PWSA U.S.A.

The Gathered View

July-August 2001
Volume 26, Number 4

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

Temi is Doing Quite Swimmingly, Thank You

By Louise Pye

The Birth

Our daughter Artemis was born on 26 June 1999. She was diagnosed with PWS three months later. I had not been happy throughout the pregnancy; there were virtually no movements and I kept returning to the hospital for scans.

Temi was born by C-section weighing 5 lbs. 15 oz. When she was handed to me, her little mouth looked strange, but she scored 9 on the Apgar scale and the doctors seemed happy.

Sadly, Temi went rapidly downhill after her birth; she could not suckle, did not cry, did not move and seemed to be getting weaker. To complicate issues, we had moved to Singapore just eight weeks before Temi was born, and I was not familiar with the medical system. Temi kept being taken from me (newborn babies are placed in nurseries whilst mothers recuperate and embark on a period of "confinement").

Temi enjoys swimming with her sunglasses and book

After three terrible days, Temi still had not fed, and her weight had dropped to 5 lbs. The nursing staff just kept calling her a "sleepy baby," and our pediatrician labeled her as "amorphic" — in lay terms, "peculiar looking" — but could shed no light on the situation. In sheer frustration I discharged us from hospital feeling totally isolated and desperately needing help.

Luckily for us, help did arrive. We managed to get hold of the name of a nurse who had experience feeding premature babies and who had spent several years working in the U.K. This was the moment when Queenie entered our lives, and thankfully, she has been helping Temi ever since. It was as if they were fated to meet, and they have become an inseparable team.

Temi bonded deeply with Queenie, who seemed to be the only person who could feed her. So many people tried, but we all failed. Through the long hours of the night, it would take my husband and I up to 2 hours to get Temi to take 2 oz. of milk, and we were exhausting her tiny reserves of strength in the process.

Those first few weeks were a total emotional rollercoaster as we veered between periods of optimism and periods of despair. No one seemed to be able to give us any answers in Singapore, so three weeks later, Queenie, Temi and I boarded a plane for the U.K. It was a risk because Temi was so weak, the hypotonia was severe and it was as if she was in a coma. We were not sure if she was up to a long-haul flight.

Furthermore, it meant I was to be separated from my son, who was totally bewildered by what was happening. Thankfully, my wonderful mother extended her visit further to help us, and fortunately we were able to arrange an appointment

Artemis continued on page 14

inside

The Prader-Willi Syndrome Association (USA)
5700 Midnight Pass Road, Suite 6
Sarasota, Florida 34242
1-800-926-4797
9 a.m. to 7 p.m. Eastern Time
Local: 941-312-0400
Fax 941-312-0142
e-mail: pwsausa@aol.com
www.pwsausa.org

Officers
President - Lota Mitchell, Pittsburgh, Pa.
Vice-Presidents -
Carolyn Loker, Plainwell, Mich.
Regina Hartnett, Springfield, Il.
Secretary - Barb McManus, N.Y.
Treasurer - Karen Goldberger, Il.

Executive Director
Janalee Heinemann

Newsletter
Editor - Jane Phelan
Associate Editor - Lota Mitchell

The Gathered View (ISSN 1077-9965) is published bimonthly by the Prader-Willi Syndrome Association (USA) as a benefit of membership.

Annual U.S. membership dues are:
$30 Individual
$35 Family
$40 Agencies/Professionals
For members outside the United States, dues are $40 Individual, $45 Family and $50 Agencies/Professionals (US Funds). We never deny parents membership for any reason.

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 at the address above.

Who's Who at the PWSA(USA) office

So you can put a name with a face when you call us, here are some of the staff and volunteers who work at the PWSA(USA) office: front row, L-R: Gilda, Jessica, Norma; 2nd row: Peggy, Janalee, David; back row: Al, Guy and friend Susan

PWSA (USA) Board of Directors

Chair - Ken Smith, Pittsburgh, Pa.
Dorothy Cooper, Alpharetta, Ga.
Steve Diaz, Oakton, Va.
Daniel Driscoll, M.D., Gainesville, Fla.
James Gardner, White Bear Lake, Minn.
Pauline Haller, Naples, Fla.
Robert Hartnett, Springfield, Il.
Michael Larson, Appleton, Wis.
Carolyn Loker, Plainwell, Mich.
Steve Lundh, Seattle, Wa.
Pamela Tobler, Orem, Ut.
Mary Ziccardi, Cleveland, Oh.

Scientific Advisory Board

Chair - Merlin G. Butler, M.D., Ph.D., Children's Mercy Hospital, Kansas City
Chair Emeritus - Vanja Holm, M.D., University of Washington
Suzanne B. Cassidy, M.D., U.C.I. Medical Center, Orange, California
Elisabeth M. Dykens, Ph.D., University of California, Los Angeles
Jeanne Hanchett, M.D., The Children's Institute, Pittsburgh
David Ledbetter, Ph.D., University of Chicago
Phillip D.K. Lee, M.D., Children's Hospital of Orange County, California
Robert Nicholls, D. Phil., University of Pennsylvania
Barbara Y. Whitman, Ph.D., St. Louis University
William B. Zipf, M.D., Ohio State University

Clinical Advisory Board

Co-Chairs - Daniel J. Driscoll, Ph.D,.M.D., Univ. of Florida Health Science Center, Gainesville
Robert H. Wharton, M.D., Spaulding Rehabilitation Hospital, Boston
Moris Angulo, M.D., Winthrop University Hospital, Mineola, N.Y.
Ivy Boyle, M.D., Bellefaire JCB, Cleveland, Ohio
James Boyle, M.D., St. Vincent's Charity Hospital, Cleveland, Ohio
Judy Brice, M.D. The Children's Institute, Pittsburgh, Pa.
Aaron Carrel, M.D., University of Wisconsin Hospital, Madison
Elisabeth M. Dykens, Ph.D., University of California, Los Angeles
Louise Greenswag., R.N., Ph.D., Iowa Child Health Speciality Clinics, University of Iowa
Brian Hainline, M.D., Ph.D., Riley Children's Hosptial, Indiana University School of Medicine
Jeanne Hanchett, M.D., The Children's Institute, Pittsburgh
Karen Levine, Ph.D., Spaulding Rehabilitation Hospital, Boston
Jim Loker, M.D., Bronson Methodist Hospital, Kalamazoo, Mich.
Helen McCune, M.S., R.D., Shands Hospital Food & Nutrition Service, Gainesville, Fla.
Suzanne Cassidy, M.D., U.C.I. Medical Center, Orange, Cal., liaison from Scientific Adv. Bd.

Ex Officio Members:
Ken Smith, Chair, PWSA Board of Directors, The Children's Institute, Pittsburgh, Pa.
Barb Dorn, R.N., President, PWSA (USA), Verona, Wis.
Janalee Heinemann, M.S.W., Executive Director, PWSA (USA), Sarasota, Fla.

We Are the PWSA Family

By Lota Mitchell

I have long joked (somewhat ruefully, it's true) that my shoe size 8-8 1/2 feet provide a firm foundation. Now I can only hope that they are big enough to fill the shoes of the outgoing PWSA(USA) president. Barb Dorn has done an outstanding and effective job — working with chapters, providing needed information, updating the Board Manual, and doing a host of other tasks that needed to be addressed. I hope that many of you will take the time to write a note or e-mail to Barb to thank her for the time, effort and commitment she has put into her three years as President.

Now let me introduce myself. A resident of Pittsburgh, Pennsylvania, I have a Master's Degree in Social Work and for the past 20 years have been an Employee Assistance Professional, providing information, referrals and short-term counseling on addictions and mental health to the employees of businesses contracting with my company for this service. I had no sooner decided at the beginning of January that I wanted to retire than the call came from PWSA(USA), asking me if I would accept the nomination for president. In June I said farewell to being an EAP and hello to being PWSA(USA) president.

Probably of more importance than my professional background is the fact that I am the mother of Julie, age 31, who has PWS. When she was born, my husband Dave and I had no diagnosis. I first learned about the syndrome through a rather tabloid type article in the Pittsburgh paper when she was five. It was not until she was 18 or 19 that there was lab confirmation (uniparental disomy) of my diagnosis.

Today, she has been in a residential placement at Keystone Pocono Residences near Scranton, Pa. for almost five years. She is doing well within the limits of the syndrome, involved in activities, working in a sheltered workshop, loves animals and word search puzzles and is happier than some of the adult children of clients I have seen. While we have experienced the ups and downs, the temper tantrums and food control issues of PWS (some severe), I can honestly say she has enriched my life. Just one example is the friends and experiences I've had in my association with PWSA(USA).

Which brings me back to PWSA(USA). One person expressed the opinion that it is like a "club." I don't think so! PWSA(USA) is a FAMILY. Like all families, its members include rich and poor, old and young, professional and parent, male and female. Sometimes its members may disagree and get mad at each other; some members are more connected than others; some seek advice, sharing or support from other members. But all are bound together, not by the bonds of blood, but by the ties of love, commitment and caring for those with PWS.

One of my favorite things to do is talking with people. So I really look forward to meeting and talking with many of you across the country.

However, it is not enough to be a family. PWSA(USA) must also be a BUSINESS if we are to survive, observing good business practices and plans, legal obligations and fiscal responsibility. Sometimes it is hard for our chapters to comply with all that is required, but it is necessary. We must always be improving the ways we carry on the business of running an organization dedicated to helping those with PWS, supporting those who care for them and increasing the databanks of information.

Last but not least is my philosophy about the presidency. Like Barb Dorn, I feel that the president must be the voice of the membership to national. In addition, the president on occasion may need to interpret national to the membership. One of my favorite things to do — in addition to gardening (recently discovered this pleasure), reading (never enough time) and bridge (why don't I improve?) — is talking with people. So I really look forward to meeting and talking with many of you across the country!

As I assume the office, I know that I'll win a few and lose a few; that is, I'll have both successes and make mistakes in the three-year term ahead. I ask for your feedback — good or bad — and your support. We are all in this thing together (to use another old cliche), and together we will somehow, some day, bring about the good and normal lives for our children with PWS that we all dream of.

Medical News

PWS and Adult Growth Hormone Defici

By Rhona Shapiro, RN MSN

Many children with childhood growth hormone deficiency grow up to be growth-hormone-deficient adults. The FDA has approved the long-term use of Genotropin for pediatric patients who have growth failure due to Prader-Willi sydrome. While testing for GH status is not necessary in children, when it is done, most are found to have growth hormone deficiency (GHD). It is more than likely that most Prader Willi adults therefore have GHD.

Adult growth hormone deficiency affects the lean body mass to fat ratio, bone density and quality of life. How does this relate to PWS?

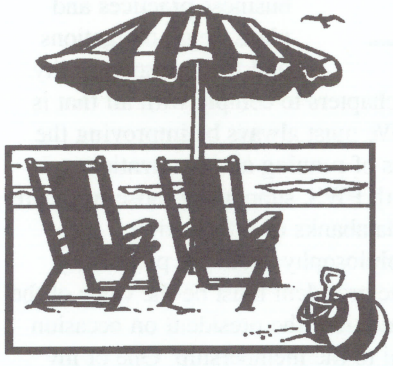
- **Abnormal lean body mass to fat ratio**: An abnormally high percentage of body fat compared to lean body mass or muscle is present. The abdomen or visceral area will contain higher than normal amounts of fat while the arms and legs will appear thin. This will be evident even when weight is normal and with regular exercise. The increased fat is related to a higher incidence of heart attack and stroke.
- **Decreased bone density**: Osteoporosis is often early and severe. Fracture rates are more than twice the norm. Because of the high pain threshold associated with PWS, individuals may have undetected fractures.
- **Quality of life**: Growth hormone deficient adults have higher rates of depression and social isolation.

Treatment of adults is different than t
children. First, doses are much smaller. A
given, usually 6-7 days a week. The injecti
smaller than an insulin syringe or resembl
syringe does not need refrigeration and is a
The syringe, about the size of a "pinky" fi
thrown away.

Decreased fat mass is often the first visible sign of improvement and will likely be apparent within six months. Bone density increases. Osteoporosis is not controlled, as in the use of medication specific to osteoporosis; bone density actually improves within 18 months. Sturdier bones are not as likely to fracture. Quality of life, such as depression and energy levels, markedly improves.

Growth hormone is an FDA-approved treatment for growth-hormone-deficient adults. The diagnostic work-up involves blood studies. These studies can be done in a physician's office, clinic or even within a group home setting. Most Medicaid payors cover the diagnostic procedure, and some pharmaceutical companies will provide free drugs while they assume responsibility for pursuing insurance coverage.

For any questions about Adult Growth hormone deficiency, please call:
Rhona Shapiro, RN MSN
Nurse Educator, Innovex
Phone: 215-361-8627
Email: *rhona-cons.shapiro@am.pnu.com*



Summer Skin ALERT!

The summer months can offer many children and adults with Prader-Willi syndrome extra challenges in the area of skin protection. Due to the fair nature of their skin, many are at an increased risk of sun burn. In addition to using a sunscreen with an SPF factor of at least 30, many people may need to do more. Sunscreen alone may not be enough.

Many need to wear more protective clothing and sunglasses. Hats can provide some protection for the face and head. Depending on its shape and the size of its brim, a hat can also protect the ears from sun exposure.

Be sun sensible

- Don't overdo. Stay out of the sun during peak sun and heat times: 12 noon to 3 p.m.
- Reapply sunscreen frequently, especially if the person is in and out of water.
- Limit the time of exposure and encourage plenty of water or fluids. Keep in mind that people with PWS often have difficulty regulating their body thermostat. They can overheat easily.
- Be aware of any medications the person may be taking that may add to this sun sensitivity.

Bugs, Bites, Plants and Itching

During the summer months, insects and plants can also cause skin problems and challenges. Using an insert repellent ma help prevent unwanted bites that can cause itching, picking and sores.

Touching certain plants such as poison ivy, poison oak, etc. can also result in severe skin reactions. When going on a hike or stroll in the woods, it is best to have the person with PWS wear long pants and/or a long-sleeved shirt. Use care when removing these items of clothing if there has been known contact with any of these plants. You may react to residue left behind.

Preventing skin problems is so much easier than treatment!

-- Barb Dorn

PWS in the News

Sen. Dole to Film PWS Public Service TV Spot

By Terri Schlange

Hi everyone, I'm Terri Schlange, mom to Eric, 6, and Patrick, 3 (who has Prader-Willi syndrome) and wife to Howard. Since I found out that Patrick has PWS, I've thought it would be great if Prader-Willi syndrome could become a household word. My dream may soon become a reality.

At my request, Senator Bob Dole has agreed to do a Public Service Announcement about Prader-Willi syndrome. The PSA will be shown nationally. Prader-Willi Syndrome Association believes there are 16,000 undiagnosed children and adults in the United States with PWS.

This is how the story begins. On March 5, I mailed Senator Dole a letter asking him how he got Congress to give funding for prostate cancer. On March 7, the day the Senator received my letter, he called me. We talked for 15 to 20 minutes. Senator Dole is a very kind and caring man.

Then I sent Senator Dole a thank you letter and asked him to do a Public Service Announcement about Prader-Willi Syndrome. On March 27, the Senator had his secretary e-mail me stating that he was interested in doing the PSA at no charge and to send him the specifics.

The next day, I called Emporia State University, Emporia, Kansas about filming the PSA. Officials there said they could film the PSA at no charge and I met with them on May 7. They recommended I call the TV stations for their addresses to get the format needed for the PSA. A PSA through the AdCouncil costs about $1.5 million over three years, which wasn't economically possible.

A scriptwriter from Callahan Creek, Inc. in Lawrence, Kansas helped me with the script at no charge. It was revised again by Janalee Heinemann, Carolyn Loker, Pamela Tobler and me. Dr. Merlin G. Butler helped with the wording for the testing part of the PSA.

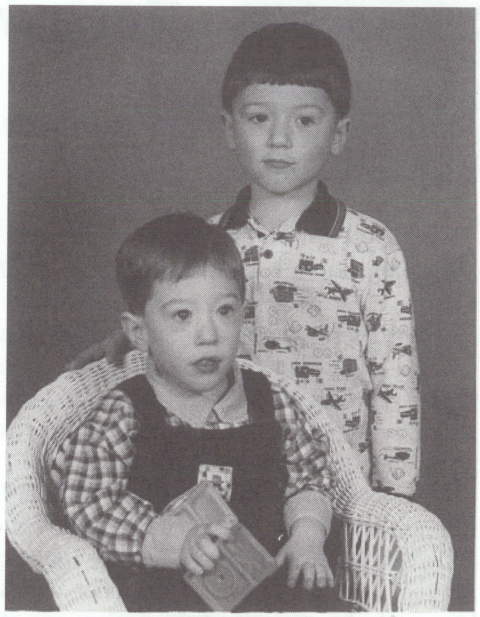
It didn't work out for Senator Dole to come to Emporia, Kansas to film the PSA. It worked better for Senator Dole to film the PSA in Washington, D.C. where he lives. Emporia State University staff will be editing the PSA.

Amanda Diaz will appear in the PSA with Senator Dole. Amanda's Dad, Steve, is on the Board of Directors and coincidentally used to work for Elizabeth Dole.

Susan Wheeler, communications director for Senator Crapo of Idaho, is working with Senator Dole's office to have the Senator film the PSA at the Republican Party's TV studio. Susan's sister is Pamela Tobler, who serves on the PWSA Board of Directors and is national public relations liaison and also mother of Nathan, who has PWS. Thanks, Susan and Pam — I think you are both awesome!

At Susan's suggestion, we will purchase satellite link time so the TV stations can download the Prader-Willi syndrome PSA into the format they need to air it.

I had already e-mailed 700 TV stations for their addresses and formats needed. I received 250 responses. For those TV stations that are unable to download the PSA, Nuvidia in Kansas City is going to donate the tapes, but dubbing costs will have to be paid, which can be up to $19.88 per tape. That will be done when funding is available.



Terri and Howard Schlange's sons, Eric, 6, and Patrick, 3, who has PWS

Because Pharmacia holds the patent to Genotropin growth hormone that is specifically FDA approved for use with Prader-Willi syndrome, I e-mailed Pharmacia and wrote their CEO Fred Hassan, asking for help with the PSA. Pharmacia has asked the public relations firm Belisto & Co. to provide press releases and media alerts so the TV stations can hook up to our satellite links to download the Prader-Willi syndrome public service announcement.

Mike Larson will put the Public Service Announcement on the PWSA(USA) web site after it is edited and condensed. Thank you, Mike for volunteering all these years to keep the PWSA web site up to date!

We hope that *People* magazine will do a story about Prader-Willi Syndrome. I have heard back from a representative at the magazine stating my proposed story will be sent to their editors.

It took many hours of volunteer work to make this PSA possible. Thank you to everyone who helped with this project!

Our thanks for ongoing support from Pharmacia for our Triage Support Specialist and the Alterman Foundation for our Crisis Intervention/ Prevention Counselor

Executive Director's View

Farewell to Two Heroes

By Janalee Heinemann

Dr. Andrea Prader, ***an honorary member of the LWPES and a true pioneer in pediatric endocrinology, died on Sunday, June 3 at the age of 81 years. The funeral was in Zürich, Switzerland on June 13th, 2001.***

Besides being a highly esteemed child endocrinologist often referred to for his work about growth in children in general, Dr. Prader was scientifically very active and productive. Together with Dr. Willi and Dr. Labhart, Dr. Prader wrote the first publication about Prader-Willi syndrome.

Dr. Prader attended our sixth National Conference in Minnesota in 1984. Everyone who met him commented on what a kind and charming person he was. Many of us had the good fortune of getting to know Dr. Prader, and Al and I rode with him on the bus to visit what was then one of the first group homes in the nation, Oakwood Residence. Our young adults with PWS did not hold him in awe as the rest of us did, so they took Dr. Prader by the arm and insisted he come with them and see each of their bedrooms.

During this time, one of the big debates was how to pronounce the name "Prader." On the bus back to the hotel, I got up the nerve to ask him, and Dr. Prader said it was Prah-der – so it became official – but we still continue to work on getting people to pronounce it right.

Below is part of Dr Prader's presentation at the banquet of that Minnesota conference.

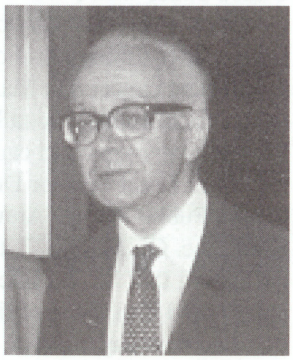
"I am delighted to be with you and I wish to express my deep gratitude for your generous invitation. These two days with you were a very stimulating and rewarding experience for me. It is impressive to see how much progress in medical knowledge and in practical management has occurred in the 28 years since my colleagues Dr. Alex Labhart, Dr. Heinrich Willi and I have given the first short description of this syndrome. On the other hand, we realize painfully how much we do not yet know and how little we can do.

"I am deeply impressed by the successful activity of your association. You were the first Prader-Willi Syndrome Association in the world which has brought together parents, doctors, other health workers and teachers. Somewhat later a similar association was founded in the United Kingdom, but I do not know of any other national association, and unfortunately we do not yet have such an association in Switzerland. Why are you ahead of us Europeans with your association? It is one of the most admirable qualities of American people to develop very powerful private initiative; to have a strong will to help each other, not to be ashamed to have a so-called abnormal child and to go public in support of these children. It is a great experience for me to see what you are doing, how you advise and help each other, how you bring together experts from various fields who can contribute to help these children, and how you have founded and organized special residences which is probably the ideal solution for many adult patients. In multidisciplinary meetings like this one each group of experts learns from the other groups. As a pediatrician, I know how much we can learn from the observations and the experiences of parents and we hope that parents can also learn from us. I have frequently admired mothers who were able to manage or to keep into certain limits, the obesity problem of their child with this syndrome, and I have learned from them for instance how to give food only as a reward for some physical exercise.

"Let me tell you now the history of our first observations. This takes me back to my own pediatric training and to my colleagues and friends in Zurich in the late forties and early fifties.

"In 1947 I started my pediatric training in the Children's Hospital in Zurich. Guido Fanconi was chairman of the department. He was a famous clinician and investigator, an excellent teacher and a very demanding boss. He taught us by his personal example, that progress in medicine depends to a large degree on precise observations. The second man in the department was Hans Zellweger, who is well known to you. The training of the residents

Dr. Prader continued on page 7



Dr. Andrea Prader

...Neurotransmitters are important for regulation processes in the brain and the nerves, and probably also involved in the regulation of appetite. I hope and strongly feel that such a substance or a neurotransmitter inhibitor will be found which will allow us to control the appetite of our patients.

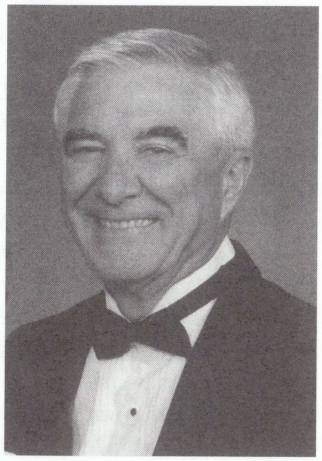
--Dr. Andrea Prader in a 1984 address to PWSA

Frank Moss - *Many of you know that on May 17, 2001 we lost one of our "warriors" – Frank Moss of Camarillo, California. Frank was a past board member, chaired the PWSA (USA) conference in 1999 in California, and was just very instrumental in negotiating our conference site in Utah.*

I was moved that the PWSA board asked me to represent them at Frank's funeral. Because I have worked in the field of death and dying for over 20 years, I was surprised at my own strong grief reaction to his death. In contemplating my reaction, I realized that it was because Frank and his wife Fran and I have been in the trenches together for almost 19 years — fighting for our own children – and all children with PWS.

Our generation of parents has an incredible bond. We were warriors on the front line. Our main goal was to save our children's very lives and to keep our own lives from becoming a nightmare in doing so. Like any veteran's group, time, distance and differences cannot diminish the bond we have – and we greatly mourn the loss of one of our heroes.

Frank's funeral service was a real tribute and a testimony of all he meant to so many people. We have known for years about Frank's dedication to the cause of PWS, both on both a state and national level. At his service I learned about the other layers of Frank's life — the kind and loving father, the steadfast friend who never said a critical word about anyone, and the man of great faith.



Frank Moss

Frank and Fran both had siblings with Down's Syndrome, lost their first baby at nine days of age, and had their youngest child Melissa diagnosed with PWS. Frank also lived with his own significant health problems for the last 20 years, but he never uttered a word of self-pity and was glad to share his talents as a brilliant businessman with both PWS and his church. Frank had a sense of humor, a sense of mission to make life better for all dealing with Prader-Willi syndrome and sense of great courage. As Bernie Siegel, M.D. once said, "Getting well is not the only goal. Even more important is learning to live without fear, to be at peace with life, and ultimately death."

Frank had a sense of humor, a sense of mission to make life better for all dealing with Prader-Willi syndrome and sense of great courage.

At the funeral, all three of Frank's surviving children gave very powerful testimony about what a great father and person he was. Two of his children, Maureen and Steve, had very touching speeches, but were a little hard to hear. Then Melissa (their daughter with PWS) stood up. Slim and well dressed, she adjusted the microphone and spoke in a strong, clear voice with pauses and inflection like a professional speaker. The entire audience was in tears, and we PWS parents shed an extra tear knowing how proud Frank would have been of her. When I complimented Melissa after about what an excellent job she did, she said, "No, we <u>all</u> did a good job!" Melissa's testimony to her father was not only in her words, but also in who she has become.

The poem inside Frank's funeral service program read…

I could not stay another day
To laugh, to love, to work or play.
Tasks left undone must stay that way.
I found that peace at the close of day.

Frank was committed to the cause of PWS until the very end. He was working on state and national projects the day before he died. I pray that Frank did find that peace, but we cannot leave his work undone. At the same hour of Frank's service in another state was another funeral – that of a 2-year-old with Prader-Willi syndrome who, for unexplained reasons, had also died suddenly.

A hero dies, and a mother cries, and we are left to carry on… because we must… because we care.

Dr. Prader - *contiued from page 6*

was mostly in his hands, and it is from him that I have learned general pediatrics during these early years. One of his main interests was muscular hypotonia in babies. If I remember correctly we have seen together Albert, our first patient with the syndrome, when his age was about 10-15 years. In 1950, I went to New York to continue my training in Bellevue Hospital under Emmet Holt and to get first hand information about pediatric endocrinology from Lawson Wilkins at John Hopkins Hospital in Baltimore. When I came back to the Children's Hospital in Zurich, Hans Zellweger had left and had become chairman of the Department of Pediatrics at the American University in Beirut. In 1957 he moved to this country. I continued to work in the Children's Hospital during these years. My main efforts were to develop pediatric endocrinology and to initiate studies on normal and abnormal growth.

"Heinrich Willi was nearly 20 years older than I was. He was in charge of the newborn nursery in the nearby Department of Obstetrics. Today, he would be called a neonatologist. My friend, Alex Labhart, was an internist who shared my interest in endocrinology and metabolism. Our first patient, Albert, had been seen as a newborn by Heinrich Willi, later by us in the Children's Hospital and when he was an adolescent and a young adult by Alex Labhart. In many discussions with Heinrich Willi we recalled other obese and mentally retarded patients who because of severe hypotonia had been in the newborn nursery for prolonged periods. We began to realize that there was a group of children with identical symptoms and findings and a typical developmental pattern forming a syndrome which had not been described previously. We presented our experience as a poster at the 8th International Congress of Pediatrics in Copenhagen in 1956, where we discussed it at length with Hans Zellweger who had come from Beirut to attend the congress. We also presented it as a short paper at the annual meeting of the Swiss Society of

Dr. Prader continued on page 11

Correlating Genetic Research with Clinical Findings

By Merlin G. Butler, M.D., Ph.D., FACMG

In research lies our hopes for successful management and treatment of our children and adults with Prader-Willi syndrome. This is the second of a two-part article by Merlin G. Butler, M.D., Ph.D., FACMG, who is Chairman of the PWSA(USA) Scientific Advisory Board, provides an overview of some current research and research findings.

Dr. Butler is chief of the Section of Medical Genetics and Molecular Medicine at Children's Mercy Hospital in Kansas City, Missouri, and Professor of Pediatrics at the U. of Missouri-Kansas City School of Medicine. One of only about 500 cytogeneticists and 1,000 clinical geneticists in the U.S., he co-headed an extensive research project on PWS while at Vanderbilt University. He is currently seeking major funding from NIH to continue the research efforts.-Ed.

Clinical and Genetic Findings

Correlating the genetic findings with the clinical (observed) features of PWS has given insights into metabolism, obesity and other findings seen in patients with this syndrome.

Examining additional findings such as the abnormal behavior in PWS subjects could allow for future treatment strategies.

Similarly, examining PWS subjects with unusual 15q11-q13 findings should allow for a better understanding of the role of individual genes in the pathogenesis (cause) of PWS.

Unexpected Activity in Genes

Unusual patterns of gene activity or expression in some PWS subjects may account for clinical variation among individuals with this syndrome.

Recently, a subset of 15q11-q13 imprinted and paternally expressed genes that were not expected to show activity were found to have some activity in a few PWS subjects. These patients with "relaxed" imprinting may be more mildly affected, which may further explain the variation seen in some PWS subjects. This phenomenon needs further investigation.

Differing Types of Maternal Disomy

The type of maternal disomy 15 (either isodisomy, meaning the same chromosome 15 from the mother but in two copies, or heterodisomy, meaning two different chromosome 15s from the mother) may influence whether a second genetic condition is present in the PWS child.

In these special patients, the mother may be a carrier of a recessive (non-functional) gene on chromosome 15 and passes two copies of the same chromosome 15 with the recessive gene on that chromosome for a genetic condition to her child with PWS. The PWS is caused by maternal disomy (isodisomy type) in her child, and a second genetic condition is seen which is due to two copies of the recessive gene. This has been reported with a child with PWS and Bloom syndrome, a rare recessive condition that we now know is due to a recessive gene on chromosome 15.

Type of Chromosome Mechanism

Variation in the size of the chromosome deletion (large or small, imprinting mutation) may produce different clinical findings.

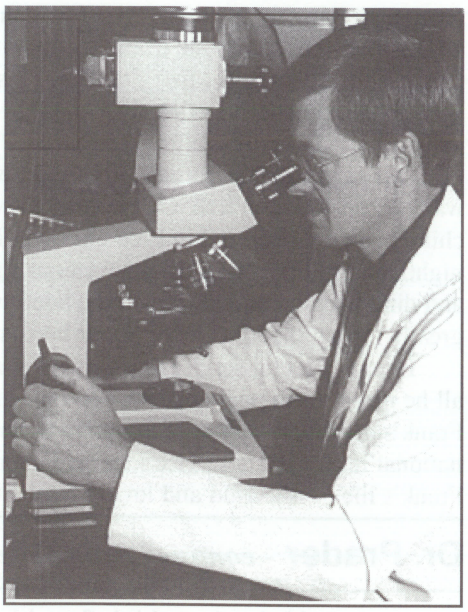
Maternal disomy 15 occurs when an egg has two chromosome 15s instead of one and is fertilized by a normal sperm with one chromosome 15. This results in a fertilized egg with trisomy 15 (three copies of chromosome 15 — two from the mother and one from the father) and 47 chromosomes.

Early in pregnancy, the father's chromosome 15 is lost, and all subsequent cells in the embryo or fetus will have the normal 46 chromosome count with two chromosome 15s (not three), but both 15s from the mother (maternal disomy). If the embryo or fetus would have maintained the extra chromosome 15 in the cells, the pregnancy would have miscarried.

There have now been reported subjects in which not every cell has lost the extra chromosome 15 from the father and mosaicism (a mixture of trisomy 15 cells and maternal disomy 15 cells) results.

Patients with this mixture of chromosome 15s may be more severely affected with a higher incidence of congenital heart disease, and more severe growth and developmental delay than the PWS subject with the typical deletion or maternal disomy 15.

The type and frequency of chromosome mechanisms causing PWS will require additional studies.



Dr. Merlin G. Butler

Unusual patterns of gene activity or expression in some PWS subjects may account for clinical variation among individuals with this syndrome.

Continued on page 9

Differences Between Deletion and Maternal Disomy Subjects

"Phenotype" means the entire physical, biochemical, and physiological make of an individual, determined both genetically and environmentally.

"Genotype" is the entire genetic makeup of an individual.

Phenotypic differences of individuals with separate PWS genotypes are of interest to geneticists and behavioral scientists alike. Identification of specific genetic defects that correlate with clinical manifestations or features will enhance our understanding of genetic imprinting and the impact of genes on clinical presentation in PWS.

In the past, hypopigmentation (i.e., lighter hair, eye and skin colors compared with similarly-aged family members) was noted to occur at a higher frequency in PWS subjects with chromosome 15 deletions.

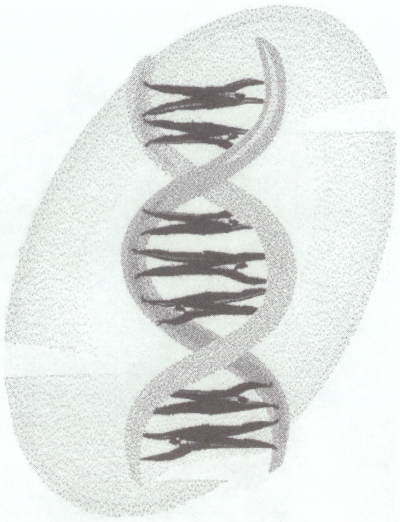
This has recently been found to be associated with a deletion of the P gene localized to the 15q11-q13 region and involved with skin pigment. This gene is usually deleted in PWS (and Angelman syndrome) subjects with the typical 15q11-q13 deletion, thus the reason for lighter hair color and complexion in those patients.

Previous studies have revealed that individuals with PWS with the chromosome 15 deletion seemed more alike in their clinical presentation. Additionally, individuals with the deletion self-injure via skin picking at more body sites than PWS subjects with maternal disomy 15.

PWS subjects with maternal disomy 15 generally have a milder physical phenotype, better cognitive function, fewer behavior problems and higher verbal skills than PWS individuals with the 15q11-q13 deletion.

However, they have decreased visual acuity and impaired stereoscopic vision compared with deletion subjects. They are also more variable in their clinical presentation and may be diagnosed at a later age than deletion subjects.

On rare occasions patients with maternal disomy 15 have atypical clinical findings. The phenotype of PWS subjects with imprinting mutations or other atypical genetic lesions of the 15q11-q13 region has not been well described because of their rarity.



Nutrition and education services, occupational and physical therapy, exercise programs, bone mineral density studies, orthopedic evaluation to rule out scoliosis and osteoporosis and behavior assessments are needed for the complete evaluation, treatment and health care management of those with PWS and their families.

Lower birth weights have been reported in PWS individuals with the chromosomes 15 deletion, and shorter birth length in PWS males with maternal disomy than males with the deletion.

PWS subjects with maternal disomy have also been reported to have a shorter course of gavage (tube feeding) with a later onset of hyperphagia (overeating) in PWS females with maternal disomy.

People with PWS and maternal disomy were also found less likely to have the typical facial appearance and less likely to show certain behavioral features of PWS, including skin picking, skill with jigsaw puzzles, a high pain threshold and speech articulation problems.

There is increasing evidence for clinical differences in PWS subjects with the chromosome 15 deletion compared with those with maternal disomy. Additional studies are under way looking at clinical differences in the different genetic subtypes in PWS subjects.

Thus, studies on clinical presentation, natural history and differences may be helpful in providing prognosis and counseling for PWS families who present with affected individuals having different etiologies (causes).

In Conclusion

Also under way is brain imaging with specialized systems (e.g., positron emission tomography, nuclear magnetic resonance spectroscopy, functional magnetic resonance imaging) in PWS subjects to further visualize and investigate regions of the brain that may control feeding, behavior and cognition or learning in PWS subjects.

Additional problems characteristically reported in PWS subjects include obsessive-compulsive disorder, intense preoccupation with food and depression, all of which require more research in order to identify and treat these features in PWS.

Endocrine evaluation should be undertaken in your child with PWS, including possible growth hormone treatment (growth hormone studies in PWS have shown to increase muscle mass and height as well as increase physical activity) or other hormone replacement.

Nutrition and education services, occupational and physical therapy, exercise programs, bone mineral density studies, orthopedic evaluation to rule out scoliosis and osteoporosis and behavior assessments are needed for the complete evaluation, treatment and health care management of those with PWS and their families.

PWSA (USA) to Offer 2 New Videos About PWS

Both videos have been sponsored by an educational grant from Pharmacia Corporation. The funding support includes the production of these videos and cost for making 1,000 copies to be distributed on a first-come, first-served basis later this fall.

The video for young parents will be a first of its kind. The producer got outstanding footage in several locations. The filming was of the young parents in the Michigan group, Dr. Butler, Barb Whitman, the Open Options Group Home in Kansas City, Mo., Ken Smith, PWSA (USA) Executive Director Janalee Heinemann, more families and the national office in Sarasota, Florida. Dr. Lee and Dr. Cassidy will be filmed in the next few weeks in Orange County, Calif.

Cost of shipping and handling is $5.00 for each video shipped in the U.S. and Canada; $10 for each film shipped internationally.

Member families and professionals of PWSA (USA) may obtain one copy of each video until the supply is exhausted.

Members of the Titus Production crew, Jason, Titus and Mike (back row), take a break from filming to pose with Mario Lopez (L) and Rori Peaton (R).

Video #1: My Child Has Prader-Willi Syndrome - Now What?

This video is for parents whose children are under 8 years old, or for medical professionals.

It offers hope, help and practical suggestions for those young families with a child newly or recently diagnosed with Prader-Willi syndrome. Medical, speech and language, physical therapy, early intervention, and family issues are highlighted.

Video # 2: Prader-Willi Syndrome - An Overview

This video is for health care practitioners or for parents to give to their health care practitioners. It provides an overview of Prader-Willi syndrome and the accompanying management issues. It is appropriate for parents to provide as a training and informational tool to caregivers in many disciplines including pediatricians, speech and language therapists, educators, psychologists, social workers and case managers.

To request your copy, complete the following information and return to the PWSA(USA) office.

Name _____

Mailing Address _____

City, State and Zip Code _____

Phone Number/e-mail address _____

Name & Date of Birth of Child with PWS _____

I do not have a child with PWS. I am a professional. Position _____

Member PWSA(USA) Yes __ No__ Local Chapter _____ **Send membership information** _____

Please send me the following:

☐ **My Child has Prader-Willi syndrome - Now What?**
(for parents of children under age 8 or for medical professionals)

☐ **Prader-Willi Syndrome- An Overview**
(for health care practitioners)

Payment Method:

☐ **Cash** ☐ **Check** ☐ **Master Card** ☐ **Visa** **Card expiration date** _____

Card No. _____ **Name as it appears on card** _____

Shipping and handling: U.S. & Canada $5.00 per video
International $10.00 per video

Total $ _____

Endocrinology in the same year. This paper was published in the German language in the Swiss Journal of Medicine (Schweizerische Medizinische Wochenschrift)....

"At first our paper did not stimulate interest in the medical profession. In 1961, Dr. Willi and I reported again on the syndrome at the 2nd International Congress of Mental Retardation in Vienna. In the same year and in the two following years, the first observations from this country were published by Hans Zellweger, and other publications appeared in the United Kingdom and in France. They were followed by reports from most western countries as well as Japan. I am flattered that the syndrome carries my name, but for unknown reasons, the name of Alex Labhart was dropped, and the name Willi has been frequently mistaken as my Christian name.

"I have continued to see many patients with this syndrome. Usually they are referred to me for confirmation of the diagnosis. My collaborator, Dr. Dieter Vischer, has written in 1971 a chapter on it in a handbook on diabetes, which has not received any attention. We have also published some observations on hormonal regulations in these patients, which disappointingly do not differ from findings in other obese subjects. My associates and I felt frustrated over these many years because we were unable to find a clue for the cause of the syndrome and for the development of the various symptoms. Already in 1956 we were aware that even in large families there is never more than one affected child. This was a strong argument against inheritance, and it helped me to convince parents that there was hardly any risk for the occurrence of this syndrome in their future children. But, of course, the parents expected more from me. They wanted me to explain the cause and wanted treatment, which would make these children completely normal. I always had to disappoint them. The only thing I could do was to tell them about my own experience and about what I had learned from patients.

"At this point, I would like to discuss very briefly my original thoughts about the cause of the syndrome. Some of you may not fully understand these scientific considerations. It does not really matter because they have no importance any more. Since it is not a familial disorder, I considered two possibilities: One was a chromosomal defect which could not be found until 1981 when Ledbetter published his paper on the deletion of a part of the chromosome #15. The other was dominant inheritance with the assumption that each patient is a spontaneous mutation and that subsequent dominant inheritance could not be observed because the patients do not reproduce. For many years I considered this possibility the most likely. Today, it is evident that I was wrong, and that the great majority or possibly all of the typical patients have a partial defect of the chromosome 15. Thus a chromosomal defect appears to be the definite cause of the syndrome. This fully explains why familial occurrence is extremely rare.

"I would like to conclude with some speculation about future developments. In recent years great progress has been reached in a group of biochemical substances which are called neurotransmitters. They are important for regulation processes in the brain and in the nerves, and are probably also involved in the regulation of appetite. I hope, and I strongly feel, that such a substance or a neurotransmitter inhibitor will be found which will allow us to control the appetite of our patients. I do not have to tell you that such a substance would be of tremendous help in the management of these children. It will remove the most formidable problem and would reduce the situation to mild mental deficiency with behavior problems and incomplete puberty, which are much easier to manage than the voracious appetite, which is so destructive for the patient and his family.

"Finally, let me thank you again for your kind invitation, and for the stimulating experience which you have given me. I wish to express my best wishes for the future to all of you, to your association, and above all to the children who are afflicted with this life-long severe problem."

North Carolina Group Home Destroyed in Fire

Ed. Note. We received the following information on May 25 from Mary Patterson, the NC state chapter president.

I wanted to share with you some devastating news from our chapter. Last Sunday around 8 p.m., the PWS Group Home in Albemarle, NC burned completely. Fortunately, all residents and staff escaped physically uninjured.

The staff was commended for their excellent efforts. However, the shock that residents, staff and families have experienced is extreme.

All of the residents' valued possessions were destroyed, including collections, Special Olympic ribbons, dolls and stuffed animals from childhood, etc. You know how important these things are to anyone, but especially to our loved ones with PWS.

At this point, the residents are all in temporary placements while the original home is being rebuilt. The house will include a sprinkler system when it is rebuilt.

Anyone wanting to donate to the state chapter to enable them to assist residents in replacing personal possessions such as furniture, TV's, clothing, etc. and/or to contribute to defraying the cost of the sprinkler system can send a check to the chapter treasurer at:

PWSA of North Carolina
c/o Barbara McDonald
1519 Guilford Ave.
Wilmington, NC 28403.

Or call Mary at 919-489-0390. Be sure to designate that the donation is for this cause.

with a brilliant doctor at Great Ormond Street — no stone was left unturned. After intensive tests we returned to Singapore and waited.

The Diagnosis

Approximately six weeks later we received the devastating diagnosis. Even the irony of her name was haunting: inspired by Greek mythology, Artemis was the lover of weeds and the wild chase over the mountain. I had been a painfully thin girl who spent most of the time running through the countryside. I had thought my daughter might share a similar passion, but on reading material about PWS I could not have been more wrong.

Temi is a strong, determined little girl who works so hard to achieve each milestone. Despite continual knocks and bruises, she picks herself up and tries again.

The next few months need no description. The pain of trying to make sense of the condition and its implications you all know only too well. To exacerbate problems, our son (18 months) became unmanageable — he was so jealous of the baby and totally devastated by the change in his hitherto happy parents and home. It was virtually impossible to have them in the same room, and whichever child I was with, I felt wracked with guilt about the other, especially as Temi needed so much stimulation. I felt I was failing her totally.

There are people in his world who are full of goodness and who seem to have a real capacity for dealing with mental and physical illness. I sadly am not one of these special people, and I thought how unfair it was for Temi that God seemed to have selected me for her. I would read about all these wonderful, motivated parents of PWS children whilst I by comparison felt depressed and exhausted. I was not even computer literate to surf the Net for information. I felt guilty to read of all the marvelous fundraising that other parents were doing — I was letting Temi down.

Gradually over the next few months our sense of perspective returned, as did our sense of humor. It was only the end of the world if we allowed it to be, and we just had to get on with it and do the best possible.

In fact, life has actually been quite good, something that seemed virtually incomprehensible to us a year ago.

Artemis at 20 months

To our delight, Artemis does not seem such a misnomer after all. She is a strong, determined little girl who works so hard to achieve each milestone. Despite continual knocks and bruises, she picks herself up and tries again.

Queenie is her patient and moving mentor, and together they have achieved great things. Temi was: sitting at 7 months; crawling at 10 months; weight bearing at 11 months; swimming underwater at 13 months; walking, pushing bricks at 15 months; walking independently at 17 months.

Temi's vocabulary is now expanding daily — car, apple, hat, ball, boy, girl, shoes. She is also starting to say simple phrases — "I don't want" is increasingly popular. We go to a normal kindergarten together once a week, and Gym walkers, too.

To summarize, Temi is a happy toddler, continually exploring her environment and babbling away. She had a great love of music and loves to bash away on the piano. When we are out, Temi gets so much attention from the Singaporeans, who love her blonde curls and ready smile. I am aware that she is slightly slower that her peers, but nobody else seems to notice, apart from comments sometimes that she looks sleepy.

We are happy with her weight and height at present, and she has not started on growth hormones as yet. If possible, we shall do without. She is presently on the 75th percentile for height and the 50th for weight; also, her muscle tone is improving daily due to all her swimming.

Temi's diet is mainly Chinese rather than Western, and of course strictly regulated — one thing we have discovered is that her mental alertness is closely related to her metabolism. Temi has to be fed at regular intervals, including four hourly at night — without this she becomes lethargic and floppy again. Overheating has a similar effect that is a constant problem, given the humidity of Singapore.

The icing on the cake (probably an inappropriate expression) was when a newspaper journalist contacted us after hearing about a little mermaid who seemed as natural under water as on dry land. He asked if he could come along to one of Term's swimming sessions. Watching her swimming and reading under water, he was so amazed that she has a genetic disorder that he asked for proof of the diagnosis. The journalist then wrote a three-page article about her and Temi made front-page news.

I know that we find it encouraging reading about other PWS children and their achievements. It always raises our spirits. I hope that reading about Temi will do the same for others.

We are so delighted with our daughter — the future seemed so bleak for us as a family when PWS exploded into our lives. Of course we are only at the beginning, and we know that there will be difficult decisions to make and difficult times ahead — but Temi is most definitely worth it!

The Chuckle Corner

The Problem with a Million Dollars
Or
Famous Last Words (I Know But...)

A friend who has always admired Clyde's writing ability and his frequent praise of his mom (yours truly) gave him a Hallmark contest form in which he could write what makes his mom the greatest and win a million dollars for the best entry. The following typical PWS conversation took place:

Clyde: Mom, it says if I win I have to be able to be in New York City on June 29.

Mom: That would be exciting.

C: I know but... we already have tickets to fly to the Prader-Willi conference then.

M: If you win, you can hire your own jet to take you to New York and then on to St. Paul.

C: I know but... we are supposed to go fishing the day before that in Minnesota.

M: If you win, you can hire a guide to take you fishing in Minnesota for walleye, then fly in your jet to Alaska to fish for salmon, then fly to Florida to go after the really big game fish.

C: I know but... I really want to go to the conference.

M: You can go to the conference and then go fishing. You can fish every day for the rest of your life if you win a million dollars.

C: I know but... we are already registered and I really don't think we should cancel going to the conference.

M: You're right. We would have to change our plans, but this change in plans might be worth it. If you win a million dollars you could go to conferences all year long.

C: I know but... I would miss work.

M: You wouldn't even have to work- ever.

C: WHAT!?! And not get paid my paycheck!?! Sorry, Mom. I'd really rather get you that gazing ball you want for your garden.

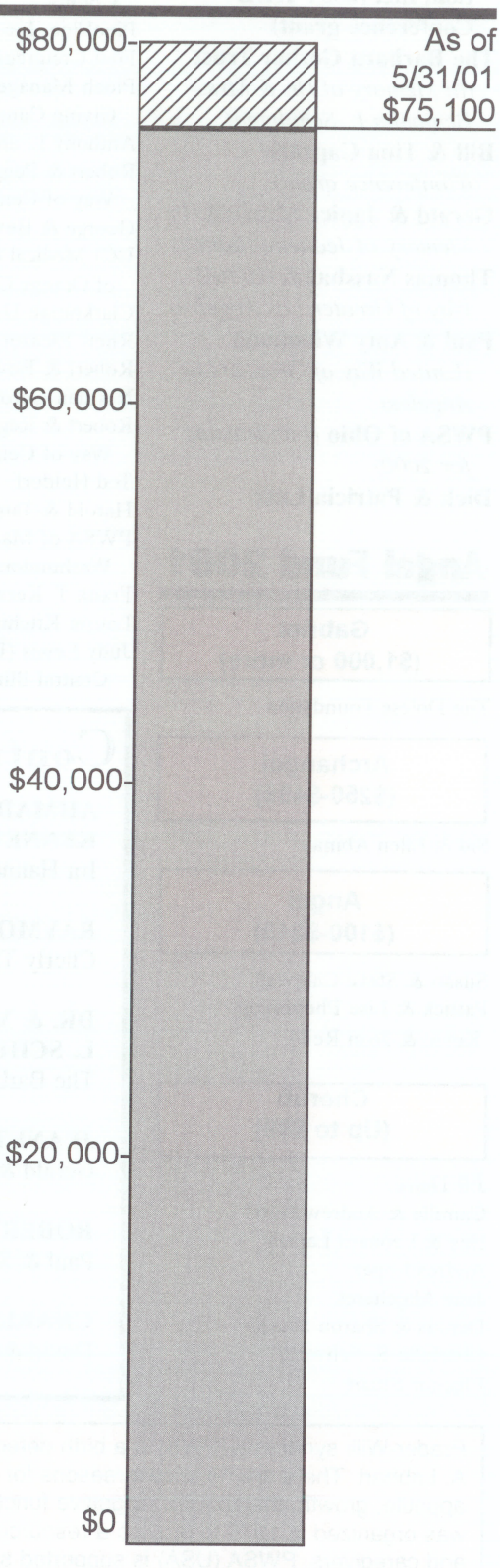
{M: ...and he wonders why I want to gaze at a ball!?!)

Hope Hays
Mountain Park, Georgia

Do you have a joke or funny story to share with readers? Please send your stories, including your name, address and phone number or e-mail address, to the PWSA office.

Angel Fund 2001

OUR GOAL
$80,000



Acknowledgements

Our Sincere Thanks for Contributions Received Through May

Major Benefactors
($500 or more)

The Prader-Willi Foundation, Inc. (2001 YAAP Conference grant)
The Barbara Gerber Trust *(In Memory of Dr. & Mrs. Benjamin L. Schulman)*
Bill & Tina Capraro *(Conference grant)*
Gerald & Janice Mitchell *(In Memory of Jeanette Rubin)*
Thomas Nussbaum *(United Way of Greater Los Angeles)*
Paul & Amy Wissmann *(United Way of Greater Los Angeles)*
PWSA of Ohio *(Fundraising for 2000)*
Dick & Patricia Lutz

Angel Fund 2001

Gabriel
($1,000 or more)

The Dolese Foundation

Archangel
($250-$499)

Sid & Ellen Abma

Angel
($100-$249)

Susan & Steve Caldwell
Patrick & Lisa Phernetton
Kevin & Joan Reilly

Cherub
(Up to $99)

Jill Deitz
Camille & Andrew Good
Bea & Leonard Larsen
Andres Lopez
Jane Majcherek
Dennis & Sharon Saacks
Charlotte S. Schwartz
Eleanor Stuart

Mission Benefactors
(Up to $499)

Allstate Giving Campaign
United Way of Buffalo & Erie County
PipeVine, Inc.
First Congregational Church
Ploch Management (Allstate Giving Campaign)
Anthony L. and Jean Antin
Robert & Peggy Baker (United Way of Central Maryland)
George & Beverly Beck
UCI Medical Center (United Way of Orange County)
Clarkrange U. Methodist Women
Rhett Eleazer
Robert & Beverly Forgues
Norman Gerou
Robert & Regina Hartnett (United Way of Central Illinois)
Tod Holdorf
Harold & Tammy Hopkins
PWSA of Maryland & Metro Washington, D.C.
Frank T. Keenan, Jr.
Laurie Kitchin
Judy Lewis (United Way of Central Illinois)
Jo Martens
Brian & Melissa Mathis
PWSA of Georgia
George & Jennifer Moreno (Pipe Vine, Inc. Campaign)
Kevin & Johnna Newton
Jim O'Farrell
Janice Piggee
Carol Potts (United Way of St. Croix)
Habib Rathle
Vanessa & Donaldo Riordan
Samuel and Patrice Scheck
Timothy & Cindy Schmehl (United Way of New York)
Ann Seigel
Laverne Sidlo
Phillip & Anne Silkoff
Kelly & Amy Soncarty
Cliff & Wanda Strassenburg
Claudene Watts (United Way of Central Illinois)
Wayne & Karen Wendel
Patsy and Jeffrey White
Liz Claiborne Foundation
Research Fund
Stuart R. Boyd

Contributions In Memory Of

AHMAD RASHAD-KENNETH HANNON
Ira Hannon

RAYMOND DORN
Cherly Thompson

DR. & MRS. BENJAMIN L. SCHULMAN
The Barbara Gerber Trust

JEANETTE RUBIN
Gerald & Janice Mitchell

ROBERT BUSH
Paul & Susan Todd

CHARLIE HOWARD
David & Sharon Howard

DIANE GREENBAUM
Rose Ann & Gary Rosenthal
Sandra & Martin Schare

FRANK MOSS
Jeanne M. Hanchett
John Malik
Stewart & Bronnie Maurer
PWSA of Georgia
PWSA of Ohio

AMY NANZIG
Elaine & Peter Logan

STUART PIKE
Esther E. Pike

CHRIS THEROS
Marlene Peter
Albert and Edithe Haener

Membership Donations

Patron Memberships
($100 or more)

James & Peri Anders
Ronald D. Ayotte
Savannah Marie Brice & Family
Thomas A. & Carol A. Campbell
Eugene & Fausta Deterling
Raymond and Phyllis Fuja
Chevron Overseas Petroleum Inc.
Eddie & Madeline Resendes
Linda & Mark Ryan
Fred & Kathleen Schloessinger
Eleanor & Richard Weiner

Contributing Membership
($50-$99)

Stanley Bogaczyk
Mindi & Richard Bressler
Tim & Terri Brubaker
Kevin & Wendy Everhart
Wesley & Colleen Fix
Tom & Sandy Giusti
Mary & David Ingalls
Deborah Johnson
Paul & Mary Gail Kowtna
Paul V. Leonard
Kenneth & Ruth Prettyman
Charles & Margaret Ranberg
Norman & Joyce Smith

In Honor of

MARY BLADEL
Kim Coene
SHIRLEY BURNETT
Charles & Dorothy Benjamin
Selma and Edward Goldstone
Betty Greene
Shirley Weiner
Lois & James Kane
AMANDA DIAZ
The Vale Club
Phyllis Atterbury Loyko
LONNIE DIXON
Virtual Developer.Com
HARRY GOERKE
Fred & Alberta Beguhl

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.