

Minutes from the April BCPWSA Meeting 2006

April 22, 2006

B.C. Prader-willi Syndrome Association

General meeting

Location: Surrey, B.C. Time: 13:00 – 16:00

Chaired by: Joanne Taylor, President

Present: Joanne Taylor, Carolyn Forsyth, Bill Griffiths, Gina Griffiths, Lindy Thompson, Betty McKay, Susan Robinson, Susan McKay, Carol Baldwin, Bev Baldwin, Rod Robinson, Frances Robinson, Marc-André Gagné, Cheryl Gagné.

1. ***Introductions.***

2. October 22, 2005 ***Minutes*** approved by Carroll Baldwin, seconded by Susan Robinson.

3. ***Treasurer report: Lindy Thompson***

Balance of \$3505 at year end (Jan, 2006).

Copy of budget report to be sent to Joanne Taylor for files.

4. ***New Business:***

Richard Brodeur Golf Tournament – August 10, 2006 - Bev Baldwin

continues to attend monthly meetings. Report and information at end of minutes.

BCPWSA Survey results – Cheryl Gagné

-Survey sent out in February. Please complete and send in if you have not. Much interest in guest speakers at meetings.

Cheryl will continue compiling information and do follow-up calls to all known affected families.

-Shared letter from Platt family about son **David Platt**.

(Letter and picture will be posted on site – Inspirational stories)

WEB Site - updates

-A Recipe page will be added to the Web Site, please send in your favourite recipes suitable for people with PWS.

-Please send in any pictures you'd like of your son or daughter for our WEB page.

Social Gathering – Summer Social Gathering

Lindy Thompson of Langley has offered her home as tentative location for this gathering. Dates to be posted soon.

Membership – Membership Dues to be received by end of March.

Baseball Tournament – **Bill Griffiths** will send information about a tournament with proceeds going to Special Olympics.

5. *Presentation on British Columbia's Special Olympics – Christie Tilton*

Christie is an athlete's representative and athlete in several Special Olympics Sports. She presented information on training, competitions and the positive influence of Special Olympics in her life.

British Columbia has 49 communities where individuals who have an intellectual disability can have the opportunity to participate in Special Olympics. Children can become involved as young as 8 years old.

Christie stressed that in this supportive environment the ability of the athlete is not as important as having fun. She states that "everyone is willing to accept you for who you are, not the way you are" and "most importantly, I get to play sports suitable to my skill level." She speaks confidently about her accomplishments and how she is happier in general and has made many friends through her involvement in Special Olympics. This young athlete truly inspired us with her love of sport and her great attitude about life. For more information about BC Special Olympics please visit: www.specialolympics.bc.ca

6. Presentation – Carolyn Forsyth – Individual Education Plans

Individual Education Plans is the learning plan that your child follows for the year in school. Their progress is measured in relation to the IEP goals. Carolyn presented on the importance of an individual education plan for a child with Prader-willi syndrome. Having a plan ensures that your child will work on specific goals. Strategies are written in the IEP plan and all members of child's educational team can then follow a consistent plan.

In the beginning of the school year, parents, the child's classroom teacher, teaching assistant resource teacher, the principal and any other specialist who see the child will get together to plan the child's IEP. During the meeting, the team will set academic, behavioural and social goals that the team wants the child to achieve during the year. This is a good time to include specific social goals around your child's food issues.

Your child will either be on an adapted program or a modified program. If they are on an adapted program they do the same work as the other students with some extra help and receive letter grades. If they are on a modified

program they do a completely different program from the other students and do not receive letter grades.

Some children in some districts are tested at Sunnyhill for Psycho Educational testing prior to receiving special needs funding. Children with Prader-willi syndrome are typically funded under chronic health category. Many thanks to Carolyn Forsyth and her informative presentation on IEP development for children with Prader-willi syndrome.

7. Presentation - Richard Brodeur Golf Tournament – Bev Baldwin

August 10th – Meadow Garden's Golf Club, Maple Ridge

144 Golfers – professional athletes, celebrities

Bev continues to work hard on this fundraiser. Extra help is needed.

Bill has volunteered to attend meetings with Bev.

The following tasks are to be completed:

- Ad for the Program – Joanne Taylor
- Logo for the Newspaper and Program – Joanne Taylor
- Banners for the kiosk – Carroll Baldwin
- Booth activity – Las Vegas Theme
 - Activity – Joanne Taylor
 - Treat – M&Ms w/ PWS – Joanne Taylor
 - Info card for treats – C.Gagné & S. Robinson
 - Signage for booth – Joanne Taylor
 - Pamphlet for booth – Cheryl Gagné
 - Decorations – Carroll Baldwin
 - WEB link to tournament – Joanne Taylor
- Donations / sponsorship / auction items
Everyone needs to continue to gather donations. As soon as you have an item contact Bev so he can let Krista (tournament organizer) know or follow up with company. Prizes are good in groups of four. Papers provided for seeking out donations. Susan Robinson has several golf contacts on the island to follow-up.

Meeting adjourned.

Next Meeting: October 21, 2006 Kelowna, B.C.