

B.C.P.W.S.A. SPRING 2011 Meeting - MINUTES

March 19th

1:00-3:00

- Introductions and celebrations – Cheryl Gagné (Isabelle has started a sit-ski program and Tails for literacy program); Heather Beach (Silas is now starting Hippotherapy and seems to be having great increases in success with his speech); Bev Baldwin (joined the geezer motorcycle club); Francis Robinson (grade 1 has been fantastic and the school has been very accommodating); Rod Robinson (celebrating Nikki standing up for herself with her sister); Alan Price (happy to not be working and exploring self opportunities), Cindy Thomson (got approval for a supportive worker to take Meghan to Strongstart program---which will allow for her to have some time for self wellness; got a walker from variety); Carroll Baldwin (Paul is now home for three weeks and today is Carroll's birthday!); Margie Sillers (Dayle has moved to a family group home with 10 people and she is loving it.); Glen Thomson (Meghan is learning how to stand up); Leah Price (still no hyperphagia and Amaia has started Hippotherapy, is at school two days a week and is "YAY" starting to potty train); John Wiens (is expecting his third grandchild); Vera Wiens (went to Hawaii and had no worries about Jill while there); Catherine Nickerson (just finished her last Master's course).
- Fall 2010 Minutes approval
 - motioned by Margie Sillers
 - approved by Bev Baldwin
- Treasurer's Report (Catherine Nickerson)
 - we have just under \$16, 000 (\$9000 is allotted to camps)
 - conferences cost almost \$5000
 - web site cost \$543.00 dollars
 - income \$3000 Richard Brodeur
 - \$2000 Canucks alumni
 - \$1400 Skating party
- Camp Funding available - applications (Catherine Nickerson)
 - up to \$1000 available per family for children with PWS aged 6 to 16 years of age (must be member in good standing)
 - camp application form is on the web site
 - if you find a camp that accepts children with PWS, please forward the information to Cheryl
- Student Research Applications (Heather Beach for Terrance James)
 - \$1500 is set aside for a research project on PWS
 - information was circulated to all universities in BC with a deadline date at the end of June. Dr. James has received a couple of inquiries, with one

from a student with high interest. More information will be updated as we receive it.

- Resources :

- **PWS-Quality of Life**; PWS-Growing Older; support web site (Heather Beach for Terrance James)

- ▲ new WEB site has been created by Dr. James...on PWS quality of life (www.prader-willi.ca) and this link can also be found on our BCPWSA site. The site will promote Canadian resources to support PWS families. Please check out the resources, leave a message on the blog, or send Dr. James an email on how to make it more useful and user-friendly. It is a work in progress. Dr. James reports visits to his site from seven different countries to date.

- ▲ Terrance James has also published two books. Members in good standing will have the postage paid by the BCPWSA. The books are available with PayPal on-line or directly from Poplar Publishing at 2766 O'Brien Rd, Courtenay, BC, V9N 9H9. Personal cheques, money orders, or institutional purchase orders are accepted. If anyone wants information about the books sent to agencies or care professionals, please contact Dr. James with the names and email addresses.

- **Starting school** – ideas for an easy transition/creation of an IEP (Cheryl Gagné)

- ▲ Cheryl Gagné shared documents on school start up for the younger families. She provided two power point presentations (one on general information about PWS for a caregiver and one on strategies for school for a young student with PWS). Also provided was: suggested initial information to bring to an IEP meeting, a list of pertinent documents that could be provided to a school, and a copy of Isabelle's current IEP that could be used as a template for creating an IEP for a like aged child with PWS. These documents can be provided electronically and modified to be personalized for your own child as he/she begins school.

- **BC Group Home living for the Adult with PWS** (Bev & Carroll Baldwin)

- ▲ Paul went to the Pittsburg Institute (through Health services out of country medical funding). Paul was morbidly obese weighing in at 371 pounds. The program was exceptional. In three months Paul lost 83 pounds. Paul then moved to a PWS home in Toronto in October for four months, where he lost an additional 62 pounds. (Vita community living is the organization that has this PWS home.) Dr. Berrall followed the patients with diet and fitness plans. (Pittsburg costs: 997\$ per day, Culford House in Ontario was around \$9000 per month.) Feb. 21st he came back to Vancouver and is living in Ottawa House (paid for by the ministry of health)...and has lost 10 pounds there. This is not a PWS specific home. There are four residents and the home has a very heavy medical

component to it. Paul is happy and much more healthy and has some independence. The downwards spiral started in Feb 2009 and two years later the family is finally having success. The structure is a key component to the success of this program. They are using the RedYellowGreen diet. Paul has set a goal weight of 165 pounds. He exercises 1.5 hours every day. He is proud and doing well.

**Advice to future families: whole process should begin prior to the age of 19 years. Pittsburg has been doing this for 30 years. The PWS Clinic in Ontario has been around for 19 years. Both Dr. Berrall and Karen Balko were extremely supportive and helped the process happen. The Ministry of Health is paying for Paul's care. PWS is an issue of Health (medical).

- Fundraising updates:
 - Richard Brodeur 2010 (Bev Baldwin)
 - \$3000.00 from our 2010 tournament
 - thank you to Bev, Carroll, John, Carla and Cheryl for volunteering at the tournament. Thank you to the families who procured items for the silent auction.
 - it is unlikely that we will receive the RB tournament for 2011

 - Nickerson & Gagné BCPWSA 2010 Skating Party (Catherine Nickerson)
 - \$1400.00 from the 2010 party
 - 2011 party may happen this year in December

 - Canucks for Kids Application 2011 (Cheryl Gagne)
 - application completed by Cheryl Gagné with information provided by Gerry Sillers; no news yet

- FPWR Gala and Medical Conference – Information (Heather Beach)
 - April 15th to 17th, 2011
 - Cindy will be attending as a member of FPWR
 - she may provide information at our next meeting

- FPWR One Small Step Walkathon 2011 (Cindy Thomson)
 - August 21st
 - Fraser Foreshore Park, Burnaby
 - Cindy Thomson will organize
 - She hopes to have the Running Room involved
 - probably a similar set up as last year
 - last year \$7000 was raised from all BC residents
 - \$10,000 goal this year
 - all funds from this endeavor go to the FPWR for research
 - anyone interested in volunteering can contact Cindy Thomson

- BCPWSA 2011 Summer Gathering (Heather Beach)
 - August 21st

- after the walk we will have some family activities and a social gathering
- Fall 2011 conference vision, suggestions and planning
 - RBC employees can organize a fundraiser for four hours
(with 5 people they work with can then also get \$1000 donation from RBC-members with contacts in the RBC will look into this)
 - directed sharing sessions at the tables
 - potential of bringing in Dr. Jennifer Miller

UPCOMING DATES:

- April 15th to 17th - FPWR Gala & Medical Research
- August 21st - FPWR One Small Step, Burnaby
- August 21st - Summer Gathering
- October 22nd TENTATIVELY - BCPWSA Fall meeting & conference

-moved to adjourn by Bev Baldwin
-seconded by Cindy Thomson.
Meeting adjourned.