



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

Toys and Equipment to Help Young Muscles

—Linda Keder

If you're still looking for holiday gift ideas for a child with Prader-Willi syndrome (or if your child is likely to have money to spend after the holidays), you might want to consider shopping specifically for some items that will promote motor strength, balance, and coordination. Here are some suggestions I've gathered from my daughter's private physical therapist and a team of therapists in her early intervention program. Many of the ideas would be applicable both to preschoolers and school-age children.

To Encourage Play in Standing Position—

(Toys that keep children on their feet promote body strength, balance, and bone density.)

✱ **Play tables** — Even before children can walk independently, they can play with their favorite objects in standing at a sturdy table or bench. You might want to consider buying or making an adjustable bench such as the ones physical therapists use, since they can be used in their highest position as a table and in their lower positions as either a seat or a step.

✱ **Large play centers** — Once a child can stand independently, one of the various types of house-keeping centers, such as a toy kitchen or workshop, or smaller units such as an ironing board, doll's high chair, or beauty salon

can maintain interest and upright activity for long periods.

✱ **Easels** — From preschool up through school years, an easel can serve as the base for many standing activities, including painting with brushes, fingers, or



sponges; drawing with crayons, chalk, or markers; playing with magnets, colorforms, felt pictures; and anything else you can dream up. (One parent I know made an easel with removable drawing surfaces so his daughter could also "weave" yarn on the frame.) Look for a sturdy easel with legs adjustable for a child's height.

To Promote Good Posture in Sitting Position—

(For seated play, it's best to have your child sitting with feet flat on the floor, knees bent at a 90-degree angle, and a table or play surface at an appropriate height for the activity.)

✱ **Kid-sized seating** — Consider a table and chair set that fits your child or a sturdy bench that can be used with various play surfaces. Sitting on a chair or bench will make manipulation of toys more successful and ensure better posture than if your child were seated on a floor or sofa.

To Encourage Whole-Body Movement—

(Movement builds muscle strength, tone, and stamina, as well as burning calories. The most important message we can give our children, though, is that movement is fun!)

✱ **Toddler push carts** — For a child just learning to walk, choose a very stable push cart (one that can't tip sideways) and weight it down with a sack of sand or bricks to slow its movement.

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✱ **Push and pull toys** — For the independent walker, consider rolling toys with strings to pull them along (to promote both forward and backward stepping) as well as toy lawnmowers, vacuums, doll carriages, and other push toys.

✱ **Riding toys** — It's best to try before you buy to make sure your child can ride the toy. If your child is having difficulty with regular tricycles or bicycles, consider ordering a tricycle from a special-needs equipment company. (Many of these companies advertise in the magazine *Exceptional Parent*. Call 800-247-8080 to request a sample copy or subscription.)

✱ **Music and dance** — A cassette player with music cassettes or the right videotape might get your child interested in dancing. A set of pom-poms, some bells or castanets, or maybe a special pair of dancing shoes or tights could build interest in dance movement. A full-length mirror helps, too (see below).

✱ **Balls and beanbags** — Balls just naturally lead to catching, throwing, and kicking, which are all terrific movement activities. Beanbags are also great for tossing and can be easily made at home with fabric scraps and dried beans.

✱ **Mirrors** — Virtually all children love mirrors, from infants on up. A large mirror on the playroom or bedroom wall can stimulate movement and increase awareness of body image. They're also a great place to make pictures with Colorforms. (Just be sure to have the mirror professionally mounted so there's no danger to your child if the mirror is broken. Non-glass mirrors are available for crib mounting.)

✱ **Mini-trampolines** — Often called "nursery" trampolines, these small rectangular trampolines (about 3' x 4' surface size) with an upright padded handle can actually hold an average-sized adult and a small child. They're great for boosting muscle tone and building leg strength for jumping and stair-climbing. (Available through catalogs and special order from toy stores.)

To Improve Fine Motor Skills—

There are tons of toys and games on the market that can challenge your child's hand and visual-motor skills. Selection really needs to be based on each child's particular skills, weaknesses, and interests. If a toy requires much more strength than your child has, it will simply cause frustration and end up being ignored.

Some small gifts that will be of help and interest to most young children with low tone include:

For hand and finger strength—

- ✱ Modeling dough (homemade modeling dough has a wonderful, soft texture for weak hands—see recipe on p. 12)
- ✱ Rolling pin and cookie cutters for modeling dough
- ✱ Finger puppets
- ✱ Bicycle horns or squeeze toys
- ✱ Calculators with large keys
- ✱ Stamp pads and rubber stamps
- ✱ Crayons, chalk, magic markers
- ✱ Finger paints
- ✱ Pop beads

For oral motor skills—

- ✱ Bubbles, bubble pipes, etc.
- ✱ Whistles, harmonicas, kazoos
- ✱ Flavored chapstick, lip gloss
- ✱ Pinwheels

Continued on page 12



resident's Message

by Janalee Tomaseski-Heinemann

This month, our tall, slim, 19 year-old son, Matt, moved into a beautiful red brick home in the St. Louis suburbs that was completely furnished with all new furniture and necessary housekeeping items. This would sound like a success story for any young man at that age, but what makes this story special is that Matt and the other two young men in the home have PWS.

At eight years of age, Matt was 108 pounds and had daily temper tantrums. Then we attended our first national conference where it appeared that every teen and adult with the syndrome was short, obese, and had significant behavior problems. At that time we could not see beyond our fears, but felt we had no choice but to band with other parents and work for a better future for Matt and all young people with PWS. As Oscar Wilde once said, *"Discontent is the first step in progress of a man or a nation."*

When he was young, our goal was to get Matt down to a size "husky." It was beyond our wildest dreams that at 19 he would be a slim 135 pounds thanks to locks on the kitchen, family vigilance, and education about the syndrome. What we could not know was that due to growth hormones, Matt would also become 5' 10" tall and be able to eat more of a normal diet without gaining weight. Eleven years ago, psychotropic (mood and behavior altering) medications appeared to be of little value to our children, but fortunately in the last few years there have been some encouraging reports on certain medications that have been helpful. Due to medication now, Matt is typically less likely to get upset

and less likely to get stuck on one issue. Although Matt has some bad days, there are more times he is likely to put his arms around me and say, "Mom, you look like you need a hug." How many parents have 19-year-olds that show this kind of sensitivity?

The concept of a specialized group home for PWS was a budding idea 11 years ago, but is now a reality in many states. Matt's home is not a group home in the traditional sense, but is called a "supported living program." The living arrangement is designed to meet Matt's needs rather than him having to fit into an already established house and program. This was unheard of 11 years ago, but is a concept growing strong in several states. We families were consulted every step of the way – from the location of the home and remodeling needs, down to the type of furniture bought and color of towels. The staff was even brave enough to let the guys pick out all of their own bed room furniture!

Although life is far from perfect for Matt, and there are times we still get discouraged, Al and I have even more hope for the future. Who knows what the next decade will bring? Ask your grandparents if they ever thought that man would walk on the moon. As for you parents of younger children with the syndrome – hold on to the words of Robert H. Goodard who wrote:

"It is difficult to say what is impossible, for the dream of yesterday is the hope of today and the reality of tomorrow."

Hopefully your future reality will be beyond my wildest dreams.

Thanks to Our Donors

Contributions Through Nov. 20th

Patron Dues (\$100+): Schenk, Rochester Foundation, Maurer, McManus, Trimble, White, Shacklett, Janes, Beltran, Riesenman, Kennan, Kircheff.

Contributing Dues (\$40 - \$99): Ripley, Braun, Munson, Moss, Singer, Mook, Wappner, Prettyman, Pearson, Harrington, Pike.

Operating: Ziifle, Wett, Gulling, Nashville Comm. Chest, Dollar-a-Week Club(Parent), Alterman, Buhai
CIT: Olson (2) **Research:** Culver, Fieldstone (Culver), Gordon, Boyd(2), Van Zomeren (2), Northwest Pediatric Society (Award to Dr. Marc Williams)

Memorials & Honoraria: Mitchell, (Shacklett), UW Tri-State, UW Monroe (Vermeulen), Klentz, Pinerman (Singer Birthday), Ulland (Ulland), Amitrani (Pagliughi), **Percy:** (Beloved Son of Verla and Steve Percy)

Willoughby, Kensey, Osthoff, Hornbeck, Radenbaugh, Patterson, Phillips, Andrews, Walter, Henley, Bertsch, Sanders, Mischke, Onstott, Shupe, Landrey, Conrad, Holm, Gilbert Southern Corp., Kiewit Western Co., Wallace, Marchant, Morton, Cady, Hall, Mentock, LaBreck, Trimmer, Gould, Campbell, Burke, Kilpatrick, McNeal, Kibben, Schultz, Murphy, Denzler, Logan, Reay, White, Muller, Wingerter, Phillips, Clements, Trampe, Faulkerson, Guernsey Stone Employees, First Interstate Bank, Gilbert Western Corp., Dolezal.

Singer (Milton, a long time member and generous supporter): Wilson, Wilton Foods, Penthouse Meats, McNamee, Springer & Thomas Inc., Lieberman, Doran, Folcarelli, Selkow, Country Club Famous Desserts, Waldman, Price.

Birthday Club:

Undesignated: Mitchell, and Castle.
Designated:

Lota Mitchell for Julie
Paul Alterman for Andy
Paul Alterman for Mark

The Power in Numbers

by Tere Schaefer

Chapters of PWSA throughout the world provide personal support, education, and advocacy in the most direct way—person to person. PWSA now has 25 chapters in the United States.

Chapters exist in: AZ, CT, DE, FL, GA, IL, KS, KY, New England (ME, MA, RI, NH, VT), MI, MN, MO, Midlantic (NJ, MD, DE, PA), NM, NY Assoc., NY Alliance, NC, OH, PA, SC, TX, UT, VA, Nothwest (WA, OR) and WI.

Many other groups and organizations are active, yet not official chapters of PWSA (USA), such as the California Foundation and PW Project in CA, and support groups in AR, IN, CO, and Western PA.

Active groups also exist in Canada, Sweden, Norway, The Netherlands, Italy, Australia, New Zealand, Belgium, France, Germany, Switzerland, South Africa, and United Kingdom (site of the 1993 International Conference). Connection and communication is maintained through *The Gathered View* and the *Chapter President's Quarterly*, as well as through the International Prader-Willi Syndrome Organization, formed in 1991.

What enormous strength and potential is represented in this network to educate others and help diagnose those yet unidentified!

Education is also spreading through the media. Thanks to Janet Pearson, WA, for bring to my attention the mention of PWS in the Nov. 2nd issue of *Newsweek* (p.77). Unfortunately, it was merely described as "...a condition marked by mental retardation and growth abnormalities." I will be writing a letter to the editor and the author of the article; maybe it will spark further interest in a complete story on PWS.

Further attention was sparked by the discussion of PWS possibly being linked to hydro-carbon exposure. Dr. Merlin Butler did an interview with a local TV station in Nashville, a portion of which appears to have been picked up by CNN. The majority of response calls we received were from the WA, OR, MT, and LA, MS, FL areas.

In the past six months we have sent out approximately 1000 information packets regarding PWS. Occasionally these days, I meet someone socially who actually knows what the syndrome is. Someday, the combined efforts of us all to educate about PWS will result in everyone we meet knowing what it is — instead of them saying, "Prader - what?"

Organization News and Notes

The 1993 Conference

Our site has been selected. We will be taking over the Scottsdale Registry Resort Hotel. We have negotiated a price of \$55, per night for singles or doubles. Registration cards will be sent with the preliminary packets in March or April.

If you have interest in presenting at the 1993 conference or on the pre-conference day, please call the National Office, at 800-926-4797.

Hope to see you in AZ!

National Office Move

The building management has informed PWSA that our rent will be doubled if we stay in our present location. The Board of Directors will not approve this increase in rent, thus a new office location must be found. As of the

printing of this newsletter a new location has not been determined. Look in the next issue for specifics on the new location. Please remember to be generous with your Angel Contributions to cover added expenses.

Planning for the Future

If you wonder what else your Board of Directors does between conferences, the answer is that they are working! In order to develop a five-year plan for PWSA(USA), each Director has been given the responsibility to develop a portion of the plan. Each section was to be completed by the end of November in preparation for the Board of Directors midyear meeting in January in Atlanta.

In addition, they continue to deal with issues and policy questions that come up between Board meetings through the Executive Committee of the Board and conference calls. Other committees of the Board, too, are at work throughout the year carrying out the specific functions.

Pittsburgh Support Meeting

The Prader-Willi Western PA support group reports they will be having an important meeting in Pittsburgh the of January 30th with the objective of getting a group home for PWS in that part of the state.

It is anticipated that at least one and possibly two representatives from the State Office of Mental Retardation will be in attendance, and it is essential that all members make an effort to be there. Anyone not on their mailing list who is interested can obtain further information about the time and location from Sandy Immekus, 5890 Monogahela Ave., Bethel Park, PA 15102, (412) 831-9291.

A Speech Brochure

Speech and language are critical aspects of life and of dealing with Prader-Willi syndrome. Parents frequently joke that there are only two modes for a person with PWS in a car, non-stop talk and sleep. However, it is no joke when the frustrations of unclear speech cause miscommunications and flaring tempers. Fortunately, there are professionals who can help with speech and language development.

PWSA's newest brochure, "Speech and Language and Prader-Willi Syndrome" outlines how to find a speech-language pathologist, what to expect from speech therapy, and why it is important. The basic content of the brochure was developed by Debora Downey, M.A., CCC-SLP, who works with infants and young children at the University of Iowa's Prader-Willi clinic. Debora has presented at the past two national conferences and has written past articles for *The Gathered View*. We are extremely grateful for her contributions to PWSA's educational efforts.

Copies of this new brochure will be available after the first of the year.

If you are interested in obtaining a copy of the Speech and Language brochure, send :

*25 cents per copy for
1-50 copies
20 cents for 51 - 100
15 cents for more
than 100.*

*Add \$1.00 per \$5.00
of order for shipping
and handling costs.*

You Ought To Be in Pictures

PWSA has an ongoing need for photographs of people with Prader-Willi syndrome that can be published in new brochures and in other publications being developed for parents, professionals, and the general public. The importance of photographs, whether to give reassurance to a newly diagnosed family or to impress state officials and service providers with the seriousness of the disorder, cannot be underestimated.

The photos we have used in past publications have been donated by parents or were taken at national PWSA conferences. However, we have a limited number of individual photographs on file with specific permission for publication. We greatly need to expand both the number and the variety of photos available for this purpose. We are especially in need of close-ups, photos with siblings, and photos of our children with PWS engaged in various activities.

We can use either color or black-and-white photographs; those with good light and dark contrasts make the best reproductions. Please attachEnclose a copy of the permission form (below) to indicate how we may use the prints you send. If you have only one copy of a special print that you'd like to share, we can take it to our printer, have a screen print made, and return your original.

So, when you find yourself in that lull between or after the holidays, dig out that big box of old photos, arrange that album you've been meaning to get to, or just dust off your camera and take a few photos for PWSA.

Your photos can make a personal and truly effective contribution to the work of PWSA.

Photo Release Form

I hereby give general permission for the enclosed photo to be used in PWSA(USA) publications.

Should the photo be used, I will receive, prior to printing, a proof of the final product for a complete release.

Enclosed is a photo of:

Age photo taken:

Other persons in photo:

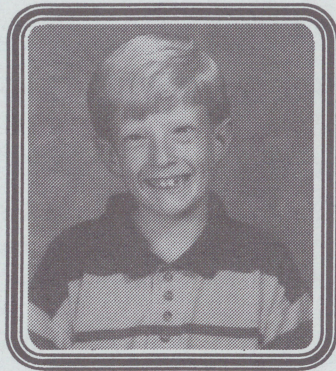
Signature:

Date:

Saying Good-Bye to a Family

On October 11, our PW son, Aaron, was killed in an accident in our driveway. He would have been 8 years old on November 19.

When Aaron was diagnosed at age 4 the National PWSA Conference had already been held in Calgary, so we waited a year to attend our first



conference in Salt Lake City. At this conference we realized we were not alone.

We live in Wyoming and we don't have a local chapter. Those annual conferences have been very important to us. The information we gained each year was great, but it was the sense of family that made it worthwhile.

At last year's conference there was a couple who didn't think their child had PWS. We were very happy for them because they wouldn't have to deal with the syndrome. They weren't as excited, saying they would miss all the people and the conferences.

We now know that sense of loss. Not only have we lost our beautiful blond baby, but we've also lost a family, all of you.

-Steve and Verla Percy

Our deepest sympathy to the Percy family in their loss. Their love and gratitude have also been expressed through this tragedy; a memorial fund has contributed \$3,500 to PWSA.

Poem

She knows what day -
"Full House" comes on TV
when is cooking day at school,
who goes swimming and
who can't and why...
She dances when it finally rains
and wants us to dance too.

When she wakes in the morning,
it's always with happy voice shouting--
"Mom, it's time to get up with me"
and it is always at exactly the same time
--everyday, even weekends!

Anything to do with babies paralyzes her,
she goes into a blissful state, watching them on TV,
gets stressed if they cry and tells me
to have one soon so she can be a big sister.

We must get up earlier if she has buttons on
her sweater
or buckles on her shoes--because
she must do each one and do it correctly.
It takes a long time but it will get done.
She must always have her teeth brushed before
we fix her hair, or it "bothers" her.
And if it "bothers" her we will all end up
"bothered."

The yellow school bus comes at 7:30 to take her
to school,
she waits anxiously by the door for it to arrive.
Beep, beep the driver signals, down the driveway
we run, her backpack smacking her in the back
as she goes. She always carries a dolly to school
with her and lets all the kids on the bus hold it
while she chats to them all. The driver smiles
patiently at this daily ritual.

Flowers bloom for Ashley, rain falls, Big Bird
talks to her and Barney the dinosaur greets her
on TV every Saturday morning.
Life is full of beautiful experiences for Ashley,
she emits love and expects love. She's five and
the world awaits her.

*Written by Angela Garcia
mother of Ashley Garcia,
who just happens to have PWS.*

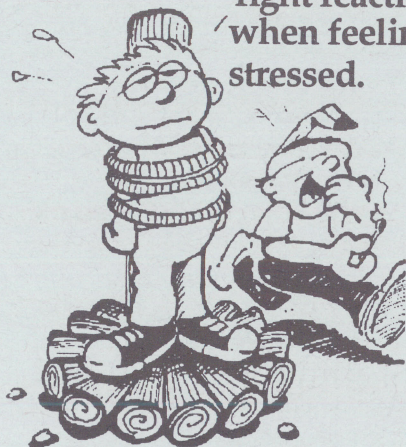
Twelve Alternatives to Lashing Out at Your Child

Children—and adults—with PWS have temper tantrums. That's news to no one who is involved with a person with PWS. So much effort is spent to find and suggest ways to cope with those situations when they arise. But what about the temper tantrums that parents themselves, as well as other caretakers, feel like having (and sometimes do) when they are totally frustrated and angry with that child or adult?

One mother describes her fury as feeling like hot oil is being poured over her and says she manages to maintain control with difficulty. Another says she yells at her child so she won't start hitting instead.

Stressful situations create in the human body what is called the "Fight or Flight Reflex." That is, there are normal physiological reactions such as muscle tension, increased breathing and heart rate, and hormonal changes which prepare the person to either do battle (fight) or run away (flight). This was a useful survival mechanism for cavemen, but today's world calls for more controlled responses.

Following are some alternatives to the "fight reaction" when feeling stressed.



- 1 Take a deep breath. And another. Then remember you are the adult.
- 2 Close your eyes and imagine you're hearing what your child is about to hear. And ask your self does this child truly understand.
- 3 Press your lips together and count to 10. Or better yet, to 100.
- 4 Put your child in a "time-out" chair. (Remember the rule: one time-out minute for each year of functioning age.)
- 5 Put yourself in a "time-out" chair. Think about why you are angry, is it your child, or is your child simply a convenient target for your frustrations and anger?
- 6 Phone a friend or PWSA.
- 7 If someone can watch the children, go outside and take a walk.
- 8 Take a hot bath or splash cold water on your face.
- 9 Hug a pillow.
- 10 Turn on some music. Maybe even sing along.
- 11 Pick up a pencil and write down as many helpful words as you can think of. Save the list.
- 12 Write for prevention information: National Committee for Prevention of Child Abuse, Box 2866L, Chicago, IL, 60690.

Hugs

It's wondrous what a hug can do. A hug can cheer you when you're blue.

A hug can say, "I love you so" or, "I hate to see you go."

A hug is "Welcome back again," And "Great to see you! Where've you been?"

A hug can soothe a small child's pain, And bring a rainbow after rain.

The hug, there's just no doubt about it-

We scarcely could survive without it!

A hug delights and warms and charms,

It must be why God gave us arms.

Hugs are great for fathers and mothers,

Sweet for sisters, swell for brothers;

And chances are your favorite aunts

Love them more than potted plants.

Kittens crave them, puppies love them;

Heads of states are not above them.

A hug can break the language barrier, and make travel so much merrier.

No need to fret about your store of 'em;

The more you give, the more there's more of 'em.

So stretch those arms without delay And give someone a hug today!

— Author Unknown



Ask the Parents

Q How do parents deal with regularly scheduled snack times?

A: —*Barb Dorn, WI*

In response to last issue's Ask the Parents, I wanted to share what we do to handle routinely scheduled snack times outside the home. We do a variety of things depending on the situation. In school, I distribute a letter outlining Tony's condition and his need for a calorie-restricted diet. (The letter follows.) I then give a list of suggestions of foods that can be sent for birthdays, special occasions, or holiday treats. I have been amazed at how many parents are sending food items on the list. On a routine day at school, Tony has milk for a snack just like the rest of his classmates. Instead of a carton, however, Tony receives 4 ounces in a cup that I supply. Last year, I sent Tony's own snack along for his morning snack but then allowed him to have the same as his classmates in the afternoon (using the same arrangement of a half cup of milk instead of a full carton). All of these measures are discussed with Tony. I try to give him choices. "Would you like to bring your own snack or would you like to have milk like the rest of your classmates? You, however, will need to have yours in a cup." Most days, Tony's teacher will share his milk with Tony, and this makes Tony feel special.

On occasion, I work as a fill-in at a local clinic. When I do this, Tony goes to a neighbor's house after school. Most times, I provide a snack for all the children. I try to make things as easy as I can for our child care provider and I have found this approach successful in preventing food-related problems.

Letter to Classmate Parents

Dear Parents,

I am writing to ask your help when sending treats. My son, Tony, has Prader-Willi syndrome. Part of this disorder is an eating disorder, so he is on a very strict diet. It would be nice if Tony is able to eat the same snacks as the other children as much as possible. To do this I need your help. Tony should not have sweets – cookies, cakes, cupcakes, etc. (If you do send these, could you please send one small one, with little or no frosting.)

Some things Tony **can** have:

Fruits (dried, fresh, or "lite" canned)—apple, dried apple snacks, applesauce with no added sugar, bananas, watermelon, cantaloupe, raisins, grapes, oranges, pears, fruit and juice bars, "lite" fruit juice, fruit roll-ups, Farley's fruit snacks.

Milk—low-fat yogurt or yogurt ice cream bars, sugar-free pudding, low-fat cheese slices, or string cheese.

Bread—mini rice cakes, graham crackers, popcorn, low-fat crackers.

Other—vanilla wafer cookies, Nutrasweet popsicles or ice cream treats, sugar-free Jello, "lite" cupcakes.

I really appreciate your help and support. If you have any questions, please feel free to call me.

Ask the Professionals

Q: There are so many mayonnaise products with names that include light, real, and cholesterol-free. What is the difference between them, and are any acceptable in a diet for a person with Prader-Willi syndrome?

A: (*Dietetic staff and students of The Rehabilitation Institute of Pittsburgh, P.A.*)

Mayonnaise is a fat and should be **limited**. However, Kraft has developed two fat-free products. They do not contain egg yolks or oils; instead they consist mainly of water with egg whites, gels, starches and gums to provide a good consistency. Because they only contain 12 to 20 calories and 0 grams of fat per serving, sandwiches can taste a little better and salads made with mayonnaise and coleslaw can be enjoyed.

These two are Kraft Miracle Whip Free and Kraft Free. Both of these products are actually free of fat! In addition, since the grams of fat are replaced, calories are also reduced. This is because fat contains 9 calories per gram, about two times as many calories as protein and carbohydrates, which have 4 calories per gram.

The list of available mayonnaise products is charted on page 11. You can see there are quite a few light and reduced-calorie products—which can be quite confusing at the grocery store.

Next Question for Ask the Parents?

How do you handle the constant repetition of questions or requests? Are there any good strategies to head the conversation onto a new track?

The product you are looking for should read Fat-Free on the front and 0 grams of fat on the back label. The chart also shows the wide range of calories and fat between regular mayonnaise and the fat-free products.

Remember, these are for one serving, which equals one tablespoon.

Types of Mayonnaise	Calories	Fat(g)
Kraft Miracle Whip Free	20	0
Kraft Miracle Whip Light	45	4
Kraft Miracle Whip	70	7
Kraft Free	12	0
Kraft Real	100	12
Kraft Light	50	5
Hellmann's Cholesterol Free	50	5
Hellmann's Real	100	11
Hellmann's Light	50	5

R equests

If you have a response, or a question for either Ask the Parent or Ask the Professional please write, or call the National Office prior to January 15th to be included in the next newsletter.

Any Bi-Lingual Children?

We will be moving next year to Isreal. Our 5-year-old daughter's strongest point is her speech. She communicates well, speaks clearly, and has good command of the English language. I am concerned how she will manage learning a new language.

Does anyone have any experience in teaching a child with PWS a second language?

Are there any bi-lingual children?

Very truly yours,
Judy Livny, CA

If you have information for Judy, please call or write Judy in care of the National Office.

Growth Hormone Survey

Hi-- my name is Alice Vallie. I am currently a senior at Turtle Mountain High School in Belcourt, North Dakota. My science teacher and I need your help in order to do a science fair project. You see my science instructor, Renee Aalund, has a 22-month-old daughter with Prader-Willi syndrome. Both she and I realize that one way to help out with Prader-Willi is to make more people aware of the syndrome. By doing a project on Prader-Willi, I can expose people at the regional, state, national and maybe even international level to the syndrome.

The area in which I have chosen to do my research is growth hormone. I know that there are several individuals with Prader-Willi syndrome who are currently on growth hormone. There are also studies currently being done on growth hormone but no major articles have been published. What I would like to do is survey as many people as I can.

I need you help to make my project a success. In turn, I will do my best to make more people aware of PWS because I feel education about the syndrome is a very important step to a cure.

If you are willing to participate in this project please return this form or call the National PWSA(USA) Office.

I have had experience with growth hormone treatments, and I'm willing to participate in the growth hormone survey. Please send me the questionnaire.

Name
Address

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A Toy Best Avoided

Finally, I read of a new board game by Parker Brothers that might encourage some undesirable movement in a child with Prader-Willi syndrome. Called "Don't Wake Daddy," the object of the game is to sneak through the house at night and be the first to get to the refrigerator without waking up the father. If you land on the wrong square, "Daddy" bolts up from his bed and you lose the race to the food. Believe it or not, it's a color-matching game targeted for preschoolers!

(Special thanks to Lynne Foltz, director of Footsteps Pediatric Physical Therapy in Silver Spring, Maryland, for her suggestions and review of this article.)

Homemade Modeling Dough Recipe

This dough has a much softer texture than the commercial kinds, which makes it easier for many kids to handle. Making your own dough is also a fun activity for a rainy or snowy day. Invite some playmates, let the children measure and mix ingredients, split up the cooked dough, and let the children add the coloring of their choice and do the kneading.

In a large saucepan, mix:

3 cups flour
1½ cups salt
2 tablespoons cream of tartar

Slowly stir in:

3 cups water (Stir until lumps disappear.)

Add:

3 tablespoons cooking oil
Several drops of food coloring

Stir constantly over moderate heat until mixture forms a ball. Turn onto floured surface and knead dough as it cools. Store in sealed plastic bag or other plastic container. (Keeps forever.) Have fun!

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