

## Minutes from the Fall BCPWSA Meeting 2008

### **B.C. Prader-Willi Syndrome Association**

### **General Meeting - minutes**

**October 25<sup>th</sup>, 2008**

**10:45 -11:45**

**Location: Century Plaza Hotel and Spa, Vancouver, B.C.**

Chaired by: Joanne Taylor, President

Present: Joanne Taylor, Cheryl Gagné, Gina Griffiths, Sukhi (support Griffiths), Gillian Leaky, Gerry Sillers, Marg Sillers, Dayle Sillers, Bev Baldwin, Carroll Baldwin, Roy Campbell, Natasha Campbell, Ray Velestuk, Joan Velestuk, Heather Beach, John Wiens, Vera Wiens, Jackie (support Ross), Barb Wheeler, Stephanie Louks, Marisa Piccolo, Dino Piccolo, Briana Piccolo, Parise Yun, Tyler Yun, Terrance James, Sue Robinson, Gordon Taylor.

Introductions

1. Introductions
2. Spring 2008 Minutes approved by Margie Sillers, seconded by Bev Baldwin.
3. Treasurer's Report: \$27, 355.84.
4. Membership dues...now due by the end of the calendar year for the following year membership. Fees remain the same at \$25.00 per family.  
*2009 membership dues are due by Dec. 31<sup>st</sup> 2008.*
5. CPWSA involvement – the Canadian Association is requesting a \$5 per family fee from our members to maintain their communications and WEB page. They are requesting this support from all provincial associations. We will forward this on behalf of all our members in good standing.
6. WEB page is up and running. Please forward pictures to Joanne Taylor. Please check it out and let us know if there are any errors or suggestions.
7. Report on Summer Social Gathering (Heather Beach)  
-6 families, a small but fun social gathering in a local park, pictures on WEB page
8. Drug Company support – Serono donated \$1000 to support this fall meeting.
9. Report on fundraising since last meeting  
- Richard Brodeur Golf Tournament (Bev Baldwin)

- ▶ \$10,000.00 raised again by tournament this year. Thanks to all who volunteer their time and gather silent auction items. Very fun and profitable year.
- Charity for Kids Golf Tournament (Joanne Taylor)
  - ▶ \$5000.00 received this summer for BCPWSA.
- Teammates for Kids (Joanne Taylor)
  - ▶ \$10,000.00 received this year for use to support children to attend summer camps.
- Gaming Commission (Joanne Taylor)
  - ▶ Declined our application.

10. Report on History of BCPWSA (Gill Leaky)

-Reported on the past history of BCPWSA. Presented detailed description and chronological events of the BCPWSA. [See Power Point.]

11. Honor – Sheila Kelton retired this summer. She was a source of support for many families in the BCCH Endocrinology. We honor her years of service to our families.

12. PWS – Quality of life. Terrance James has been researching PWS since the 80's. He is publishing the fruition of his recent works in the spring. He will present more information in the Spring. He is interested in having more photos of people with Prader-willi syndrome in typical situations. Please email him these pictures.

13. Educational Grant – No applicants for the fall intake of BC students. Motion by Joanne Taylor to repost grant information for the Spring session. Seconded by Margie Sillers.

14. Allocation of funds:

- Summer camp support or Camp fees – allocated \$10,000.  
(Summer 2009)
  - ▶ Money has been allocated to send children with PWS to camp. This money may be used to cover the cost of the camp and/or the cost of the support worker. Any member in good standing will be able to apply one time for camp financial support for up to \$1000.
  - There will be an application process established by the executive.  
(M. Sillers/B. Baldwin)  
(To be posted in the Spring on the WEB site.)
- Canadian Endocrinology Meeting – GH accessibility  
(Ontario, February 2009)
  - ▶ Money has been allocated to send two representatives from the BCPWSA and to send one knowledgeable member from the PWSAUSA to attend the Canadian Endocrinology Meeting in Ontario in February. All costs for transportation and lodging will be covered. A daily food allowance will be provided. Information would be presented on the benefits of Growth Hormone Use for children with PWS. Members attending would present at

the Spring conference. Any interested members need to speak to the executive as soon as possible. (C. Baldwin/L. Price)

- PWS Housing research  
(Spring 2009)

▶ Money has been allocated to send two representatives from the BCPWSA to research the Ontario group home for people with PWS. All costs for transportation and lodging will be covered. A daily food allowance will be provided. Representatives attending will present information gathered at the Spring conference. Any interested members need to speak with the executive as soon as possible. (C. Gagne/M. Sillers)

15. Election information

- President – Joanne Taylor (by acclamation)
- Secretary – Cheryl Gagne (by acclamation)
- Treasurer – Catherine Nickerson (by acclamation)

16. Planning Spring 2009 conference and meeting

- location (booked by end November)
- date (Saturday, April 4<sup>th</sup>, 2009)

Information will be posted on the WEB site as the executive plans this upcoming conference.

Meeting adjourned.

Motioned by Margie Sillers.

Seconded by Parise Yun.

Dinner and Fundrasier followed at Chivanas featuring “The Swills” music group.

Next meeting: April 4th, 2009 Vancouver B.C.