and a medical degree at Albany Medical College, Dr. Driscoll completed a residency in pediatrics and a postdoctoral fellowship in medical genetics at Johns Hopkins.

— Jane Phelan, Editor

'Incredible Losers' Make Lose-A-Thon A HUGE Success

By Jodi O'Sullivan, Community Development Director

From January through May, 46 people enrolled in the first "class" of the PWSA (USA) Lose-A-Thon. Many graduated with honors and became Incredible Losers! Some will be held back because of health or personal reasons. All merit recognition for achievement as together they lost more than 192½ pounds and to date have raised $23,254 for PWSA (USA).

Perhaps nothing is as telling of the fulfillment and struggles with challenges as the participants' own words:

- "I feel so much better as the weight is slowly dropping. I've always tried "fad" diets to get the weight off and they work temporarily; but this is a lifelong commitment we have made as a family and we are all feeling better about our eating habits and exercise we are getting. Thank you PWS for changing our lives." ~Teresa P.
- "The Lose A Thon was a great experience and success for me and PWSA (USA)! Since the beginning of the year I have lost nearly 20 pounds and I am feeling great. Also with the Lose A Thon, I received $2,900 in pledges so far and am hoping to receive a few more hundred dollars. Thank you to PWSA (USA) for the chance to help them as well as myself and others out in this great cause!" ~Jonathan S.
- "I achieved my weight loss goal of 30 lbs. which was 11.5%. The 4-month period is over but I continue to be conscious of my calorie intake and exercise.... Kayleigh will continue to be my inspiration to uphold these high standards of fitness and diet. I hope every participant uses this experience to change their poor eating habits permanently and set an example in their community that sedentary lifestyles and over eating are a detriment to our society as a whole, not just in the PWS community." ~James S.
- "I've lost 22 pounds so far. I thought it would be easy. The Lose-A-Thon gave me the motivation to lose the pounds. I'm going to keep at it. This cause is near and dear to me. My nephew Jake has Prader-Willi and he means the world to me. So any effort or weight I can lose to help him and others like him lifts my spirits!" ~Janine S.
- "The struggle has been difficult, but I would still appreciate donations to encourage me to keep trying." ~Kelly G.

Donations are still being accepted and are still motivating some participants to keep going! For PWS, for health, for life, please show your support. The fundraising goal is $30,000 and we're almost there.

Contributions may be made online at http://www.pwsausa.org/fundraising/lose-a-thon/index.htm or sent directly to the PWSA (USA) office.

Our thanks and praise goes to those who led the way. Best wishes for their continued good health!

PWS Awareness Week 2006

Local Efforts Help Spread Awareness to Thousands

Thanks to the hundreds of volunteers and their efforts to promote awareness of PWS, we were able to inform thousands of people about the syndrome. These efforts help people to understand the daily struggle of those with PWS and their families and help foster acceptance in a society that shuns those who are overweight. Awareness of PWS also helps save lives. Here is a sampling of events from around the country.

Lisa and George Varndell, Grantsville, Maryland

Lisa and George are proud parents of Addison, 11, and Georgie, 23 months, who has PWS. The local newspaper, *The Republican*, published a full-page feature story about Georgie and PWS. Lisa spoke to RNs from the Healthy Families program, serving children birth to 5, and gave information and resources to help identify those with PWS. Radio stations ran public service announcements. The Varndells circulated an e-mail titled "Georgie's Story" to family and friends, asking them to forward it. As a result, at least one child 5 months old was diagnosed. Lisa is serving as a parent mentor for this family.

In a Sibling Care Workshop, Lisa gave PWS bracelets to all participants along with discussion of the challenges faced by PWS youth. The Varndells distributed more than 200 bracelets and a case of 2006 calendars to area residents. Georgie's family, friends and therapists wear their bracelets all year long.

Lisa, along with Georgie's pediatrician, Dr. B. Alan Haworth, and Yvonne McConnell of the local Infants & Toddlers Program, plans a presentation at the Grand Rounds of Garrett County Memorial Hospital. She is also conducting a workshop for county school staff to tell them about potential issues facing school-age children with PWS.

Next year the Varndells are planning to do even more, working toward a walk or other large event to raise more awareness and contributions.

Dawn Romine, Pickering, Ohio

Dawn, mother of Julianna, 16 months, with PWS, contacted local media and was able to get an article about PWS in the Lancaster Eagle-Gazette, along with interviews on local radio and TV. She said all her media contacts have verbally agreed to try and do yearly reports during Awareness Week.

She also got four local municipalities in Fairfield County, Ohio to sign proclamations about PWS Awareness Week.

Corenna Hacker, Appleton, Wisconsin

Corenna, whose daughter MacKenzie, age 2, has PWS, works in a law firm that has five offices statewide and about 300 employees. She sent an e-mail and photos of MacKenzie to her co-workers, and another to her family and friends outside of work. She received a number of responses from people who didn't know about PWS and were glad to receive some information she attached from the PWSA (USA) web site. She wrote: "One attorney responded that he has friends who have a son with PWS; he is now about 35 years old from Green Bay. What a small world it can be!"

Nina Roberto, New York City

"Everywhere I go, PWS always seems to come up.... People are so intrigued to hear about the syndrome, so many questions are asked and I'm happy to answer them all," writes Nina, mother to Niyani, 13; Sonny, 4, who has PWS; and Lennon, 2.

She has created a poster and circulated it throughout her community; done a radio interview; spoke to more than 50 people at the Richmond Hill Block Association meeting, including parents, teachers and law enforcement, and wrote an article for their newsletter; wrote articles about PWS for the February 2006 *Exceptional Parent* magazine, the *Chronicle* newspaper and web site, and Sonny's school newsletter; and gave a talk in her daughter's class. Nina's friend Mia Bolaris-Forget wrote an article about PWS in her company's online newsletter www.lifamilies.com.

A big, big thank you to everyone who works on PWS awareness. You are making a positive difference for so many families. Special thanks to our PWSA (USA) Awareness Committtee: Julie Ayotte, Carroll Beeson, Debbie Lange, Nina Roberto, Lisa Varndell, Barb McManus, Carolyn Loker and Jodi O'Sullivan.

Go to www.pwsausa.org, to download and print information about PWS. You can also view a public service announcement Awareness Week Spokesman Clint Hurdle of the Colorado Rockies major league baseball team.

— Jodi O'Sullivan, Community Development Director and Jane Phelan, Editor

Research - *continued from page 5*

Educational Issues Questionnaire

The UCLA Behavioral-Genetics Clinic and the UCLA Lili Claire Family Resource Center are conducting a needs assessment of teachers and parents of children with specific genetic disorders. We are seeking answers to our research questionnaire about your child's educational strength, limitations, behavior concerns, and how the school program is tailored to his/her specific needs. The questionnaire should take 30-40 minutes to complete. For more information or to participate in the study, contact:

Rebecca Cox, Ph.D., Technical Support Coordinator
Rm. 58-218E, 760 Westwood Blvd., Los Angeles, CA 90024
Telephone 310-794-9516; e-mail
GENESTUDY@mednet.ucla.edu
Principal Investigator-Bhavik Shah, M.D., UCLA Department of Psychiatry
UCLA IRB# G03-01-073-03; Expiration: October 26, 2006

Fundraising From the Home Front

Grass Roots Support for PWS: It All Adds Up

♥ In **honor of her daughter Lea**, 10, who has PWS, **Tina Capraro** hosted a Christmas open house with a friend who offered her home. "We invited women from our community and asked that instead of a hostess gift, they make a donation to PWSA (USA). The event netted $17,730. "Giving a check to PWS is very gratifying because I know it helps many families in need," said Tina. "It is very rewarding and you'll be surprised at how many people will come forward with their generosity."

♥ In Texas, **Jen Dean** hosted a Pampered Chef party and from a percentage of sales netted $346 for PWS research. Her 1½-yr-old **son Tanner** has PWS. "I really had mixed feelings about mixing Pampered Chef with PWS. But I then realized I could seek out the best equipment and healthy recipes to help promote a better lifestyle for Tanner…. The funds that can be raised and the awareness of a healthy lifestyle for all, not only for PWS, made this a no brainer," Jen reported.

♥ When **Sarah Lord** heard her 3-year-old **niece Grace Harvey** was given the diagnosis of PWS, she and her family were shocked and overwhelmed. "My sister Camille came to PWSA (USA) and was given immediate support and information, especially from Carolyn Loker. Dr. Merlin Butler was kind enough to call and e-mail my sister with medical advice and suggestions," Sarah writes. "I wanted to give my support to my niece and planned a fundraiser for PWSA (USA)."

Then the family got some great news, Sarah reports. "On the wonderful advice of Dr. Butler, my sister got a second opinion at Massachusetts General Hospital and with repeat genetic testing it was determined that my niece was misdiagnosed…. We are grateful for all the help and support by PWSA (USA) and I still wanted to have a fundraiser and educate for Prader-Willi." Sarah donated $1,003 from the concert on behalf of her niece.

♥ **Deb Whiting** organized an April Dress Down Day in which more than 80 employees of the Madison County Department of Social Services in Wampsville, New York participated. Donations netted $291 in honor of her **nephew, Grant Whiting**, who has PWS. The employees contributed $3 to wear jeans and in turn received the PWSA (USA) information brochure and orange bracelet. Future events include casual day next year.

♥ **Patrick and Lisa Phernetton** netted $3,000 for PWS research at their 3rd annual "Music For Mickey Concert" in Evansville, Indiana. The concert is named for their 9-year-old **daughter Mickey**, who has PWS.

"The night was a huge success…. and Mickey had such a good time. We also showed a video between the groups that details what PWS is and how it affects the entire family," Lisa reports.

Do not let what you cannot do interfere with what you *can* do. ~ John Wooden

"We were lucky to meet Ron Kingery and Scott Whitehead of Hometown News, who have not only come to play for us but brought other great stars Kevin Sharp, Bryan White and Lila McCann. They have pledged to come back again next year."

Lisa and Patrick encourage everyone to get involved with awareness and fundraising. "If we all keep trying and keep working, we can make a difference, a little at a time."

Anyone interested in having a charity concert in their area should feel free to contact Ron and Scott thru their promo-tions agent, Nancy Tunic, at 615-353-2778 or ntunick@grassrootspromo.com

♥ Concerts may be challenging to organize, but they can be very successful. **Aimee Patel and Reagin Curran** organized one **in honor of** Reagin's infant **daughter Emily** (and Aimee's **niece**), diagnosed with PWS at 7 weeks. Held at Bennigan's Restaurant in Hamden, Connecticut, the concert netted $7,500 for PWS research.

Live music featured local bands Nero Hawley and Down to One, Aimee's husband Sujit's band. He is Emily's godfather and proud uncle, who wrote and sang a song for Emily that brought tears to the crowd, Aimee writes. "We are excited and proud that we more than doubled our goal." They plan to do at least one event per year.

♥ In Colorado, **Roxanne Wolfer** organized a Tupperware Fundraiser in **honor of her son Trevor,** and netted $946. "Trevor is such a cute little boy who has PWS who has captured so many hearts here in our valley. Together we have been able to educate lots of people and build new relationships," his mom writes. "I was surprised how many people cared!" People who came to the party told others about it, and there were orders from people who weren't able to be there too. Because of everyone's generosity I was able to send in a lot more than I was expecting and I decided that my effort was well worth the small amount of time I put into it!"

♥ This June, **Dorothy Morse** set up a PWS awareness booth and held a raffle at the Shrimporee Festival in Aransas Pass, Texas. The effort, to **honor her granddaughter Roxy,** 4, of Peyton, Ohio, who has PWS, netted $1,453 for research and the general fund. "In three days of talking to people about PWS, only about eight people had heard of it. But now, a few hundred people know about it," Dorothy says.

— Jodi O'Sullivan and Jane Phelan

If you'd like to try a fundraiser for PWS, find a list of activities and events in support of PWSA (USA) and chapters at our web site: http://pwsausa.org/fundraising/events/index.htm

View From the Home Front

When Nicholas Went to Harvard

By Lisa Peters

My son Nicholas is 4 years old. We receive care from many specialists at Children's Hospital in Boston, who are affiliated with Harvard University. Harvard has initiated a new program for their medical students, one that I hope will not only create smart doctors but also compassionate ones. Harvard is trying to introduce their students to the human side of genetic syndromes. What is it like from the parent's perspective? What is daily life like for families who are struggling to raise children with syndromes like PWS?

Nicholas, 4, who has PWS, with his beloved SpongeBob pillow

This year an unusual genetics class was offered at Harvard, where students could study one of four different syndromes. Lucky for us, one of them happened to be PWS. The students study the syndrome for the entire semester and are encouraged to ask questions and learn about the human side of PWS. At the end of the term, they write a paper and participate in a panel discussion forum. The panel consists of physicians, researchers and parents/children who are living with the syndrome.

Nicholas and I were fortunate to be asked to participate. So on Friday afternoon, Nicholas and I went to Harvard University.

The sun shone brightly as Nicholas and I walked through the Harvard campus to the science building. Towering on either side of us, large brick buildings stood solidly. Their tall windows seemed to stare down at us as if to ask, why are *you* here?

As we walked through the grounds, I felt intimidated. How many great minds walked these very steps? How many brilliant minds surrounded us now? What could I possibly say to these important folks? How would I make them understand?

Everywhere, students of every nationality scurried quickly from building to building. And yet here I stood accompanied by a small, beautiful child who was holding my hand. We didn't fit into these surroundings. In fact, I am sure we looked silly walking across The Yard clutching Nicholas's favorite Sponge Bob pillow. Many students smiled quietly to themselves as they saw Nicholas lovingly hold his large blue and yellow pillow friend. Yet here we were to teach these great minds the meaning of the word "compassion."

We entered the science building. Chemical equations hung like portraits from the walls. We entered a large auditorium where I was placed on a chair in front of the class next to an endocrinologist, a previous Harvard graduate, and given a microphone. Here I sat, a mother, more comfortable in a playroom than a discussion group. A mother who fights so hard each day to get one child to listen now sat before over 100 students all eager to listen.

As I began to speak, Nicholas climbed into my lap. He placed his Sponge Bob pillow on my chest and gently lay down his head. Before me a sea of young, eager faces listened closely to my words, wondering what life must be like for the two of us.

As I was speaking, Nicholas grabbed my face and kissed me, and accidently burped right into the microphone. "BURP!" Nicholas turned, looked at the students, and smiled a grin like a Cheshire cat, as if to say you see, I am really just a boy, not a disorder. And for a moment, they looked at him and laughed and understood the meaning of the word compassion.

As much as I was hoping my words could make them understand, it was this sweet, silly moment that seemed to reach them.

After it was over, many students came up to meet Nicholas. And as I stood in this great institution, this pillar of learning, I recognized how fortunate I am to have such a teacher in my life, such a teacher in this world. I felt that if Nicholas and I did nothing more in our lives, it would be OK. For today we educated the world just a little bit.

Lisa and Nicholas live in Georgetown, Massachusetts

The Chuckle Corner

I Need My Growth Hormone!

Each night Anna receives her growth hormone shot after she has fallen asleep. But one time we did not have a shot for her because the shipment delivery was delayed. I prayed that she would stay asleep so that she wouldn't get anxious that she had not received her injection.

In the middle of the night, however, I suddenly heard little footsteps as she came running to me saying, "My shot, my shot, you forgot to give me my shot!"

I explained to her about the shipping delay.

Anna was still very concerned. "But I'll get short, Mom, and I want to be tall like you!"

Carolyn Loker
Kalamazoo, Michigan

View From the Home Front

Kids Do the Darndest Things!

Noelle, 4, who has PWS, after giving herself a haircut

Unbeknownst to me, Noelle and my younger sister Stephanie were sitting at the table coloring when Stephanie asked Noelle if her hair was getting in her face. When Noelle said that it was, Stephanie suggested that Noelle should ask Mommy to trim her bangs. But neither of them said anything to me.

A few days later, I went to get Noelle up from her nap and discovered that she had taken herself to the bathroom. As she pulled her pants up and turned to walk away, I noticed a chunk of long hair hanging from the waistband of her pants. I asked, "Noelle, did you find scissors and cut your hair?"

Noelle turned to face me with a large grin and a big "yes," which clearly conveyed that she thought she had done me a favor in trimming her bangs before I got around to doing it. Ah, the joys of parenting, with or without PWS! **Amy McDougall, Fulton, New York**

FAQs about PWSA and FPWR

How Are PWSA and FPWR Related?

Although the two groups have a professional and mutually respectful relationship, the organizations are not related. Prader-Willi Syndrome Association (USA) ("PWSA") and the Foundation for Prader-Willi Research ("FPWR") are two separate and distinct organizations with entirely different mission statements.

PWSA's current mission statement is as follows: *PWSA (USA) is an organization of families and professionals working together to promote and fund research, provide education, and offer support to enhance the quality of life of those impacted by Prader-Willi syndrome.*

FPWR was founded in 2003. FPWR's mission is as follows: "*The mission of the Foundation for Prader-Willi Research is to eliminate the challanges of Prader-Willi Syndrome through the advancement of research."*

PWSA plays no role in how FPWR raises funds or makes decisions regarding how those funds are spent. Similarly, FPWR plays no role in how PWSA raises funds or makes decisions regarding how those funds are spent. Each organization is solely responsible for developing its own policies and procedures and for ensuring that its activities comply with applicable laws.

Each organization (PWSA and FPWR) has a research grant procedure involving an annual RFP (Request For Proposal) process. The organizations do communicate to coordinate RFP release dates and to keep each other abreast of funded research projects. This assures that the limited PWS dollars are used efficiently.

If I Want My Donation to be Used Only for Research, Which Organization Should I Give To?

That decision is entirely up to you, the donor. Regardless of which organization you choose, if you specify that your donation is to be used only for research, the recipient organization must use it for research. PWSA (USA) segre-gates all of the funds it receives according to the purpose for which the funds were donated. We can use money from the general fund to support research, but we cannot use research-designated funds for anything except research. Thus, if you make a donation to PWSA (USA) that is designated solely for research, you can be confident that it will be used only for research, and that the research projects approved will have been examined by PWSA (USA)'s Scientific Advisory Board and/or the Clinical Advisory Board, as appropriate.

Does PWSA Sponsor Research?

Yes, certainly. PWSA was established in 1975 and incorporated in 1977. Along with its other activities, PWSA has been funding PWS-related research for over 20 years, since 1983. In 2005 alone, PWSA (USA) collected and commited over $200,000 toward research. For a complete list of research projects funded by PWSA, go to www.pwsausa.org and click on "Research," or call 1-800-926-4797. As noted above, PWSA has a research grant procedure involving an annual RFP process.

Why Haven't I Heard About PWSA-Sponsored Research Before Now?

PWSA has always tried to bring to the attention of our members and others affected by PWS the latest information about results of PWS-related research, through conferences, our publications, the web site, *The Gathered View* or otherwise. We probably haven't been quite as vocal as we could have been about advertising which research projects we have funded and how much of each project has been funded by us. If you haven't heard it before now, rest assured that PWSA does fund research and has been doing so for over 20 years.

Because PWSA is involved in so many aspects of the syndrome and touches so many disparate groups involved with PWS – for example, medical and behavioral crisis cases, presentations at medical conferences, the bereavement program, parent mentoring programs, publications and international support efforts – we think we bring a unique perspective that enhances our research funding decisions.

If you prefer the way FPWR funds research, that's certainly your prerogative. You may learn more about FPWR by going to www.pwsresearch.org. We hope you continue to support PWSA (USA) research and thank you for your support and trust that we all want what is in the best interest of our children with Prader-Willi syndrome.

View From the Home Front

I Want To Share My Story

By Max Manning

College student Max Manning, 22, has PWS

I am a freshman in college. I have to deal with something every day that most people don't have to deal with. It is called Prader Willi Syndrome. PWS is a rare genetic disorder that occurs in children. It is a deletion of the 15th chromosome. Sometimes I wonder why I was born with this syndrome and why I have to deal with the problems it causes.

Everyday is a battle with myself. I have to deal with depression and the uncontrollable hunger. One reason I am depressed is because there is no cure for Prader-Willi and I have to live in a very restricted environment where food is locked up. With all the weight loss medications you would think it would be easy to find one that would work with me, but with Prader-Willi I never know how a medication is going to affect me emotionally. So usually when medications help others, they can cause more problems with me because of Prader-Willi.

At times because of the syndrome I am not myself. It takes complete control over me and causes me to do things that I wouldn't normally do. It really hurts my feelings and makes me feel worthless when people make fun of me because of things I can't control. Kids make fun of me because of my weight and for not being the same. Even with all the harassment and judgments made against me, I was created for a reason and I am perfect the way I am.

There are some positive aspects of my syndrome. Because of my disability I have been able to connect and become friends with others who have disabilities because I can relate to how they feel. I have learned that it is really important to look deep inside a person to see who they are, instead of judging them by only what you physically see.

At what seemed like the lowest point in my life, I went to Latham Centers, where they have a special program for people that struggle with Prader-Willi. At Latham Centers I learned how to take control of the syndrome. Going to Latham Centers has helped me through the tough times in my life, and has helped me grow closer in my relationship with others. I remind myself that nobody is perfect and that even when I am hurt by others it is important to forgive because they know not what they do. And I want people to look at me for the person I am on the inside, not for what I look like on the outside.

At first school seemed boring because it was too easy because I knew most of the material and it wasn't challenging enough. Then I was transferred over to Latham and school became harder because the material was on a high school level. While I was going to Latham I heard about Project Forward, which is a program at Cape Cod Community College. I applied to the program and got accepted there. Which was a big accomplishment for me because I never thought that I would be able to go to college because of the issues that I have to deal with everyday. There, at College, I met Mr. Dailey and Mrs. Kimball. They helped me to realize that I could overcome my issues. The Program was designed to help their students to have normal life experiences even though they have disabilities.

At Latham the teachers were taught to help the students to become independent in their community. There I was able to get a job at Crocker Nurseries where I had a job coach to assist me when needed. I learned job skills at Latham to help me to keep a job. The job skills they taught me were to be on time, clean, tidy, and to call when I can't work. It is also important to listen carefully to my boss so that I could get the job done correctly. Using the proper language and being polite are also important while on the job.

When I first arrived at Latham I didn't know anybody so I had use my abilities to make friends. That was hard for me because some of the students went through some hard times in their life. So when I approached them they step back. But over time they got to know me and we became friends.

Then I graduated from high school in 2005. Then I was transferred to their adult program where my skills at Latham came into place. Like learning how to live with housemates and their needs as well as mine. There I was able to make new friends. Then I met someone that became my girlfriend.

I also participated in Special Olympics, swimming, bowling, and finally track and field. Project Forward and taking mainstream classes at Cape Cod Community College are also activities I enjoy.

While attending these academic activities in my spare time I go to work out at Planet Fitness in South Yarmouth.

A Note From Max's Mom

Max wrote this story for his Peer Leadership class at Cape Cod Community College in Massachusetts. He read it for that class, as well as at Parents' Day. Max's story was meaningful to many people in the room that day. As his mom, I was impressed by his courage, his insight, and all his accomplishments — the most important of which is his pride in sharing his story. As is so true for many children and adults with PWS, Max is a remarkable person and I hope you enjoy his story.

Anne Manning, Charleston, Massachusetts

International View

A Hello From Our Member in Croatia

Juraj, 4, who has PWS, with his Labrador Luna

Sorry because my English is bad I hope that you can understand me. My name is Ivka Cop from Croatia, Europe. I am your member and I visit your web pages since 2002. Without those web pages I would be lost. My son Juraj is now 4 yrs old. And by this time I didn't establish association in Croatia but I will do it this month. Now I am fighting to get GH therapy for our children here in Croatia and that is very dificult here. I must explain doctors why is GH good for our kids and then they must write to our Ministry of Health to get it. So I was asking Dr. Moris [Angulo] to help me with getting his opinion. I also hope that some day you will came to Croatia and we will meet in personal.

From IPWSO President Pam Eisen: "I've been in regular contact with this mom for a long time. I feel as though I am Juraj's grandmother as I've been through most of his stages and have shown his beautiful photos to so many. I plan to meet this brave Mom in person, as I visit our associations in Eastern Europe this year."

Education - *continued from page 6*

This can make a big difference in terms of the school's ability to meet your child's needs in the best possible way. Our children require more supervision and structure, along with an environment that can cater to their variable moods, poor frustration tolerance, and inflexible natures. The staff must understand that our children must always be supervised around food, that they will manipulate, sneak, and charm their way to more snacks and larger portions at lunch time.

The staff need to understand that our children are complicated, and be aware that all of their training and experience, their behavior modification plans, and all their teaching techniques need to be rethought and revised because our children will not respond consistently to any one method of intervention.

Social pressures of "fitting in"

The pressure of having to fit in socially with typically developing children increases with age. Expecting the staff at your child's school to be patient, accepting and able to manage children within the school building is reasonable; however, expecting other young children to do the same is not.

Academic demands placed on the children in an integrated class are greater. In many integrated classes, children with special needs are expected to learn to act and behave and function just like their classmates. For most children with PWS this may be very unrealistic, and the stress produced by these expectations, both academically and socially, is not healthy for our children.

Self-contained special education classes should be able to challenge children to learn and to live up to their individual potential. The brighter, more cognitively able children should have more difficult school work to tackle. Those with fewer behavioral problems who fit in well socially with their peers should have ample opportunity to do so.

Tolerance and acceptance

Most parents who have a child with special needs seem to wish that their child has friends who do not have disabilities. With age, this notion becomes harder to fulfill. My 7½-year-old daughter interacts mainly with her siblings, cousins and children who are somewhat older than she, and are more patient, accepting and understanding of her limitations. She attends a small special education class with other children who have disabilities, as well as a Sunday morning religious studies group and a summer camp for special needs children.

This works best for her. She is happy and content. She does not know that her friends have special needs, nor does she care. She likes to be around them because they accept her and like her for who she is. I've noticed that my daughter gravitates toward children with Down's syndrome who are high functioning. They may not be as cognitively bright as she (depending on the child), but like our children, they are usually very affectionate, stubborn, and also like to eat. This is a great match!

I also find that I can be more comfortable around other mothers when their child too has special needs. We can compare war stories, give each other advice, and even take turns with play dates to give each other a break. It usually works out well for mother and child.

Our children are always developing and changing. Try to be open-minded to the necessary school and/or program changes that your child may need. The younger your child is when you begin this process, the easier it will be for everyone in the long run. For my family, the road from integrated to self-contained was a long, hard, and painful one. Now that we have arrived and see the results, we have no regrets.

For more information about education issues, go to our web site, www.pwsausa.org. Click on Members Only for a list of articles that you can download, or click on Publications for additional listings.

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.

Amanda Patton

She was special, especially to me, her Mumma, and her Dear Old Dad. Her relatives and many friends have wonderful memories of her and how she touched our lives by making everyone happy and upbeat when she was present.

Amanda had many challenges in her life coping with PWS. She truly believed there was nothing she could not accomplish. She proved that in so many ways. She completed high school in special education. Later, she wanted to go to college… and she might have, if she had not died at the age of 48. She had a special way with animals…won medals in Special Olympics for swimming.

Shortly after she was diagnosed with PWS in 1987, we were invited to join a support group of parents who had children with PWS. After 2 years…PWSA of Arkansas was incorporated. As a small but very active group we traveled throughout Arkansas. … After 4 or 5 years, the number increased greatly. Amanda always went with us; she wrote and gave her own speech.

Amanda and a group of girls with PWS moved into a group home in 2000. Amanda lived there happily…. The girls lost over 1,000 pounds in the four years Amanda lived there.

Since her death on April 16, 2004, we have been overwhelmed with [responses] from people…who felt our daughter was special to them.

We miss Amanda deeply, and thank God for entrusting us with the special gift of her life.

With loving memory, Mumma and Dear Old Dad

Amanda's mother Paula Patton was the first president of PWSA Arkansas and her dad Jim is also a former president.

Russell Crivaro

Russell was the youngest of five siblings. We all loved him in spite of his condition, PWS, and the many difficulties and sorrows associated with someone who happens to be born different.

Russell was the smallest of our parents' children at birth. After his first two years of life or so, Russell appeared to be gaining a lot of weight. We remember him crying frequently and whining to our mother how he was hungry and needed to eat. Tears were frequent with Russell along with some outspokenness and difficult behavior at times. He could be hard to reason with.

PWS was unknown when Russell was born in 1954. Obviously, no treatment was available, much less understanding family, friends, neighbors, and worst of all, the medical community. The frustration we had as we "dragged" Russell from doctor to doctor only to be told his overeating was due to our mother's cooking. We knew different; we knew Russell was sick somehow. Our family's knowledge of PWS surfaced too late in his life. He was in his forties before he was diagnosed. Our parents died blaming themselves.

Russell did not go into puberty until he took Growth Hormone in his forties. I remember watching the many physical changes taking place.

For all us siblings, we remember that Russell struggled and suffered from badly behaved adults. We think he was the strongest man we've ever known in spite of no muscle tone. Russell died unexpectedly at the age of 48 in a nursing home. In our eyes, he was a hero, a pillar of strength in spite of PWS and our living in darkness most of our lives with nowhere to turn. We all only wish our parents would have known he had PWS.

Crivaro Siblings Raymond, Arthur, Camille and Joan

Matt Gardner

On May 1st our long-time conference volunteer and PWS sibling, 32 year-old Matt Gardner, died suddenly. In spite of his own long-term health problems, Matt was always involved with Prader-Willi syndrome causes.

He will be deeply missed by all who knew him, especially his brother Larry, who has PWS, and his parents, Jim and Joan Gardner. Jim is our past board member, and Joan has chaired many conference programs. Jim and Joan organized the large 2001 combination national and international PWS conference in Minneapolis, Minnesota.

Through this family's years of support to Prader-Willi syndrome causes, and their current involvement in the next international conference in Romania, they honor both Matt and Larry. "*The true way to mourn the dead is to take care of the living....keep on with your work and bring joy to others.*" (Edmund Burke)

Our hearts go out to the Gardners. Our love goes with Matt.

— Janalee Heinemann

Our 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, please contact the PWSA (USA) National Office.

Contributions In Memory Of

Andrew Hill
Thomas Hill
Yvette McGee
Theresa Edge
Tamara Upleger
Stanley & Patricia Bitel
Norwood & Suzette Jewell
Monique Cuspart
Michael & Kathleen Hale
Loris & Anne Costa
Dianne & Bruce Woods
Cheryl Ford
Ca-Sandra & Learlean Tutt
Enyka Matthews
Edward & Kathleen Kaminski, Jr.

Ann Morrison
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Margaret Dickson
Kevin & Margaret Moloney
Kathy Riley
George Benzie, Jr.
Daniel Romanow & Andrew Zelermyer
Timothy Ford
Levine Chapel Inc
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Colleen Doherty
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Lillian Fladmark
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Lorraine Diamond
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Mary Lou Millenbach
Matilda Bauser
John & Dorothy Zator

Cheryl Krolczyk
Larry & Pat Krolczyk

Matt Gardner
Jim & Carolyn Loker
Janice Forster, M.D.
Daniel J. Driscoll, Ph.D., M.D.
Lota & Dave Mitchell
Louise Greenswag, R.N., Ph.D.
Allen & Janalee Heinemann

May Smith
Eleanor & Richard Weiner

Ramona Piver
Horace T. Piver, Sr
Teresa and Don Wilfong
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Scott Crocker
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Warren & Miriam Fish
Priscilla Morales
Marilyn Pizzi
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Update From the PWS Multidisciplinary Clinic in Israel

We have recently reviewed the clinic charts of 49 Prader-Willi patients seen in consultation at the Prader-Willi syndrome multidisciplinary clinic at Shaare Zedek Medical Center in Jerusalem, Israel.

Headed by Prof. Varda Gross-Tsur, a pediatric neurologist, the clinic staff includes specialists in child psychiatry, behavioral and education psychology, endocrinology, and nutrition, all working on a voluntary basis. Consulations with orthopedic, pulmonary, and ENT physicians familiar with Prader-Willi syndrome are obtained as needed.

Patients from all parts of Israel are seen in our clinic at least once a year. A summary letter of the evaluation with specific recommendations is sent to primary care physicians so that necessary tests and treatment can be performed in the community.

The male:female ratio is 26:23. Age distribution includes 21 children below age 10 years, 16 between age 10 and 20, and 12 young adults older than 20 years. A specific molecular genetic diagnosis was recorded for 38 children of whom 56% had deletions, 39% had uniparental disomy, and 5% demonstrated an imprinting defect.

Growth hormone treatment was approved in Israel for use in children with Prader-Willi syndrome only 3 years ago. To date, 12 of our patients have been treated with growth hormone. Of the 21 children younger than age 10 years, at the most recent clinic visit, 7 were receiving growth hormone (33%).

Sixteen of all 18 patients older than 18 years live in hostels or special residential settings.

Clinic staff members work closely with the local Prader-Willi organization to promote increased awareness of this condition among health professionals, school personnel and the public at large.

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Thank you for Contributions through May 2006

We try to be accurate in recognizing contributions, and apologize for any errors or omissions. If you notice an error, please tell us.

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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.

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