



THE WISCONSIN CONNECTION

THE NEWSLETTER OF THE PRADER-WILLI SYNDROME ASSOCIATION OF WISCONSIN, INC.

Volume I, Number 3

March 1995

MISSION: The mission of the Prader-Willi Syndrome Association of Wisconsin, Inc. is to educate and assist families and professionals in dealing with individuals with Prader-Willi Syndrome.

State Officers:

President:

Mike Larson

Vice President:

Pat LaBella

Secretary:

Bonnie Jones

Barb Dorn

Treasurer:

Tom Scheidegger

Office Address:

P.W.S.A. of WI, Inc.
305 Amanda Way
Verona, WI 53593
608-845-9597
Fax 608-845-9638

PWSA of WI, Inc. is a chapter of the Prader-Willi Syndrome Association (USA)
2510 S. Brentwood Blvd.
Suite 220
St. Louis, MO 63144-2326
800-926-4797
or
314-962-7644
Fax 314-962-7869

LEGISLATIVE UPDATE - WISCONSIN 1995-97 BUDGET

On Tuesday, February 28, 1995 Barb Dorn spent the morning in meetings attempting to get a better understanding of how the 1995-97 State Budget might impact persons with disabilities, especially those with PWS. The six inch budget document is filled with subtle changes in funding as well as some major program cuts. Some of the main points have been summarized below. Please EVERYONE, contact your legislators today. We especially need your help if you have a Republican legislator. Often times these legislators vote and support "party lines" unless we can inform them of important issues. We hope you have seen how recently persons with disabilities have been visiting the state capitol as well as being featured in many newspaper articles. We are not happy with this budget.

If you do not know who your legislator is or you want to leave a phone message, CALL THE LEGISLATIVE HOTLINE (608)-266-9960 or 1-800-362-9472

To write Representatives with last name A-L: PO Box 8952, Madison, WI, 53707

To write Representatives with last name M-Z: PO Box 8953, Madison, WI 53707

To write Senators: PO Box 7882, Madison, WI 53707

SSI CUTS

Governor Thompson's budget proposes to discontinue the entire STATE SSI supplement for over 17,000 people who do not receive federal SSI. These people are people who are able to work somewhat or who receive some small income source but who still have a monthly income which is very low. At the present time, these people also receive Medicaid to help them cover their health care costs. These 17,000 people will lose this Medical Assistance. Legislators say that these people should be able to get this MA but they will have to reapply for it through their Social Service Dept. We worry that many of these individuals will not be fully informed of this or may not be able to travel to their Social Service Dept to fill out the 25 page form that is required. This will need to be done every 6 months. The 17,000

(Cont. on page 2, see UPDATE)

Notes From The President...

Mike Larson

This writing thing is still new to me, but over my term of being President I will try to share with you some of my thoughts and experiences about being a parent of a child with Prader-Willi Syndrome and President of this organization. Not that my writing will be so worldly and thought provoking, but perhaps someone else will have a similar experience or feel the same way. Nor do I imply that this is the way everyone should feel or act, but this is how I think and feel. I feel this ties into the underlying, unspoken mission of this organization of "You are not alone!".

A large portion of this issue of the Wisconsin Connection is devoted to the proposed cuts in SSI benefits that will have major impact on many individuals with Prader-Willi Syndrome. Barb Dorn has summarized pending legislation along with how we as individuals can voice our concern and make known our wishes to our elected officials. The question we have to ask is ... If we don't voice what we want or don't want to our elected officials, who will? A phone call, a quick letter to a congressman, it doesn't take a lot of time, please exercise your and your children's rights. We do so much for our children now, this extra effort can make a big difference. There will also be Disability Awareness Rally, April 26, 1995 noon to 1 PM at the State Capitol Rotunda. Call the state office for more information.

The estate planning seminar is scheduled for May 6th in Appleton, WI. It should prove to be very beneficial for those with questions in the area of estate planning and how to best provide for our children with and without handicaps after we die. More information will be circulated in April. The seminar will be co-sponsored with the ARC of Outagamie County.

Please remember to renew your membership for 1995. They are slow coming in this year. It is important to renew your membership and try interest a friend or family member to join. Memberships would make a great gift to caregivers and professional you come in contact with.

Before closing I would like to add a personnel note extending our deepest sympathy to Barb Dorn and her family on the loss of Barb's mother Jeanette Becker. From what I have learned about her from Barb and others, she had contributed greatly to Barb's family and to this organization. Our thoughts and prayers are with the Dorn's and Becker's during this time of sorrow.

Mike Larson

2701 N. Alexander St.

Appleton, WI 54911

Phone: 414-749-1174

Fax: 414-749-0906 or 414-738-8539

Internet: Mike.Larson@vpi-app.ccmil.valmet.com

Conference Announcements!

Wisconsin TASH will be holding its Annual Conference on March 24 & 25, 1995 at the Midway Hotel - 1005 S. Moorland Road, Brookfield, WI 53005. Keynote speakers will be Joe Shapiro and Alice Rose. Mr Shapiro writes on social policy issues for U.S. News and World Report and is also the author of "No Pity", a brilliant, political, and human interest book will change forever the way we see people with disabilities and will inspire all to recognize that the disability rights movement is here to stay. Ms. Rose has been the principal of ProgressWorks since Dec. 1989. ProgressWorks, located in San Francisco, is a small business dedicated to the design and development of multimedia applications for persons with disabilities, their families, and professionals. Other topics that will be covered include ADA Issues, Designing Effective IEP's, Curriculum Adaptions, Assisitive Technology...more. For more information contact Laura Owens-Johnson @ (414) 277-8506.

UPDATE (Cont. from page 1)

recipients will experience an average loss of income of \$60/month - some will lose as much as \$180/month. This group includes 8,000 elderly people, 8,600 adults with disabilities, and 400 children. Some of these persons may be persons with Prader-Willi Syndrome.

The Governor simultaneously proposed a 6.5% inflationary increase in state SSI benefits for all other SSI recipients. We support an SSI inflationary increase; there have been excessive SSI cuts in the last 3 years. We are not in favor of the Governor dividing SSI recipients like this. We need to join together to protest these cuts.

PERSONAL CARE

The proposed budget would eliminate personal care as a Medical Assistant benefit and transfer \$15.4 million in state revenues to Community Aids. Counties would not be required to use the money for personal care of any specific purposes. Also, this change will result in the loss of the 60% federal matching share under the MA program. We have many adults with PWS who have personal care workers come in and prepare their meals and check on them. It is estimated that over \$5,000 people will be affected and the loss of the federal share will exceed \$50 million over the biennium.

FAMILY SUPPORT

The Governor is also proposing that Family Support funds (Cont. from page 2)

be sent to the counties and put into the Community Aids program and not be specifically marked for these services. There are no mandates for counties to use this money for Family Support. Let's just leave the funding organization for Family Support the way it is. There are many

issues in the 1995-97 budget. A few areas have been highlighted. Contact your legislators. They are taking notice and listening because many people are already responding to these cuts. Make a phone call; write a letter. Your response CAN make a difference. If you have any questions, call Barb at the state office. She will do her best to answer your questions.

times legislators keep track of their voter's wishes by filing these letters by topics. Here is a sample of one issue

WHAT DO I SAY.. WHAT SHOULD I WRITE WHEN TALKING TO MY LEGISLATOR???

Many times we would like to call or write our legislator, but we aren't sure what to say or write. Barb was able to give some examples and you can edit them to your situation or issue.

WHAT IF I DON'T KNOW WHO MY LEGISLATOR IS?

Call the Legislative Hotline Number: 1-800-362-9472

"Hello my name is Barb Dorn and I live in Verona and I'm not sure who my Assembly person is or who my senator is. I would like to find this out and leave them a message."

**The secretary will give you that information and take a message for your legislators.

"I am the parent of a 10 year old boy with PWS, a rare disability. I would like to share my concern and ask that Senator Winecke not vote in favor of the budget whereby the governor is proposing to cut SSI funding for persons who are receiving Wisconsin SSI only.

I would also like to ask that Senator Winecke not to vote for the budget in the area of Family Support. The governor is not proposing any budget cuts in this program but he is wanting to put these funds in to the Community Aids Program. There are no mandates that counties use these funds for this program and it could be spent on anything. Families need these funds protected." When making responses by phone, keep your conversations brief and to the point.

WHAT DO I SAY WHEN I WRITE A LETTER?

I make my letters more personal. I enclose a picture of Tony and begin by telling my legislator a little more about our situation. This is also a time when I enclose a Shelly pamphlet (PWSA USA pamphlet). We need to send a message loud and clear. You can elaborate a little more about your concerns but once again keep things fairly brief. Many advocates suggest that you write a separate letter for each issue. Many

305 Amanda Way
Barb Dorn
Verona, WI 53593
608-845-9597

March 17, 1995

Senator Joe Winecke
PO Box 7882
Madison, WI 53707

Dear Senator Winecke,

I am the parent of a 10 year old boy who was born with a rare genetic disorder called Prader-Willi syndrome. He is in third grade at Sugar Creek Elementary where he receives special education services. I am enclosing a pamphlet to share with you about his disability. He is living at home with his family. He offers us many challenges but we are able to do this because of many supports.

I am writing you today to voice my concern over the recent budget proposal which would eliminate funding for 17,000 individuals receiving the state SSI. Although we do not receive SSI for our son, we know of many disabled persons who rely on this funding to help them meet their basic needs. By cutting this funding, these individuals would also lose their medical coverage. Even though they could "reapply at their social service office," this process is often very complicated and overwhelming for these individuals. The system isn't always very informative about when, where, and how these forms should be done. The disabled and elderly often don't have the resources to get to and from these offices as well as fill out the 25 page form every six months.

We need more programs and funding to support keeping the disabled and elderly in the community. Possibly this funding could come from the increases that the governor has proposed for nursing homes over the next 2 years. I would appreciate a response as to your views on this issue and how you will vote. Please don't forget the disabled and elderly in your community.

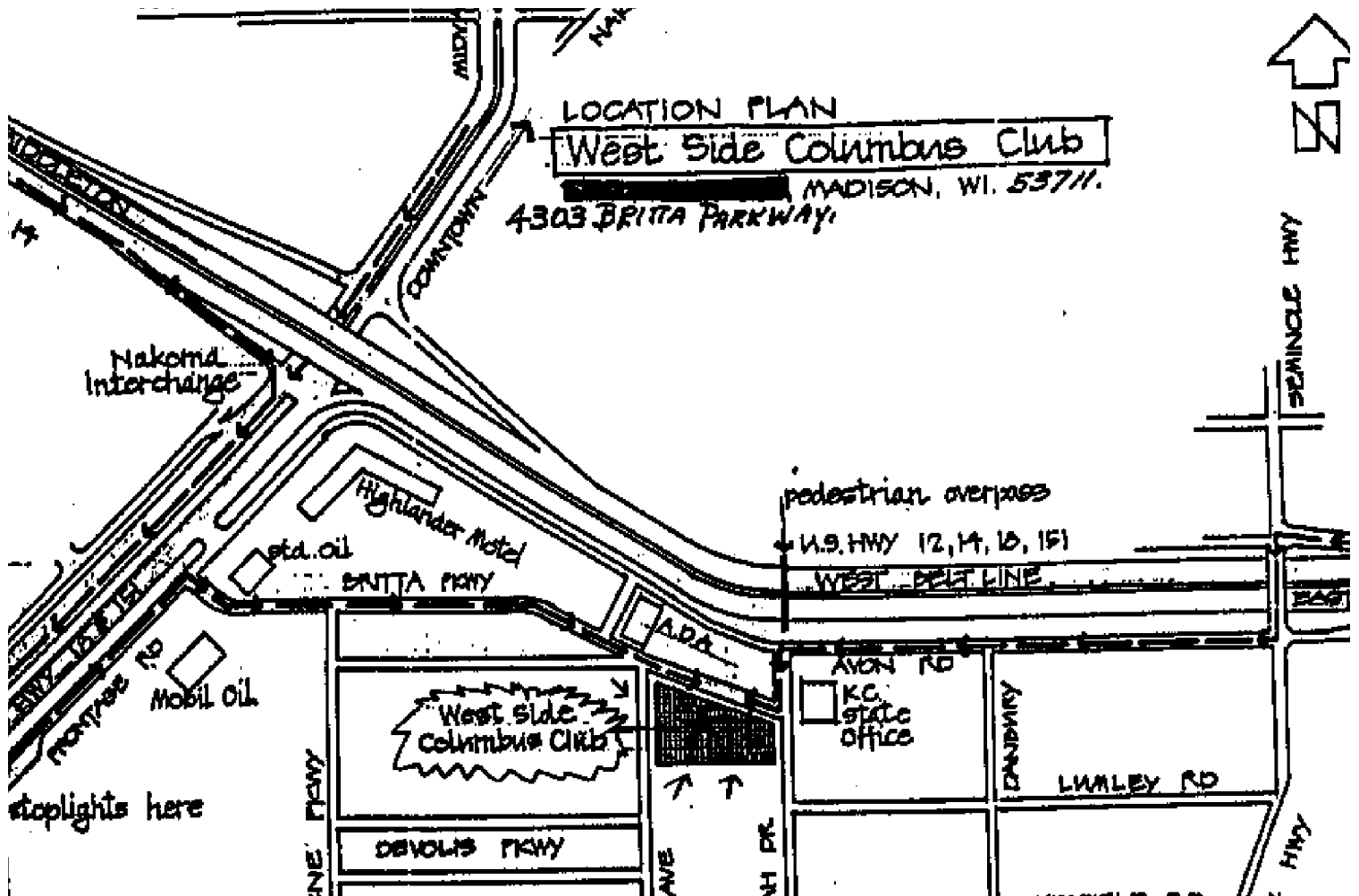
Sincerely,

SPRING DANCE MUSIC, DANCING, PRIZES, FUN!

When: Saturday April 1, 1995
Where: West Side Columbus
4303 Britta Pkwy. Madison
Time: 1:30 - 3:30 PM

Music will be provided by KART-TUNES - a complete disc jockey services

A 100 calorie snack & sugar free punch will be served.

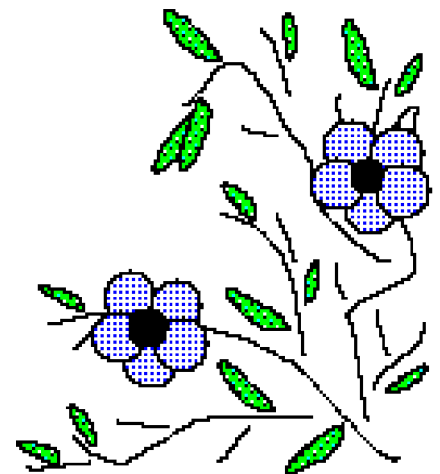
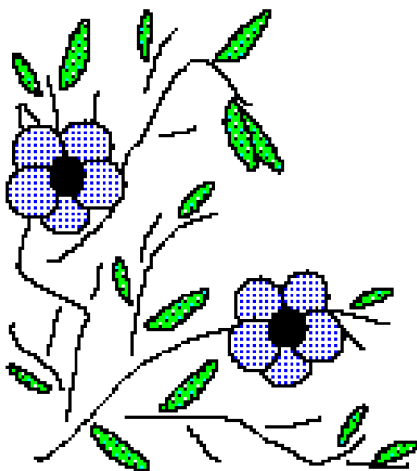
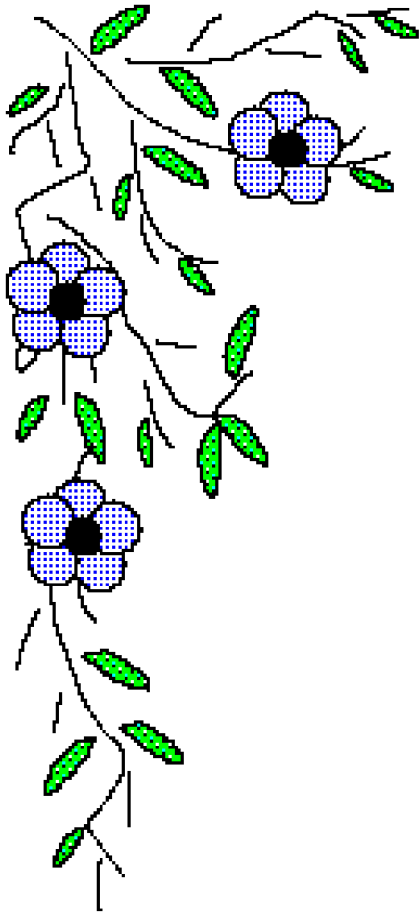


A Memorial to My Mom

by Barb Dorn

Recently my mother, Jeanette Becker suddenly and unexpectedly died. It is a loss that will be felt by my entire family. My mom was very supportive to me, to my family, to Tony, and to Prader-Willi Syndrome. She was always there to lend a helping hand during the many crisis our family has experienced. She spent a great deal of time at our home. She grew to understand the joys, stresses and strains of raising a child with Prader-Willi Syndrome. She was always so good about having "special" food for Tony and didn't mind eating promptly at 5:30 p.m. She was never judgmental of temper tantrums. She could see the frustration and pain in both Tony's and our eyes. She was also always one of the first to renew her membership in our organization and lend a hand in the clerical work that comes along with running the state office. She was my friend and I will miss her more than words can ever express.

It was my mothers wish to have money that was donated in her memory to go towards P.W.S.A of WI, Inc. As a memorial to Jeanette Becker, our organization has received approximately \$1800.00. I want to thank everyone who contributed to this, as well as the entire Becker family.



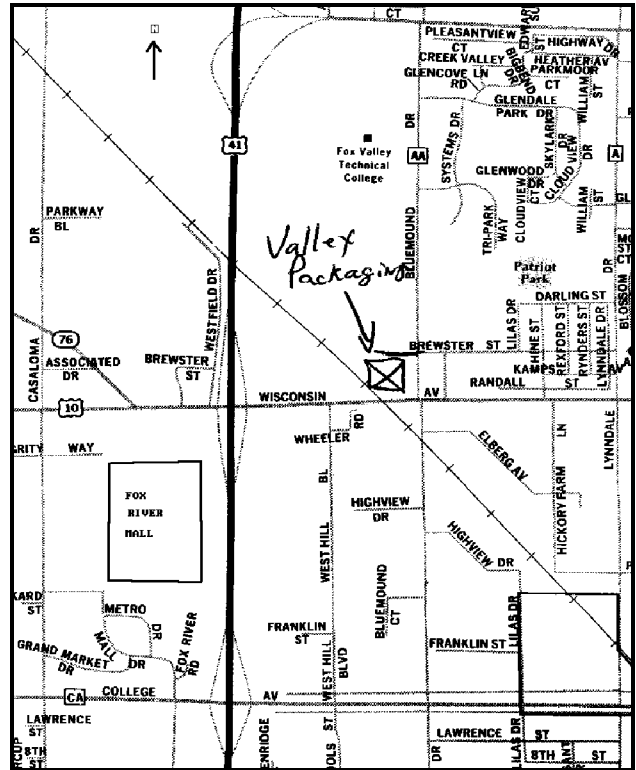
ESTATE PLANNING SEMINAR

WHEN: Saturday May 6, 1995
TIME: 1:30 - 4:00 P.M.
PLACE: Valley Packaging
3375 W. Brewster, Appleton, WI

A representative from a firm called Estate Planning for Persons With Disabilities will be giving a free two hour seminar on comprehensive life planning.

***CHILDCARE WILL BE PROVIDED but we are asking to please call the state office if you are planning using child care. We would like to know how many we need to plan for.

If you or someone would like to volunteer to help with the children please call the state office.



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