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The Gathered View

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

Celebrating 25 Years of Dedication to People with Prader Willi Syndrome

Anniversary Year Begins a 'Millennium of Hope'

The Year 2000 marks 25 years that PWSA has been in existence, striving to improves the lives of people with Prader-Willi syndrome and their families. It was in late 1974 that Gene and Fausta Deterling, the parents of a little boy named Curtis, began the process of forming an organization that would become PWSA (USA). The organization was officially launched in 1975, and the first issue of *The Gathered View* was published in July of that year.

When the Deterling family began its journey, there were only four published articles on Prader-Willi syndrome available in the world. Their bringing together of interested families and professionals started a revolution. Today, PWSA (USA) is a thriving organization, and research on PWS is expanding by leaps and bounds.

We begin a year of celebration and remembrance with a tribute to our founders. Had it not been for Gene, Fausta, and the other parents who were our first advocates, we might not be celebrating today!

From the association's archives: PWSA Co-founders Gene and Fausta Deterling at the 1984 national PWSA conference in Minnesota with Dr. Andrea Prader (right), among the first to identify the syndrome, and Dr. Vanja Holm (front), PWSA's first Scientific Advisory Board chair.

inside

The Prader-Willi Syndrome Association (USA)

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The Gathered View welcomes articles, letters, personal stories and photographs, and news of interest to those concerned with Prader-Willi syndrome.

Communication regarding *The Gathered View* or PWSA membership and services should be directed to the national office of PWSA (USA) in Sarasota, Florida (see address information above).

Editor/Desktop Publisher NEEDED

PWSA (USA) is recruiting for a person or persons to take over the job of editing and laying out *The Gathered View*, the Association's national bimonthly newsletter. Linda Keder, our chief editor for more than five years, has asked to be relieved of her duties by June of this year so she can devote more time to her family, to local advocacy, and to other pursuits. While we hate to lose her, Linda's resignation offers a great opportunity for other talented members to become involved with PWSA at the national level.

The position of editor involves gathering and developing newsletter content, writing, editing, proofreading, and preparation of camera-ready pages for printing. Editing or journalism background and desktop publishing skills are highly desirable. Contract pay is negotiable.

Interested persons are urged to contact Janalee Heinemann as soon as possible by fax (941-312-0142), or by mail to PWSA (USA), 5700 Midnight Pass Rd., Suite 6, Sarasota FL 34242. Kindly send a brief summary of your publications experience and a sample of your work.

Call for Nominations

PWSA (USA) Board of Directors

For the July 2000 elections, the Leadership Development Committee requests that names of members interested in, or recommended for, a position on the board be submitted no later than March 31, 2000. Board terms are three years.

Recommendations should include a brief description of the candidate's qualifications to serve on the board. Send recommendations by mail, fax, or e-mail to the attention of the Leadership Development Committee Chair, c/o PWSA (USA), 5700 Midnight Pass Rd., Suite 6, Sarasota, FL 34242; E-mail: PWSAUSA@aol.com; Fax: 941-312-0142.

25th Anniversary Presidents' Messages

Instead of one President's Message, we bring you two in this issue of *The Gathered View*. As we begin our 25th anniversary year, it seems fitting to include thoughts from PWSA's first president, Gene Deterling, as well as from our current president, Barb Dorn.

Who Would Have Guessed?

by Gene Deterling, First PWSA President

We never would have guessed 25 years ago that the organization we founded in 1975 would grow to the strength it is today. The first formal announcement of the organization was in the June 1975 issue of *The Exceptional Parent,* followed shortly afterwards by announcements in other publications, including medical journals. We actually had a handful of founding members before that date, since we had begun working on the organizational plans in December 1974. The Neason family in Washington state became our first official member by paying the $5.00 annual dues on May 1, 1975. Shirley Neason became our first editor of *The Gathered View,* which made its debut in July of that year. The organization at that time was called Prader-Willi Syndrome Parents and Friends.

By the end of 1975, we had 48 paid members and we were off and running. Thanks to a healthy donation that year from members and friends of the Webster Leyshon family, whose daughter had recently died due to complications of obesity, we even had operating funds to keep us going through the year. But we weren't really organized yet.

It was just Fausta, my wife, and I in the beginning. I was working on formalizing and perpetuating the organization, and Fausta did everything else. I appointed myself as the Director. We didn't really have any officers until we selected a Board of Directors and had our first meeting in May 1977, at which time I officially became the first president and treasurer, and Fausta became the official secretary. The name of our organization was changed at the time to The Prader-Willi Syndrome Association.

From that humble beginning, the organization has not only grown and strengthened beyond our original imagination, but it has become a quality, respected association of people who continue to work diligently for the good of our people with Prader-Willi syndrome. Fortune has smiled upon us, for we now have an organization managed and supported by absolutely the best people in the world. We know the future will be good for us, but none of us can imagine how much better it will be at the end of the next 25 years.

A Message of Thanks

By Barb Dorn, PWSA (USA) President, 2000

As we start off the new millennium, I am very proud and pleased to kick off PWSA (USA)'s 25th Anniversary celebration year. I felt it was only appropriate to include a President's Message from Gene Deterling, one of our founding parents and the first president of PWSA (USA). Gene and his wife have had the privilege of witnessing firsthand all of the accomplishments and progress that we have made in supporting persons with PWS for the past 25 years.

An anniversary is a time that we all stop and take a look at how we began and reflect on all that we have accomplished. It is also a time to acknowledge and thank all who have worked so hard at getting us to where we are today. Over the next year, we will be highlighting some of these special people and events.

Personally, I admire all those who took on the enormous challenge of forming a national organization. I know how overwhelmed I become at times with the hard work and commitment that it takes to keep our local state chapter active as well as all the work that goes on at the national level. It is now my task, as well as yours, to say thank you and keep this organization moving forward.

This anniversary celebration is a time to acknowledge people—special people who have made a significant difference in the lives of persons with PWS across this nation and around the world. Words just can't express the gratitude that we all feel.

Our theme for this year is "A New Millennium of Hope." As we enter this new century, we have many reasons to be hopeful. We have accomplished a lot over the past 25 years, and we dream of accomplishing much more in the years to come. We must never lose hope. We must always stop and remember where we were, where we are now, and where we want to go. It takes people, committed people, to continue making progress. Thanks to all who have helped us start this journey and welcome to all who will continue to keep us moving forward.

Happy Anniversary, PWSA (USA)!!!

Prader-Willi Syndrome Association (USA) Annual Executive Director's Report

Highlights of 1999

by Janalee Heinemann

Thanks to the support of many volunteers both nationally and locally, a dedicated staff, and generous donors, we had a very productive year in 1999. The following are the highlights — but by no means totally inclusive of all that has been accomplished. As I wrote many years ago, and one parent just quoted in a recent letter I received — we *are* in this boat together. The boat is getting sturdier and the crew is getting greater in numbers and strength. Thanks to all who helped in so many, many ways.

STATISTICS

- Added 291 new members this year— a total of 2,287 members.
- Our Web site receives 6,400+ pages of requests a day.
- Provided a record number of 24 families with conference grants this year. Were able to obtain outside funding for several of these grants.
- Provided free membership and newsletters for 78 families in hardship situations and to 43 adults with PWS.

NEW PROGRAMS

- Clinical Advisory Board was established, giving us two major medical boards.
- Initiated a Grandparent Program. Increased our Grandparents database from 5 to 107.
- Initiated a Pen Pal Program.
- Initiated a Recycled Love Program (recycling large sized clothing).
- Provided bereavement support for 118 families; 28 new families were added.

SERVICES PROVIDED

- PWSA (USA) creates, publishes, and distributes free more literature than anyone in the world on the subject of PWS.
- Sponsored the San Diego national conference, which had approximately 1,100 people in attendance. Of those, we had over 300 in the youth program, including over 200 with PWS. There was a record of 62 children in the 0-5 age program.
- Provided crisis intervention for hundreds of families.
- Provided educational information and school advocacy for hundreds of school systems.
- Provided medical information for hundreds in health-related fields.
- Provided information and crisis support for hundreds of group homes/ supported living homes. Currently, 106 such providers are members.
- Provided early intervention literature for families with newly diagnosed infants and toddlers — a dramatic increase in calls over previous years.
- Provided information for hundreds of student reports.
- Provided support for 36 state and regional chapters that are active, reactivating or in formation, and for support groups.
- Executive Director met with six state chapters and made presentations at their conferences.
- Dramatic increase in e-mail support.
- Awarded a research grant for a study of "Neuroanatomical Correlates of Hunger and Satiation in PWS."

INTERNATIONAL SUPPORT PROVIDED

- Our e-mail and Web site have assisted families and professionals in 52 countries in the last year. (Almost daily contacts through e-mail.)
- Improved international communication and relationships through the Gardner family's hosting a visit with the IPWSO president in Minnesota.
- Planning upcoming international conference in the U.S.
- Hosted a booth at the Endo '99 conference, which had 6,156 attendees — primarily endocrinologists — from many countries.

PUBLICATIONS

- Obtained a grant to buy equipment that improved the quality of our videotapes.
- Published a *Health and Medical Issues* booklet of article reprints.
- Revised the following publications:
  Handbook for Parents
  Medical Alert brochure
  Birth to Three booklet
  Spanish booklet
- Purchased the remainder of *Prader-Willi Perspectives* booklets.
- Completed State Chapter Organization Manual.

OFFICE IMPROVEMENT

- Completed a personnel manual.
- Improved appearance and functionality of the office — with no expenditure of PWSA operating funds.
- Increased office volunteer support.
- Obtained a temporary half-time AARP employee at no cost to PWSA.

NATIONAL AWARDS

- Received award for our Web site
- Received "Telly" award for our *Searching for Solutions* video.

FUND DEVELOPMENT

- Exceeded our 1999 Angel Fund Drive goal of $75,000.
- Initiated an endowment fund, thanks to a $40,000 memorial gift.
- Obtained our first major corporate donations for a national conference.
- Were awarded our first two major grants: 1) from Ronald McDonald Children's Charity Foundation, and 2) from the Gerald J. and Dorothy R. Freeman Foundation.

Ballplayer Pitches In

When a group home for young men with PWS in St. Louis needed new furniture last year, St. Louis Cardinal Ray Langford stepped up to the plate … Ray and his wife donated $5,000 toward the new furnishings for the supportive living home, operated by Open Options in St. Louis, Mo. The PWSA Missouri Chapter and Open Options held an open house honoring the Langfords on October 24, 1999.

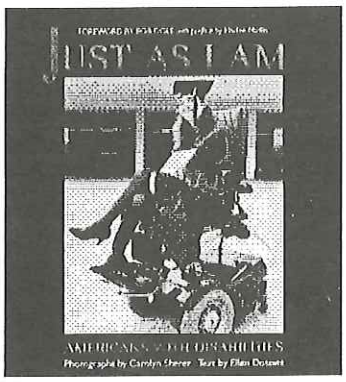
Jermaine Robinson, one of the home's residents, was on hand to show off the new furniture (photographed with his mother, Beatrice) and to have his picture taken with Ray. Jermaine weighed 385 pounds when he first entered a group home in Missouri five years ago. Now he's down to 145 pounds! Way to go, Jermaine!

Looking for a Pen Pal?

My name is Regina. I am 23 years old. I live in Redmond, Ore. I have PWS.
Also I have diabetes (when I was 17 I had it)—two double wammies! I would like a pen pal each day. Does not matter if it is male or a female. I am an aunt. I love to ride horses, swimming and skiing and bowling, soccer and computer games and nintendo64 & gameboys. I love to write to people. I work at a mill.

You can write to Regina by e-mail:
reginasweetpea@aol.com

Fall Title on Disabilities Features Prader-Willi Syndrome



Just As I Am: Americans with Disabilities
Photographs by Carolyn Sherer, Text by Ellen Dossett
1999, Crane Hill Publishers, Birmingham, Alabama

The Americans with Disabilities Act of 1990 has removed many physical barriers facing people with disabilities in this country. However, as former Senator Bob Dole writes in the foreward to this new book, it is the "invisible attitudinal barriers that are even more hurtful and excluding." This book, with photographs and stories of 40 individuals with disabilities, is an attempt to work on changing those attitudes. And, on page 78, the story of 22-year-old Andy Morris introduces readers to Prader-Willi syndrome. Andy has physical difficulties resulting from his weight of 370 pounds, but he has a happy life at home and in his community. Andy does assembly work part-time, assists with the local sports teams, and enjoys 'coon hunting. Andy's story includes a brief description of PWS and a great photo of the smiling young man with his two hunting dogs. The profiles in this book cover a wide range of disabilities to make the point that, regardless of our impairments, we are alike in having desires and goals in our lives—and the need for opportunities to achieve them. This is a beautifully executed and powerful book and, fortunately, one that helps teach about *our children's* disability. *—Linda Keder*

First Documented Instance of Fertility in PWS

Most of what has been written about Prader-Willi syndrome states that people with PWS are infertile, or at least that no case of fertility (pregnancy) has been documented. A recently published case, however, makes it necessary to reconsider the fertility issue and the advice given to families of teens and adults with PWS.

The scientific newsletter of the International Prader-Willi Syndrome Organisation (IPWSO) noted last spring that a Danish PWS newsletter contained a story about a woman with PWS who gave birth. The case finally appeared in a medical journal in November 1999, verifying that this birth did occur, that the mother did have PWS, and that the baby was normal. (See box, right.)

To put this news in perspective, we've asked members of PWSA's Scientific and Clinical Advisory Boards to offer us some guidance on the issue of fertility in PWS.

Details of the Case

In 1999, the first case of a female with PWS who became pregnant and delivered a live-born child was identified by Dr. Arne Akefeldt and his coworkers in Sweden. He described a 33-year old woman who satisfied diagnostic criteria for PWS and was found to have maternal uniparental disomy for chromosome 15. She had no menstrual periods until the age of 29, shortly after she was started on citalopram, a selective and potent serotonin reuptake inhibitor (same category of medication as Prozac). She then began to menstruate regularly, every four weeks. When the citalopram was discontinued her menstrual periods became sparse and infrequent, a pattern which has continued. She was subsequently started on fluoxetine (Prozac) and had significant and rapid weight loss from 118 kg (260 lbs) to 55 kg (121 lbs). At about the same time, she began having a sexual relationship with her boyfriend and became pregnant. Following an uncomplicated pregnancy, she gave birth to a normal child by cesarean section. Genetic testing of the infant by FISH and SNRPN probe were normal, and she has done well for the four months since her birth.

Suzanne B. Cassidy, M.D.
Chair, PWSA Scientific Advisory Board

Reference: Akefeldt, A. and others. (1999) "A woman with Prader-Willi syndrome gives birth to a healthy baby girl." Letter to the editor. *Developmental Medicine & Child Neurology* 41: 789-790.

Advice for Families, Caregivers

Dr. Suzanne Cassidy, head of PWSA's Scientific Advisory Board, comments:

"This case, the only known case of someone with PWS proven by genetic testing who became pregnant, is an important one. The relationship of the weight loss and the serotonin reuptake inhibitors to fertility is unknown. However, other women with PWS who lost significant weight began to menstruate many years past the usual time for women in the general population. Since all males and females with PWS were believed to be infertile, birth control has not been considered an issue in PWS. However, care should be taken in maintaining this stance. There is no easy way to determine fertility in a female, and since this woman became pregnant when she was having sparse and infrequent periods, lack of menstruation may not be an adequate reason for reassurance."

Dr. Phillip D.K. Lee, an endocrinologist who serves on PWSA's Scientific Advisory Board, comments:

"The report of a pregnancy in a woman with PWS is not particularly surprising from a physiologic standpoint. It has been known for many years that the hormonal conditions which are required for potential fertility are present in some women with PWS and there have been occasional reports of normal puberty and menstrual cycles. In both men and women with PWS, the hormones which are relevant to fertility can be stimulated by medications such as clomiphene and, possibly, one or more of the medications involved in this report. The major limiting factors for fertility and pregnancy in PWS have been the lack of sexual interactions and the fact that men and women with PWS do not usually receive treatment which facilitates fertility.

"The important message from this report is that although most individuals with PWS probably do not have regular or frequent sexual relationships, such interactions are certainly possible. Therefore, it is incumbent upon caretakers to offer appropriate counseling with regard to protection against sexually-transmitted diseases and, particularly for women with PWS, pregnancy. This is particularly important in light of improvements in medical care for individuals with PWS and the increased likelihood for social integration. Healthcare professionals and other caretakers should also give careful consideration to the many medical and ethical issues raised by this case, including issues related to the rights to fertility, pregnancy and child-rearing and the unique considerations related to prenatal care and fetal genetic screening."

—Report compiled by Linda Keder

FERTILITY—*continued*

Dr. Moris Angulo, an endocrinologist on PWSA's Clinical Advisory Board, comments:

"Appropriate amount and pulsatile secretion of gonadotropin-releasing hormone (GnRH) from the hypothalamus is a prerequisite for both the initiation and maintenance of the reproductive axis in humans. Failure of the hypothalamus to release GnRH results in hypogonadotropic (low gonadotropins, FSH and LH) hypogonadism (sexual infantilism). In general, it is accepted that individuals with Prader-Willi syndrome (PWS) have this form of hypogonadism due to hypothalamic dysfunction. The clinical presentation of functional hypogonadism can vary from mild to severe. In the severe or complete form of hypogonadism the clinical presentation is that of primary amenorrhea (absence of menses) and absence of thelarche (breast development). In the mild/moderate forms, however, near or normal sexual maturation is not unusual.

"Most girls with PWS have primary amenorrhea and immature breast development; however, cases of normal or even precocious sexual development have been reported in the literature. This variety of sexual development is an index of the functioning of the hypothalamic-pituitary-gonadal axis. In general, the presence of breast development and menses is considered as a clinical marker of the functioning of this hypothalamic-pituitary-ovary axis in otherwise normal girls. Most adults with PWS are not married and have limited sexual contacts. Girls with PWS, however, with normal or near normal secondary sexual characteristics including breast development and menses may indicate a lesser degree of hypothalamic dysfunction, and therefore should be counseled about the risk of pregnancy.

"Although we do not have a comparable clinical marker for normal functioning hypothalamic-pituitary-testes axis as in females, adult males with PWS with normal penile length and testicular volume should be equally counseled in the meantime."

New PWSA Clinical Advisory Board Membership, Mission Announced

Due to the increasing medical, behavioral, and social complexity of issues for individuals with Prader-Willi syndrome (PWS) and their families, the PWSA (USA) Board of Directors decided to create a Clinical Advisory Board (CAB) consisting of a multidisciplinary network of medical and allied health professionals. In July 1999 at the PWSA national meeting in San Diego, the first members of this new board met and agreed that their mission was to:

1) develop and help implement treatment guidelines that meet the multifactorial needs of individuals with PWS;
2) promote educational efforts; and
3) serve as a resource for questions related to the physical, social and emotional health and well-being of individuals with PWS, their families, and those professionals who provide a wide variety of services and support.

The Clinical Advisory Board is made up of specialists from various fields who have a strong interest in enhancing the care provided to individuals with PWS and their families. Specialties represented on the board include behavioral management, cardiology, clinical genetics, developmental pediatrics, endocrinology, nutrition, pediatrics, psychiatry, and psychology. In addition, two board members are parents of children with PWS.

Daniel J. Driscoll, Ph.D., M.D., and Robert H. Wharton, M.D.
Co-Chairs, PWSA (USA) Clinical Advisory Board

Members of the Clinical Advisory Board

Moris Angulo, M.D.
Winthrop University Hospital
Mineola, N.Y.

Ivy Boyle, M.D.
(Parent)
Shaker Heights, Ohio

Judy Brice, M.D.
The Children's Institute
Pittsburgh, Pa.

Aaron Carrel, M.D.
University of Wisconsin Hospital
Madison, Wis.

Suzanne Cassidy, M.D.
(Scientific Advisory Board Liaison)
Case Western Reserve University
University Hospitals of Cleveland
Cleveland, Ohio

Daniel J. Driscoll, Ph.D., M.D.
(Co-Chair)
University of Florida Health Science Center
Gainesville, Fla.

Elisabeth Dykens, Ph.D.
University of California - Los Angeles
Neuropsychiatric Institute
Los Angeles, Calif.

Louise Greenswag, R.N., Ph.D.
Iowa Child Health Speciality Clinics
University of Iowa
Iowa City, Iowa

Brian Hainline, M.D., Ph.D.
Riley Children's Hospital
Indiana University School of Medicine
Indianapolis, Ind.

Jeanne Hanchett, M.D.
The Children's Institute
Pittsburgh, Pa.

Karen Levine, Ph.D.
Spaulding Rehabilitation Hospital
Boston, Mass.

Jim Loker, M.D.
(Parent)
Kalamazoo, Mich.

Helen McCune, M.S., R.D.
(to start in June 2000)
Shands Hospital Food & Nutrition Service
Gainesville, Fla.

Robert H. Wharton, M.D.
(Co-Chair)
Spaulding Rehabilitation Hospital
Boston, Mass.

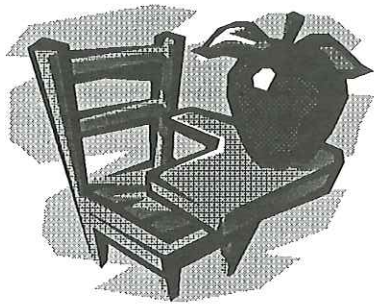
Ex Officio Members:

Ken Smith
Chair, PWSA Board of Directors
The Children's Institute
Pittsburgh, Pa.

Barb Dorn, R.N.
President, PWSA (USA)
Verona, Wis.

Janalee Heinemann, M.S.W.
Executive Director, PWSA (USA)
Sarasota, Fla.

Discipline of Students Receiving Special Education Services



by Jacquie Brennan, Attorney At Law, Houston, Texas

The original federal law dealing with special education, which later became known as the Individuals with Disabilities Education Act (IDEA), was first passed in 1975. Although it was a very detailed act, it did not address the subject of student discipline. It was left to the courts to apply the provisions of the law to disciplinary situations. This led to great disparity in the treatment of student discipline in a special education context. When Congress re-authorized IDEA in 1997, it intended, among other things, to put into law exactly what could and could not be done in the way of disciplining special education students. The intention was good, but the result was not. Congress wanted to make discipline of students with disabilities the same as discipline of students in regular education, as much as possible. The law was not precise enough, however, to make it clear exactly how this parity would be achieved. School administrators, parents, teachers, and lawyers have all been waiting for the Department of Education to issue final regulations. These regulations, it was hoped, would clear up the confusion of the Act in the area of discipline. It has taken two years for the Department of Education to issue final regulations in this controversial area.

I focus my law practice solely on disability law, which includes law related to special education. The issue of disciplining students who receive special education services accounts for over half of all the calls I receive from parents with school law concerns. School districts frequently trample the rights of students with disabilities in an effort to remove all perceived discipline problems from the school. This article cannot address all of the areas of discipline addressed in the regulations, but it will discuss one of the most controversial aspects—disciplinary suspensions. It all starts with how to count to 10. You think that's easy? Think again.

Counting to 10

IDEA says that, if a student is removed from the placement in his IEP for more than 10 consecutive school days for disciplinary reasons, this action constitutes a "change of placement." That means that an IEP committee or team meeting must be held. This seems rather straightforward, but it does not address the much more common occurrence of short-term disciplinary removals of fewer than 10 days. If a school gives a student three-day suspensions, but does this five times during a school year, the student has been suspended from school for 15 days. Arguably, this is not a change in placement. Or is it? Does it make a difference if the suspensions are "in-school suspensions?" Does it make a difference if the student's disciplinary problems are only on the bus and, therefore, the suspension is only from the bus? The final regulations resolve many of these problem areas.

The regulations do place responsibility on the school district if a student is removed from his IEP placement for a total of 10 days, even if each of the removals is for less than 10 days. Here is where the problem of how to count to 10 is encountered. *Any* day, or even any part of a day, on which a student is sent home for disciplinary reasons counts as one of the 10 days. This is true whether the child is sent home on "suspension" or "expulsion" or "emergency suspension" or "time out" or "cooling-off period" or "we can't take it anymore, come get this child." So those days are relatively easy to count. However, if students are given in-school suspension (ISS) or if they are sent to an alternative education program (AEP), counting becomes more difficult. The guidance in the Discussion of the Regulations says that ISS would not be considered a change in placement "as long as the child is afforded the opportunity to continue to appropriately progress in the general curriculum, continue to receive the services specified in his or her IEP and continue to participate with children without disabilities to the extent they would have in their current placement." Since most children in ISS or even AEP do have these opportunities, it is doubtful that these days could count toward the 10 days as a change in placement.

On the Bus

Counting to 10 on the bus brings up another problem. If a child is suspended from the bus only, because of disciplinary problems on the bus, the problem is whether those days are counted toward the 10 days. The solution is found in the IEP. If the child's IEP does not state that special transportation is offered to the child, then the disciplinary removal from the bus does not count in the 10 days removal, even if the child's parents have no other way to get him to and from school. However, if the child's IEP does state that special transportation is offered, then the disciplinary removal from the bus would count toward the 10 days, even if the child's parents bring him to school so that no days are actually missed.

What Comes After 10?

The school district is required to schedule an IEP meeting once a student has been removed for more than 10 days. These meetings will no doubt become known as "11th Day Meetings." In reality, the meeting does not have to happen exactly on the 11th day. The regulations say that the meeting is to be held "not later than 10 business days after ... first removing the child for more than 10 school days in a school year."

At the IEP meeting, the members of the IEP committee or team will call for a functional behavioral assessment (FBA) of the student. The purpose of the FBA is to provide a basis for a behavior intervention plan (BIP). The scope of the FBA, or even how it is to be done, is not clear in the regulations. The IEP committee will decide how each FBA should be done and what it should include. It could involve individualized testing and/or psychological evaluations, both of which would require parental consent. On the other end of the spectrum, it could involve merely reviewing the information that is already in the student's file, such as teacher reports, conduct cards, disciplinary reports, evaluations, and information from parents.

If, at the IEP meeting, the committee decides that it will look only at information it already has before it, it could then proceed to coming up with a BIP. If it decides that further testing and evaluation are needed, then the IEP committee will have to reconvene to create the BIP.

Who Orders What

Even after the 11th Day Meeting, the school still has the right to give short-term suspensions to students with disabilities. The new regulation dealing with this issue says: "School personnel may order, to the extent removal would be applied to children without disabilities, the removal of a child with a disability from the child's current placement for not more than 10 consecutive school days for any violation of school rules, and additional removals of not more than 10 consecutive school days in that same school year for separate incidents of misconduct (as long as those removals do not constitute a change in placement ...)."

Under this regulation, there are two kinds of removals—those that constitute a change in placement and those that do not. If the removal amounts to a change in placement, it can be ordered only by the IEP committee. If it does not, then any school official can order it.

Change in Placement

We have waited a long time for a definition of this term and we have it at last: "For purposes of removals of a child with a disability from the child's current educational placement ... a change of placement occurs if (1) the removal is for more than 10 consecutive school days; or (2) the child is subjected to a series of removals that constitute a pattern because they cumulate to more than 10 school days in the school year, and because of factors such as the length of each removal, the total amount of time the child is removed, and the proximity of the removals to one another."

So a change in placement occurs when there is a pattern of removals. Determining whether there is a pattern is to be determined on a case-by-case basis. If there is disagreement about whether several removals constitutes a pattern, this would ultimately be subject to due process and judicial proceedings. This means that the school can suspend the student repeatedly, say that it does not constitute a pattern of removals, and then the parent's option is to file for a due process hearing. This is an option that is financially, physically, and emotionally draining for parents.

If the school district orders a student with a disability to be suspended for any amount of time after the 11th Day Meeting, the school district must convene the IEP committee to "review the BIP and its implementation to determine if modifications are necessary." If any person on the IEP team, even a parent, thinks that a modification to the BIP is needed, "the team will meet to modify the plan and its implementation, to the extent the team determines necessary." The school district can remove the student from school for more than 10 days, but after that 10th day, the school must "provide services to the extent necessary to enable the child to appropriately progress in the general curriculum and appropriately advance toward achieving the goals set out in the child's IEP."

Danger

If a child with a disability brings a weapon to school or to a school function, or knowingly has or uses illegal drugs while at school or a school function, the student can be removed from the child's regular placement for up to 45 days. Additionally, if the school thinks that the child with a disability is substantially likely to injure self or others in the regular placement, school officials can ask a hearing officer to order that the child be removed to an interim alternative educational setting for up to 45 days. Even after the 45 days, if school officials still believe the child is a danger to self or others in the regular placement, they can request an additional 45 days in the alternative educational setting. These extensions can be requested every 45 days if there is a continued belief that the child would be substantially likely to injure self or others if returned to the regular placement.

The IDEA regulations have helped parents, advocates, attorneys, and school officials to better understand IDEA and the changes made to the Act in 1997. They have not yet cleared up all of the confusion. As more IDEA cases make their way to due process hearings and court battles, more interpretation by the courts will shape the way disciplinary problems for children with disabilities are addressed.

New from NICHCY

These new publications by the National Information Center for Children and Youth with Disabilities may be helpful to you. All are available on the Internet (www.nichcy.org) and in printed copy (Call NICHCY at 1-800-695-0285).

Questions and Answers about IDEA—#ND21, 2nd Ed., January 2000, a 28-page overview of the requirements of IDEA and the IEP process. (First copy free; $4 each additional copy)

Individualized Education Programs—#LG2, 4th Ed., September 1999, a 32-page document on IEP requirements, including the federal regulations. (First copy free; $2 each additional copy)

Interventions for Chronic Behavior Problems—#RB1, October 1999, an 8-page research brief. ($2 each copy; on NICHCY's Website under "Research")

The Prader-Willi Alliance of New York

will hold its

10th Annual Conference

May 5-6, 2000

Ramada Inn
Albany, N.Y.

Confirmed speakers include:

Elisabeth N. Dykens, Ph.D., associate professor of psychology in UCLA's Neuropsychiatric Institute and a member of both PWSA's Scientific and Clinical Advisory Boards; **Daniel J. Driscoll, M.D., Ph.D.**, associate professor of pediatrics and medical genetics at the University of Florida Medical College, co-chair of PWSA's Clinical Advisory Board and a member of its Board of Directors; and **Edmund G. Haddad, Ph.D.**, who will address sibling issues. **Thomas A. Maul** of the New York State Office of Mental Retardation and Developmental Disabilities will deliver the keynote address. Also planned are sessions on nutrition and on the role of the service coordinator.

The Ramada Inn offers a special conference room rate of $70 a night for rooms booked by April 21. Call the hotel at 518-489-2981 or visit the Web site: www.ramada.com.

To receive conference registration materials, contact:

The Prader-Willi Alliance of New York
267 Oxford Street
Rochester, NY 14607
Tel.: 716-442-1655; Toll-free in New York: 1-800-442-1655
Fax.: 716-271-2782

Kansas News

A group of persons interested in PWS from both Kansas and Missouri have been meeting quarterly over the last year at Children's Mercy Hospital in Kansas City. One reason for holding the meetings there is that Dr. Merlin Butler, M.D., PhD., a genetic researcher associated with Vanderbilt University in Tennessee, moved his practice here in 1998. (Several of his colleagues will be joining him soon.) Another reason was the density of the population and a nearby group home for people with PWS (Southern Roads in Grandview, Mo.).

The meetings are sponsored by Mike and Carolyn Hamblin (past president and secretary of the disbanded Kansas Chapter), parents and "Prader-Willi Syndrome Advocates," and Teri and Barry Douglas, parents and vice presidents, Kansas City region of the Missouri Chapter. Discussions have included a variety of subjects dealing with PWS, accented by a guest speaker. Most recently we were honored to have former National PWSA President and Board Member Dr. Delfin Beltran (now retired and living in Kansas to be near his daughter Sarah) attend. He is willing to devote more time to the PWS cause and is currently involved in researching the possibility of starting a group home in Wichita.

Our next meeting is scheduled for April 15, 2000, at CMH, 2401 Gillham Rd., KCMO, from 1-4 pm. Child care is provided by volunteers and siblings. We hope to have more of you from both Kansas and Missouri in attendance. For more information, call Prader-Willi Syndrome Advocates at 1-800-320-8408.

We think that 2000 will not only be the 25th anniversary of PWSA (USA) but also a year of progress for those of us in Kansas and Missouri!!

HAPPY ANNIVERSARY, PWSA (USA) !!!

If Wishes Came True

Board Member Carolyn Loker tells how the photo flyer of her daughter Anna (on the next page) came into being:

Janalee had put me in contact with a wonderful mom, Kathy, from Michigan. Her 3-year-old daughter, Brooke, had just been diagnosed with Prader-Willi syndrome. Brooke also has a rare mitochondrial disorder. It was because of Kathy's persistence that Brooke was diagnosed with PWS even though the professionals believed her difficulties were due to the mitochondrial disorder.

Kathy works with a good friend of radio personalities "Bob and Tom," broadcasting from Indianapolis and syndicated throughout the United States. Bob and Tom have produced CDs for charitable purposes. This friend believed that if we could prove that 100 percent of all proceeds would go into research we could convince Bob and Tom to list PWSA (USA) as one of their charities.

Jim and I, being from Indianapolis and being fans of Bob and Tom, decided to write a letter to include in the proposal. I felt a letter was not enough and that a picture of our daughter Anna would make it more personal. The poem was included to try to touch their hearts.

Bob Hartnett (who designed PWSA's poster) graciously volunteered to do the finishing touches and graphics. A copy of the letter and picture was also sent to PWSA (USA). The association plans to use the picture on folders for grant requests, awareness, and new parent information. I had no idea that this one passing thought would produce such a response. When Janalee asked for permission to reprint the picture and poem, I was concerned that it might make new parents sad. She assured me that it was touching, not sad—positive and encouraging that our children can do well.

In the face of adversity and a dual diagnosis, Kathy has been an inspiration to me. We are still anxiously awaiting a response from Bob and Tom. If it does not occur, my purpose, my passing thought, my wishes for all our children still might come true. In God's time, I am sure it will.

—Carolyn Loker

Hello

My name is Anna Elizabeth, I am five years old, and I have Prader-Willi Syndrome.

If Wishes Came True

I wish I could eat like other kids do
I wish I wasn't hungry all the time
I wish I didn't get sad when mommy and daddy tell me I can't have something to eat
I wish I could run and jump with kids at school
I wish I could talk to my friends
I wish my family didn't have to worry about me so much
I do know that I am special...that's what everyone says
My mommy and daddy tell me, "Maybe some day, my precious little one,
your wishes can come true...just maybe!"

XOXO
Anna

The Angel of Hope ...

(above) was drawn by Maria Silva and computer-enhanced by Bob Hartnett to grace the materials for this year's PWSA national conference.

The inspiration for the angel logo came out of a meeting of Year 2000 Conference Co-chairs Maria Silva and Lota Mitchell with PWSA President Barb Dorn. The figure is a symbolic representation of hope. She holds in her left hand, nearest her heart, the PWSA logo on the conference torch. She looks toward it, for it is truly the symbol of hope in the new millennium as PWSA (USA) continues to strive to improve the quality of life for all those whose lives are affected by PWS.

Parents, Note!

Invite your child's teachers (many school districts will provide funding for professional development, but they do their budgeting early—so ask now), doctors, therapists, social worker, and others working with your child to attend this year's national conference!

Announcing

The 22nd Annual National Conference

of the

Prader-Willi Syndrome Association (USA)

"Millennium of Hope"

July 20-22, 2000

DoubleTree Hotel
Pittsburgh, Pennsylvania

Hope is the theme, and hope is the thread that will wind throughout the program that is being planned.

The conference will begin and end on high notes. Our keynote speaker, Dr. Stuart Robertshaw, will raise your spirits and lower your stress! Our closing speaker on Saturday, Dr. Merlin Butler, will speak on "Hope for the Future"—which is what we all want to hear about: what hopes and dreams that we have for our children may be realized in the years ahead through the work of medical, genetic, and behavioral research. These are "Don't miss!" presentations!

In between, there's lots for everyone—sessions about young children, about the school years, and about the adult with PWS. Old-timers can enjoy a time for "Memories and Mirth," and grandparents will have an opportunity to get together. Many, but not all, sessions on Friday will have emphasis on behavior and its management, and Saturday morning will be devoted to medical and genetic information.

Of course, the social and sharing aspects of conference will not be neglected. Wednesday evening will feature a mixer designed to help people get acquainted. Families and folks can get together Thursday evening in the hotel ballroom where they can choose from a smorgasbord of activity stations, or just hang out. Friday evening's banquet will be a celebration of PWSA (USA)'s 25th anniversary. At the same time, the kids will be enjoying their banquet, followed by a dance with a video DJ.

The Youth and Adult Activity Program (YAAP), accepting individuals with PWS from infants to adults and their siblings up to age 15, has a full program planned. While parents and providers attend the conference, ages 6 and up will be enjoying a carnival complete with prizes, puppet shows, face painting, arts and crafts, bingo, and a day-long visit to the Pittsburgh Science Center, among other activities. The little ones, from birth to age 5, will have a separate program. There will also be some special sessions for siblings and for older teens and adults with PWS who wish to participate.

Plan, too, on seeing the sights of Pittsburgh and the surrounding area. Pittsburgh no longer deserves its smoky, smudgy, sooty reputation of the past. It is now a clean, revitalized, beautiful city nestled in the Golden Triangle among three rivers. River trips on the Gateway Clipper fleet, the Andy Warhol Museum, the Pittsburgh Zoo, Frank Lloyd Wright's Fallingwater, and the Carnegie Museum are just a few of the local attractions worth visiting.

Rooms at the DoubleTree Hotel can be reserved by calling 1-800-222-TREE or 412-281-3700. Mention the PWSA (USA) conference to get the special rate of $97 a night.

Registration materials will be mailed to PWSA members and posted on the PWSA (USA) Web site (www.pwsausa.org).

Watch *The Gathered View* for more information.

Conference Grants

Want to attend this year's PWSA (USA) national conference in Pittsburgh but can't afford the travel and registration costs? There are a number of possible sources of financial aid that you can explore:

- ***Each state's Developmental Disability (DD) Council*** provides federally funded grants for disability-related purposes. The grant may need to go through a sponsoring nonprofit organization, such as your local chapter of PWSA, The Arc, Parent-to-Parent, or other disability-related organization. Each state will be different, but the money is there (our tax dollars!) for us to use. The purpose of your request should be expressed in terms of your DD Council's stated goals, such as "education and training," "family support," "community participation," or "self-advocacy and empowerment." To locate your state's DD Council, call NICHCY at 1-800-695-0285 or go to their Web site: www.nichcy.org
- ***PWSA (USA) helps some families*** each year who could not otherwise attend the national conference. Grant requests should be sent by letter to the Executive Director, PWSA (USA), 5700 Midnight Pass Rd., Suite 6, Sarasota, FL 34242, and must be received at the national office by **April 15** to be considered. Grant application letters must include: 1) the size of your family and ages of your children; 2) an indication of your income and expenses; 3) a brief summary of difficulties your family is experiencing in dealing with PWS; 4) which conference or travel expenses would need to be covered by the grant and the estimated amount you would need; and 5) whether anyone in your family has attended a previous PWSA national conference.
- ***Your local PWSA chapter*** may offer grants for this purpose; give them a call.
- ***A direct request for help to airlines, motels,*** and other trip-related companies has won some creative families donations and discounts to help with their expenses.

Call For Presentations

For the Service Providers' Conference Day
Wednesday, July 19, 2000
Pittsburgh, Pa.

The Prader-Willi Syndrome Association (USA) enthusiastically encourages submission for presentations at the 2000 Service Providers' Conference Day.

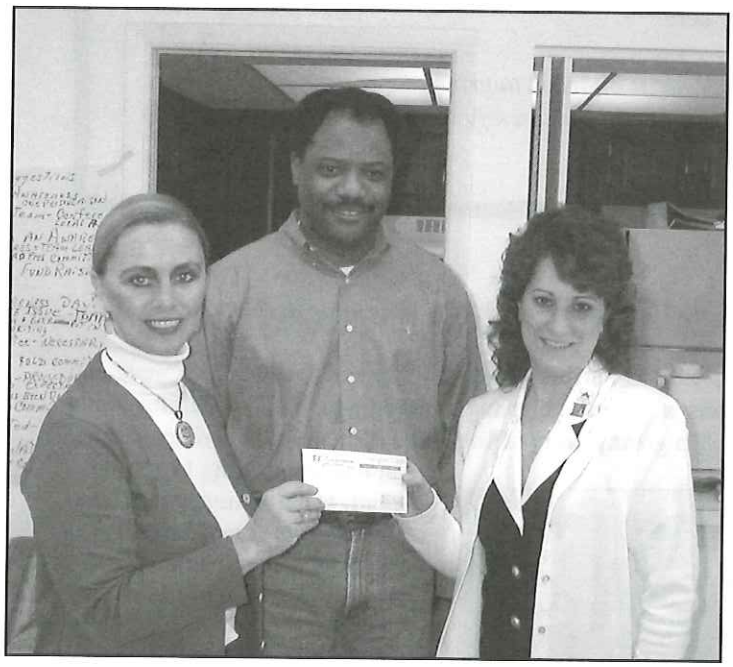
We welcome your best ideas, solutions, and practices! Nationally, providers in residential, work, and school environments possess a wealth of creative answers to the many challenges of supporting people with Prader-Willi syndrome.

Share your knowledge with others by presenting at this year's "Millennium of Hope" conference.

Forms for presentations are in the mail to providers on our national mailing list. If you have not received one, or for any other questions, please contact the 2000 Service Providers' Conference Co-Chairs:

Mary K. Ziccardi
REM Consulting Of Ohio, Inc.
Regional Director
Phone: (440) 473-0601
Fax: (440) 473-0603
E-mail: maryk@brightnet.com

Ken Smith
The Children's Institute
Program Manager
Phone: (412) 420-2420
Fax: (412) 420-2424
E-mail: KSM@the-institute.org



The Children's Institute in Pittsburgh has donated $10,000 to PWSA (USA) for our 2000 Conference Youth and Adult Activity Program. Ken Smith, program director at The Children's Institute and Chair of the PWSA Board of Directors, presented the check to PWSA Executive Director Janalee Heinemann (left) and 2000 Conference Co-Chair Maria Silva (right) during the board's January meeting in Sarasota.

Searching for a Certain Physiatrist ...

Are you—or do you know—a physiatrist who attended the PWSA (USA) conference in San Diego last summer?

Dr. Robert Wharton is trying to locate the mother of a young child with PWS who attended last year's conference and who practices physiatrics (the branch of medicine that deals with physical therapy).

She is asked to contact Dr. Wharton either by telephone (617 573-2637) or e-mail (Robert_wharton@hms.harvard.edu).

The Chuckle Corner

What do you say when you're caught in the act? Jim Kane of Towson, Maryland, shares this chuckle about his 18-year-old daughter, Kate.

Kate began a new school program in September 1999. She attends high school in the morning and then works at a job in the afternoon. She is accompanied to the job by her job coach.

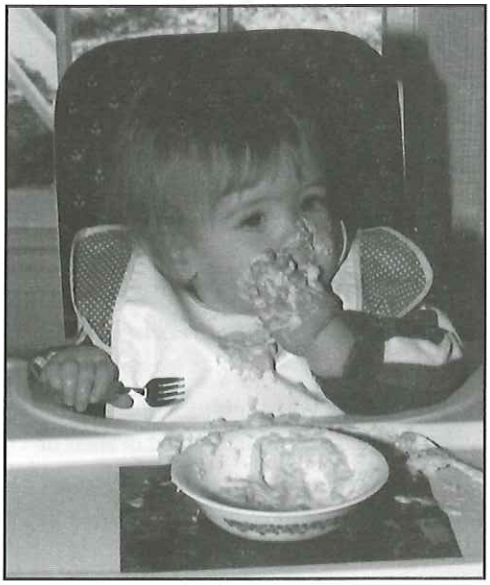
Her first job was in the computer training facility for the local county. The office was located on the ground floor of the courthouse building and just down the hall from the 911 emergency call center (which operates 24 hours a day and has kitchen and sleeping facilities).

One afternoon Kate wandered into the kitchen and the refrigerator. Her job coach stuck her head into the kitchen at the same time Kate was peeking into the fridge. Kate poked her head up and said, "I'm not really here."

Jim adds that "Kate is on track to graduate in June with a full high school diploma and is currently working at her job and enjoying life."

Infant, Toddler Photos Needed

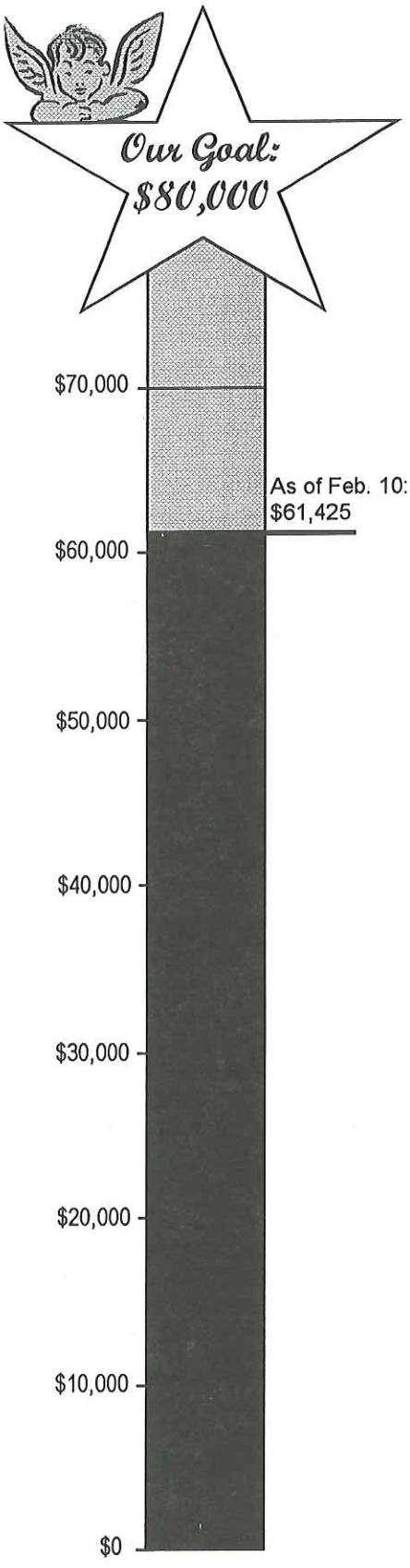
For a new PWSA booklet on nutrition for the infant and toddler years, we would like some photographs of babies and young children with PWS in feeding/eating situations. If you have a great picture of your little one enjoying a bottle, wearing an NG tube, sitting in a high chair, tackling finger food, etc., we'd love to consider using it in this publication. Children will not be identified by name in the publication.



Please send your photograph(s) to the attention of Brenda at PWSA, 5700 Midnight Pass Rd., Suite 6, Sarasota, FL 34242. Write your child's name and age on the back of each photo. Include a note giving PWSA your permission to publish the photo(s). Please include your name and phone number, in case we need to contact you.

Thank you!

PWSA's 1999-2000 Angel Fund Drive



Contributors will be listed in next month's issue of The Gathered View.

Use of Growth Hormone in PWS: A Parent Survey

PWSA wants to gather information from as many families as possible whose children with PWS have been treated with growth hormone. This survey will be used to develop educational materials for families and as a possible basis for further research. Your answers will be kept confidential, and no one will be identified by name in any publication. If you would like to share more details of your experience with GH treatment or photos of your child taken before and after GH treatment, please enclose those with your survey form. For survey accuracy, please contact your child's doctor if you are unsure of the answers to any questions.

THANK YOU FOR YOUR ASSISTANCE!

Child's name: _____ Age: _____ Birthdate: _____

Sex: ___ Male ___Female Current Height: _____ inches Current Weight: _____ lbs.

Genetic diagnosis: ___ Deletion ___ Uniparental disomy ___ Imprinting mutation ___ Unknown

1. Approximate date (month and year) your child started GH treatment: _____
   a. What was your child's height and weight at that time? Height: _____ inches Weight: _____ lbs.
   b. What dosage of GH did your child start on? _____ milligrams per injection *OR* _____ milligrams per week
      Number of injections per week: _____

2. Is your child still receiving GH treatment? ___ Yes ___ No

   If Yes—

   a. Is your child in a GH research study? ___ Yes ___ No (Location of study: _____)
   b. What dosage of GH does your child now receive? _____ milligrams per injection *OR* _____ milligrams per week
      Number of injections per week: _____

   If No—

   a. Give the approximate date (month and year) GH treatment ended: _____
   b. What was your child's height and weight at that time? Height: _____ inches Weight: _____ lbs.
   c. What dosage of GH did your child last receive? _____ milligrams per injection *OR* _____ milligrams per week
      Number of injections per week: _____

3. Was your child tested for growth hormone deficiency? ___ Yes ___ No

   If Yes—

   a. Did your child's test show a GH deficiency? ___ Yes ___ No
   b. Was it a GH stimulation test? ___ Yes ___ No (If yes, what type? _____)

4. How difficult was it to find a doctor who would prescribe GH treatment? ___ Very ___ Somewhat ___ Not Difficult

5. How difficult was it to get your medical insurance to pay for GH treatment? ___ Very ___ Somewhat ___ Not Difficult

6. How difficult was it for your child to adjust to getting the shots? ___ Very ___ Somewhat ___ Not Difficult

7. What were your child's height and weight <u>after one year of GH treatment</u>? *(If treated less than one year, skip to Q. 7.)*
   Height: _____ inches Weight: _____ lbs.

8. Does your child have scoliosis (lateral curvature of the spine)? ___ Yes ___ No

   If Yes—

   a. Did the scoliosis either develop or worsen while your child was on GH treatment? ___ Yes ___ No
   b. What follow-up and treatment has your child had for scoliosis?

(Continued on next page)

9. During the first year of GH treatment, did you observe changes in any of the following areas in your child?
(check ✓ if you saw a change, and describe what you observed)

CHANGE?	IN CHILD'S:	DESCRIBE THE CHANGES YOU OBSERVED
	Muscle strength & ability	
	Physical activity level	
	Breathing	
	Alertness/Sleepiness (including nighttime sleep pattern/hours of sleep)	
	Appetite	
	Number of calories eaten (without excess weight gain)	
	Behavior	
	Appearance	

10. Did your child develop diabetes while on GH treatment? ___ Yes ___ No

11. What other changes—either positive or negative—have you observed in your child during GH treatment?

12. If your child received GH for more than one year, what were the effects of continued GH treatment?

13. If your child has stopped getting GH treatment—
    a. What was the major reason(s) for discontinuing GH treatment?

    b. What changes did you see in your child after GH was stopped?

(Attach extra sheets, if needed, to answer any of the above questions. Please number your answers to correspond with questions.)

14. Would you be willing to participate in additional surveys on the subject of growth hormone treatment? ___ Yes ___ No

Your Name: _____ Telephone: _____

Address: _____

City: _____ State: _____ Zip: _____

(If you are sending photographs of your child, please enclose a statement giving permission for PWSA to publish the photos without identifying your child. Please label the backs of any photos you send for our record keeping.)

Please return this survey by April 15 to: PWSA (USA), 5700 Midnight Pass Rd., Suite 6, Sarasota FL 34242