

# **B.C.P.W.S.A. SPRING 2012 Meeting - MINUTES**

**April 6<sup>th</sup>**

**4:00-6:00 - Burnaby, B.C**

- **Attendance-** Heather Beach, Alan Price, Lara Musa, Glen Thomson, Cindy Thomson, Catherine Nickerson, Mandy Young, Antonette Soriano, Starlah Hanna, Al Young, Cheryl Gagne
- **Fall 2011 Minutes** approval – Glen Thomson, Heather Beach
- **Treasurer's Report** (Catherine Nickerson)  
-See attached Statement
- **Camp Funding** available - applications (Catherine Nickerson)  
-new application form is available on line for the 2012 year  
(2 applications have received and approved this year so far)  
-See attached Form
- **Student Research Final Presentation** (Lara Musa)  
-See attached Handout and Power Point Presentation
- Terrance James update (Cheryl Gagné)  
Dr. James is doing well after his pacemaker surgery. He is still a huge support to the PWS community. The association is thankful and reminds members that Dr. James has a website that people can visit for more information on PWS. He can be contacted at: [tn-james@shaw.ca](mailto:tn-james@shaw.ca)  
"After one year of operation my website has had visitors from 64 countries. I believe that the supports and services provided in Canada are of high interest to families elsewhere. Approximately 80% of the visits are from North America, with Canadians visiting twice as much as Americans. I am always open to ways to make the site more useful to Canadians. I am particularly interested in responding to blog questions or topics of interest."
- **Fundraising updates:**  
-Nickerson & Gagné BCPWSA 2011 **Skating Party** (Catherine Nickerson)  
(See financial statement-fundraised \$1589.00) – Easy fundraiser, great fun for families, perhaps running it as a joint activity with a few families to use same facility and invite multiple groups of friends. If you want organization ideas contact Cheryl or Catherine)  
  
-Fall (Pre-Christmas) **Tupperware sale** (Cheryl Gagné)

(See financial statement-fundraised \$193.60) Fundraiser was easy to do on line. If lots of people make purchases...it can be easy profit. Perhaps run this another time next year.

**-Gaming Grant Application Update** (Catherine Nickerson and Cheryl Gagné )  
Application is now ready to be sent. Issues with setting up a new bank account impeded the executive from meeting the Nov. 30<sup>th</sup> deadline. It was many hours of work to create the proposal and to get the necessary account set up. This will be sent this summer, well in advance of the deadline. It will require more hours of updating to the documents for the application to include the most recent financial statements.

**-Chiropractor** 'donate funds from treatments' – (Catherine Nickerson)  
Drs. Dang and Thomson donated some funds from treatments totaling \$162.

### **-Other Ideas**

- \*Mandy suggested organizing a fundraiser dinner. Without some serious Business/corporate participation, this could become a financial strain on the friends and families with PWS. (feeling obliged to participate yet not financially capable)
- \*Variety Children's charity – Cindy will inquire to see if there are ways/ideas to fundraise or have their support
- \*Lara is involved with the Rare Disease association as volunteer coordinator and will try to find us some information on ways they have been successful with raising funds.

- **Fall 2012 conference** possibility, financial feasibility
  - possibility of using the BCCH, Child and Family Research Institute location (Mandy will look into this as a possible location)
  - possibility of more volunteer speakers or volunteer workers
  - our venue will be meager unless we can increase the incoming funds
  - cost to attend will be reduced for members in good standing to defer the costs of the conference

- **Other services and activities:**

- \***Strongest Families BC** – Behaviour consultations (Heather Beach)
    - New program available. It is for families of children with mild to moderate behaviour problems from ages 3-12. 12 week program via telephone with a behaviour consultant. It is free. If you need help, advice, they may be of additional service/support. You need a referral from a physician. They may not have experience with PWS but should have experience with problematic behaviours. More information can be found by contacting Heather.  
[beachbums\\_2@hotmail.com](mailto:beachbums_2@hotmail.com)

- \*Neufeld Institute – Information session on **attachment parenting**. There is a presentation on 'Alpha Children'...children who are demanding, bossy and controlling or particularly defiant. Session is going to be on Saturday, May 5th at

Vancouver Technical Secondary School. There is a cost of \$125. Further information can be found by contacting Heather. [beachbums\\_2@hotmail.com](mailto:beachbums_2@hotmail.com)

\*FPWR Gala and Medical Conference – Information (Heather Beach)

-Friday, April 20<sup>th</sup> to 22<sup>nd</sup>, 2012

-Two day conference including medical professionals speaking on:

-The use of Oxytocin in Prader-Willi Syndrome patients - Dr. Taubert

-The Mouse Model (a mouse with PWS) - Rachel Weverick

-Endocrinology PWS specialist - Jennifer Miller

-Research update and progress made for FPWR – Theresa Strong

Sessions will also include ways to connect with families and strategies to assist families in coping with PWS.

- FPWR One Small Step Walkathon 2012 (Cindy Thomson)

-Sunday, August 26<sup>th</sup>, Fraser Foreshore Park, Burnaby

-arrangements were made for walk last fall

-there will be airbrush tattoos, photos, Tim Horton's coffee, prizes for participants,

-families are welcome to start creating their fundraising pages. If you need more

information on how to become involved, email Cindy Thomson.

[cindythomson@gmail.com](mailto:cindythomson@gmail.com)

If you fundraise \$40 you will get a T-shirt. You can create a team for fundraising.

The Burnaby page can be found at: [www.onesmallstep.fpwr.org](http://www.onesmallstep.fpwr.org)

The goal this year is to raise 1 million dollars for research for PWS.

- BCPWSA 2012 Summer Gathering

Cindy has offered the clubhouse facility. Mandy Young will communicate with Cindy to choose a date convenient and to communicate to the executive.

- Sharing Tips and Strategies & social session

-Heather shared:

Shirataki noodles – a 0 calorie noodle (also 0 nutrition, but perhaps a useful substitute for stir-fries for families trying to avoid a higher carbohydrate intake, or cutting calories in any way possible)

Cookbook – 400 calorie fix – easy visual representations of lower calorie options (also contains nutritional content breakdown)

-Cindy shared:

Is using communication as a strategy ‘ food is in the tummy’ ...when she says ‘I’m hungry right after eating.’

Got a Nalgen sippy cup (just for water) and is encouraging daughter to use this special cup for drinking water

-Starlah shared:

She is starting sign language for communication.

Is struggling with finding low calorie snacks.--- Dried seaweed as a chip replacement was suggested (high in sodium though.)

Crustless quiche with vegetables was suggested. The cookbook Eat , Shrink and be Merry was suggested (but to watch the

portions.) Airpopper popcorn was suggested. Jessica Seinfeld's cookbook on using pureed vegetables to incorporate vegetables was suggested.

-Antonette shared: that first impressions are important for her son. If water is given in a blue sippy cup, then that cup can only be used for water. If there is a consistency, it will stick for him and he might have more of a connection with that.

-Alan shared: MIG (Modified interaction guidance) Uses your role as a parent as a behaviour management practice. In the role of the “esteem builder” (do nothing but sit and watch and give attention to that item the child is paying attention to)...they have found significant improvements in behaviours. You can dedicate 5-10 minutes with this strategy. You do not guide but you wonder out loud about that item, show interest in what the child is interested in. They have seen fantastic changes in their child.

- New items - none

#### UPCOMING DATES:

April 20<sup>th</sup> to 22<sup>nd</sup> - FPWR Gala & Medical Research

August 26<sup>th</sup> - FPWR One Small Step, Burnaby

Summer Gathering - TBA

BCCH Next meeting - TBA

BCPWSA Fall meeting & conference – Executive to determine

Adjournment – Mandy Young, Cindy Thomson