June 1995
Volume XX, Number 3

The Gathered View

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

Florida Passes PW Law

Just a year after the Connecticut chapter's legislative win, the state of Florida passed a similar bill in May to extend disability services to persons with Prader-Willi syndrome who have IQs greater than 70. Like many states, Florida had required an IQ below 70 for most persons with disabilities to qualify for services such as residential placement, respite care, and transportation. As a consequence, a number of families in Florida who were in desperate need of residential services for their children with PWS found that they were ineligible because of IQ. The new law, which was enacted through the enormous efforts of many parents in the Florida PWSA chapter and local professionals, adds Prader-Willi syndrome to a short list of disabilities that are exempted from the IQ requirement and guaranteed services in that state.

In the June issue of the *Gator-Willi News*, Florida chapter lobbyist Caroline Kelly gives a two-page, blow-by-blow account of the chapter's year-long legislative campaign. She describes their basic strategy: "first, to collect the data from our PW population on which to base a financial impact assessment (i.e., numbers and IQs); secondly, to identify a senator and a representative willing to sponsor our bill; and, next, to learn the procedures necessary for effecting legislative change." She notes that "the Connecticut chapter was very helpful in describing the procedures we needed to follow, and the Advocacy Center in Tallahassee provided us with guidelines for dealing with the legislature."

The Florida bill was almost derailed when the state service agency submitted an estimate of the economic impact of the legislation totalling millions. The Florida chapter knew from its survey that "the fiscal impact was minimal" and launched a letter-writing campaign to refute the agency figures. Through perseverance, Florida parents and professionals were able to demonstrate that there are considerably fewer persons with PWS in Florida than would normally be computed from the estimated incidence rate, and that, of that population, less than 25 percent have IQs greater than 70. In addition, because of varying ages within this group, the need for services would be staggered. Since they had "done their homework," the chapter's data were accepted as the most reliable, and the bill moved along to an eleventh-hour passage.

"Florida Statute #393 now includes Prader-Willi syndrome by name as a developmental disability! Florida PW families are elated. It will mean an immediate difference in the lives of at least four of our young people and a better life

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First Awareness Day Was a Great Success

For the hundreds of you who worked so hard to make our first-ever national Prader-Willi Syndrome Awareness Day a resounding success, please—*right now*—pause for a brief moment and either take a bow or give yourselves a hand. We believe that all of our objectives were met.

Chapters of PWSA (USA) from coast to coast pulled together in a unified effort to build awareness under the theme "A New Horizon for Prader-Willi Syndrome." Successful fundraisers benefiting both individual chapters and our national organization generated a great deal of interest. And we told our story over and over at malls, to medical groups and elected officials, and to reporters for newspapers and radio and television stations.

While we are still attempting to gather information, here are a few barometers:

- We were hoping that several hundred persons would sign the Awareness Day letters that were sent to President and Mrs. Clinton and Vice President and Mrs. Gore; 1,832 signatures were collected.
- We were hoping initially that a "dozen to 15" members would be willing to travel to the nation's capital to help out on Washington Activities Day; more than 110 were on hand.
- And we were hoping that most of our chapters would participate with at least one Awareness Day activity or event; in reality, most of our

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inside

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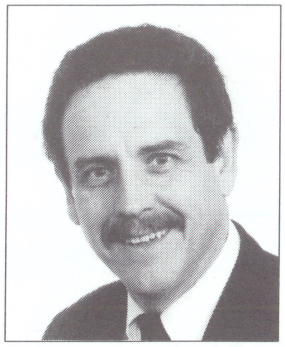

Out of the Office

by Russ Myler, Executive Director

What an exciting year this has been so far in the national office. We have spent about one-third of our work hours talking on the phone with members, the general public, professionals, and the press. Awareness Day/Week was a tremendous success all across the country (as you will read in this issue). The publications committee is developing new information items and updating old ones. The second edition of *Management of Prader-Willi Syndrome* is off the press and available. Our national resources directory is more fully developed, and we are referring more people to group homes, treatment centers, and professionals on a state-by-state basis. (As an example, we have 221 group homes in the database so far.) We are moving further toward your request that we have the most complete information resources available relating to every aspect of the syndrome.

Even though we have a great deal of information here, we do not assume we have it all or know it all. We need to consistently hear from you. We know, for instance, that we do not have the names of all of the group homes, treatment centers, and professionals who have experience with the syndrome. We have not yet developed information pieces on subjects that need attention. We have probably not identified some member needs. This is where we need to hear from you.

If you know of a resource for persons with the syndrome or their family, if you know of a facility opening (or closing), don't assume we know of it; tell us about it. If you have a suggestion for a product or service the Association could offer, please suggest it. The Association is here to meet your needs, and we rely on you to express those needs.

Write us, fax us, or call us with information, ideas, and suggestions. PWSA (USA) is *your* association!

P.S. It just occurred to me that 20 years ago there were NO group homes for persons with PWS; now there are more than 221. Our Association can get things done!

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Opinions expressed in *The Gathered View* are those of the authors or editors and do not necessarily reflect the views of the officers and board of directors of PWSA (USA). *The Gathered View* welcomes articles, letters, personal stories and photographs, and news of interest to those concerned with Prader-Willi syndrome.

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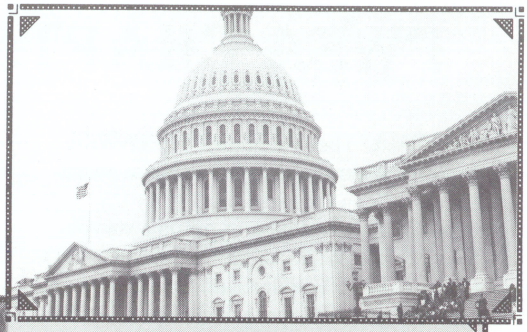
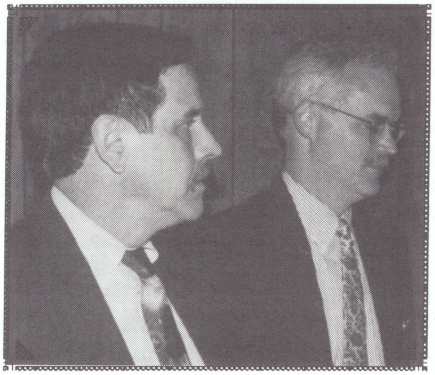
AWARENESS DAY SCRAPBOOK

The photos and reports on these three pages are testimony to the enormous effort, teamwork, and excitement involved in Awareness Day 1995!



May 2 was a cold, wet day in D.C.—not the gorgeous spring day we'd envisioned—but, after an energizing morning of visiting offices in the House of Representatives, we were undaunted in our determination to hike to the west terrace of the Capitol for a group photo.



Executive Director Russ Myler and Board Chair Jim Kane prepare to brief the volunteers gathered at the American Legion Hall on Capitol Hill.

Board Members Pauline Parent (fifth from left) and D.J. Miller (wearing hat) pose with PWSA Secretary Viki Turner (center, next to D.J.), GV Co-editor Linda Keder (far left), and friends from the Pennsylvania and Maryland/Metro D.C. chapters.

Awareness Day—*Continued from page 1*

chapters tackled multiphased strategies and covered virtually all of the target areas, including fundraising, public awareness, legislative and medical community contacts, and scores of pitches to the news media.

Thanks again for all that you have accomplished in the name of awareness. We certainly will look back on our first effort as being successful in terms of enhanced awareness about the cause that brings us together, financially rewarding for those chapters that conducted fundraisers, and lots of fun, as well.

Don Goranson
PWSA Vice President

Senator Jay Rockefeller (second from right) came out of a hearing to meet with us and receive a plaque of appreciation for his Congressional tribute to PWSA. With the senator are Jim, Kit, Kate, and Molly Kane, Leonard Hacker, and Linda Keder.

PWSA CHAPTERS AND AFFILIATED GROUPS

ARIZONA "The first annual Prader-Willi Syndrome Awareness Day to increase awareness of PWS and to raise support for the Prader-Willi Association of Arizona was observed with a 'Walk-Along' in Freestone Park in Gilbert, Ariz. Families and friends of people with PWS gathered for the walk, pledges, fun, and camaraderie. Press releases were sent out, and at least one news article detailed the event and provided information about PWS."

—Christy Montgomery, Vice-President

CALIFORNIA FOUNDATION "Jim Koerber, President, participated in the Washington D.C. day and was able to meet with our senators' staff. Governor Pete Wilson issued an Awareness Day statement. Awareness packets were sent to 33 TV stations and 24 major radio stations (however, no response). Packets were sent to 50 Family Resource Centers, 21 Regional Centers, 13 Area Boards on Developmental Disabilities and select hospitals. One family had an article published in Cal-Tech's *Women's Club Bulletin*."

—Fran Moss, Executive Director

FLORIDA "After the past several months of intense effort by our state members, literally thousands and thousands of people in Florida who had never heard of Prader-Willi syndrome are now aware that the syndrome exists and that its victims are real people!! We did a great deal in printed articles, from church newsletters to very large newspapers. Our main emphasis was not to make money, but to bring about legislative change within the state of Florida [See front page story.]. Over 200 letters and informational packets were distributed, as well as making many personal visits and telephone calls to our senators and representatives. We held our spring conference at Deerfield Beach on April 29 with 93 people in attendance. Our organization in Florida is growing, and even though it may be bittersweet, we are rapidly making new friends. The awareness effort in Florida will continue relentlessly."

—Wauneta Lehman, President

GEORGIA The Georgia chapter held its "First Annual 3-K Walk for Prader-Willi Syndrome," dubbed "Walk Toward a New Horizon." A special issue of *The Georgia View* reports: "Over 200 people attended our concurrent walks in Athens, Atlanta, and Augusta. Over 1,000 names were collected on petitions showing support for the public awareness efforts being organized and promoted by PWSA/GA and PWSA/USA. Over $2,000 was raised, and donations are still coming in! Requests for information on Prader-Willi syndrome and PWSA/GA are coming in as well, which is the truest sign of success."

—Hope Mays, Executive Director

INDIANA "The PWSA of Indiana is just starting to form a chapter, and what a great way to start with activities focused around Awareness Week. The chapter's small group of parents, professionals, and kids took great strides this spring with helping those in Indiana become more aware of PWS. Media kits, provided by the national Association, were the springboard for two radio talk shows, two newspaper articles, an article in the Purdue University School of Education Alumni News Bulletin and an Indianapolis TV news segment! WOW! These items featured parents, some of our leading professionals, and kids with PWS, and reached many people who had never heard of Prader-Willi syndrome before. With the efforts of many, the Indiana group was also able to specifically focus on the medical community. Awareness letters, Medical Alert brochures, referrals to clinical genetic services, and referrals to PWSA, national and local, were sent to the 1,700 family practitioners and pediatricians in Indiana. With these efforts for increasing awareness in 1995 and the continued formation of the Indiana chapter, the group is off to a great start for improving the lives of those with PWS."

—Leo Schertz, President

IOWA "Our newly formed PWS Association of Iowa publicized PWS on TV in Waterloo and Davenport; on radio in Cedar Rapids, Humboldt, and Decorah; and in nine newspapers. We feel this is an exciting start toward public awareness of this syndrome. Our goal is to eventually build a group home in Iowa, so we have quite a project ahead of us."

—Jan Barnes

KENTUCKY "Handed out leaflets to motorists … faxed a PWS paragraph to Jefferson County School System (given to all teachers), and faxed letters to various newsletters that covered several states. Ten press packets sent to TV and newspapers [resulted in] a 30-minute taping on the syndrome on one of our Western Kentucky TV stations—WPSD—shown in four states. Parents and PW clients met with the governor to sign a proclamation for national PW Day. Sold 100 phone cards and 72 T-shirts with PWSA logo. The Kentucky chapter is still committed to spreading the word."

—Rick Settles, President

MARYLAND/METRO D.C. "Our chapter was proud to contribute about half the person-power present for the national PWSA's Washington Activities Day. Throughout our region, we spread awareness through mailings—to families, to directors of special education and early intervention programs, to disability service providers, and to major medical institutions—and we added at least a dozen new member families to our roster as a result. Our big success was a raffle of donated prizes, with the drawings held at a chapter picnic on May 6. We had a great time and netted approximately $4,000 to split with PWSA! We had a lot less luck with press coverage but we'll keep trying."

—Linda Keder, President

MICHIGAN "PWS Awareness Day was a success in Michigan. It was inspiring to see our state organization go from a nervous, quivering they-want-us-to-do-WHAT? group, when we first heard about the awareness campaign, to a confident, cooperative, enthusiastic, 'well-oiled' machine that took on the challenge and triumphed! Our big event was a walk-a-thon held in Grand Rapids April 29. We had over 150 participants. That was preceded by a media campaign—we got several articles in the print media, a couple of radio spots, and a TV interview. We also invited many officials to our event and sent them our new brochure. Persons with PWS, their families, friends, and service providers all pitched in and enjoyed the experience. We definitely created some awareness, made a few—very few—'learning' mistakes, and ended up liking each other more, knowing each other better, and feeling more connected to each other."

—Helen Warner-Bell, President

MINNESOTA "During the months before Awareness Week, we managed to send out around 200 letters to TV, radio, and newspapers all across the state. The end result was the Barbara Carlson radio show broadcasted a segment on PWS, and both channels 5 and 11 presented a program segment on PWS. In addition, the *St. Paul Pioneer Press* newspaper placed a notice about our Awareness Week on April 27. Due to these programs airing, we have been able to reach out and find nine additional people who need our help. We are still hopeful to hear from more people in the months to come."

—Bridgette Tangen, Treasurer

MISSOURI "Russ Myler, Barbara Whitman, Jan Wallis and I participated in an interview with television channel 5's Jennifer

SPREAD AWARENESS COAST TO COAST

Blome, for 'St. Louis Sunday,' a local talk show which aired on April 30 at 10:00 a.m. A 50/50 raffle was conducted—net ticket sales were $1,026—and our grand prize winner ($513) was Sheryl Wiexeldorfer, a 30-year-old with PWS from Blue Springs, Mo. Second place received a Pasta House (restaurant) certificate worth $10, and third place received a PWSA T-shirt. An information booth was set up at a local shopping center, Mid-Rivers Mall, in St. Peters, Mo. Information was handed out from Friday, April 28, through Sunday, April 30, but there were very few visitors."

—Paula Kollarik, President

NEBRASKA "We had a Bowl-a-thon April 29 with 47 bowlers and raised nearly $2,800. On May 2 one of the local television stations aired a segment at 5:00 and 10:00 called 'Family Health' that was very descriptive about the syndrome. We sent out letters about Awareness Week, information on the Bowl-a-thon, and the new brochure to all the educational units in Nebraska. We signed a proclamation with the governor and presented him with a T-shirt; we also signed a proclamation with the City of Omaha. Geneticist Bruce Buehler, through University of Nebraska, aired a very informative segment at noon on PWS in early April. We had a radio station make public announcements about Awareness Week. We have registered with the library and other agencies as a support group. We had booths set up at two different functions that dealt with children with disabilities. We have ongoing efforts to get something in our newspaper and several other informational magazines which reach several cities around the area."

—Roger Rhoads, President

NEW ENGLAND "The New England Chapter recognized Prader-Willi Awareness Week together with the New York Alliance at our annual joint conference. This year the conference was hosted by the New England Chapter and held at the Marriott Hotel in Burlington, Mass., on April 28 and 29. Close to 200 people were in attendance, including parents and other family members, care providers, scientific and medical experts, and many individuals with PWS. One of the highlights of the conference was a panel of young adults with PWS who answered questions from discussion leaders and the audience on residential living and PWS in general. Other speakers included co-directors of the Center for Prader-Willi Syndrome and Related Disorders at Spaulding Rehabilitation Hospital, Dr. Rob Wharton and Dr. Karen Levine; Dr. Suzanne Cassidy of the Center for Human Genetics at Case Western Reserve University; and Dr. Terrance James, a Rehabilitation Consultant from British Columbia. The conference ended with two round-table discussions—one for parents with children under 12 years old and one for parents with older children."

—Debbie Gravallese, Secretary

NEW YORK ALLIANCE "The Alliance's co-hosting of a conference with the Prader-Willi Syndrome Association of New England during Prader-Willi Awareness Week was an overwhelming success. The Alliance sent press releases about Awareness Week to 36 newspapers and cable TV stations. The fund-raiser in conjunction with Awareness Week was 'skip a lunch' and donate the cost ($5)."

—Henry Singer, President

NORTHWEST Highlights of the chapter's activities included: "a rummage sale in Granite Falls, Wash., by Neil and Tammy Byron, which raised $650. Billie and Steve McSwan of Pasco, Wash., sold many T-shirts and long distance phone cards. Leftover T-shirts are being donated to the group home in Woodinville, Wash. Press packets were sent to eight newspapers, and the resulting articles in some generated a number of calls.

Nancy MacDonald and son Craig, 17, were in a front-page article in the *Journal American* (Seattle's Eastside newspaper) about life in a PW home. This article generated the interest of Seattle TV station channel 5. A TV interview (to be aired on 7:00 'Evening Magazine') was done at the Bedford-Brookhaven PW group home, at Craig's high school, and with the MacDonalds in their home."

—Nancy MacDonald, Co-President

OHIO "On May 6 we held a state-wide conference at Children's Hospital in Columbus for professionals and families. We had 160 attendees, and 16 children participated in child care. Conference speakers represented a broad spectrum of disciplines: nutrition, law, psychiatry, pediatrics, endocrinology, education, residential services, and more. At the end of the conference, we had a cocktail party and were able to share our feelings about the day. We were unable to develop a fund-raiser but are considering a 5K run in the future. Lastly, we developed a state brochure and started distribution at the conference."

—Pat Shiley, Executive Director

PENNSYLVANIA "On Sat., May 6, the PWSA of Pa. met at Willow Street School and held a fund-raiser. We asked members of our organization to collect monetary pledges for exercises to be done by individuals with PWS and their family members during a two-hour period of time. Ten individuals with PWS and their families attended, and approximately $1,000 was raised. Additional amounts were also raised by others who were unable to attend the event."

—Debbie Demko, President

WESTERN PA. ASSOCIATION "PWS was featured on the *Pittsburgh Post-Gazette's* weekly Health & Science page on May 8. Spotlighted were my daughter, Julie, 25, and Steven Immekus, 5, son of Sandy Immekus, president of PWWPA [a support group]. Additional information was provided by Jeanne Hanchett, M.D., pediatrician at The Rehabilitation Institute of Pittsburgh."

—Lota Mitchell

UTAH "We were able to have a television cover story about PWS (CBS affiliate) with an appeal to the television audience to help us find undiagnosed persons with PWS. This story was two three-minute segments after the evening news on two separate nights. Because of this we have discovered at least two new persons with PWS in the area and perhaps a third. It was excellent exposure and coverage we would not normally be able to afford, and it has established contacts within the television station for future exposure. We also tried to get several shopping malls to allow us to have a PWS display and talk to people about PWS. One major mall did allow us to do this. Our members also circulated flyers and brochures to medical clinics and libraries in the area."

—Dennis & Glenna Smith, Co-Presidents

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Editor's note: Although we did not hear from all chapters in time for publication, we know that a number of others had activities going on during Awareness Week. For example, Arkansas and South Carolina held workshops for service providers. Connecticut planned a swim-a-thon, and North Carolina a yard sale and silent auction. Delaware members distributed information at a shopping mall, and families in Colorado and New Jersey sent information to medical and other providers. Because of all the reports we *did* get, there wasn't enough space in this issue for chapter photos. We expect that you'll see some at the Seattle conference, and we hope to publish some in a future *Gathered View*.

Thanks, chapter presidents, for the tremendous response—and congratulations on a truly impressive awareness campaign!

The Special Job for a Special Child

by Donna Adee
Minneapolis, Kansas

Donna's son, Nathan, died of PWS-related causes in April 1992. She wrote the following words about his life and its purpose. This is a shortened version of her original article, which was published last December in Parenting Treasures. Donna is now working on a book to be entitled: God Doesn't Make Junk, Lessons from Nathan and Other Special Needs Children. In her letter to PWSA, Donna writes: "I'm thankful you are getting the word out about Prader-Willi because parents need to know that it isn't the end of the world and with some encouragement they can raise that child in their own home. If I can be of help to any parents, have them call or write."

"There is something wrong with your son, Mrs. Adee," Dr. Wedel announced shortly after the birth of our third son. That was the start of our 27-year adventure with Nathan.

... The doctor wasn't sure that Nathan would live, but I was and believed that God would have a special job for Nathan. That job was one I never would have guessed.

His doctor called him a "Miracle Baby" when he survived that first year, but Nathan's genetic handicap affected his motor and mental abilities. From a limp rag-doll beginning, Nathan slowly progressed to walking and talking. Early on, he loved our Old Testament Bible story records and listened to them by the hour. Once he heard the story, he remembered every detail.

Nathan never met a stranger. Unlike our other two children, Nathan talked to everyone. If we had visiting missionaries at church, Nathan quizzed them, "Do you work with Indians?" If they did, he had more questions. ... I thought that special job God had for him might be working with Indians. But that wasn't to be.

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School life brought new problems. No one knew how to teach Nathan. Since we didn't know the real cause of his problems, his teachers asked us to take him to the Kansas University Medical Center for a diagnosis. After a series of tests, the neurologist called us to his office and dumped the devastating news: "Your son has Prader-Willi syndrome. He probably will never be able to do anything in school. Just take him home and keep him happy. He won't have the fine motor skills to button a shirt or zip a zipper." I was too distraught to tell the doctor that Nathan was already buttoning his shirt and zipping his zippers.

We enrolled him in kindergarten where he had problems staying awake and doing simple writing. When the educational psychologist recommended that Nathan go to special education the next year, we agreed, but it was not a good choice for Nathan. He picked up the negative attitudes of the other children. After much prayer we decided to mainstream him and to work with the teacher. Today we would have home schooled him since we tutored him morning, evening, every weekend, and summer as well as sent him to public school. If given in small doses, Nathan could understand most subjects, but with his poor writing skills he was always behind in his work.

Once he learned to read, Nathan couldn't be stopped. He read constantly. History excited him—if the library didn't have a children's book on the Czars of Russia, the Emperors of China, or President Eisenhower, he would ask "What do you have in adult books?" And he read them and remembered meticulous details. Once he learned that Anastasia, daughter of the Russian Czar, was related to Prince Phillip of England, he insisted on writing to the monarch about her situation. He received a letter back from Phillip's secretary. I was sure Nathan would become a researcher in a large library, but his health problems prevented that. He just could not stay awake.

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At 13, the more obvious signs of PWS began to plague Nathan and us. First, the school nurse discovered a severe back curve during a routine test for scoliosis. We again prayed for wisdom as we went from our local doctors to specialists in Kansas and California. After choosing to wait on fusing 13 vertebrae—a course recommended by the doctors—our local doctor was to tell us years later, "You made the best choice; they have found that fusing doesn't work."

> ***"Many times I wondered if Nathan and our family would survive this trial and if Nathan's many problems would keep him from God's special job."***

The next obvious symptom was the one that makes it impossible for most patients with PWS to live with their families: they literally eat themselves to death. ... We hid food, kept all sweets out of the house, and padlocked the refrigerator, but Nathan would invariably find the forbidden food. He continually gained weight on a diabetic diet. Many times I wondered if Nathan and our family would survive this trial and if Nathan's many problems would keep him from God's special job.

Following drivers' education at school, Nathan earned his driver's license, a feat the school psychologist was sure he couldn't accomplish. After long days and nights of studying, he graduated from high school. We felt they should have given his parents a diploma for tutoring.

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One morning after graduation Nathan announced, "I want to live in my own apartment." That was a surprise to us as well as almost impossible for him. He would have to cook diabetic meals and do his own washing and cleaning, but he convinced us he could do it. We found an apartment for senior citizens and the handicapped in our small town.

Nathan received one meal a day at the hospital. He had a

(Continued on page 7)

In Memory of Beate Vogl-Maier

On April 19, 1995, Beate Vogl-Maier died at the age of 65 of inflammatory breast cancer.

Bea served as senior coordinator for chronic illness and developmental disabilities at The Rehabilitation Institute of Pittsburgh (TRI). It was she who in 1981 developed the treatment program there for Prader-Willi syndrome—the only one of its kind in the United States—and oversaw it until her retirement in August 1994.

Jeanne Hanchett, M.D., a member of the PWSA Scientific Advisory Board and a pediatrician who worked with Bea at TRI, pays the following tribute:

"It was my pleasure to work with Bea Maier for nearly 18 years. Her knowlege of this syndrome was wide-ranging and remarkably complete. Her compassion for persons with PWS led her to extend herself on their behalf until the end of her life. The PWS families she worked with over the years numbered more than 300, all of whom appreciated her skill, her counseling, and her wisdom. She was able to develop a program here at The Rehab Institute which is known internationally. All of us who worked with her learned much from her and will continue to develop, maintain, and improve this program in the future."

Bea Maier was honored by the Association last year at the national conference in Atlanta.

Born in Germany in 1930, Bea came to the United States as a child of about 10 during World War II. Her son Jerry Vogl says her family actually sneaked out of Germany on a train at night and went to England and then Canada before arriving in the United States. She became a naturalized citizen in 1955. She did her undergraduate work at Barnard College and earned both her Master's degree and Ph.D. from the University of Pittsburgh. Her doctoral dissertation, completed in 1984, was on children with PWS and the effects of TRI's program on their weight, fitness, and certain social characteristics. Before joining TRI, where she worked for over 25 years, Bea taught nursery school and at the School for the Deaf.

At her funeral services, it was noted that Bea had opened her family to a foster son and two stepdaughters in addition to her own three children and that in a sense she had included in her "family" the children and young people with PWS and their families. At the national conference in Atlanta in July 1994, she received recognition as one of two PWSA honorees for the year.

The comments of Jeanne and Rhett Eleazer, of Columbia, S.C., are representative of the feelings and experiences of many of the families whom she helped:

"Bea Maier and the program she developed at The Rehabilitation Institute of Pittsburgh came into our lives when our son Billy was in crisis. His weight was over 300 pounds, and he was on oxygen. In three months he lost over 70 pounds and was able to move into a group home. Bea dedicated herself to the treatment of our loved ones who struggle daily with PWS. She will be missed—but her contributions and spirit will be with us always."

—Lota Mitchell

special love for the elderly and head injury long-term patients and spent hours visiting them. They looked forward to his visits, so the hospital asked him to teach a Bible study to the head injury patients. He used his Bible story records to tell stories and form simple questions. ... He had at last found something he could do, but it didn't last. He couldn't handle the discipline problems of the head injury patients and had to quit.

He enjoyed the freedom of staying in town, but it soon took its toll on his health. Being unable to control his eating, he gained 40 pounds in eight months, and his loneliness caused him to spend too much time with the other residents. They complained and Nathan came home.

For years we had been looking for a special group home for Nathan. He was apprehensive about the idea but willing to try. However, the restrictions and being away from family and his animal friends made him miserable. After he ran away just so he could phone us, we brought him home to stay. I despaired of Nathan being able to do that special job God had for him. His health problems wouldn't allow him to do even a part-time job.

He was happy and more content than he had been in years, but we could see his health slowly deteriorating. His diabetes, asthma, and obesity were robbing him of everything he enjoyed. We could see we were slowly losing him.

Nathan's asthma attacks put him on oxygen for up to six hours a day, and it was an effort for him just to walk the stairs from his bedroom. Yet he wanted to go to town with me that spring morning; he visited the head injury patients at the hospital and purchased Easter baskets for his niece and nephew. The Lord took him to his heavenly home on a beautiful spring Sunday morning a few days later.

We now realize Nathan's special job from God was to show our family that God gives only good gifts, that with those gifts He gives the wisdom, strength, and comfort needed to care for the gift. ... Nathan accomplished the special job that God had for him, and his work on earth was finished at the age of 27.□

Research

The following articles concerning Prader-Willi syndrome were published in English-language journals in the first six months of 1995. Most journals are available in major libraries and research centers.

MEDICAL

Hakonarson, H., Moskovitz, J., Daigle, K.L., Cassidy, S.B., & Cloutier, M.M. (1995). Pulmonary function abnormalities in Prader-Willi syndrome. *Journal of Pediatrics, 126*(4), 565-70.

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GENETICS

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Leisti, J., Kokkonen, H., & Kahkonen, M. (1995). A molecular and cytogenetic study in Finnish Prader-Willi patients. *Human Genetics, 95*(5), 568.

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Villa, A., Urioste, M., Bofarull, J.M., and Martinez-Frias, M.L. (1995). De novo interstitial deletion q16.2q21 on chromosome 6. [Reports clinical similarities to PWS.] *American Journal of Medical Genetics, 55*(3), 379-83.

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PSYCHOLOGY

van Lieshout, C.F.M., Hoondert, V., & Fryns, J.P. (1995). Personality profiles of youngsters with Prader-Willi syndrome and youngsters attending regular schools. *Journal of Intellectual Disability Research, 39*(3), 241.

(Sources: MEDLINE database, National Library of Medicine; UnCover database, Colorado Alliance of Research Libraries. Listings with a single page number may be longer than one page.)

PWS and Cleft Palate?

Dr. Robert D. Nicholls and colleagues would be very interested in learning about any persons with PWS who have true cleft palate or cleft lip.

Dr. Nicholls writes: "Colleagues of mine have made a directly relevant research finding in the mouse gene region that is equivalent to the large PWS/AS deletion region in humans. They have submitted a manuscript on their work in the mouse, but further research is needed to see if this has any relevance to human disease. I would be interested in hearing from the family or the physician looking after the relevant patient if the association of PWS and cleft palate is known to occur."

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Diagnostic Criteria for Prader-Willi Syndrome

The following criteria for a diagnosis of Prader-Willi syndrome are based on Holm et al. (Pediatrics 91, 398, 1993). Because infants and young children have fewer symptoms than older children and adults with PWS, the scoring system differs by age group.

Major Criteria

(Count as 1 point each.)

__ 1. Neonatal and infantile central hypotonia with poor suck, gradually improving with age

__ 2. Feeding problems in infancy with need for special feeding techniques and poor weight gain/failure to thrive

__ 3. Excessive (crossing two centile channels) or rapid weight gain on weight-for-length chart after 12 months and before age 6; central obesity in the absence of intervention

__ 4. Characteristic facial features with dolichocephaly in infancy, narrow face or bifrontal diameter, almond-shaped eyes, small-appearing mouth with thin upper lip, down-turned corners of the mouth *(three or more of these characteristics required)*

__ 5. Hypogonadism—includes any of the following, depending on age:

a. Genital hypoplasia (*in males:* scrotal hypoplasia, undescended testes, small penis and/or testes; *in females:* absence or severe hypoplasia of labia minora and/or clitoris)

b. Delayed or incomplete gonadal maturation with delayed pubertal signs after age 16 (*in males:* small gonads, decreased facial and body hair, lack of voice change; *in females:* no or infrequent menses)

__ 6. Global developmental delay in a child younger than 6 years; mild to moderate mental retardation or learning problems in older children

__ 7. Hyperphagia (excessive appetite)/food foraging/-obsession with food

__ 8. Deletion 15q11-13 (>650 bands, preferably confirmed by fluorescence in situ hybridization) or other appropriate molecular abnormality in this chromosome region, including maternal disomy

Sum of Major Criteria Points:_____

Minor Criteria

(Count as ½ point each.)

__ 1. Decreased fetal movement or infantile lethargy or weak cry in infancy, improving with age

__ 2. Characteristic behavior problems—temper tantrums, violent outbursts, and obsessive/compulsive behavior; tendency to be argumentative, oppositional, rigid, manipulative, possessive, and stubborn; perseverating, stealing, and lying *(five or more of these symptoms required)*

__ 3. Sleep disturbance or sleep apnea

__ 4. Short stature for genetic background by age 15 (in absence of growth hormone intervention)

__ 5. Hypopigmentation—fair skin and hair compared with other family members

__ 6. Small hands (<25th percentile) and/or feet (<10th percentile) for height age

__ 7. Narrow hands with straight ulnar border (outer edge of hand)

__ 8. Eye abnormalities (esotropia, myopia)

__ 9. Thick, viscous saliva with crusting at corners of the mouth

__10. Speech articulation defects

__11. Skin picking

Sum of Minor Criteria Points:_____

Requirements for a Diagnosis of PWS:

From Birth to Age 3—*Five* (5) total points are required, of which *four* (4) must be from the major criteria list.

Age 3 to Adulthood—*Eight* (8) total points are required, including at least *five* (5) from the major criteria list.

Supportive Findings *(The following are not scored but increase the certainty of a diagnosis of PWS.)*

1. High pain threshold
2. Decreased vomiting
3. Temperature instability in infancy or altered temperature sensitivity in older children and adults
4. Scoliosis or kyphosis (curvature of the spine)
5. Early adrenarche (pubic or axillary hair before age 8)
6. Osteoporosis (demineralization, or thinning, of the bones)
7. Unusual skill with jigsaw puzzles
8. Normal neuromuscular studies

Food for Thought (and Vice Versa)

by Linda Keder

I never thought much about food and its role in our society until my daughter, Lesley, was diagnosed with PWS five years ago at age 1. Since then, I probably think about it more often than Lesley thinks about her next meal or snack.

My first thought about how we could best help Lesley with respect to diet was that we would simply deemphasize food in our lives, creating a little cocoon for her where food was simply not a major factor. (Who did I think I was fooling?—My husband and I love to eat!) My first indicator that this plan would not work was a visit to the public library, where it seemed at least half of the picture books I pulled out had food themes. And, although we stuck to PBS TV shows, there were problems there too—that lovable Cookie Monster, for one. The Christmas our *best friends* gave Lesley a plastic Burger King Whopper and fries kind of clinched it for me. We couldn't "protect" Lesley from food. Before we knew it, we had a toy kitchen in our playroom and a copy of Eric Carle's *The Very Hungry Caterpillar* just like everyone else. Neither seemed to cause hunger—so far, so good!

Since Lesley would unavoidably be exposed to food she couldn't have—or couldn't have much of—my next strategy was to identify as many nutritious, low-calorie foods as possible and to give Lesley choices as often as possible. My reasoning was that having choices would help her feel in control, more independent, and less deprived, as well as promote communication skills. Even before she could talk, Lesley was able to make her choices for meals by pointing to picture symbols on communication boards that I'd been urged by her speech therapist to make. (You can make simple picture boards using cutouts from grocery store ads.) This strategy seems to have worked for us. We basically follow the American Dietetic Association's Exchange System, letting Lesley choose her fruit at all three meals, her starch at breakfast and lunch, and her protein at lunch (I can't interest her much in vegetables yet.). We try to plan an evening meal that the whole family can share.

My major concerns now are outside the home. Food is such a big part of social events, and there are so many new forms of interesting-looking junk foods and drinks that Lesley is bound to start feeling left out. I worry how much to tell a birthday party host and whether Lesley will soon demand to buy the high-fat school lunches.

The one bit of encouragement I have is that more people and groups seem to be speaking and taking action about the quality of school lunches and children's diets in general. In fact, I just read that the USDA passed final regulations requiring more healthful school meals by 1996-97 and that they've teamed up with Disney to promote better diets. "Lion King" characters Pumbaa and Timon apparently will be starring in a series of public service television announcements on healthful food for children.

I know I'll be watching the school lunch developments closely. Parents similarly inclined might want to check out two recent books that give plenty of armament for improving young diets: *What are We Feeding Our Kids?*, by Michael Jacobsen, Ph.D., and Bruce Maxwell (Workman Publishing, 1994), and *Dr. Attwood's Low-Fat Prescription for Kids*, by Charles Attwood, M.D. (Viking, 1995).

The First Time

Do you remember the first time your child sneaked food? I am sure your first thought was like mine: "I have got to keep a closer eye on him (or her)." Then the second time you catch them, you are really aggravated with yourself for being so careless.

I remember well the first time I caught my 3-year-old son, Andrew, with food. It was a chocolate popsicle. He tried to hide it behind his back. The funny thing was, he had his back towards me. So he was holding it right in front of my face! Not only that, the freezer door was still wide open! Along with the basket he stood on to reach the freezer to get it!

Like so many other parents of children who have Prader-Willi syndrome, you hope your child will be different. I can remember thinking to myself, "My son is not that bad." We will never have to lock our food away. But as Andrew gets older, food is more important to him each day. Almost every time we get in the car to go someplace, Andrew's question is, "What are we havin'?" when we get there. And you better tell him it's something he likes, such as "hamburger," or he throws a fit.

But you know sometimes it's easy to forget about his love for food. When I look at his beautiful face, all I see is a a happy-go-lucky little boy. When he gets up every morning, about 5:30. And his Mom tells him to come and get in bed with us. The first thing his mother and I hear from Andrew every morning is, "I want to eat."

After his Mom (who is not a morning person) scolds him for getting up too early and convinces him to get into our bed, I lay on my side of the bed and sometimes chuckle. As if Andrew needs to remind us he wants to eat breakfast. I just think to myself, I know, son, I know …

Brian Norton
Missouri

(reprinted with Brian's permission from the Missouri chapter newletter, *The Missouri View*)

Sib Session Offers a Chance to Vent

by Lota Mitchell, M.S.W.

The Pennsylvania chapter's April meeting in Hershey was focused on sibling issues. Jeri J. Goldman, a clinical psychologist, led discussions first with a group of children with PWS and then with a group of their siblings. Dr. Goldman is Supervisor of Special Education for schools in Camden, N.J. Prior to that, she had 18 years of experience working with the Woods School's Prader-Willi program.

When the groups rejoined their parents, Dr. Goldman reported on the PW group's discussion. They seemed not only to have a range of ability to control their behaviors and food-seeking, but also a range of interest in being able to have control. (She commented initially that "one doesn't necessarily go with the first thing they say," as many people with PWS readily deny and only after a while may admit to certain behaviors.) While food obtained "illegally" might be consumed all at once, there were reports of food saved as well. Some children were able to see the risk in their eating. And some wondered why they had gotten the syndrome instead of their sibling.

John Homer, 14, from Carlisle, who has a younger sister with PWS, reported the following points from the sibling group (many bearing out the comments on our *Gathered View* sibling survey last year):

- It's awkward being younger than the child with PWS and being put in charge of them—all responsibility but no authority. (Dr. Goldman recommends parents confer that authority.)
- You can't win and you feel trapped if you get in an argument with them—even when you're right, they'll never acknowledge it. (Dr. Goldman commented that parents experience this also.)
- Family sometimes revolves around the sibling with PWS, e.g., how often you can eat out, doctor appointments, money—this produces feelings of annoyance and neglect.
- If the environment is controlled by the parents, there is less demand and burden on sibs to enforce. (Dr. Goldman says that routine pattern is good.)
- A worry: What happens when parents aren't able to care for the child with PWS any more?
- The person with PWS is favored in an argument, and parents tell the sibling to "just ignore it." This feels like the parent is taking the side of the child with PWS and not acknowledging how hard "ignoring" is. And too often the sib ends up being the one to get yelled at.
- You don't feel right hitting them—but they can hit you. It helps and is easier if the parent steps in.
- Sibs need space to themselves, e.g., for private time, to have friends in.
- They might appear to be slow or overweight, but they get stuff fast and stash it—and that's another source of annoyance.
- Sibs need a parent to take problems to. □

Banana Popsicles

Peel a medium banana
Cut in half and insert popsicle sticks, if desired
Wrap halves in plastic, then in foil
Freeze and enjoy!

Gelatin Cutouts

4 envelopes unflavored gelatin
3 small (4-serving) packages sugarfree flavored gelatin
Mix with 4 cups boiling water and stir to dissolve
Pour into 13 x 9 inch pan and refrigerate
When jelled, cut into squares or use cookie cutters to cut shapes.
(Not overly sweet like the ones using all flavored mixes)

Topping for Fruit

Put low-fat cottage cheese in a blender with a small amount of Sweet 'N Low (or other sugar substitute)
Blend until smooth
Serve on fruit (with angel food cake, for special occasions)

Watermelon Cooler

3 ice cubes
4 oz. ripe watermelon, cut in cubes, seeded
1 tsp. lemon juice
4 oz. seltzer or sparkling water
Shave the ice cubes in a food processor and transfer to a tall glass
Puree watermelon until liquid, add lemon juice and water and blend
Pour over ice (through strainer, if desired)
Garnish with mint leaf or lemon slice

Pineapple Shake

3 oz. fresh pineapple chunks
¾ cup skim milk
Process pineapple in blender or food processor until finely chopped
Add milk and process about a minute (until thick and frothy)

WANTED:

A PWSA MEMBER WHO'S ALSO AN IBM EMPLOYEE

IBM Corporation will donate computer equipment to a nonprofit organization if one of its employees is involved with that organization. If we have any IBM employees out there who are willing to help PWSA in this regard, please call Jim Kane (410-321-9788) or Russ Myler at the national office (800-926-4797).

(Continued from page 1)

in the future for many others," Caroline writes. Chapter President Wauneta Lehman cautions her fellow chapter members against having a "false sense of security." Although "the battles ahead will be easier," she warns, "they still exist." She adds: "We have made it this far and we won't be stopped now. PWFA is a formidable force."□

Editor's note: Any chapter seeking similar legislation in their state(s) should call the national PWSA office for information and people to contact in Connecticut and Florida.

Our Deepest Thanks

for contributions received in April and May

AWARENESS DAY

Chapter Fund-sharing

Prader-Willi Assn. of Minnesota
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In memory of Gretchen Hamill—
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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.

PWSA USA