



# THE HORIZON

UTAH PRADER-WILLI ASSOCIATION NEWSLETTER

November 2008

Check our updated web site at:  
[www.upwsa.org](http://www.upwsa.org)

## President's Message

As winter weather approaches, hopefully you are all warm in knowledge that your children are doing well and are surrounded by people who love them and have their best interest at heart.

What a great few months we have had! We all enjoyed an informative state conference and the medical clinic is up and going and is a resounding success. Thanks in part to your help, Senator Buttars got re-elected. We hope to enjoy success again with the legislature this year. Senator Buttars has been a true ally to our organization and has moved us ahead several years in the care available for our children. Debbie Mason, our Care Manager, is an extraordinary soul and we are thrilled to have her help. She is capable and gets things done, so make sure you make your family available to her.

We look forward to our Christmas party on December 6th. We also will have a "work night" in March. We are hoping to send our children to Camp K again so gear up for a fundraiser of some sort this spring.

Most of all, know that we are here to help each other. The support and comraderie that we share helps us all through this journey a little easier and with a lot more love.



Sincerely,  
Lisa Thornton  
UPWSA Pres.

## Care Manager & Clinic

Our first medical clinic opened on September 5 - truly an historic moment for all concerned! Six children went through the clinic and were able, in one morning, to have appointments in pulmonology, genetics, endocrinology, speech, psychiatry, and nutrition. The doctors then met and set up action points for the families to complete, with the help of our care manager. Remember, the clinic is for children under 18 and only for Utah families, as dictated by the Utah Health Department that hosts the clinic. Our next clinic will be held on December 2nd and the families are busily preparing to attend.

Our Care Manager, Debbie Mason, has contacted and is working with all the families with children under 18. Once the December 2nd clinic is completed, she will begin working with families of children over 18. Families are making incredible progress and Debbie is a great resource. As a registered nurse with years of experience and contacts, she is helping all of us make great strides in the care of our children.

## Upcoming Events

### UPWSA 2008 Christmas Party

When: 11:30-2 p.m. - Sat. Dec. 6th  
Where: Primary Children's Hospital,  
100 N. Medical Drive  
Salt Lake City, UT 84108

Everyone is invited to the annual UPWSA Christmas Party! There will be lunch, Santa, and lots of fun!

If your last name begins with:  
A-H bring a veggie plate,  
I-Z bring a fruit plate.



## Spring Parent Meeting

When: 7:00 p.m. - Fri. March. 13th  
Where: Primary Children's Hospital,  
100 N. Medical Drive  
Salt Lake City, UT 84108

In March we will be holding a "let's get it done" night. Each family will come and we will have stations set up to get issues resolved and to work on the "Careful Steps" program. The stations will include such helps as getting special needs trusts drafted, receiving help with school issues, and making plans for specific medical needs. This will be a night you won't want to miss. When you leave, you will have something concrete completed that has been bothering you for years! If you need to bring your children, please call with the number of children so we can provide activities and helpers to make the night fun for them.

## Don't Forget...



Please remember to send Michelle Hollbrook, our Education Specialist, your IEP's to look over. She is here to answer questions and advocate for our children so that they can have a successful school experience!

Michelle's email [farm722@msn.com]