

The Gathered View

for the Younger Set

National Newsletter of the Prader-Willi
Syndrome Association

November-December 1991

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Fighting those Holiday Gains

by Edie Crisostomo

We're now in the midst of that season all calorie-counters dread: the November-December holiday season. These can be especially trying times for a person with PW, because several weeks of uncontrolled munching and high-calorie meals can undo a year's worth of weight loss! With careful planning, however, we can minimize the weight gain. Here are some planning tips that might help you get through these food-oriented holidays.

If you're currently not locking your cupboards and refrigerators, it would be a good idea to plan a special holding place for the holidays that can be locked. Rearrange the kitchen cabinets temporarily so that all the high-calorie goodies are in one cupboard, for example, then put a temporary lock on it. Or, you might consider using a portable refrigerator with a lock on it in the basement for perishables, or making temporary use of a storage cabinet or spare room as a holding area.

Having a food storage place that locks will not only lessen the chances of sneaking over the holidays, but PW persons often seem to be more comfortable and less preoccupied with food if

they're aware that it's safely away in some inaccessible location. If your locking place has a key, by the way, the best place to keep it is on the person of some trusted family member. If you hide the key, be sure that your individual with PWS will search until the key is found! (We suggest combination locks as a better alternative.)

Plan to have a supply of low-calorie snacks and other meal items available. If you have the time to make some special holiday-related treats, all

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Spotlight on Committees

Trust and Advocacy Services Committee

by Curt Shacklett, Chair

We are continuing our research regarding the establishment of an advocacy and trust service for Prader-Willi persons in order to assist families in their estate planning concerns for their PW child. Initially, the purpose of the trust service is to provide a list of parents or other interested and responsible persons who would be willing to serve as private trustees to manage funds given to a lifetime trust or one established in the last will of a deceased parent of a PW person. The individual trustee would oversee the investment and use of the funds for the benefit of the PW person until the death of the PW person, or until the trust terminates. It is anticipated that the trustee would serve without compensation but would be reimbursed for all expenses associated with trust duties and could be bonded if requested by the trustee or the parents who created the trust. Of course, the trustee could resign at any time and a successor would then be appointed.

It is suggested that the trust document created by the parent of the PW person be reviewed by the national office prior to acceptance by the trustee to assure at least minimal compliance with certain legal and practical requirements. Our plan anticipates that upon the death of the

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President's Message

by Janalee Tomaseski-Heinemann

In order to get the services we so desperately need, we parents of children with PWS have to emphasize the bizarreness and trauma of the syndrome. These visions of chained refrigerators and destructive temper tantrums often overshadow the gentler side of our children. The kind and loving things they do are not the acts that get media attention or group homes approved. But it is the part that reminds us of how much we love them--and the part that sometimes breaks our heart.

I see our son, Matt, trying to be a good person and find his place in the world, yet struggling against impossible odds. Of course, there is the obvious struggle of feeling deprived of food (the most important drive in his life) in such a food oriented society. But the struggles go far beyond just dealing with food.

● There is the Matt who wants desperately to drive and faithfully studied the "rules of the road" book, yet now has to come to grips with the fact that his younger sister just got her license--and he doesn't have his.

● There is the Matt who wants to be independent and take care of himself, yet has had to deal with rejection after rejection after spending hours circling job want ads and making calls.

● There is the Matt who thought Richard was his "best friend in the whole world," who had to deal with the sadness of finding out that Richard wants nothing to do with him anymore. Richard, who now does have a license and a job, said he was embarrassed by Matt.

● There is the Matt who wants a girlfriend, but unfortunately, he wants a "normal" girlfriend, and just ends up looking at girls longingly, and tries to be cool, flirt a little--and dreams.

● There is the Matt who wants very much to be "cool," but doesn't quite know how. He asks for his sister Sarah's advice on clothes, then doesn't follow it. He buys popular tapes for his radio--yet never plays them. He tries hard to walk like a teen, talk like a teen, and joke like a teen--but can never quite pull it off.

● There is the Matt who wants to take political responsibility, so he registered to vote. He studies the issues seriously and has come to his own conclusions (some of them rather unique) of how to save the world from crime and corruption. And although it is difficult for Matt to think abstractly, he is searching for a relationship with God and tries hard to figure out how to deal with good and evil.

I think there are two such different sides to a child/adult with PWS that it is hard for an "outsider" to understand. Let's face it, it is difficult for us parents and caregivers to accept. The same Matt that cut up all his clothes also graciously thanked us for buying him a shirt. The Matt that

can spew vile words out of his mouth for hours during a tantrum--will also tell us how much he loves us and hugs us goodnight.

The Matt who can embarrass us to tears by creating a scene at an important event--may surprise us by being exceptionally charming and polite at the next event.

● Which is the real Matt? We think it's the loving, gentle side that struggles in an unfair world of things beyond his reach. He hates the other side as much as we do. Matt once wrote us, "The bad part is in side my body. The good part is out side my body. I just wish all bad part going away from me...I just wish can fix, but can't fix for me...The bad thing about me real hard for ever body to understand. Tell ever body I am very sorry!" We feel very sad at times too, Matt. Someday we hope we can "fix" it for you and all young people with Prader-Willi Syndrome.

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PW Celebrities

Each individual with PWS touches our lives, especially when they have moments in the spotlight. The Gathered View would like to have a special feature in each issue highlighting those shining moments, a special experience, or accomplishment. In order to do this, the National office needs to hear from you. Be sure to include the thoughts and reactions of the celebrity in their own words.

This issue's spotlight is on Mr. Stuart Williams.

Stuart is 40, and his sister, Betsy, tells us he is doing well. His siblings have been taking turns bringing him food since Stuart's mother recently passed away. Betsy wanted to share her brother's success with us. She sent us an article by Gail Kelley from the June 9, 1991, issue of The Boston Globe.

The following are excerpts from that article:

Stuart's parents were successful sculptors who encouraged their son to explore art for himself using Craypas and markers. They encouraged him to draw because his arms lacked strength and stamina to maneuver a brush at an easel. Stuart has created works which are described as "Folk Art." Many of his works are of animals and the farm on which he has lived all of his life. Stuart enjoys giving his works rather lengthy titles, such as "That darn rooster. Always crowing at sunrise. I will peck his buns. We have eaten the last of the apples. Maybe we will have gotten even with him."

Stuart produced the art work for two

calendars, has had private showings, and has been commissioned. Stuart says when he is creating he feels as though his mind is frolicking and he just can't stop.

He comments about how he refuses to sell any of his work to family members because he wants people to buy his art for pleasure, not out of desire to do him a favor. At the end of the article, Gail quotes Stuart as saying: "I'm not afraid to mention I'm a very special person inside."



Congratulations, Stuart, on your success and the pleasure you bring to others' lives!

Special Thanks to our Supporters

*From mid-September thru the end
of October*

Research and
Operating = \$1417.00

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Contributing Dues: (\$40-\$99)
Alternatives (Bell), Amren,
Gemar, Wicks, Ruzicka, Singer,
Mleczewski, Kumm, Willinsky,
Lehman, & Toby.

Patron Dues: (\$100+) Gardner,
Groenboom, Shacklett, Braun,
DiCosimo, Miller, Fleming, Tal-
bot.

Hannah's Parents pronounce her special

This column appeared in "Dear Abby" in October, which traditionally has been Down's Syndrome Awareness month. We can certainly relate to the thoughts and feelings expressed in this column because of our own experiences living with a person with PWS.

Abby's column:

On the birth of their second daughter, Hannah Marie, Greg and Janet sent the following announcement:

Dear Friends and Family: Our beautiful second daughter, Hannah Marie, was born July Fourth. We want to add a personal note to this announcement because we would like you to know that Hannah was born with Down's Syndrome.

In the last few days, we have experienced many ranges of emotions and have learned a great deal about all the positive ways Down's Syndrome can affect our daughter and our family.

Hannah is a beautiful, responsive baby, and we hope you will accept her into your hearts without pity or reservations. Please don't feel that you have to pretend that she is 'normal' and please feel free to ask any questions you may have about her.

With God's help, we hope Hannah will grow up strong and healthy. We want you to share in the joy of her progress along the road to maturity. She may travel that road a little more slowly than others, but we will consider each new milestone in her life a blessing.

Continued

Parent Seeks Suggestions

The National office frequently gets questions about potty training and night bed-wetting. We don't have an exhaustive supply of information on this topic, but we will share what we know and ask for additional suggestions and comments from all of you.

Potty training typically takes place about the average age, some children slightly later. We have heard of difficulties with bed-wetting, not due to physical or psychological difficulties, but due to sleep patterns. Suggestions for how to handle this problem include setting alarm clocks for the children during the night, or if you go to bed later, waking them before you turn in and supervising a trip to the bathroom.

What if a child has not been trained yet and a family is experiencing a great hardship paying for specialized diapers? There is one source of possible funds: Katie Beckett was a parent with needs not being met, so she pushed the federal government into providing assistance for extraordinary costs associated with having a handicapped child. Katie Beckett funds must be applied for by each state, so they may or may not be available in your state.

If you, the readers, have suggestions, ideas, and experience in these areas, please share them with National --it will help us to help others.

All I Want for the Holidays

Everyone has a holiday wish list! PWSA is no exception!

We often ask our members for input and information about their experiences, and sometimes special expertise.

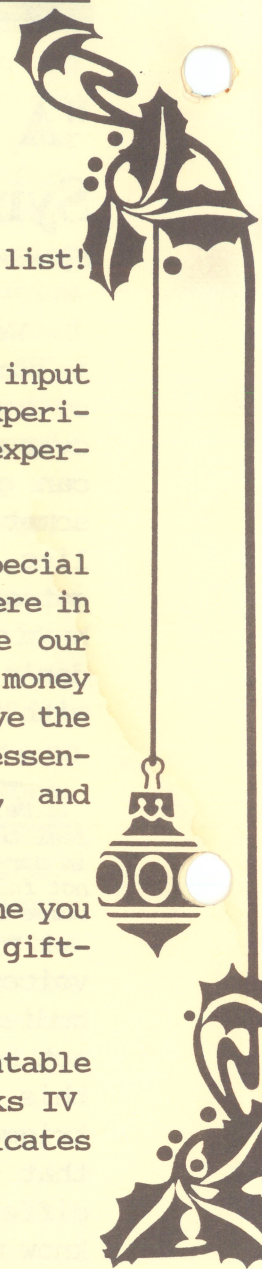
This year we also have some special requests of items we could use here in the office which would improve our operations. We could spend the money for them, but we would rather have the money you contribute go to the essentials-- more brochures, books, and crisis situations.

Thus we ask if you, or someone you know, have the ability to give a gift-in-kind:

Computer Scanner - IBM compatible
Software Program - Grammatiks IV
MCI Long Distance Gift Certificates
Video Camera
TV/VCR Combo Unit

**Anxiety does not empty
tomorrow of its sorrows,
but it does rob today of
its strength.**

Anonymous



(Continued from Page 1)

the better. Examples: air-popped colored popcorn strung into special necklaces or bracelets, sugarless holiday candy, or diet Jello cut into fun holiday shapes with cookie cutters. Mexican Salsa makes an excellent fat-free dip, especially served with celery sticks. Refreshing drinks can be made with sparkling water colored with a little food coloring or fruit juice. Dessert pies made with graham cracker crusts moistened with fruit juice, with simple fruit fillings or diet Jello, can help make the meal complete. Or better yet, serve frozen fat-free dessert bars such as Sugar-Free Popsicles, Crystal Light Bars, etc. Arrange a meal and snack time schedule with your family and stick to it as much as possible.

Try to plan special activities for your person with PW, especially during meal preparation times. Rent some holiday videos, or buy a special holiday puzzle or books. Save some decorating or holiday chores until the last minute, such as trimming the tree, coloring homemade greeting cards, or arranging the dinner table.

Make it clear that no one but the cook and special assistants are allowed in the kitchen while meals are being prepared. And, if possible, keep the door shut. Or have the non-cooks spend meal preparation times in designated recreation areas as far away from the kitchen as possible.

Do not set any food out on the table before the entire meal is ready to be served. It's also not a good idea to leave unattended "help yourself hors d'oeuvres," such as bowls of nuts or cheese and crackers. After meals, immediately clear all left-overs from the table. Put all the food away into your special holding area, including those items that relatives might be taking with them when they leave.

If the holidays will be spent at a relative's house, involve them in your planning. You can offer to bring along a cupboard lock for goodies, and

special treats for your person with PW, and plan the activities. Grandma and Grandpa may insist that since it's the holidays one cookie won't hurt, and they're right; but one cookie repeated several times during a week-long visit can add up to a lot of excess calories! Try and set limits, or try explaining to relatives that PWS is similar to diabetes; too much of certain foods can seriously endanger your child's health!

Remind friends and relatives that food items do not make good gifts. If they do their shopping in the cheese company catalog, you might suggest that they look for toys or other non-food items, or order not readily edible items such as wild rice or frozen steaks. Avoid holiday decorations using food or candy. Be especially careful not to use any decorations which look like food but are dangerous if consumed (ornaments made with salt-flour dough, for example). One PW family with a young child put Candy Canes high up on the tree, figuring the child wouldn't be able to get them. A week passed and it appeared as if none of the Candy Canes had disappeared; they thought she had done really well. On closer examination, however, they discovered that the Candy Canes had all disappeared from the back of the tree! To this day, they still wonder how she was able to get them and what happened to the wrappers.

With plenty of advanced planning, getting over the holiday hump can be less stressful for the family and persons with PWS. Be sure to involve your son/daughter with PWS in your planning as much as possible. Let them know in advance exactly what will be expected of them, what rules they will be expected to follow, and what will be the consequences if those rules are broken.

PWSA would like to wish all our members safe and happy holidays. Be sure to share with us your holiday successes (or failures) from which we can all learn.

The Calendars Are Coming- The Calendars Are Coming

In 1991, a calendar was created which included a general overview of the syndrome. For 1992, the calendar will take another step forward, moving from providing basic information to offering more practical tips and more photos.

We will be providing complimentary copies to Patron and Contributing Members, as well as anyone who contributes \$25.00 or more to the annual fund raiser.

If you would like to order some of our calendars for holiday gifts, or just to have more around the house, please send \$5.00 to National for each one desired.

I would love _____ 1992 Calendars.

Enclosed is my check.

Please mail them to:

Name:

Address:

Phone:

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