

B.C.P.W.S.A. SPRING 2013 Meeting - MINUTES

April 14th

1:00-4:00 - Burnaby, B.C

- **Attendance-** Heather Beach, Alan Price, Leah Price, Bev Baldwin, Al Young, Lorele Houde, Brent Lefebvre, Holly Lefebvre, Glen Thomson, Cindy Thomson, Mandy Young, Antonette Soriano, Yvonne Bloomer, Rupert Gadd, Frances Robinson
- **Fall 2011 Minutes** approval – Bev Baldwin, Brent Lefebvre
- **Treasurer's Report** (Frances Robinson for Cheryl Gagne)
-see attached update
- **Reports/Updates:**
 - * Mandy reported on seeing nutritionist Melanie Silverman. According to Mandy, she was very knowledgeable. Cost is \$150. The consultation consists of a one hour skype or email or person consultation. After this consultation there is a one month period of unlimited follow up questions. Melanie is located in Laguna Beach, CA. Mandy's insurance did not cover. One very good aspect is that the Philosophy is to include the nutrition of the whole family.
[Website: feedingphilosophies.com](http://feedingphilosophies.com)
- **Rare Disorders Group:** This group meets once per month, on the third Wednesday of each month. The group invites different speakers to each meeting. This is a really great support group. Meetings at BC Children's Hospital from 7pm – 9:30pm. All ages. Great supportive group to attend. They host an annual rare disorders gala \$120 per ticket.
- **Grant to modify the kitchen.** Yvonne Blomer (who has recently published some poems) gave an update on their grant to modify their kitchen. Grant is from a program called Giving in Action. This program is usually for families with children with disabilities to make the home more accessible. There is a website as a guide to assist in the application of this grant Yvonne states they had to fill out letter of inquiry regarding the problems with your kitchen that you want the grant to address. Yvonne stated that it can be a challenge to convince the program to do a kitchen renovation. Process involved the letter of inquiry and lots of calls to check why our kitchen will actually make things more accessible. They needed two quotes from builders after the plans were developed. Quotes must also be open while you wait for the approval process and not all builders are willing to do this. Grant will cover basic renovations. Anything else is your own expense.

Process took two years. Suggestion is to have also letters from OT and PT along with doctors letters and information. Yvonne states they used a locking system for all their cupboards from Lee Valley across from Ikea on United Boulevard in Coquitlam.

- Heather spoke about **pursuing the Autism diagnosis**. Her son must fit at least some of the categories in order to be considered. 3 categories were assessed. Heather thinks they may squeak by on the PDD-NOS designation. The diagnosis will allow for \$6000 per year for children over 6 years of age to help with therapy costs. Children younger than 6 qualify for \$20,000. These funds will help since services drop off significantly during school years. Process can take one year. Yvonne Blomer shared that her son Colwin also has the diagnosis as well as Bev Baldwin's son. Bev stated that more than one diagnosis can be helpful, especially later to help our children to qualify for services.
- **FPWR Conference in Toronto**. Cindy Thomson is going to the Toronto conference. Dr. Jennifer Miller from the University of Florida will be speaking on Saturday and Sunday. All information is on the FPWR website. The conference is usually available after on videotape and it may even be webcasted live. Check the website. Cindy shared that she really appreciates the parents getting together. Suggestion that we here should also get together socially, with a mom's getaway weekend.
- **Fundraising Updates:**
 - *Cindy discussed wine and cheese fundraiser idea. Cheryl and Catherine's skating party went well. Expenses were \$499 and party raised almost \$2,000. Frances is asking if there are any interested families in Surrey, Coquitlam or the Valley who would like to participate in fundraiser hosting a movie morning at the Clova Cinama in Cloverdate. Upfront cost of \$150, but all ticket sale proceeds will go to BCPWSA. Contact Frances is interested.
 - ***Gaming Grant**: We were turned down for the Gaming Grant. Heather has the letter of refusal available for perusal. Letter states that we as an association had too much money. We must have spent more than half of our available funds before qualifying. **Our programming must have been in place for 3 years already.** Funds cannot be used for travelling costs which pose a problem for us in terms of inviting good speakers. Bev suggested that we ask organizations e.g. Legions, Kiwanis, Lyons in all of our communities to give us some of their gaming monies. If members are interested in writing to their local charity, we can look at providing a suggested form letter.
 - ***QSP magazine fundraiser** is running. Response mainly over Christmas. This is an easy fundraiser. Put it out on your FB and ask any other family members.
 - *Heather will host a fundraiser at Rocky Flat Bread Pizza in Vancouver. The organization is very accommodating. Fundraising nights are Tuesday nights once

per month. Your charity gets 10% of the take for the night. Heather will also set up a table, silent auction, face painting etc. No date yet. Suggestion is 100 people to attend plus the regulars who come. Heather will let us know of the date. Hope that you can come and bring your friends who live or work downtown. Maybe Take Out will also be available. Hoping for a school year date. Start time will be 5pm till closing time.

*All **Camp Grant monies** have been spent. Cheryl may apply for this grant again in the future.

- **Conference for next year:** \$6,000 still left over. May hold it again at the YWCA. All members are encouraged, if they know of a good location, to let Heather know. Requirements are for a big main room with some smaller breakout rooms. At moment, we will plan for the YWCA again. Also suggestions for speakers are also welcome. Suggestions included Dr. Chanoine for BCCH Endocrinology, behavioral topics, financial planning, nutritionist, speech therapists. Cheryl also had knowledgeable adults at the conference to lead adult PWS groups. Hopefully she will be able to these helpers again for our conference. We have usually received good feedback from the attendees. Glen suggested a workshop of future strategies coming up, future findings and research
- Heather talked about **Pharmanac** showing good potential for skin picking. One study showed promise for people who have hair pulling.
- Endo clinic wants to put together a Newly Diagnosed Information Package. Heather collaborated on this with BCCH. Any suggestions can be forwarded to Heather who will pass the information along to Endocrinology.
- BCPWSA is now on Facebook. This is an easy way to connect with BC parents. Anyone can post on it and make suggestions to other about interesting things relevant topics.
- Discussed again **many different sporting opportunities** for our children. Eg. Soccer Dogs, Challenger Baseball, Special Olympics, Swimming. Leah suggested 50% off private lessons for special needs kids in Vancouver. PNE gets wristbands and you can skip the line up for special needs kids. Also don't have to buy tickets for the adults. Reminder that companions on airlines are travelling for free but please be mindful that there are limitations. BC Ferries also have a companion program.
- Leah has brought some puzzles. Suggested that parents bring the puzzles their children don't want to use anymore to future meetings to participate in an exchange.
- Cindy Thompson has set up this year's **One Small Step Walk** again. Same location. Fire trucks again. No Tim Horton's this time, but Cindy is looking into

Starbucks. Airbrush tattoos. Looking into prizes for either walkers or silent auction items. Cindy's brother will be taking pictures again. Cindy's brother may be able to set up some food (BBQ) for sale after the walk.

- Bev shared that Paul has been in Hillside Centre in Kamloops since August. This is the Neuropsych. centre for the province. Most residents have acquired brain injury. Focus on dual diagnosis, i.e. Developmental disability and mental health issues. This program is working very well for Paul. Previously he was in CLBC group home. Once discharged, Paul will be going to a Connect community in Langley called Cheshire Homes Agency. Each unit has 5 residents. This is a rural area. Program allows for goal setting and work towards these goals. Referral from the Hillside Centre.
- **Free Sharing:** Cindy Shared that Megan and her went to the Variety Club telethon. First PWS child on the telethon. Cindy will contact Vancouver Sun for our walk perhaps. Cindy will talk to Carla who does their fundraising for tips.

UPCOMING DATES:

April 20th to 21st FPWR Gala & Medical Research

August 25th - FPWR One Small Step, Burnaby

BCPWSA Fall meeting & conference – Executive to determine

Adjournment - Frances Robinson, Rupert Gadd