



The *Gathered View*

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

Reflections on My Trip to Israel

By Janalee Heinemann, Executive Director



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Although there was some trepidation about me going to Israel to speak to their national PWS organization, it was a trip I felt I needed to make. Unfortunately, in this day and age, when we think of Jerusalem, the first image that comes to mind is not that of a holy city, but one of suicide bombings and military strife.

What my husband Al and I found when we got there was a city of beautiful people who opened their homes and arms to us, and a site with historical, cultural and religious depth beyond our understanding in the USA. Not surprising, we also found that the same issues and characteristics of Prader-Willi syndrome are in Israel as they are all over the world.

Of course, military police and guns were everywhere, and for us, those soon became a backdrop and a reminder of how precious and fragile life and relationships are. Perhaps that is part of the reason why the people we spent time with in Israel seemed so special. They appeared less caught up in the material trappings we see in America, and more focused on relationships and making a difference in this world.

Our hosts for the trip were the president of the Israel PWS organization, Urith Boger, and her husband Herzl Bodinger, former commander of the Israeli Air Force. Urith, a former actress, has a 22-year-old son with

PWS and is currently a scriptwriter, but in spite of her busy life, Urith spent almost the entire week with us. She had set up the conference, and arranged for us to meet PWS parents and children in a variety of settings.



Our hosts in Israel took us to many special places there. From L-R: Uzi Wexler, former chief Jerusalem city planner; Urith Boger, Israel PWS president; Janalee Heinemann; and Urith's husband Herzl Bodinger, former commander of the Israeli Air Force.

I spoke at Sharee Zadeck Hospital, then throughout the week met with PWS families and professionals in 10 different settings, including two hostels and two kibbutz. We met families who were ultra Orthodox Jews, Muslim Arabs (who were fasting for Ramadan), and reformed Jews — often in the same setting. The one thing they had in common is that all were concerned about their children and wanted to learn and do the best they could for them.

Israel continued on page 12

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Password this issue is NEW
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Evaluation of Breathing Abnormalities with Sleep Apnea in PWS

Problems with sleep and sleep-disordered breathing have been long known to affect individuals with Prader-Willi syndrome (PWS). The problems have been frequently diagnosed as sleep apnea (obstructive [OSA], central or mixed) or hypoventilation with hypoxia. Disturbances in sleep architecture (delayed sleep onset, frequent arousals and increased time of wakefulness after sleep onset) are also frequently common. Although prior studies have shown that many patients with PWS have relatively mild abnormalities in ventilation during sleep, it has been known for some time that certain individuals may experience severe obstructive events that may be unpredictable.

Factors that seem to increase the risk of sleep disordered breathing include young age, severe hypotonia, narrow airway, morbid obesity and prior respiratory problems requiring intervention such as respiratory failure, reactive airway disease and hypoventilation with hypoxia. Due to a few recent fatalities reported in individuals with PWS who were on growth hormone therapy (GH), some physicians have also added this as an additional risk factor. One possibility (that is currently unproven) is that GH could increase the growth of lymphoid tissue in the airway, thus worsening already existing hypoventilation or OSA. Nonetheless, it must be emphasized that there are currently no definitive data demonstrating GH causes or worsens sleep disordered breathing. However, to address this new concern, as well as the historically well-documented increased risk of sleep-related breathing abnormalities in PWS, the Clinical Advisory Board of the PWSA (USA) makes the following recommendations:

1. A sleep study or a polysomnogram that includes measurement of oxygen saturation and carbon dioxide for evaluation of hypoventilation, upper airway obstruction, obstructive sleep apnea and central apnea should be contemplated for all individuals with PWS. These studies should include sleep staging and be evaluated by experts with sufficient expertise for the age of the patient being studied.

2. Risk factors that should be considered to expedite the scheduling of a sleep study should include:

- a. Severe obesity - weight over 200% of ideal body weight (IBW).
- b. History of chronic respiratory infections or reactive airway disease (asthma).
- c. History of snoring, sleep apnea or frequent awakenings from sleep.
- d. History of excessive daytime sleepiness, especially if it is getting worse.
- e. Before major surgery including tonsillectomy and adenoidectomy.
- f. Prior to sedation for procedures, imaging scans and dental work.
- g. Prior to starting growth hormone or if currently receiving growth hormone therapy.

Additional sleep studies should be considered if patients have the onset of one of these risk factors, especially a sudden increase in weight or change in exercise tolerance. If a patient is being treated with growth hormone, it is not necessary to stop the growth hormone before obtaining a sleep study unless there has been a new onset of significant respiratory problems.

Any abnormalities in sleep studies should be discussed with the ordering physician and a pulmonary specialist knowledgeable about treating sleep disturbances to ensure that a detailed plan for treatment and management is made. Referral to a pediatric or adult pulmonologist with experience in treating sleep apnea is strongly encouraged for management of the respiratory care.

In addition to a calorically restricted diet to ensure weight loss or maintenance of an appropriate weight, a management plan may include modalities such as supplemental oxygen, continuous positive airway pressure (CPAP) or BiPAP. Oxygen should be used with care, as some individuals may have hypoxemia as their only ventilatory drive and oxygen therapy may actually worsen their breathing at night. Behavior training is sometimes needed to gain acceptance of CPAP or BiPAP. Medications to treat behavior may be required to ensure adherence to the treatment plan.

If sleep studies are abnormal in the morbidly obese child or adult (IBW greater than 200%), the primary prob-

lem of weight should be addressed with an intensive intervention – specifically, an increase in exercise and dietary restriction. Both are far preferable to surgical interventions of all kinds.

Techniques for achieving this are available from clinics and centers that provide care for PWS and from the national parent support organization (PWSA-USA). Behavioral problems interfering with diet and exercise may need to be addressed simultaneously by persons experienced with PWS.

If airway-related surgery is considered, the treating surgeon and anesthesiologist should be knowledgeable about the unique pre- and postoperative problems found in individuals affected by PWS (see Medical News article regarding “Anesthesia and PWS” written by Drs. Loker and Rosenfeld in *The Gathered View*, Vol. 26, Nov-Dec 2001). Tracheostomy surgery and management presents unique problems for people with PWS and should be avoided in all but the most extreme cases. Tracheostomy is typically not warranted in the compromised, *morbidly obese* individual because the fundamental defect is virtually always hypoventilation, not obstruction. Self endangerment and injury to the site are common in individuals with PWS who have tracheostomies placed.

At this time there is no direct evidence of a causative link between growth hormone and the respiratory problems seen in PWS. Growth hormone has been shown to have many beneficial effects in most individuals with PWS including improvement in the respiratory system. Decisions in the management of abnormal sleep studies should include a risk/benefit ratio of growth hormone therapy. It may be reassuring for the family and the treating physician to obtain a sleep study prior to the initiation of growth hormone therapy and after 6-8 weeks of therapy to assess the difference that growth hormone therapy may make. A follow-up study after 1 year of treatment with growth hormone may also be indicated.

Members of the Clinical Advisory Board are available for consultation with physicians and families through PWSA (USA).



President's View

Guiding Principles for Parental Management

Lota Mitchell

Until 2 ½ years ago, I was an Employee Assistance Professional, working in corporate settings. My job was to provide employees with information, referrals, and short-term counseling. As an EAP, I needed to know a little about a lot of areas, so I went to many, many seminars.

Attending one on Attention Deficit (Hyperactivity) Disorder (A.D.H.D.), I quickly became aware of many behavioral similarities with PWS. One presenter referred to the Ten Guiding Principles for Parental Management of A.D.H.D., from a book entitled *Taking Charge of A.D.H.D.*, by Russell A. Bankley, Ph.D. I took avid notes, tucking them aside to share at some later date with PWSA (USA).

Last week the notes happened to resurface. So that "later date" is now. These principles are good for parenting in general, but especially applicable, I think, to our children with PWS.

Peace, Lota

THE PRINCIPLES

1. Give your child more immediate feedback and consequences.

- Later on, the child may not remember what s/he did and why it's wrong.
- Individualize the consequences for both the child and the transgression.
- *NOTE #1: Consequences are "what happens next;" they are not always negative.*
- *NOTE #2: When a child with PWS is having a meltdown, feedback may have to wait.*

2. Give your child more frequent feedback.

- Give both positive feedback for appropriate behavior (too easy to forget this) and negative for unacceptable behavior.
- Do this in nonjudgmental, non-punitive terms.
- Explain to the child what the consequences will be when s/he behaves inappropriately.
- Also clarify what the appropriate behavior is.

3. Use larger and more powerful consequences.

- As the child grows older, change the consequences.
- If the consequence hasn't been effective, move up to the next level.

4. Use incentives before punishment.

- Don't mislabel this as "bribery."
- The child must earn the incentive by his or her behavior, *not* receive it beforehand.
- Punishment may be necessary, but try positive approach first.

5. Strive for consistency.

- No parent can be 100 percent consistent — and they shouldn't beat themselves up for not being able to — but it is a goal to work toward.
- The rule on Monday is the same rule on Thursday.

6. Act, don't yak.

- Less (talk) is better than more.
- Sometimes the only technique parents use is yelling at the child.
- When this is the case, the child's self-esteem (and the parent's, too) starts to deteriorate.

7. Plan ahead for problem situations.

- Example: take coloring books to a restaurant.
- Know what problem situations are going to arise, and develop a plan.

8. Keep a disability perspective.

- Don't forget this child has a problem.
- But — because the child has a problem doesn't mean you just feel sorry for him or her and there are no consequences.

9. Don't personalize your child's problems or disorder.

- Doing so can cause more pain and distress.
- Feeling guilty — it's not your fault — can make parents irritable and less effective as parents.

10. Practice forgiveness.

- Try to keep in perspective that staying angry at the child — or yourself — just creates more stress.
- When things go wrong, forgive the child, and forgive yourself.

Praise for PWSA (USA)

- The new home page for PWSA.USA.org is beautiful! I have not been on the website in quite some time and needed to look something up. Boy! Was I pleasantly surprised!
- David, first of all I can't thank you enough. Your work in helping me deal with this matter has been so supportive and informative, even at times when I just wanted to give up. Please thank all of your association, and tell them I am so proud of their work in being a recognized organization.
- Janalee, David, Gilda and Siobhan: I just want to thank you all for making our trip to the office yesterday so much fun for the kids. You sure didn't have to do anything at all for them. However, they were certainly happy you did.

Chapter View

Several chapters have new presidents. Focus this issue is on **PWSA of Michigan's** new co-presidents, Jon & Chris Hendrick. They are parents of Lauren, age 2 with PWS, who is "doing great," and Blake, 5, in kindergarten. They received so much support when Lauren was born that they wanted to "give back." Jon works for his family's body shop, and Chris has been service manager for a retail furniture store for 17 years. Chris says they "had lived a sheltered life, thinking everything was perfect, we learned fast."

Also in the spotlight is **PWSA of New Jersey**. Maybe other chapters will get ideas from what Marge Royle, wife of past president Doug Taylor writes:

"Nearly 100 individuals who work with people with PWS in New Jersey are better able to help our kids, thanks to Barbara. J. Goff, Pfizer, Inc., and the Prader-Willi Clinic of New Jersey. On October 29, the Prader-Willi Clinic held a dinner presentation for school personnel, including teachers, aides, child study team members, school psychologists, and school nurses. The dinner featured B. J. Goff, Ed.D., Assistant Professor of Education at Westfield State College in Massachusetts, and frequent national speaker and consultant on PWS. In addition, Shari Fallet, D.O., a co-founder of the New Jersey PWS Clinic, gave a presentation on medical and genetic aspects of the syndrome. The New Jersey chapter provided displays and free brochures and other resources. One of the more than 80 attendees reported, "That was the most I ever learned in a training event in the shortest amount of time." The program was made possible through a generous grant from Pfizer.

On October 30, nine group home staff from four different agencies spent a morning with B.J., learning more about PWS and how best to manage the behaviors of their clients with the syndrome. Because the numbers in attendance were lower, staff members were able to receive personalized help in discussing weight and behavior management. This event was sponsored by the New Jersey chapter, which also provided information packets for attendees to take home to staff members who were not able to attend, multiplying the impact of the workshop. Again, attendees were very enthusiastic about what they had learned."

The president of the **Prader-Willi Alliance of New York**, the Hon. Daniel Angiolillo, has met with Commissioner Thomas Maul of the New York State Office of Mental Retardation and Developmental Disabilities to "discuss an ambitious agenda of issues affecting the PWS community in NY State." This included the need for a center similar to the Children's Institute in Pittsburgh, additional group homes, and respite care for families, among other topics. We wish them luck in accomplishing their goals. The **Alliance** Conference "2004" is scheduled for April 30 – May 1 in Albany.

Georgia Prader-Willi Association held a Family Retreat and Annual Meeting Nov. 21-23 at the Roosevelt Institute in Warm Springs, Ga. The weekend included the "Little White House Thanksgiving Tour."

— Lota Mitchell, Associate Editor

Nominees wanted for PWSA (USA) Board of Directors

Who can be a Board Member?

Any member of PWSA (USA), which includes parents, caregivers, adult relatives, grandparents and professionals, may submit his or her name for consideration.

Who is qualified to be on the Board of Directors?

Anyone willing to volunteer time, talents and expertise to support the mission of PWSA (USA).

What are the expectations of a Board Member?

Board Members are required to attend two board meetings a year, one at the annual PWSA (USA) conference and one in January at the PWSA (USA) national office in Sarasota, Florida.

What is the term of office?

The Board Member serves a 3-year term and can run for three terms consecutively.

Are there any other responsibilities?

Conference calls, e-mail and mail votes are required throughout the year. Each Board Member is expected to be on at least one committee. Current committees are: Leadership Development, Publications, National Conference, Crisis/ Intervention and Training, Finance, Funding and Grant Development, Board Advisory, and Executive.

How to Apply

Names of members interested in or recommended for a seat on the PWSA (USA) Board of Directors should be submitted to the committee no later than March 15, 2004.

Recommendations should include a brief description of the member's qualifications to serve on the Board.

Please send recommendations by mail, fax or e-mail to:

PWSA(USA)

Attention: Ken Smith, Chair, Board of Directors
5700 Midnight Pass Rd., Suite 6

Sarasota, FL 34242

Fax: (941) 312-0142 or e-mail: national@pwsausa.org



Executive Director's View

What Makes an Adjusted Adult with PWS?

Janalee Heinemann

During our 30-year-old son Matt's recent visit home at Thanksgiving, I was again touched at what a good person he has become, and knowing intimately about all of the crisis situations we get at the office, had to ask myself why.

I am grateful he is doing so well, but what makes the difference between Matt and some other young adults with Prader-Willi syndrome (PWS) who have good parents, yet are such a challenge? In my searching for answers, right or wrong, I have come up with the following possibilities:

Medication – Personally, I think that lower doses of psychotropic medications in combination are very beneficial in treating the many emotional and behavior issues that are inherent to the syndrome. Unfortunately, there is no magic bullet in treating our “kids.” And since their major issues vary (well described in the recent article written for us by Drs. Gourash and Forster, “Behaviors and Disorders Associated with PWS,” *The Gathered View*, Vol. 27, Nov-Dec 2002; and in past articles by Barb Whitman, Ph.D.), and they all respond differently to medications, we do not have an easy prescription plan. I cannot help but think, though, that there has to be a better roadmap of “most likely to succeed” medications that we can share with professionals. This was our goal in mind when we approved research money that will be focused in this particular area.

Genetics – Although Matt has the classic deletion, and has had all of the classic characteristics, including years of varying levels of challenging behaviors, the picking compulsion, and a significant and creative ability to forge for food, I have certainly known worse in the degree of the problem. This brings us to the new revelation of two categories of deletion reported by Dr. Merlin Butler at our PWSA (USA) 2003 conference in Orlando. (The following is my very simplistic interpretation. See the Sept-Oct *Gathered View* or buy our abstract booklet for more details.) In their research at Children's Mercy Hospitals and Clinics, Kansas City, Dr. Butler has categorized the two separate types of deletion. The first he is calling Type 1 (T1) deletion which has more of a deletion of genetic material — and significantly more maladaptive behavior. Whereas Type II (T II) deletion has less of a deletion — and generally less maladaptive behavior than either Type 1 or in some areas, those with UPD.

Age – In another study reported at conference this summer by Elisabeth Dykens, Ph.D., of UCLA, people with PWS typically significantly improve in behavior in their 30s and 40s (see the Nov-Dec 2003 *Gathered View*). I can see a gradual change in Matt over the last 10 years in that he is

much more accepting of who he is and of what he can or cannot do.

Management – Although I feel we did a lot right in Matt's behavior and food management in the earlier years, and I have written on this topic, I do not think this is the entire answer. I do know though that I still believe in my philosophy that no matter what our children's problems are, we must challenge them to be decent human beings. Society will not be all-forgiving as a parent will, and many, many people with significant disabilities end up expelled from school and in jail — including some with PWS. Children with PWS must learn that no matter how upset they are, hitting, hurting and destroying others' property is never OK! I also have to give great credit to Matt's staff at Open Options in St. Louis, Missouri. Some have been with him the entire 10 years he has been living in Open Options supportive living homes. Matt has won awards at work and also for Client of the Year (actually it was Consumer of the Year, which is the current phrase, but I hate that term since our children “consume” too much.) Although Matt gave the staff great grief that first year, both Matt and the staff (they were fairly new at the PWS challenges back then) grew in their understanding and love for each other.

Letting Go – And Letting Him Grow — I think one of the biggest challenges for our parents is learning how to avoid sabotaging supporting living placement once their

Thriving on GH



Matt Heinemann, 30, who has PWS

Another separate but positive report: Matt has been on the adult growth hormone research study in St Louis for about 7 months, and the positive changes are remarkable. He had been gaining weight, but since being on the study, he has gone from 192 pounds to 140. He is now under goal weight!

Of course his body shape has changed dramatically, and he went from having quite a belly to having a flat stomach. Beside the obvious physical one, the most noticeable change we observed was that his energy level dramatically improved.

More subjective is that it appeared he was more satisfied with his diet. His tremendous interest in food is still there, but he appeared less intent at getting more food. We will be very interested in following the results of this study.

Matt continued on page 7

Join The PWS Family on the Internet

PWSA(USA)'s website has many web and e-mail resources for support. You can find the state chapters and other affiliated organizations. You can find links to other resources such as Search Disability's dictionary, Parent/Family Support Medical Information, Disabilities Advocacy, Federal Level Education, Medical, Education, Respite, Camps and other services, and Yellow Pages for Kids with Disabilities.

To access these links, either go to www.pwsausa.org, click on ENTER, then click on the button on the left, LINK, OR go to www.pwsausa.org/index.html and click on the LINK button on the left.

You can join our eGroup support groups for ages 0-5, 6-12, TEENS, and siblings (under other links on the website).

While the eGroups are set up by age, it is important that membership of the lists stays within the issues and conditions related with that group. For instance, if a 4-year-old is seeking food or having behavioral issues in a pre-school, then the group for 6 to 12 makes sense. The 0-5 list

is wonderful for the baby or toddler. The TEENS list is into the severe issues of adolescents.

In all cases, the groups want members who are into the particular issues of the age group. A baby (newly diagnosed) should not be in the 6-12 or TEENS list, because it would be difficult for the parents to talk about their issues if they knew that a young mom was in there reading the e-mail messages.

Barb McManus, our Webmaster, encourages mothers of little ones not to be on the older lists for two important reasons. First, when her child gets to that age, he or she may not have the same issues, because with ongoing research things will change. Second, Barb says, "Why worry about what might be? Your baby is a precious little creature who is going to give you much love. Take your time to get to know him or her before worrying about the future. Enjoy your baby now."

— **Lota Mitchell, Associate Editor**

Matt - continued from page 6

children with PWS move away from home. You spend your life advocating for your child and protecting him/her from the hurts of the world, and then you are supposed to turn your child over to strangers when s/he becomes a young adult. It is an understatement to say that this is difficult to do. One of the advantages we had was my years of exposure to seeing how parents often inadvertently and unintentionally sabotaged their adult child's placement by overinvolvement post placement. I compare it to a divorce situation where the child learns to play one parent against the other. I think it is crucial that from the beginning, a strong direct line of communication is set up between staff and parents — and not have the person with PWS be the link between.

Of course, when Matt first went into placement, he tried every trick in the book. I remember one call where he was upset because the staff did not make his favorite meals. When I asked him what that was (since I thought they were *all* his favorite) he said, "lobster bisque and quiche lorraine." I responded, "Matt, what are you talking about? I have never made either of those dishes in my life!"

We decided early on that we would screen his calls. We told Matt that he had to learn to relate to the staff and resolve his differences with them, and after days of upset calls, told him we would only respond when he had positive things to say. This may seem harsh, but we did listen to his woes on the answering machine, and if we thought there might be a real issue, would discreetly call his staff to work on the issues without him knowing we had done so. I knew it was absolutely crucial for him to learn how to resolve his issues and not to be dependent on us to do so for him.

Sometimes I do think we do not give our adult children with PWS credit for having the ability to resolve issues, or

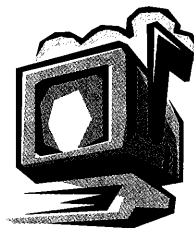
give them the opportunity to really grow up. For your other adult children, would you call the president of their university or their landlord once they leave home? I hope not.

Of course a parent may say, "But my child with PWS is more vulnerable and dependent on his/her caregivers." That is true, but as I said above, your children still have to be the best they can be.

As a parent, after placement, you have to decide what battles with staff are important and which ones can be let go. Most important is to not play the role of rescuer. There is a strong possibility your adult child will use you and abuse the staff. The staff may then resent you and not establish the needed relationship with your child.

Have an agreement with the managing agency about who you should go to with issues, and what the back-up plan is if that does not work. Again, go to them without your child knowing you did so. Then help your child brainstorm ways s/he can resolve their own problems. Once they have learned to do this (or at least think they did it on their own) they will feel empowered to do so in the future. Also, for every time you have to privately criticize staff, make sure you have spent double that time complimenting them for what they did right.

We think the world of Matt and his key staff. Has every staff person been appropriate? No. But Matt has learned to get along with almost everyone — and to whom he can go within the agency if he has a problem. Is there one answer for why Matt is doing so well? No, but there are some obvious pieces to the puzzle, and we can continue to work toward finding where the other pieces fit in. I want all parents to feel about their children the pride and peace we feel about where Matt is with his life.



Winter Warning for the Adult with PWS

Due to a couple of recent calls about significantly low body temperatures in people in their 30s and 40s with PWS, and knowing we have had such calls in past winters, I thought it would be helpful to run this abstract by the late Dr. Jim Hanchett and his wife, Dr. Jeanne Hanchett from the 1999 PWSA (USA) conference.

Sadly, as you know from our last *Gathered View*, we no longer have Dr. Jim Hanchett to consult with, but I have talked to his wife, Dr. Jeanne Hanchett. The big question is, How low can a person's temperature go without being life-threatening? There is not a clear answer, but in the one new situation, it went down to 88° F.

Dr. Hanchett knew one woman with PWS who had a temperature of 81°... and lived to tell about it! Dr. Hanchett noted that with PWS, you have to look at other clinical signs such as: Is the person eating? Is the person acting unusually sleepy? Is the person acting disoriented? Those with the lowest body temperatures (temperatures below 90° F) have been known to go into an almost coma-like state.

If the person with PWS has a temperature below 94° F, the main advice is WARM THE PERSON UP! If a person with PWS (usually an adult) is known to have had episodes of significantly low body temperature and

lives in a northern state, use more caution. During cold weather, use extra care to bundle the person up with scarves, gloves, hats, heavy boots, etc.

If the person is acting OK, allow as much normal activity as possible, but use caution. If the person is sleepy, not interested in food and not his or her usual self, check the temperature. If it is below 94 degrees, put the person in a warm place, such as a bed with several blankets or an electric blanket.

If you have had similar incidents, it would be good for us to keep records on such incidents, so please call, e-mail or write us on the details.

— *Janalee Heinemann*
Executive Director

Hypothermia in Prader-Willi Syndrome

By James E. Hanchett, M.D. and Jeanne M. Hanchett, M.D.

The Children's Institute, Pittsburgh, Pennsylvania

The Children's Institute (TCI) has had a program for persons with Prader-Willi syndrome (PWS) since 1985 and has seen more than 400 patients ranging in age from a few months to 60 years.

Percentage overweight has ranged from 20 percent to more than 300 percent. From this population, two patients age 40 and 46 years were recognized to have a recurrent hypothermia syndrome. They both had the onset of this hypothermia in late November while living in the Mid-Atlantic area of the U.S. They had repeated episodes during the winter and experienced relief during the summer months and then had recurrence during the following late fall.

The 46-year-old man died abruptly over 4-6 hours the following October. This occurred several months after discharge from TCI and it is unknown if hypothermia was present.

The 40-year-old female had recurrence of symptoms the next winter and still survives.

Both had been on psychoactive drugs(s) that might have retarded shivering; tardive dyskinesia was previously mentioned. However, withdrawal of these medications did

not prevent recurrence of hypothermia, and persisting frank tardive dyskinesia after medication withdrawal was not observed. Data was obtained from both outside medical records and direct observation at TCI.

Hypothermia syndrome began with a change in behavior followed by decreasing activity proceeding to near coma. Hypothermia (81°-94°F), decreased blood pressure, bradycardia and slow respirations were discovered. Lab studies revealed decreased hemoglobin, low WBC, decreased platelets, hyponatremia without acidosis or hyperkalemia, and elevated renal and liver function tests. All of these changes return to normal levels over several days as the patient is rewarmed. Sepsis was frequently suspected but blood cultures were negative. Both hypothermic patients were noted at TCI to have ear probe temperatures from 91°-101°F but without the resultant syndrome of mental decline, functional deterioration and lab changes.

In order to more broadly define the problem of hypothermia in PWS persons, nine patients were surveyed over 24 days. Six patients dropped their temperature to 92-95° when

ambient temperatures were below 66° F, despite walking vigorously and appropriately clothed in an exercise program. Following the outdoor walk and inside the building at 72°, all body temperatures were back in the range of 98-99°F. This group confirms the reports of Bray et al. (Medicine 1983).

Webb (Amer J Physiol 1995) presented heat regulation as a physiologic method of handling metabolic heat rather than temperature regulations per se, i.e. heat production from metabolic activity is the primary variable, with the resultant body temperature a function of heat loss.

In the person with PWS there is hypotonia and progressive obesity with inordinate drive to get food, yet the consequence is hypoactivity, very poor muscle mass/strength, and an apparent inability to maintain body heat, especially if there is a significant environmental gradient.

In these two patients [cited on paragraph two above] episodes of profound hypothermia with multiple abnormalities were noted. When reversed, they resumed their usual PWS baseline state. Of great interest,

Hypothermia continued on page 12



PWSA (USA) Annual Conference

June 30 - July 2, 2004

The Lodge at Sawmill Creek Resort - Huron, Ohio

"Explore the Possibilities" is this year's conference theme, and the conference chairs are already doing that: a group of committed parents from three states have joined together to make the 2004 Conference possible. Conference Chairs are Janice Agarwal of Indiana, Johanna Costello of Ohio and Carolyn Loker of Michigan. They will be our pioneers at working with a multi-state group, and we are excited to try this new model for organizing a conference.

WHEN? Scientific Day, Providers Day and Chapter Presidents will be meeting Wednesday, June 30, and the General Conference for all ages will be held Thursday, July 1 and a half-day on Friday, July 2.

WHERE? The Lodge at Sawmill Creek Resort is a beautiful setting in Huron, Ohio, just outside Sandusky, less than an hour from the Cleveland and Toledo airports and 2 hours from Detroit & Columbus. For more information about The Lodge, go to: www.sawmillcreek.com

HOW? To get your reservations at the discounted conference rate of \$99.00 per night for up to 4 people, call Globetrotter Travel at 800-322-7032, or e-mail to pwsa-usa@globetrottermgmt.com.

Plan NOW for grant requests for 2004

Suggestions: Start to look at alternative, local grant sources. Have your request in writing, be prepared before you call. Do not wait, many funds get used up early in the year.

- State Developmental Disability Council – Call 1-800-695-0285 NICHCY or check their web site www.nichcy.org
- Check with your local state PWSA chapter for grant funding
- If you have a relationship with a local church, check for funding
- The ARC (disability related funding)
- Parent-to-Parent (disability-related funding)
- And then... PWSA (USA) Grants

All grant recipients will be required to be or become members of PWSA (USA). If the membership cost is a problem, a Scholarship Membership can be requested.

So that we can assist more families, grants may not always include airfare. All reservations will be made through our travel group.

Check our web site for

the latest 2004 Conference information

www.pwsausa.org

Requesting a conference grant from PWSA (USA)

Please use the following criteria when preparing your grant request.

- Names of family members you hope will attend (maximum of 4 people, please); list ages of children. Provide address, e-mail, and telephone contact numbers.
- Reason for wanting to go to the conference, benefits you hope to achieve, what you wish to learn and how you will *share* information.
- Explain any special financial and/or emotional needs of your family.
- Required funding for what purpose: registration, lodging, travel, etc.
- How much you can afford to put toward the conference cost.
- What grants have you received in the past (national or local conferences).

Submission Deadline for PWSA (USA) grant applications: April 30, 2004

State Chapters should put information into January and February 2004 newsletters. Sufficient time must be allowed for families to make requests from other local organizations early in the year before money is gone.

Grant requests may be e-mailed to: national@pwsausa.org or Faxed to: 941-312-0142 or mailed to: Prader-Willi Syndrome Association
5700 Midnight Pass Rd. Ste. 6
Sarasota, FL 34242
Attn: Grant Committee

Kristin-Dawn has come a long way and feels blessed

My name is Kristin-Dawn Elliott. I live in Kennewick Washington. I was born diagnosed with Prader Willi Syndrome. I was supposed to be unable to walk and talk and play but I actually walk, talk, play, read and write quite well. I was supposed to live until i turned 21 years of age but i was diagnosed with diabetes so ended up be given a longer life. I am twenty two years old now. When I started school, I thought i wasn't going to make it through. My mother and father thought different. My mother and father pushed me to achieve every step of the way. I was picked on a lot by other kids because they knew i was handicapped but my mom was always there to make things better for me. All through elementary school i was in special ed classes, but then middle school came. In middle school i was in reagular classes along with specialized classes. I got through middle school with flying colors and reached High school. In High School, I was mostly in regular classes struggling and not struggling and i was in some special ed classes to help with my studies and to get through the difficult one with help. I was an excellent student at Kamiakin High because I was always on the honor roll and i lettered in academics. My senior year i went through job training as a class. I worked at Sears and then i volunteered at The Kennewick Life Care center. I loved the Kennewick Life Care Center. While working at the center i became friends with a group of old women. My best friend was Clara. I came every day to read to her and talk to her and it just brightened her day. I graduated from high school with a

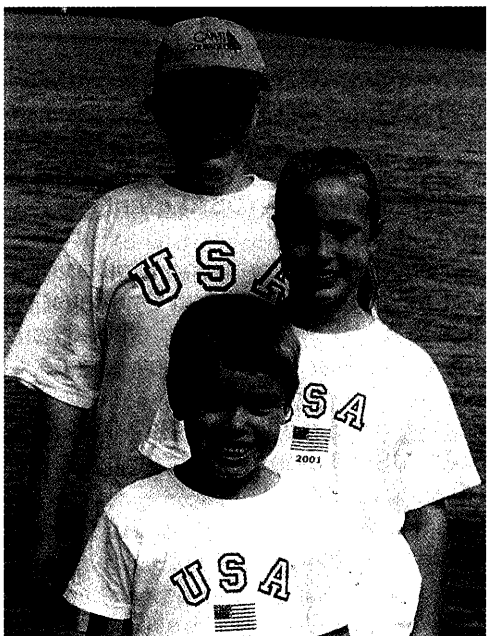


Kristin-Dawn Elliott, 22,
is looking for a group
of pen pals to chat with

four point o and continued the job at the center. I then moved on to college to earn a degree in childhood education because i got a certificate from Ti Tek saying that i was certified to be a daycare provider. I went to CBC for two or three years but then i quit because the math was too difficult. I think i have come a long way for someone who was born mentally retarded. What can i say i was blessed by god.

i am looking for a group of pen pals to chat with on line or through the mail box.

The Sibling View



My Brother Has A Disability

Editor's Note: Reed Linderwell of Dubuque, Iowa was 8 years old when he wrote the following about his brother, Tyler 14, who has PWS.

My brother is special because he has special needs. If you see him say hi. On our baseball team there is a kid who is nice to my brother. Travis is helpful and kind because he plays with him and is his friend. Sometimes he doesn't no what he's saying so I help him out. Theres a kid on our baseball team that is mean to him. Sometime I get mad at Bryce. Sometimes I get mad at my brother and sometimes I'm no paichent with my brother.

Once he went to Ames with my mom and when they came back they were mad at each other. So at night my brother and I slep on the floor. Then we had a long talk about his trip. You can notice that he is fat because he eats a lot and that is part of my brother's Disability.

Tyler Linderwell,
who has PWS,
and his siblings,
Jillian, age 11, and
Reed, now 9.

View From The Home Front

A Very Special Birthday Girl

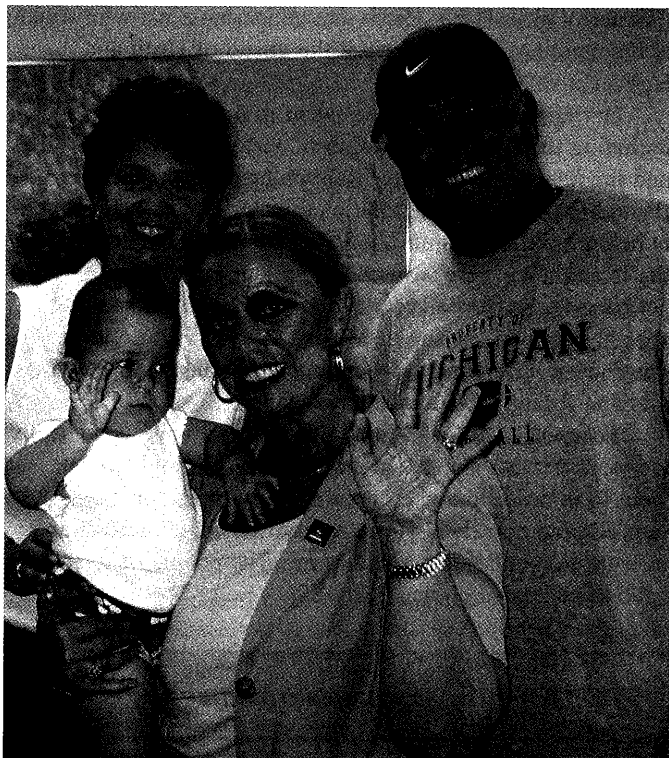
Jessika Dickinson, who has PWS, is really growing up. When she turns 12 on March 24, 2004, Jessika has decided on a very special kind of birthday remembrance.

She doesn't want birthday gifts. Instead, she wants everyone to make a donation to PWSA (USA). Her decision shows a remarkable level of maturity, don't you agree?

Jessika lives in Grand Island, New York. She is the granddaughter of Board Member Barb McManus.



Jessika Dickinson,
who has PWS



Hurdle Team visits PWSA (USA) in Florida

PWSA (USA) Executive Director Janalee Heineman, center, welcomes major league baseball Colorado Rockies Manager Clint Hurdle, his wife Karla and daughter Madison to the association's national headquarters in Sarasota. One-year-old Madison Hurdle has been diagnosed with PWS. Madison is doing exceptionally well, and the Hurdles say she is the "joy of our lives."

We welcome writings from siblings for *The Sibling View*: good experiences, bad experiences, we want to hear what you think. They can be signed or anonymous, whichever you prefer. Send them to the attention of Lota Mitchell at the PWSA (USA) national office, or e-mail to her at ljeholms@juno.com.

The Chuckle Corner

Our son, Logan, then 2 years old, who has PWS, was being tested for his cognitive level for placement in a Developmental Preschool Program.

The teacher asked him, "What barks?"

Logan answered, "dog."

The teacher asked, "What meows?"

Logan answered "cat." (Actually, it was something that sounded like it could be cat).

Then he was asked, "What sleeps?"

Logan thought for a moment and said "Daddy."

They counted that as a correct answer. ☺

Jenny and Chad Buchanan
Richland, Washington



Please send your joke or funny story to the PWSA (USA) office. Be sure to include your name, phone number and address in case we have any questions.

Web Site Has Medicaid Info

Check out the following if you have ever wondered what is available with your Medicaid Card.

The federal and state governments finance Medicaid jointly and, within broad federal guidelines, the states administer it. This arrangement allows states flexibility in designing their own benefits packages subject to certain minimum requirements.

To better understand the Medicaid program's flexibility and varied services for eligible populations at a state level, the Kaiser Commission on Medicaid and the Uninsured (KCMU), along with the National Conference of State Legislatures, is releasing a new online database on Medicaid benefits in the 50 states, DC, and the U.S. territories.

The new database, available at <http://www.kff.org/content/2003/20031027/>, is based on a survey conducted by Health Management Associates.

The database is comprehensive, with information about benefits covered by each state, for what populations the benefits are available, and the limitations, co-payments and payment rules that apply to the benefits. The database is searchable by Medicaid benefit as well as by state.

I hope this helps anyone with a Medicaid Card or who is considering applying for the coverage. Take care.

Vickie Fetsko, Grafton, Ohio

Vickie is wife to Stephen and mom to Stephen, Jr. (known as Andy, age 10), Jonathan (age 9) and Jason (almost 5, who has PWS).

As Al said, "With Prader-Willi, you can throw out the rule book on cultures." Just as in America: 1) the young children are doing great, thus their parents are hesitant to get involved with the larger group and be exposed to the parents of the older children. 2) The parents of school-age children are fighting to get their children's needs met in the school system, and are trying to decide whether their child's needs would be best met in the regular school system or the special school system. 3) The parents of older children struggle with behaviors and have their humorous and incredible stories on food foraging: One story was of a young man who would get to the kitchen from his bedroom in his hostel by crawling along a ledge four stories high. Another was of a young man who ran away and gained 24 pounds in the 7 hours he was gone! 4) The children and adults with PWS are lovable and fun.

Urith and Herzl wanted us to also see and learn all we could about Israel. Close friends of Urith and Herzl are Uzi Wexler, former chief Jerusalem city planner and chairperson of more Israel organizations than I can remember, and his wife Daniella, a former judge and writer. They provided a delightful meal and a tour of the behind-the-scenes growth and issues of Jerusalem.

The complexity of the problems, the passion and commitment to such diverse religions and cultures, all within easy shooting distance of each other, became so much clearer than I could have learned from a distance. Some neighborhoods have what look like sound barriers along the side of the road. In reality, these are bullet barriers to prevent shootings from a rival community that is so close that cars driving by could be hit with bullets. If you add to the typical issues of a PWS family the fact that no one has remained untouched by suicide bombings, and the worry about their children in the military, then you can understand the mixture of strength, chronic grief and appreciation for community that our families in Israel have. They forge ahead with an attitude of "Life must go on."

After many, many years of communicating by snail mail and e-mail, meeting the people of Israel was undoubtedly the highlight of our trip. At the conference I was delighted to meet Henry Singer's (former New York chapter president) daughter Bonnie, who teaches in Israel, and Margot Finks, who first wrote me 10 years ago when her son was an infant. I was also touched to meet the mother of a child with PWS who died 20 years ago at 5 months of age. She worked at Sharee Zadeck Hospital and came because she saw my name on the program. She remembered that we were the couple who provided them information on the syndrome so long ago when her father, a St Louis physician, contacted us shortly after we organized the St Louis Chapter. I was also honored to see some of my writings in Hebrew — not that I would have known they were mine, or even recognized my name, without Urith giving me a copy and explaining what they were.

Janalee with
Urith and Herzl's
son Doron,
who has PWS.



I was very impressed with the professionals and their obvious dedication and love for the PWS children they work with, including Varda Gross, physician who is in charge of the PWS clinic, who spoke at the conference, and hosted a meal for us; Larry Gentsil, who runs the PWS hostel; psychologist Yael Landaw, who took us to the Wailing (Western) Wall; Harry Hirsh, the endocrinologist who spoke at the meeting, and the staff at the hostel of Urith and Hertzl's son, Doron.

During our visit we were taken to many special places, including the Masada, the tomb of Jesus, the Wailing Wall, and the late Prime Minister Rabin's memorial site. We floated in the Dead Sea, took pictures at the wall (fence) that is being built to separate the Palestinian settlements from the Israeli. (We were warned to take our photos quickly, and get back in the car before we got shot.) We also had the special honor of staying at Mishkenot Sha'anamin, a guesthouse in Jerusalem where many famous people of the arts and foreign dignitaries have stayed.

I cannot say enough good things about how wonderfully we were treated, and the great lengths Urith and Herzl went to in order to make our trip special both for the families and ourselves. I am so grateful we chose courage over caution and made the journey. The people of Israel have to make that choice every day.

Hypothermia - continued from page 8

caloric restriction of 600 calories per day combined with progressive increasing exercise in the Children's Institute PWS Program did not lead to worsening hypothermia.

Does this scenario in PWS persons suggest a diversion of nutrients from growth and development to useless storage only partly overcome by the drive to "mass action" eating by the patient with PWS, with resulting secondary behavior and hypothalamic consequences, as envisioned by Jackson et.al. (CIBA Foundation Symposium 1996).

*First presented at the 1999 National PWSA (USA)
Conference in San Diego, California.*

Fund-raising

Where We Are Going

By Francine Diemer and Mark Camille

In the 1960s when Hollywood was still producing biblical epics, there was one with a title that stands out for our organization: "Quo Vadis." Where art thou going? is a question that organizations and individuals must periodically ask themselves. For those of us in development positions, it forces and forms strategic thinking and planning.

Mark Camille is PWSA(USA)'s new part-time director of corporate and government development, and Francine is also part time, focused on community development and individual fund-raising. We view our efforts to raise funds for PWSA (USA) as an opportunity to do good and are enthusiastic as we approach our tasks. We hope to bring about not only short-term, but also long-term success for the organization and are pleased to be a part of this cause. We would like to share with you some of the areas in which we'll be working.

We will be approaching large corporations that we identify as potential sponsorship partners. This may be because they have charitable foundations, have a history of philanthropy similar to the goals and values of PWSA (USA), or whose corporate image suggests interest in an organization like ours.

We will be approaching foundations whose express focus is on children, healthcare, education or other areas into which we might fit, either programmatically or with research.

We will be approaching the sports and entertainment industry to help raise awareness and to raise funds. Awareness could be helped tremendously through this venue.

We will be approaching government officials, both elected and appointed, to attempt to increase the funding for PWS, for both research and programs.

We seek your assistance and involvement. **Many of you have contacts with large corporations that might be beneficial to PWSA (USA).** We ask you send an e-mail with the pertinent information to Mark at dirdev@pwsausa.org. He will be glad to work with you and/or handle it from there.

We want to work with you on ways to increase awareness and funding from your efforts on a local level. Francine would love to support you with any individual or group fund-raising ventures.

The biggest charities in our nation are groups who are united and have one goal in mind: to make their organizations the leader in whatever they are endeavoring. To accomplish this goal for PWSA(USA), we'll be trying new things to get our membership engaged and to attract new supporters. You'll probably be hearing from us more often and in different ways. You may see more appeals for donations in your mailbox from us, or from time to time we might give you a call to ask you to help us open the door somewhere.

Perhaps more importantly, we'll be asking you to become an even more engaged advocate for PWSA(USA). Our organization has gone a long way and we are on the brink of reaching the next level, which will mean a variety of things — from increased services for you and your children to increased awareness of Prader-Willi syndrome and increased support for research.

But just as a skilled mountain climber doesn't reach the summit without help from his equipment and team, we can't reach our summit without your continued help and support. Your input, ideas and suggestions will be vital. No idea is too crazy or "off the wall." We want to hear from you, for if we are to reach the next level for PWSA(USA), we need the help of all and we need to do some thinking outside the proverbial box. E-mail Francine at comdev@pwsausa.org.

PWSA(USA) is changing lives. It's not work that is done in a vacuum; it's work that's done by a community of people (all of us), with one goal in mind: to improve and enhance the lives of everyone impacted with Prader-Willi syndrome and related conditions.

We look forward to hearing from you!

A Tip From The Treasurer

Fund-raising for a Purpose – State it Up Front

When holding a fund-raiser for a specific purpose other than general operating expenses, you must state the purpose on all PR and other materials associated with the fund-raiser, including tickets. If the purpose is not stated prior to the event, the funds raised would be accounted for as unrestricted revenue.

— **Karen Goldberger,**
Treasurer, PWSA (USA)

Providers/Carers Program Help Wanted

The planning committee of the 2004 International Prader-Willi syndrome Conference/9th Australasian Conference is seeking your assistance in designing a provider/carers program. The Conference will be held in Christchurch-South Island, NZ from April 9-12, 2004.

Providers/Carers Day will be held on April 9. We wish to ensure that the topics are relevant and presenters are experts in that area.

We are also interested in any suggestions from providers/carers regarding recommendations of PWS professionals as presenters in any of the topics identified.

Please go to the following web site address and complete the survey, even if you do not plan to attend the conference: www.pwsausa.org/conference/5thworldconf.htm Or e-mail BJ Goff at the following address: galagof@msn.com

Fund-raising for the Love of Josilyn Faith Levine

Ryan Decides to Make Strides

On October 19, 2003 Ryan O'Sullivan achieved two major milestones: he finished his first marathon *and* completed his first fund-raiser for PWSA-USA, raising over \$7,000 for PWS research.

Ryan, age 31, began running in early 2003 as a means to get in shape and lose weight. After the marathon bug bit him, he found himself diligently following a training schedule to get ready for the Columbus Marathon, an event near his home in Dublin, Ohio.

He soon realized the potential that his personal goal had as a means to help those living with PWS, including his niece, Josilyn Faith Levine, who lives in Florida and who turned 16 months old the day he ran the marathon.

"The marathon was a goal of mine. I do not consider myself a runner, and never had been, but I decided that I would run for Josilyn, and she was a huge motivator for me," said Ryan. "When I felt that I might not finish at mile 24, I thought about Josi and all my family and friends who supported my efforts through their encouraging words and generous donations, and I couldn't let a single one of them down."

So Ryan persevered, and finished the race in 3 hours, 47 minutes, feeling elated and exhausted at the same time.



Ira & Ronnie Levine To Host PGA Golf Tournament Fund-raiser

During PWS Awareness Week on May 1, 2004, Ira and Ronnie Levine will be hosting a PGA national golf tournament fund-raiser in Palm Beach Gardens, Florida, in honor of Josilyn Faith Levine. Proceeds will go to the Josilyn Faith Foundation, and a majority of the funds raised will be given to the PWSA(USA) research fund. We thank the Levines in advance for their support and encourage anyone interested to consider participating. For more information call 1-800-606-2733.

"It really goes to show how anybody can incorporate a fund-raiser with relative ease into a goal or event they are already planning to do," Ryan said. "I wrote to my family and friends, telling them what I was trying to accomplish and why, and most of them sent money. I can never thank them enough. The funds they sent will make a difference for those living with PWS, but just as importantly, it gives the whole Prader-Willi community hope."

Ryan's Marathon Donors

Don & Elizabeth Armstrong	Sherry S. Johnston
Brian & Angela Arnold	Shana Treadway & Jordan Factor
Richard N. Baxendale	Kathleen M. Keck
Diane & Daniel Berinstein	Chris & Heidi Kennison
Boroff Family	Katherine Kirk
Laura Brown	Sandra & Gary Kodish
John & Victoria Buford	Bob & Nicole Koviak
Amy Carpenter	Thomas & Holly Kreber
Sue Ann & Edna Carpenter	Steve Kutner
Dennis & Renee Chang	Jodi & Ross Laufgraben
Amy & Pierre Chao	William Lehrburger
Craig Cherkas	Anna Leightman
Karen & David Cotton	Ben & Janis Leightman
Kevin DeLongchamp	Michele & Stephen Leightman
Lia DePirro	Wendy & Michael Levine
Steven Dezse	Lawrence & Bernice London
Amy & Todd Dickenson	Marco & Molly Magnano, III
Carmen & Jane DiGiovine	Bob Mahaffey
Carmen & Michalle DiGiovine & Family	Gregory & Susan McCrabb
Charles & Barbara Dowd	James & Megan Medenis
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Susan Furste & Everett Carpenter	Sally & John Mountcastle
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Deborah Fergus	Todd Nemenz
Seth & Michelle Fliegel	Jodi & Ryan O'Sullivan
Jamie Fleckner	Kelly O'Sullivan
Carole & E. Michael Fliegel	Michael & Kathy O'Sullivan
Fliegel Family	Sean & Courtney O'Sullivan
Glenn & Kathleen Furman	Su H. & T.J. O'Sullivan
Matt Gershner	Thomas & Elizabeth O'Sullivan
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Mark & Susan Goodman	Pamela & Timothy Rothka
Bernadette Travers & Grandma O'Sullivan	Robert & Elyse Rubin
Eileen A. Graziano	Hilary Ryder
Paul & Julie Graziano	Matthew & Rebecca Sanders
Michael & Mary Henry	Betty T. Schiff
Steven & Laura Hilton	Jane Schiff
Crisanne Hitler	Lara & Eric Schwartz
Kevin & Kristin Hogan	Timothy & M. Luanne Shaughnessy
John & Patricia Howlett	Kevin & Jennifer Shea
John R. Howlett	Stacey Shepherd
Michael & Jennifer Howlett	John & Dana Siverd
Lauri & David Hyland	Raymond Smith
Edward & Patricia Janis	Peter & Mary Suarez
Natalie Jankiewicz	Mark & Lori Velky
Marvin & Yvonne Jassie	Weinstein Family
	Tracy & Jason Woodrum
	J. Yargytz



Angel Fund

Golden Harp Society (\$1000 and above)

Rajiv Gujral
Anne O. Urquhart Miller (in
honor of Danielle White)

Choir of Angels \$500-999

JoAnne Riley Barron (in honor
of Jacob Ford)
Joseph A DiFilippo (in honor of
Grace Larmer-DiFilippo)
Jean & Douglas Lowe (in honor
of Jackson Lowe)
Terry & Debbie Mieczewski
William Parrillo
John & Debbie Stallings

Golden Angel \$250-499

Daniel & Linda Jannette, Sr.
Elizabeth Kenney
James Bicknell & Mary Ann
Lockhart, Jr.

Angel \$100-\$249

Josie & Vance Adler
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Norman A. Berkeley
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Jere & Isa Breneisen
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Hill)
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Maurice & Jean Vermeulen
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honor of Cameron Robert
Wallace)
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of J.R. Headley)
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Cherub Up to \$99

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Lisa Youngblood)
Arlene & Bartlett Bowles
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