

B.C.P.W.S.A. SPRING 2010 Meeting - MINUTES

- In attendance: Cindy Thomson, Glen Thomson, Vera Wiens, John Wiens, Felisa (community guest), Antonette Soriano (with sister and children), Jessica Hill (with children), Leah Price, Alan Price, Rod Robinson, Francis Robinson, Lindy Thompson, Parise Yun, Heather Beach, Cheryl Gagné
- Fall 2009 Minutes -Approved by: Cindy Thomson
 -Seconded by: Parise Yun

REPORTS:

- Treasurer's Report (Cheryl Gagné for Catherine Nickerson)
 -Current: \$18,548.28
 (\$9,000 allotted to camp and available by application.)
 (\$1,500 allotted for Okanagan Fitness Funding and available by application.)
 (We received \$2100 from Lululemon to be used for fitness and wellness by children with PWS living in the Okanagan.)
 (We received \$2,000 from BC Hockey – Thank you, Sillers family.)
 (We received \$2,126 in donations from a skating party fundraiser held in Kelowna. Thank you, Nickerson and Gagné families.)
 (Richard Brodeur monies received this year totaled: \$3,000.)
- Report on: Student research progress (Cheryl Gagné for Terrance James)
 -On recommendation from and under the supervision of Dr. Gibson at UBC, the recipient of the BCPWSA student research award (Whitney Quong) has been replaced by Stephanie Lau. Stephanie will present at the 2010 fall conference.
 -Leah shared that Dr. Gibson is still looking for participants to partake in a study on PWS and PWS-like disorders; -interested families should contact Dr. Gibson directly at UBC.
- Report on: BC PWS Clinic – April 16th (Heather Beach)
 On April 16th the BC Children's hospital Endocrinology department will host a PWS Clinic for families with children ranging from 0-5 years of age. A nutritionist and a social worker will be available for either morning or afternoon sessions. All appointments with Dr. Chanoine will take place that day. Childcare is provided as necessary.
- Report on: Alberta PWS Clinic (Heather Beach)
 Alberta also has PWS Clinics. There is little information about these available. Of interest - is the arrival in July 2009 of Dr. Andrea Hagg to Alberta. Dr. Hagg is well versed in PWS and an advocate for use of GH.
- Report on: WEBINAR – Truth about Consequences – (C. Gagné for Y. Blomer)

Some BCPWSA members participated on November 19, 2009 on the PWSAUSA WEBinar titled "The Truth About Consequences". This forum provided some strategies to a variety of behaviours families may be experiencing with their child with PWS. Copies were made available to members in attendance.

- Update on: Terrance James' research and writing projects:
 - Two books are expected to be out by this summer:
 - 1) Prader-Willi Syndrome: Growing Older.
Deals with individuals over the age of 40.
 - 2) Prader-Willi Syndrome: Quality of Life
A comprehensive look at quality of life from the perspective of those with PWS and their parents/caregivers.
 - Books will be available for purchase at our fall meeting. Dr. Terrance James will speak briefly on his writings at our fall 2010 meeting.
- Report on: University Florida Research Project - (Cheryl Gagné)
The Gagné family participated in the University of Florida's clinical research study investigating the effects of growth hormone therapy on the natural history of Prader-Willi syndrome, in Gainesville, Florida this spring.
Family shared some medical results from the study and exactly what data and results this study provided for them.
- Report on: Canadian Organization for Rare Diseases - CORD (Heather Beach)
 - On April 9th and 10th from 8:30-4:30, at the Delta Vancouver Suites, CORD is hosting a two-day training seminar entitled "How Drugs are Funded in Canada: What Every Patient Should Know".
 - Heather Beach will attend and speak on this at the fall conference.

FUNDRAISING UPDATES:

- Richard Brodeur 2009 (Cheryl Gagné for Bev Baldwin)
2009 funds provided from the Richard Brodeur Charity Golf tournament totaled \$3000.
- Poinsetta Fundraiser (Heather Beach)
Heather sold some poinsettias in her store this year. Anyone interested in taking on this fundraiser, please contact Heather. It is easy to do; it is more profitable if a larger number are ordered.
- LuLuLemon Grassroots Charity donation (Cheryl Gagné)
Cheryl applied for this in the Okanagan Valley at their Lululemon store. She reminded members that there are many groups out there that may have similar projects. If you are unable to apply yourself, please forward any information you may come across to the executive of the BCPWSA.
- Nickerson & Gagné BCPWSA Skating Party (Cheryl Gagné)
The Nickerson and Gagné families hosted a winter skating party for families and friends. They rented a rink, purchased insurance and invited people they know to attend and to bring a donation for the BCPWSA. Over \$2000 was raised. If you want to host a similar event, please contact them for ideas or an explanation of how to organize it.

- Donations: Friends and families can donate at any time to the BCPWSA. This can be done on line (through paypal) or by mailing a cheque to the BCPWSA (address on our WEB page). Receipts are issued for income tax purposes.

UPCOMING EVENTS:

- Richard Brodeur 2010 – **July 8th** Pitt Meadows (Cheryl Gagné for Bev Baldwin)
 - We have once again been invited as one of the charities at the Richard Brodeur Golf tournament.
 - As in the past, donations are needed for the silent auction.
 - Please see the information posted on our WEB Page.
 - Bev Baldwin has agreed to attend the monthly meetings. Please contact him with donations or for more information.
- FPWR One Small Step Walkathon 2010 – **August 15th** (Cindy Thomson)
 - Cindy would like to set up committees for the organization of the walk this year (set-up, food, break-down, advertisement, media contacts, a clown, a face-painter, etc.)
 - sponsors are also needed
 - prizes will be available for different levels of fundraising (donations of more prizes would be beneficial.)
 - a goal needs to be set on how much money we hope to raise
 - all funds from this walk will go to the FPWR-Canada for research projects about Prader-willi syndrome
- BCPWSA Summer Gathering – **August 15th**
 - Will be organized by the executive and Leah Price.
 - It was decided to have this gathering on the same day as the walk. More information will follow shortly. Location will be the same park as for the fundraising walk. By joining these dates we hope to have a larger amount of members available to attend.
- REMINDER: Camp Funding available (Cheryl Gagné for Catherine Nickerson)

“Money has been allocated to send children *or young adults* 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. *Priority will be given to first time applicants.*”

 - Cheryl Gagné moved to amend the wording to our camp funding
 - Parise Yun also moved to amend the wording to our camp funding

A discussion ensued. Changes indicated in italics above.

Motioned by Francis Robinson. Seconded by Heather Beach. Motion passed.

(Application is posted on the WEB site. Copies provided at meeting.)
- Okanagan Fitness Funding available (Cheryl Gagné)

“Money has been allocated to support families to provide an activity that promotes health, wellness and fitness for a child with Prader-Willi Syndrome who lives in the Okanagan Valley. Any member in good standing, who currently resides in the Okanagan, will be able to apply one time for financial support for up to \$500.”

-Cheryl Gagné moved to accept the wording of our Okanagan Fitness Funding.
-Seconded by Parise Yun and Cindy Thomson. Motion passed.
(Application is posted on the WEB site. Copies provided at meeting.)

- FPWR Medical Conference – May 14-16th (Cheryl Gagné)
 - The FPWR-Canada Medical Conference will take place in Toronto from May 14th to 16th. Current committee members of the FPWR-Canada will attend. Executive motioned to send one or two members to attend the conference this year. Attending members would present to the BCPWSA at the fall conference.
 - Discussion followed.
 - Motioned by Leah Price, Parise Yun.
 - Seconded by Francis Robinson. Motion passed.
 - Members interested in attending as representatives of the BCPWSA must contact Cheryl Gagne by April 15th, 2010.*
- Fall conference will take place on October 23rd. Executive will try to book same location as in past. Executive will try to continue to provide the adult sessions and child care for the “0-5 years” age group. Suggestions were taken as to potential upcoming topics of interest for members.
Executive will plan and communicate to members as soon as information is available.

UPCOMING DATES TO NOTE:

- April 16th – BCCH PWS Clinic
- May 2nd – “Extreme Makeover” presents a family with PWS
- May 14th to 16th FPWR Medical conference
- July 8th – Richard Brodeur Golf Tournament
- August 15th - Summer Gathering
- August 15th – FPWR Walkathon
- October 23rd Fall Conference

Adjournment

-Meeting adjourned by: Heather Beach
Seconded by: Parise Yun

Members stayed to have lunch and to socialize.