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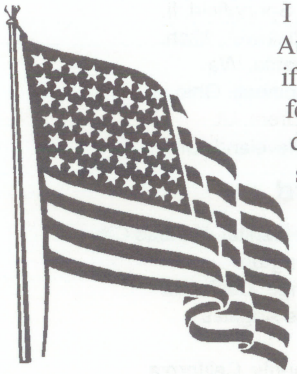
PWSA U.S.A.

The Gathered View

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

A Time to Grieve... A Time to Heal... A Time to Carry On

By Janalee Heinemann, Executive Director



I have a file named "post 9-11-01." At this time in our history, it seems as if everything is post 9-11-01. It may feel the same as when your child was diagnosed with Prader-Willi syndrome. Everything was changed from that point on. First the shock, then the intense grief, the fear, the anxiety about the future and then the difficult question of "how do we go on from here?"

The sense of being united with others who are fighting the same battle is a feeling we also know on two levels – as Americans and as PWS parents. Because we are a family, and often share our experiences and feelings about PWS, I would like to should share with you a few of the e-mails and calls I received "post 10-11-01." Some names will not be shared, but as we know all too well at this point, the experience could have happened to any of us.

From around the world — On that fateful day of 9-11-01, I received a phone call of concern and support from our IPWSO International President Girogio Fornasier of Italy, who said his prayers were with us. We also received e-mail messages of support and comfort from national PWS leaders from around the world, such as the following from France:

"I was very honoured and happy to be the French delegate at the International Prader-Willi Syndrome Conference in Saint Paul. We are very grateful to the American association to have organised it. I would like to tell you that Prader Willi France and I feel very close from you also on those days of ordeal and mourning for America. Yours sincerely, Christel Nourissier."

From the wife of our New York state chapter president: "It's by the grace of God that Henry was not at work that morning. His office is in the same block as the World Trade Center. All of his fellow workers had to run for their lives. No one was hurt to their knowledge, but they are unaware of the shape of his office. Henry was working at the primary elections and not in this office. They are in shock and grieving tremendously."

From a young father who works at the White House: "Thanks for your support and prayers, we all need them now! My life has changed forever, as many Americans have experienced. This is the first chance I've had to respond to e-mails since that horrific morning. It brings great sadness to have to witness our Pentagon being hit by terrorists. I was there on Constitution Avenue near the Washington Monument when it occurred. To see the panic in the eyes of our countrymen and watch the fire and smoke drift by the Washington Monument throughout the city made me think back to when this nation first fought for its liberty and was born a United States. The only good that will come of this is that this country will unite and become even stronger! All of our lives will change, as mine has done since that dreadful day!

"I appreciate your support and concern. I've held Roll Calls and gave prayers for our fallen comrades at the World Trade Center and prayed for all of our men and women who may fall in the coming months. My wife's sister lost 700 employees at the World Trade Center Tower #1. This strike hits all of our lives, but remember, this country will grow stronger every day because of it! God Bless."

From Linda Ryan, a mother in California: "I'm still sitting here, almost a week later, in disbelief and utter sadness. Those of us who travel globally truly realize the impact on our freedoms. Mark left yesterday for Belfast, London and Athens and I was awake and in tears most of the night until I heard he was safely in his hotel early this morning.

"My niece, Julie, who is a reporter for *Newsweek*, did a live report from the scene and had to run for her life as the 2nd tower collapsed. My brother Phil is a nurse and he spent the morning doing triage and then days organizing the deliveries of emergency hospital equipment from all over the USA to the site. My other brother is a dentist in Washington, D.C. He

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inside

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At this holiday season
let us remember loved ones,
honor those who serve others
and pray for peace

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.

The PWS World Goes High Tech and High Support

PWSA (USA) has been busy in the tech area, and now it is roll-out time for some exciting new support and e-mail groups. Already under way is an E-Group for PWSA (USA) Board and Officers and an E-Support Group for Parents. An E-Group for Chapter Leaders is on the drawing board and is expected to be up and running between the first week of December and the first of the year. An e-mail group has one address, and all messages are sent to all the people who belong to that group. Membership in the group is by invitation, making it easy to include all who should be included.

Auxiliary Membership system – In an effort to educate those who interact with people with PWS and provide them with the most current information, members will now be able to establish auxiliary memberships for grandparents, teachers, doctors, etc. The sponsoring member will be billed $15 for each auxiliary membership. The auxiliary membership is a full membership which includes *The Gathered View* newsletter and discounts on our publications. See the Auxiliary Membership Form on pages 11 and 12, go to our web site or call the national office (1-800-926-4797) to obtain the auxiliary form.

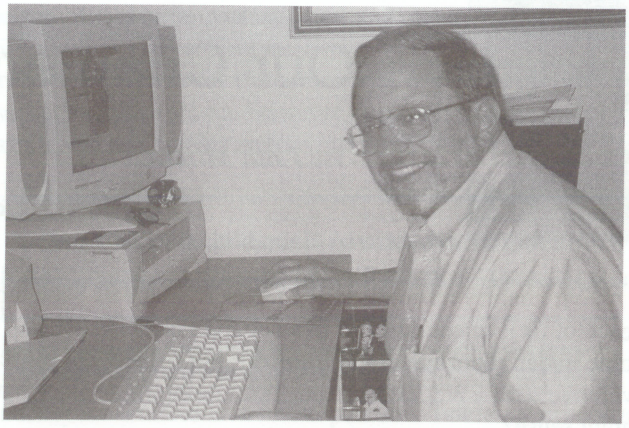
Supportive Living database and website – to maintain updated information on supportive living alternatives. It is important to know all of the supportive living options available for our loved ones who have PWS. This database will offer information about possible placements that will cater to your child's needs in your area or surrounding area.

E-Support Groups for Parents – PWS E-Mail Support/Information Program is an e-mail discussion group generating wonderful support and information for families who have children with PWS. Also included in our list family are professionals who care about our children, who are seeking to learn from the family experience, and who may offer more information from their professional vantage point. Our goal is to connect families and professionals from all over the world. Together we can build a brighter future for our children and build healthier families.

These groups will be divided into three age categories. The first group will be for the parents of young children, ages 0-5. (This group is up and running). The second group will be for school-age children, 6-17. The final group will be for parents of teenagers. These lists will be able to focus on the particular age group and will pertain only to those who are on each list. This will be a wonderful way to communicate with one another. For further information, go to our web site.

E-Chapter Leaders Group – This group, created to increase communication between national and local chapters, and also communication between chapters, will include all Chapter presidents, officers and board members. It will replace the Chapter Presidents' Quarterly (CPQ) as a more effective and current communication tool, permitting timely messages about new developments and increasing the flow of information to many more key members in the chapters. The CPQ has been very useful, but it has its limitations, such as going to only one person and not allowing for exchange of help and support between chapters.

NOTE to Chapter officers and board members: Please make sure your president has your e-mail address to send to national before Dec. 1, so that you can be included in the E-Chapter Leaders Group, or send it, along with your state affiliation, directly to Jessica Mancheno at national.



PWSA office gets tech upgrade

A technological Angel from heaven dropped into our lap – and stayed for three weeks! Manny Emmanuel, grandfather to two- year-old Isabel and father-in-law to our board member, Rob Lutz, donated more than $7,000 worth of computer equipment to our office. He drove it here from New Jersey, then stayed to upgrade us all to Microsoft Office 2000, put us on a server and set up an electrical and automatic data backup system.

Future Programming

E-Support Group for people with PWS – Our children and adults with PWS often ask for pen pals. This will be a way for them to communicate to one another via e-mail. It will be moderated by an adult. We will also be organizing an e-support group for parents of adults with PWS.

Registration web forms for conference and a confirmation system will ease the conference registration process. Immediate confirmation that we received your information and that you are approved will be available. We hope also to have hotel registration and confirmation via email.

Shop The PWSA(USA) Web Mall

With the PWSA(USA) Internet Shopping Mall, shoppers have their choice of 140 top Internet merchants who pay "Your Organization" commissions on all purchases. Shoppers pay the same prices for their purchases, and PWSA(USA) gets a commission up to 14 percent on every sale.

This is a great way for supporters who shop on-line to help even more. Merchants like Amazon, CDNOW, Borders.com, Disney, ESPN, L.L. Bean, Lands End, CVS.com, Hallmark, and FTD are participating.

The mall can be found at www.pwsausa.org. All shopping is fully secured, and the mall respects and offers full privacy protection. A newsletter is even available to shoppers to find out about sales and specials. The mall is simple to use and navigate, and it really makes shopping easy.

Speech Therapy - *continued from page 5*

The prognosis

While "outcomes vary… the factors that appear to contribute to prognosis include:

- individual characteristics of the child; [including] receptive ability, cognitive ability, desire to communicate, age at which appropriate treatment is begun (preschool age is desirable) and attention span
- the extent to which other speech and/or language issues are present
- the extent to which therapy is tailored to the unique issues present in the child
- the extent of family participation and involvement in therapy follow-through at home.

The bottom line is, "with appropriate help, many children with apraxia of speech make wonderful gains in their expressive ability."

Apraxia of speech is a specific medical diagnosis covered by most insurances.

For more detailed information about apraxia, contact the national nonprofit for apraxia — the Childhood Apraxia of Speech Association, 123 Eisele Rd., Cheswick, PA 15024; (412) 767-6589; Internet: www.apraxia.org; e-mail helpdesk@apraxia.org.

Lisa Graziano of Redondo Beach, California is the mother of Cameron, age 2½, and volunteers as a PWS New Parent Mentor.

In Search of Angels For Our Annual Angel Fund Drive

Annual giving to non-profits is expected to be limited this year due to the generous response to our national crisis. We applaud these efforts, and encourage everybody to do their part in helping our country.

We also recognize that the needs of our children struggling with Prader-Willi syndrome have not disappeared. We must fervently continue our work to free our children from their unrelenting hunger and to free them from all that limits their potential.

We need your help more than ever! We ask you to send us the names of relatives, friends, and anyone else you feel might be appropriate to receive our Annual Angel Fund card.

The events of September 11 have kindled a new spirit of generosity for many. It is our hope that this same spirit will carry us through this difficult time. Help us spark the fire of support within those you know. Please give us the opportunity to reach out to the angels you know by calling our toll-free number, 1-800-926-4797.

Presidents - *continued from page 4*

NORTH CAROLINA — Married with two children, Ted, 10, with PWS, and daughter, aged 3, **Mary Patterson** has a Master's in Social Work and worked in that field for 10 years, including with children with emotional and behavioral disturbances. She then got a degree in computer engineering and works full time for a producer of telecommunications and Internet equipment. She is now thinking of her next career, dreaming of doing clinical trials of pharmaceuticals. She has been president for the past year.

GEORGIA — This is one of the few fortunate chapters who have both president and Executive Director. President **Greg Talley** is a chiropractor who has been involved with the chapter since Tom, now 19 and Greg's only child, was diagnosed at the age of 3. Greg gives **Hope Mays**, the executive director, credit for doing most of the work, but he was instrumental in getting funding from the state of Georgia, which has allowed the chapter to provide many services to its members, most recently the opening of a full service clinic.

Hope was widowed when her only child, Clyde, now 21, was very young. She works 20-25 hours a week. The chapter office will be moving out of Hope's house into new space very soon.

COLORADO — **Lynette Hosler,** previously a first- and second - grade teacher and a stay-at-home mom now, has been president for 6 years. She is also a deacon in her church. Her daughter, Jennifer, 8, who has two younger sisters aged 5 and 2, was diagnosed at 3 months and is doing "great." Lynette feels particularly fortunate because she has so much family support, living in the same town as her parents and three sisters.

OKLAHOMA — The mother of Brandon, 27, **Daphne Mosley** has a good job that she really likes as executive assistant to the chief of staff in the Oklahoma State Department of Education. She also served a term on the PWSA(USA) Board of Directors.

ILLINOIS — Her sister's child, Cody, 9, brought **Karen Engelhardt**, into the PWS family. She is a devoted aunt to take on the chapter presidency, but right now she is really struggling. A nurse in the computer department of a hospital, she works 50-hour weeks and isn't home much. She is hoping that "someone with drive" will take over next.

INDIANA — The proud father of daughter Riley, aged 2½, **Troy Keen** is a mechanical engineer who is in building and maintenance oversight. He also has a background in radio and telecommunications and is computer savvy. Add to all that the fact that he is doing the cookbook for PWSA(USA) which is almost done and should be available before long.

Don't we have a wonderful and diverse group who have put their shoulders to the wheel? We can be proud of each and every one of them — and let's tell them so! In the next issue of *The Gathered View*, more of our chapter presidents will be featured.

Anesthesia and Prader-Willi Syndrome

By James Loker, M.D. and Laurence Rosenfield, M.D.

Introduction

This article discusses anesthesia as it relates to individuals with Prader-Willi syndrome. Anesthesia is the field of medicine that deals with the protection of patients during painful and/or unpleasant diagnostic, therapeutic, or surgical procedures. Some individuals with PWS have minimal health problems and present minimal risk for anesthesia, while others have problems with obesity, obstructive apnea and pulmonary hypertension. Their physician should individualize any recommendations for the patient. The patient's clinical condition is the most impor-tant aspect of the pre-operative evaluation.

Prader-Willi syndrome is a genetic disorder involving chromosome 15. The incidence is 1:15,000, and it is the most common genetic disorder known to cause life-threatening obesity in children. Prader-Willi syndrome by itself does not increase the risk with anesthesia; however, there are common characteristics that should be taken into consideration with anesthesia.

Prader-Willi syndrome by itself does not increase the risk with anesthesia; however, common characteristics should be taken into consideration with anesthesia.

Information for the Anesthesiologist

Issues Affecting Prader Willi Syndrome and Anesthesia

As stated earlier, there is nothing unique to individuals with Prader-Willi syndrome and their response to anesthetics. There are, however, health issues that can alter the course of anesthesia.

Obesity

Obese individuals are more prone to obstructive apnea, pulmonary compromise, and diabetes. Each of these should be taken into account when preparing for anesthesia. The individual may have altered blood oxygen or blood carbon dioxide levels that will change his or her response to medications including oxygen. Pulmonary hypertension, right-heart failure and edema may necessitate evaluation by a cardiologist or pulmonologist prior to surgery. An ECG to detect right ventricular hypertrophy may be beneficial to assess pulmonary hypertension.

Frequently obese individuals with PWS may have significant body edema (extra fluid) that is not fully appreciated due to obesity. This should be carefully evaluated, and if necessary, diuretics used before and after the anesthesia. Airway management can be a particular problem when conscious sedation is used.

High Pain Threshold

Individuals with PWS may not respond to pain in the same manner as others. While this may be helpful in post-operative management, it may also mask underlying problems. Pain is the body's way of alerting us to problems. After surgery, pain that is out of proportion to the procedure may alert the physician that something else is wrong. Other possible signs of underlying problems should be monitored.

Temperature Instability

The hypothalamus regulates the body's temperature. Because of a disorder in the hypothalamus, individuals with PWS may be either hypo- or hyperthermic. The parent or caregiver can be helpful in letting the anesthesiologist know what the individual's usual temperature is. Although there is no indication of a predisposition to malignant hyperthermia in PWS, depolarizing muscle relaxants (i.e., succinylcholine) should be avoided unless absolutely necessary.

Thick Saliva

A common problem in PWS is unusually thick saliva. This can complicate airway management, especially in cases of conscious sedation or during extubation (when a breathing tube is removed). Thick saliva also predisposes an individual to dental caries (cavities) and loose teeth. Oral hygiene should be evaluated prior to anesthesia.

Food-Seeking Behaviors

It is vitally important that any individual undergoing general anesthesia or conscious sedation have an empty stomach. This reduces the risk of aspiration of the stomach contents into the lungs. Individuals with PWS generally have an excessive appetite and may not tell the truth if they have eaten just prior to surgery. Any individual with PWS should be assumed to have food in the stomach unless it is verified by the caregiver that he or she has not eaten. A tube may need to be placed in the stomach to assure no food is present prior to attempting to place the breathing tube. Some individuals with PWS may ruminate (regurgitate some of their food) and are at higher risk of aspiration.

Hypotonia

The majority of infants with PWS are significantly hypotonic. This usually improves by 2-4 years of age. The majority, however, continue to have lower muscle tone than normal individuals. This may be a problem in the ability to cough effectively and clear the airways after use of a breathing tube.

Skin Picking

Habitual skin picking can be a significant problem in PWS. This can complicate healing of IV sites and incisional wounds. Usually if these remain well covered, they will be left alone. Depending on the individual's cognitive impairment, restraints or thick gloves may be needed to protect surgical wounds during healing.

Anesthesia continued on page 8

Difficult IV Access

Due to several problems including obesity and lack of muscle mass, individuals with PWS may pose difficulties with insertion of an intravenous line. A stable IV line should be present in any individual undergoing anesthesia.

Behavior Problems

Individuals with PWS are more prone to emotional outbursts, obsessive-compulsive behaviors and psychosis. They may be on extensive psychotropic medication, and the possible interaction of these medicines with anesthesia should be appreciated.

Growth Hormone Deficiency

All individuals with PWS should be considered growth hormone deficient. The FDA has recently recognized a diagnosis of PWS as an indication for growth hormone therapy. Growth hormone deficiency does not appear to alter cortisol release in response to stress; so steroid supplementation is not necessary. Individuals with PWS who are not on growth hormone treatment may have smaller airways than would be expected for their body size.

Information for the Caregiver

An anesthesiologist is a physician with four years of residency specializing in anesthesiology. Pediatric anesthesiologists will have more experience in the unique problems presented by children, but they may not be available in all locations. Certified nurse anesthetists are nurses with 2 years of anesthesia school. They practice full-time anesthesiology under the supervision of an anesthesiologist.A basic understanding of the types of anesthesia is important to understand its impact on the body.

General Anesthesia

General anesthesia is a state of controlled unconsciousness usually involving a combination of narcotics, muscle relaxants, and/or inhalation anesthetics. It also involves placing a tube in the windpipe to protect the patient's airway and placing the individual on a ventilator (breathing machine). This type of anesthesia is used when a patient must be asleep and all muscles completely relaxed or when the procedure will take a long time. It should always be done under the care of an anesthesiologist or certified nurse anesthetist.

Conscious Sedation

Conscious sedation is a type of anesthesia where sedatives are used, but the patient is intended to remain at a level of consciousness such that he can be aroused, follow commands and talk, and yet be sedated enough that he has no memory of the event and hopefully no pain.

By varying the amount and types of medications, the level of consciousness can be altered depending on the patient's anxiety, metabolism and tolerance to drugs such as alcohol and opiates. These medications are potent enough to produce the wide range of levels of consciousness, from essentially wide-awake to general anesthesia without a breathing tube.

Therein lie the problem and the dangers with this type of anesthesia. By giving too much conscious sedation medicine, a patient may achieve a state of general anesthesia, yet not have experts around to manage airway problems that could occur — that is, to place a breathing tube or oral airway device to keep the tongue from obstructing the airway.

This form of anesthesia is of most concern to family members of those with Prader-Willi syndrome because it is used in situations where appropriate monitoring of the patient is not always carried out, and availability of anesthesia care providers may be lacking. The doctor or nurse performing the sedation should have a clear understanding of airway reflexes and the ability to manage respiratory depression and difficult airway problems. It is very important to understand the patient's condition and have the appropriate monitoring and medical professionals available to manage these potential complications. Conscious sedation is often used in combination with regional and local anesthesia (see below).

Regional Anesthesia

Regional anesthesia involves blocking nerves to parts of the body. It can involve a small region, such as part of the arm, or a larger region with spinal anesthesia. Anesthesiologists usually use regional blocks for surgery below the chest. Dentists also use them for dental work. Conscious sedation is sometimes used in conjunction with regional anesthesia.

Local Anesthesia

Local anesthesia involves injecting numbing medicine into the skin, but not blocking the major nerve plexus. It is generally used without an anesthesiologist and carries the lowest level of concern.

Conclusion

People with PWS can safely undergo anesthesia. Risks are related to their general health before the procedure. The majority of complications do not appear to come from general anesthesia, which is always closely monitored, but from poorly monitored conscious sedation. Only a physician familiar with the patient and his or her individual medical needs can make valid medical decisions. Ensure good communication with your physician, and do not hesitate to ask questions if matters seem confusing.

Understanding Anesthesia

By Delfin J. "Sam" Beltran, M.D.

Anesthesia has been called the greatest advance in modern medical care. It is a controlled, reversible state of insensibility that permits surgical treatment of abnormal conditions. Anesthesiology is the study of the anesthetic agents and their effect on the human. More than 150 years of studies have failed to reveal why multiple unrelated chemicals can produce this condition.

Formal scientific university medical school investigations have been undertaken by anesthesiologists since the 1920s (Wisconsin: Waters - 1926). These studies produced new, safer anesthetic agents and techniques, along with life

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Understanding Anesthesia -*continued from page 8*

supportive equipment and monitors. People considered too ill to undergo corrective surgical procedures because they would probably die under the anesthesia only 50 years ago, can now safely undergo life-altering interventions requiring teams of surgeons and anesthetic support for more than a day.

Statistically the odds of not surviving an anesthetic 50 years ago was quoted as 1 in 15,000; approximately the same ratio as the occurrence of Prader-Willi syndrome. Recent studies indicate the current rate of fatal complications due to anesthesia are 1/25th of that quote. One in 400,000 are the odds used to define the chances of being hit by a car while walking on the sidewalk of your home town. This is not a guarantee of safety. When an individual undergoes a medical procedure, an undesirable outcome can occur without a known causation. No human knows and understands all of the mechanisms that create and maintain life, or all of the variations that exist from one moment to the next in any individual.

When you sign an informed consent for surgical treatment under anesthesia, it means that you understand that these undesirable effects can occur even under the most ideal conditions available. No one can force you to accept any medical treatment for yourself or your child. Medical care is offered according to the available means to treat the medical condition. In some cases a statistical probability may be offered, but that is based on prior experience with other patients and has no valid predictive value for any one patient or his or her future.

Fear of anesthesia is the most common reaction parents have when they are told that their child needs to have surgical treatment. The patient usually has significant apprehension that will remain until the senses have been removed by medications. These mind-altering medicines are usually given as soon as a pre-operative evaluation by the anesthesia doctor has been completed and the patient is waiting for his or her turn in the operating suite. While the patient is undergoing surgery, those waiting have anxious moments and worry when the start is delayed or the procedure is prolonged. In many situations the preparation for the procedure may take longer than the accomplishment, and the duration of a treatment can never be accurately predicted.

The chromosome changes that mark Prader-Willi syndrome create no changes that make anesthesia inherently more dangerous than for a person without the altered gene patterns. Obesity compromises health with or without PWS. The metabolism of anesthetics in PWS does not cause longer recovery periods. Inappropriate food ingestion can cause vomiting and aspiration pneumonia with or without the syndrome. PWS does not cause any known change in how our bodies live that will increase the risk of anesthesia.

Dr. Beltran's Tips for Caregivers

Ingestion of solid food or non-clear fluid after bedtime is a standard cause for cancelling anesthesia for that day. Check with the anesthesia team for current rules regarding clear fluids prior to anesthesia. Different age groups or medical conditions may require a different rule. If the person with PWS is to be hospitalized, the staff must be informed of possible food foraging and a special limited caloric diet must be prescribed.

The administration of daily medications used by the patient must be confirmed with the anesthesia team. Some medications and alternative therapies may require a week's delay for safe anesthesia. Special attention should be given to medications used for asthma or breathing diseases as well as infections. If the patient has allergic rhinitis or a cold, the anesthesia team needs to determine the appropriateness of conducting the anesthetic.

If the person with PWS has complications of PWS or other medical problems the team needs to know about the condition and any ongoing treatments.

If anesthesia will be required for a dental or outpatient procedure, this should be confirmed at the time the procedure is scheduled. Determine that a qualified anesthetist will be available to conduct the anesthetic. Ensure that the anesthetist is provided with the information contained in this article prior to the day of surgery.

When behavior disorders or communication and mobility problems complicate the condition of the person with PWS, it is the responsibility of the care-givers to ensure safe transportation and sufficient support persons both to and from the procedure. Recent studies identified that the deaths related to outpatient surgery were as likely to occur in a motor vehicle accident on the way home compared to the unlikely death during the treatment procedure.

Reduced pain medications may be sufficient to manage post operative discomfort because of the altered pain perception of PWS. This may reduce the likelihood of undesirable side effects.

People with PWS often have lower normal temperatures. If so, a normal reading may really be a fever for that person.

In this day of government and managed care, most hospitals are understaffed by qualified professionals. If a person is to be hospitalized, it is advisable to plan on providing your own support to your family member while under this level of care.

Sam Beltran, M.D.has been an anesthesiologist for many years and is the father of Sarah, AGE who has Prader-Willi syndrome.

Correction

In the September-October 2001 issue of *The Gathered View*, we incorrectly identified the woman performing "Fly High" with IPWSO President Giorgio Fornasier. She is soprano Monika Fuhrmann of Germany, secretary of IPWSO. Our apology to Monika, we sincerely regret this error.

watched in horror, knowing his daughter and her fiancé live and work just blocks from the WTC, only to see his horror continue as the Pentagon was hit. He is still finding out the names of his patients/friends who were senselessly killed.

"I'm praying for each of us to have the strength we need to get through this terrible time and for what's to come. Take care."

From a mother in New York, Michelle London, president of the Prader-Willi Alliance for Research: "The son of one of my assistants was a firefighter. His partner was found in a hospital in New Jersey. He is still lost. The debris has now been cleared from my office building. Everything that remained is burnt. The building has now been taken over by the feds and used as a morgue. I have fled to Pennsylvania for a few days rest, but my fears came with me." **Later from this same mother:** "We are very concerned today that the cement retaining wall from the Hudson river next to the World Trade may not hold. If this happens, the remaining building in the complex will fall. Also today we found out that several colleagues who worked in the building directly north of my building did not make it out, having been struck within their offices by falling debris. I am being called back to work on Monday and will be 1.5 blocks from my regular location and I am none to happy about this. National guards are on every corner handing out masks to help people to breathe over the thick dust."

From one of our physicians: In a phone call with Dr. Rob Wharton, who is on our Clinical Advisory Board, I learned that his brother was manager of the World Trade Centers. He did get out alive, but had been on one of the top floors at the time.

From a pilot friend who was a New York Firefighter: I had another phone call from an old friend who is a TWA pilot from St. Louis, who called me because one of his best pilot friends just got a diagnosis of PWS for his child.

John was president of Operation Liftoff for years while I worked with children with cancer. We volunteered on many special projects together. Meanwhile, John told me that he had just come back from working the rescue efforts. John's dad is a retired fireman in New York, and John was once a fireman there. John said he could not recognize streets when he got to New York because they were so damaged and full of dust and rubble. He said 50-plus fire trucks were destroyed. The stories of the human toll are so overwhelming in numbers that most people try to separate from it. He said the firemen just work the ruins, go to funerals and sleep. Then they get up and start all over again.

John has volunteered in the field of death and dying for years, and in his own life makes Indiana Jones look like a tenderfoot. In spite of this, he told me he cried like a baby all the way home from New York on the plane. After we talked, John was going back to New York the next day for two funerals of firemen. One was a fireman whose wife is expecting a baby.

A young man with Prader-Willi syndrome: The impact on our children of all ages was poignantly expressed through Phillip Keen. Phillip was a member of the One List, and e-mailed how distraught he was about the terrorist acts. Phillip e-mailed the group, "Pray for me because I cannot stop eating." A few days later, his aunt found Phillip dead in his bed. (See page 14 for Phillip's story.)

How do we go on from here? We are all struggling with the answer to that question. In my own internal struggle, I turned to the lessons I learned while working for 10 years with children diagnosed with cancer. I was especially close to the teens with cancer. Helping them learn how to cope and go on with their lives was a challenge – with rewards beyond compare. Like all of us post 9-11-01, they had to learn how to live and find joy in their lives, never knowing when the elusive killer, cancer, would shatter their lives again. As one teen who had been battling cancer for years said to me, "We have grown up together. We have seen too much and lived through too much. The coping skill of denial that worked for us when we were younger won't work for us anymore. Now we have to stare death in the face, deal with it, and then figure out how we can go on from here – to live life as best we can – if it's 6 months or 60 years we have left." We talked about what we wanted the most out of life. He said it would be that people would remember him with respect and love.

As Prader-Willi parents, friends and relatives, you have... learned to love and fight for a child the world would see as less than perfect.

These teens saw life at its best and its worst. They died many times over – through the death of a dream, the death of a career, the loss of a leg or the loss of their hair, the loss of their innocence. The similarity for us is that we have also lost our innocence, and are now seeing people at their best and their worst. The acts of the terrorists and the acts of the firemen and police who risked their lives will forever be etched in our minds. We are also now "dying" many times over through the loss of physical and financial security. Every time we hear of a new anthrax victim or of a new threat we had not even thought to worry about before, a little bit of us dies.

Is this the dark side of life? Or is the dark side of life a superficial world where nothing counts but your looks, your wealth and whom you impress? As Prader-Willi parents, friends and relatives, you have already taken the first big steps beyond superficiality. You have learned to love and fight for a child the world would see as less than perfect. You have learned to look into the depth of a person's soul and to sacrifice for another.

You know the mixture of feelings that come with a special needs child – that pain, joy, love, anger, compassion, grief, patience and understanding all go hand-in-hand. You have learned to live with fear and uncertainty. Like my teens with cancer, you have learned that there are many things beyond your control, and yet you must carry on.

What will happen to us? I do not know. I only know that in the time I have, I can make a difference in this world. So can you. Help me to help our children. Together we can continue to look for an answer to their hunger and fight for their freedom from all of the controls that their hunger must bring – as we fight for freedom for all of us around the world.

The Prader-Willi Syndrome Association (USA) Auxiliary Membership Application

FOR AUXILIARY MEMBERSHIP ONLY

5700 Midnight Pass Road, Suite 6, Sarasota, Florida 34242

Telephone: Toll-free (800) 926-4797 • Florida (941) 312-0400 • Fax (941) 312-0142

• E-mail: PWSAUSA@pwsausa.org

Member Name(s): _____ _____

(First) (Last)

Org. Name _____

(Title/Affiliation/Organization, if applicable)

Address: _____

_____

(Street)

_____ _____ _____

(City) (State) (Country) (Zip/Postal code)

Telephone: Home (_____)_____ Work (_____)_____ **E-mail:** _____

Name of Person with PWS _____

DUES FOR AUXILIARY MEMBERSHIP ONLY

	U.S. Addresses	Outside the U.S.	Amount Enclosed:
AuxiliaryMembership	$15 per person	$25 US Funds per person	Auxiliary dues $ _____
			Additional contribution $ _____
			Total $ _____

MAKE CHECKS PAYABLE TO: PWSA (USA)

Note: International orders must be paid in U.S. currency, international money order, or through a bank with a U.S. clearinghouse

FOR CREDIT CARD PAYMENTS: ☐ **Master Card** **OR** ☐ **Visa**

Card No. _____ Exp. _____

Name on Card _____

PWSA Policy on Member Lists: We encourage our members/auxiliary members to share information both for research on PWS and for family support and other member networking. As a general policy, these lists are never sold for commercial purposes. Please indicate by checking the appropriate box(es) on the other side whether we may include your name or your auxiliary member in these two lists:

Research List—Research projects, often in the form of surveys, may solicit participants from this list of members. All research proposals must be approved by the Scientific Advisory Board of PWSA (USA) before release of this list.

Membership Sharing List—Your name may be given out and will appear in a published membership list available for sale to PWSA members for networking purposes.

NO RELEASE—Your name will be kept on a confidential list, available only to PWSA officials.

Signature _____

For futher explanation, see page 3 of this issue or contact our toll free number, 1-800-926-4727

BE SURE TO COMPLETE THIS PAGE *AND* PAGE 12

PWSA (USA) Auxiliary Members

1) Name(s): _____ _____
(First) (Last)

Address

_____
(Street)

_____ _____ _____ _____
(City) (State) (Country) (Zip/Postal code)

Telephone: Home (_____)_____ Work (_____)_____ **E-mail**: _____

Families — What is the relationship of the person(s) above to the person with Prader-Willi syndrome or organization?

❑ Parent(s)/guardian(s) ❑ Sibling ❑ Grandparent ❑ Other Relative ❑ Other/Professional_____

Member List: ❑ Research List ❑ Membership Sharing List ❑ No Release

==========

2) Name(s): _____ _____
(First) (Last)

Address

_____
(Street)

_____ _____ _____ _____
(City) (State) (Country) (Zip/Postal code)

Telephone: Home (_____)_____ Work (_____)_____ **E-mail**: _____

Families — What is the relationship of the person(s) above to the person with Prader-Willi syndrome or organization?

❑ Parent(s)/guardian(s) ❑ Sibling ❑ Grandparent ❑ Other Relative ❑ Other/Professional_____

Member List: ❑ Research List ❑ Membership Sharing List ❑ No Release

==========

3) Name(s): _____ _____
(First) (Last)

Address

_____
(Street)

_____ _____ _____ _____
(City) (State) (Country) (Zip/Postal code)

Telephone: Home (_____)_____ Work (_____)_____ **E-mail**: _____

Families — What is the relationship of the person(s) above to the person with Prader-Willi syndrome or organization?

❑ Parent(s)/guardian(s) ❑ Sibling ❑ Grandparent ❑ Other Relative ❑ Other/Professional_____

Member List: ❑ Research List ❑ Membership Sharing List ❑ No Release

==========

4) Name(s): _____ _____
(First) (Last)

Address

_____
(Street)

_____ _____ _____ _____
(City) (State) (Country) (Zip/Postal code)

Telephone: Home (_____)_____ Work (_____)_____ **E-mail**: _____

Families — What is the relationship of the person(s) above to the person with Prader-Willi syndrome or organization?

❑ Parent(s)/guardian(s) ❑ Sibling ❑ Grandparent ❑ Other Relative ❑ Other/Professional_____

Member List: ❑ Research List ❑ Membership Sharing List ❑ No Release

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BE SURE TO ALSO COMPLETE PAGE 11

We Remember

By Janalee Heinemann, Executive Director

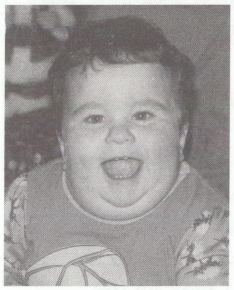
Forward: I have written more in detail about the death of some of our special members in this newsletter for two reasons. First, each of our young people with PWS had something special to offer this world – and we, along with their families, want to share who they were and what they meant to the people who loved them. Second, when we have shared information in The Gathered View about a death, other families often commented they wanted to know what the cause of death was, because we fear the unknown more than the known.

As most of you are aware, we have a bereavement follow-up program coordinated by our volunteer, Norma Rupe, who lost her own daughter. We also have articles that we are more than willing to send our members free of charge.

The following is more than the recording of the death of our young members with Prader-Willi syndrome. It is a testimony to their lives. There is an Indian belief that you live on through your loved one's memories of you. You are not truly dead until the last memory of you is gone – so we remember – and our children live on through that shared memory.

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

Michael Schaffer



Our hearts go out to our youngest angel, 4-year-old Michael Schaffer of Flugerville, Texas, who died unexpectedly on Oct 16. He was the youngest child of Debra and Tom Shaffer. Debra and Tom said that Michael never knew a stranger and was loved by everyone. He was very happy, always smiling, and a people person – everyone was drawn to him.

Michael's death was unexpected: he had been playing and lay down with his family to watch TV when he suddenly could not catch his breath. He was rushed to the ER, where he was intubated, but his heart rate dropped and medical staff members were not able to save him.

To add to the tragedy of Michael's death, in spite of the request for an autopsy by his parents and the pediatrician, the medical examiner refused. We worked with their compassionate pediatrician, Dr. Sam Mirrup, the funeral home, and two physicians on our Board to solve this urgent problem. We were able to get a pathologist from a nearby children's hospital to agree to do the autopsy. The pathologist consulted with our physicians prior to the autopsy regarding what to look for. The hospital agreed to do the autopsy for no charge, and the funeral home took care of the transportation. The family could have been charged $1,200-$1,500.

Most people do not realize that a medical examiner can refuse an autopsy. If the medical examiner deems that it was not a suspicious death, and that the cause of death is known, that examiner can choose not to do the autopsy. In Michael's case, the medical examiner put on the form as cause of death "a result of aspiration pneumonia due to Prader-Willi syndrome, natural." We will aid this family in continuing to pursue the real cause of death. They deserve an answer.

Danny Shaz

Danny died on September 3rd at age 30 of a weight-related heart attack. He was living at home with his parents, Dr. Sol and Vicky Shaz of Rockville, Maryland, the second of five children. Danny's father writes, "Danny was a perpetual Peter Pan. He graduated high school – a great achievement for him. He never resented his brothers and sisters who were academically gifted, but was proud of them and rejoiced in their success.

"Danny knew of no malice to anyone. Of the violence in the Middle East, Danny had a solution. He said, 'Why don't they play baseball, basketball and soccer together instead of fighting?'"

Denise Capitani

Denise, who was 37 years old, lived with her mother Helen in Cherry Hill, New Jersey. She died on August 14 in the hospital due to weight-related causes. Prior to her death, her brother Bob was her strong support and advocate. Bob said "Denise had a very strong faith that kept her going and just days before she died, while on a ventilator herself, she wanted to know how others on the sick list at church were doing. She always thought more of others than she did herself."

Denise was the volunteer transportation coordinator for the American Cancer Society for three counties. Bob also said of his sister, " She didn't run great, she didn't walk great – but her heart was made of gold."

Stephen Singer

Stephen died on August 18 at age 52. His parents are deceased and he lived at Keystone Community Residence. Joy Smith from Keystone said that "Stephen was extremely affectionate, and loved dogs. Their family dog, Ginger, died 40 years ago, but Stephen had not given up on finding him again." Stephen was very close to his siblings, Richard, Linda and Judith. Stephen also loved spending time with his nieces and nephews. His sister Linda said "Stephen was a very social person and sensitive to others' feelings. His favorite song was 'You Are My Sunshine' — and that is how we felt about him." When Stephen would hear of the death of a person he knew, he would tell his sister, "I am going to live my whole life!"

Stephen choked to death on a piece of food that became lodged in his larynx. There have been other deaths such as Stephen's due to sneaking food that is then gulped down quickly as a whole piece. Due to a poor gag reflex, food lodges in the throat and the person cannot cough it up.

We Remember continued on page 14

We Remember

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Stephen Elwin Roberts

Stephen was 37 years old and died October 7 during a visit at his parents' home of an apparent heart attack. He lived at the Avatar group home since its inception. His parents, Elwin and Eileen, have played a major role in their Utah state chapter of PWSA (USA). Elwin is a bishop in the Mormon Church.

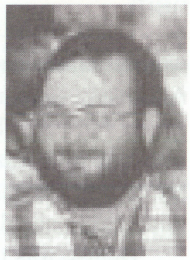
Stephen graduated from Layton High School. He participated in Special Olympics, and earned medals in bowling, swimming, basketball, track and field. Stephen loved to play the piano, read and play with his nieces and nephews. The family said that Stephen touched the lives of everyone he knew.

Tim Morrison

Tim died the end of September at age 45. He lived in a non-PWS facility in Jacksonville, Illinois. Tim died of weight-related respiratory failure.

Tim's parents are deceased. Tim's sister Mary Ann said "Tim was loved by everyone and he loved everyone and everything. Tim had a special gift of making everyone feel that they were his favorite."

Phillip Keen - Born 5/27/70 – Died 9/18/01



Note: The following is part of an e-mail that Phillip sent his friends on the One List. Several of the group e-mailed to say that he would be greatly missed. We also hear from his sister Veronica Sjolander, who wrote, "Phillip was just a most wonderful child and I am so thankful that God made him my brother." His brother Bobby Keen said, "Phillip was a special gift from God, and he taught us many things such as patience and kindness... he always had a gentle touch, he never hurt anyone." As Phillip always said, "God bless." God has blessed us many times with special people like Phillip in our lives.

"My name is Phillip Keen. I am a 30-year-old resident of Pasadena, Texas. I have a life long genetic disorder/birth defect called Prader-Willi Syndrome (PWS). I was born May 27, 1970 at St. Joseph's hospital in Houston, Texas, about 6 weeks premature. At the time she had me, my birth mom was single, still in school, and could not handle a baby with problems. So I was a foster child the first 4 years or so of my life.

I am truly blessed with many things that are typically not common with PWS and that many people with PWS would just dream about, as we are fighters. All my life, we literally fought tooth and nail to get me over the various hurtles of life. We were not going to take the typical PWS answer. We were also not going to take "no" for an answer.

I did go through all of school and graduated high school. I was in regular classes throughout my entire K – 12th grade school years. I just barely graduated by the skin of my teeth. After graduation in May 1989, I tried going out to San Jacinto Junior College for a semester. College was not for me.

During my early childhood years, we had many doctors and rehab technicians working with us. One student optometrist who was studying out at the University of Houston came and lived with us for a number of years and worked diligently with me to get me to seeing better. We went to many doctors and rehab places. We also had many doctors and rehab technicians come to our house and worked with me.

I have a keen interest in computers. Dad got me into the field. I started working with computers around 1975. Back then you had to literally buy them as kits and build them yourself. Not just any body could get them. Part of Dad's assignment was to test various systems to see which one(s) would be good for the company. Since he was gone most of the time, I was the one that did most of the testing and so forth. Everything I know about computers came through first hand experiences, trial and error, by reading many computer books at the various bookstores and in the library, and by participating in many discussions on electronic computer bulletin boards, message forums, and the user net newsgroups.

We have been very active in church all my life. I accepted the Lord Jesus Christ into my life around 7 or 8 years old. Since he became my personal savior, I have not had to be in the hospital nearly as much. Typically about once a year now I have to be hospitalized for something, but even that is slimming down. I am all the time doing various church activities and ministry projects. There are about 7 churches here in the area that I do some kind of ministry work at.

When I am not at church or at the computer, I am frequently playing my musical keyboard. I self taught myself how to play that too. I got the basics down in piano lessons, but due to school, I was unable to finish piano lessons. Essentially now, when I play the keyboard I am still at the computer as I have my keyboard hooked up through the computer. I have a wonderful website with some of the songs I play on the keyboard on it.

My only source of transportation is an adult non-motorized tricycle, as I cannot drive and Pasadena does not have a public transportation system. That is also my main source of exercise too. I essentially ride it all over Pasadena.

We never did have to lock our refrigerator or kitchen cabinets like many PWS people have to. My family was very strict with me regarding food. I was not allowed to freely go into the kitchen. I was allowed a daily 10 a.m. and a 3 p.m. snack, and occasionally in the evenings while we were all sitting around watching television or playing games we would fix some popcorn and I could have a bowl of it if I wanted too. In later years, my snacks began to be more like small meals though. I did have the over eating problems, but it was not as bad as most PWS people. Now that I am on my own, I typically keep myself busy so I am not constantly thinking about food.

See you later; take care, and God Bless.

Best Regards,
Phillip Keen

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We Remember

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Tim O'Leary

Tim was the husband of our Missouri Chapter board chairperson, Judy, and father of four children including Timmy, who resides in one of the supportive living homes at Open Options in St. Louis, MO. Tim fought a long and courageous battle with cancer, and passed away on October 10th peacefully with his family by his side. The O'Leary's were one of the first members of our MO state chapter, and we have laughed and cried together over many battles and triumphs – but Tim's greatest triumph was how he overcame his fear and anger about his illness and learned to "live until he died."

Dear Tim – We hope you are having a great golf game in heaven. ~

Janalee & Al

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Frank Yoder
S. Cohen & Mr. M Burns

Due to the volume of memorial contributions for Howard Merritt Christman, they will be listed in the next Gathered View.

Acknowledgements

Our Sincere Thanks for Contributions Received through September

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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.