

## B.C.P.W.S.A. FALL 2011 Meeting - MINUTES

-Introductions – Cheryl Gagne, Marc-Andre Gagne, Cindy Thomson, Glen Thomson, Lindy Thompson, Crystal Crafta, Parise Yun, Erin Hall, Tim Hall, Alan Price, Jeff Bumstead, Darlene Riberics, Tammy Finns, Jene McConnachie, Antonette Soriano, Gina Griffiths, Mandy Young, Al Young, Joan Velestuk, Ray Velestuk, Bev Baldwin, Carroll Baldwin, Bev Ross, Gerry Sillers, Marie Sillers, Trudi Jameson, Debra Munroe, Betty McKay, Susan McKay, Terrance James, Marisa Piccolo, Leah Price, Louanne Atkinson, William Gibson, (Lisa Marques, Danny Marques, Tonia McGregor, Briana Piccolo, Alona Shoemaker, Dayle Sillers, Shae Velestuk, Tyler Yun), Heather Beach

-Spring 2011 Minutes approval- [Cindy Thomson, Margie Sillers]

-Treasurer's Report [Cheryl Gagne for Catherine Nickerson]

- **Current balance: \$12,294.02**

(\$12,092.54 in bank plus \$201.48 waiting to be transferred from Paypals)

\$6,476.08 is currently allocated for camp money

\$5817.94 current remainder of funds available

-Funds available for application [Cheryl Gagne for Catherine Nickerson]

-If you are a member in good standing and have not submitted summer camp funds requests for the 2011 year, please complete application forms (on website) and contact Catherine. Three families applied for summer camp funds this year and received funding for camp fees and/or supportive childcare help at camp.

-Membership Fee Reminder [Cheryl Gagne for Catherine Nickerson]

-\$25 family membership due by December 31<sup>st</sup>, 2011

(for 2012 Membership in good standing)

-Being a "member in good standing" provides you with the regular communications from the association, allows your attendance and vote for our two yearly meetings and summer gathering, provides two members of your family with a discounted fee for the BCPWSA annual educational conference/workshops, provides for childcare for your child with PWS (aged 0-6 years) during our meetings/conferences, allows for access to summer camp funds for your child with PWS (aged 7-16), allows for complimentary attendance of your youth/adult with PWS for our annual Adult Sessions (including social activities, an educational presentation, a fitness activity and craft activities).

-Fundraising updates:

- Tupperware [Cheryl Gagne]
  - We will try to send out a fundraising email prior to Christmas for this. Thank you to those who supported the spring campaign.
- Canucks for Kids Grant Application update [Cheryl Gagne]
  - We applied for funding to be able to provide a social/educational/activity program for our middle aged group of people with PWS. Despite meeting all requirements of the application, the Canucks for Kids were inundated with applicants this year and ours was denied. We will pursue this in the

future again. Thank you Gerry Sillers for providing application information to the executive. Thank you Cheryl Gagne for completing the application and program proposal.

- Other fundraising ideas
  - [Cindy Thomson] – suggested inquiring with Chiropractor/Naturopath to see if they would donate \$1 per person for a week while displaying information on PWS
  - [Glen Thomson] – suggested completing an application for Gaming funds and inquired if the association had done this in the past (we had and were denied in 2008) It is a detailed application process and the executive asked if anyone was willing to take on the application process. Glen agreed to locate application information and send it to the executive.
  - [Cheryl Gagne] – reminded members of the possibility of having a Skating party (or other event) around Christmas (renting facility, insurance) and inviting friends and families to attend with a donation to the BCPWSA. These families have been successful in the past and will pursue this again this winter.

-Reports:

- FPWR One Small Step Walkathon 2011 – [Cindy Thomson]  
Cindy was the host for the FPWR coordinated walk in BC. Anyone willing to help or organize a separate walk should contact her. The FPWR is a separate association with the specific goal of raising funds for the advancement of research in PWS.  
Visit their website: [www.fpwr](http://www.fpwr)  
The FPWR goal next year is to have 112 locations world wide. Cindy encourages you to support this important endeavor. Thank you to those who helped this year and see her to sign up for next year. Mark your calendar: Sunday, August 26<sup>th</sup> 2012 is the tentative date set for the FPWR walk!
- Information on: BCCH PWS Clinics – workshop sessions [Cheryl Gagne]  
The BC Children's Endocrinology department has been providing its families with work shop/informational clinics twice annually. The last one took place in September and the next one is scheduled for Friday, March 2<sup>nd</sup>, 2012. If you have not been contacted by the endocrinology department at BCCH, inquire with them.
- Studies: Dr. Gibson, Dr. Haqq, Dr. Chanoine [Heather Beach]  
**Dr. Gibson** : as presented by Lara Musa this morning. "Quantitating Visceral Fat as a predictor of cardio metabolic risk using whole-body MRI scans: Comparison of subcutaneous and visceral adipose tissue distribution between people with Prader-Willi syndrome and controls.  
Information is also posted on our website.  
**Dr. Haqq**: has added a possible travel reimbursement for the Edmonton session.  
Information available on our website.  
**Dr. Chanoine**: – Thyroid function study

- If interested, please contact him at BCCH.
- Alberta PWSA AGM – [Terrance James]  
Attended the Alberta AGM and wanted to underline the importance of remaining cohesive and communicative between other associations. Commended the BCPWSA and FPWR on having a supportive, cooperative and collaborative relationship.
  - Website – [Terrance James]  
Link to website is on bcpwsa website : [www.bcpwsa.com](http://www.bcpwsa.com)  
His website is: [www.prader-willi.ca](http://www.prader-willi.ca)  
Many hits internationally inquiring about what is happening in Canada for the progress and treatment of PWS.  
To submit a post, visit the website or contact Terrance directly.
  - Baldwin family update [Bev & Carroll Baldwin]  
Following the spring presentation (see minutes), Bev and Carroll updated us on the wellness of their son Paul. He is now down to 178 pounds. As an adult, he has the same wants and needs of a typical adult. He has settled into a routine and is now in a supportive, very structured home in BC. The process was not easy and Paul's health (weight and mental health) were put at risk. The Baldwin's underlined the importance of starting the transition to adulthood very early on. The structures need to be in place to fully support the behaviours and health needs of the individual. It is better to have the structures in place prior to reaching adulthood and to attempt a proactive transition. The Baldwin's suggest working with the therapists and medical practitioners to have a check list on what should be in place to facilitate transition.  
Dr. Berrall (Ontario) and the Pittsburg Institute were very supportive and knowledgeable.  
Louanne Atkinson from BCCH will look more into the creation of a check list.
  - New Business – CLBC being scrutinized at the moment
    - writing a letter and having a voice is timely at this point
    - the BCPWSA will draft a letter on our behalf (Heather Beach)
    - families are encouraged to send a letter individually to their MLA, Christy Clark and to the head of CLBC
  - Fitness app idea [Alan Price]
    - Presented on his new App for iPhones
    - This idea embraces the technology of the youths today but integrates fitness. To have the app function, the participant actually has to move/be active.
    - He has created: Digido Interactive Inc. where you can download apps that encourage fitness activity and that are targeting the 6-12 year olds.
    - The Apps created thus far are: Motion Maze, Motion Maze Trick or Treat and Pop and Dodge.

- BCPWSA – Elections / Appointments

[Bev Baldwin managed the elections and appointment process]

- President – 2012 by acclamation – Heather Beach
- Secretary – 2012 by acclamation – Cheryl Gagne
- Treasurer – 2012 by acclamation – Catherine Nickerson

-proposal by members to add a Vice-president positive to the executive

- Vice-President – 2012 by acclamation – Mandy Young

-SPRING Meeting Date and Location to be determined by executive

Adjournment – [Bev Baldwin, Margie Sillers]