

## B.C.P.W.S.A. FALL 2010 Meeting - AGENDA

-Introductions – Cheryl Gagné, Heather Beach, Terrance James, Heather McConnachie, Tammy Simms, Ainslin Harpsin, Bev Ross, Jodi support for Jill, Gina Griffiths, Bill Griffiths, Ken Bouvet, Audrey Bouvet, Antonette Soriano, Tony Pakniyat, Tim Hall, Erin Hall, Iona (support for Bill), Brenda Loney, Susan McKay, Rod Robinson, Frances Robinson, Lindy Thompson, Marisa piccolo, Jane McConnachie, Moon Yun, Parise Yun, Joan Velestuk, Ray Velestuk, Carroll Baldwin, Bev Baldwin, Catherine Nickerson, Gerry Sillers, Margie Sillers, Paula Bentley, Alan Price, Leah Price, Cheryl Gagne, Jeff Bumstead, Marc-André Gagné, Joan James, Carla Large

### **-Spring 2010 Minutes**

- approved by Parise Yun
- seconded by Margie Sillers

### **-Treasurer's Report (Catherine Nickerson)**

- just over \$14,000.
- money is still allotted for camp and fitness activities
- some fundraising moneys to still come in (Richard Broeur) which has been less than in the past. We need to look at different sources of income or fundraising.
- Funds available for application (Catherine Nickerson)
  - \$9000 camp available
  - \$1500 fitness Okanagan

### **-Membership Fee Reminder (Catherine Nickerson)**

*-\$25 family membership due by December 31<sup>st</sup>, 2010*  
(for 2011 Membership in good standing)

### **-Fundraising updates:**

- Richard Brodeur 2010 (Bev Baldwin)
  - we were again beneficiaries for RB Golf tournament
  - typically there are rotating recipients, 4 years so far
  - we raise donations for silent auction, other prizes
  - 18<sup>th</sup> hole with an activity
  - \$3000 to come in this year
- Poinsettia Fundraiser 2010 (Heather Beach)
  - greenhouse sales
  - you pay the cost and you mark it up to what you think you can sell them
  - Heather made \$136 last year
  - if interested, see Heather
- BC Hockey Association made a generous donation of \$2000.00
  - there may be the potential to apply for Canucks for Kids grant

- Gerry Sillers will look into this
- Cheryl Gagné will begin application process once she hears from Gerry

**-Reports:**

- FPWR One Small Step Walkathon 2010 – August 15<sup>th</sup> (Heather Beach for Cindy Thomson)
  - good turn out
  - good fundraising
  - \$7000 from the BC group (some members were walking in Alberta too)
  - T-shirts, firefighters, airbrushed tattoos
  - special recognition to Cindy Thomson
  - simultaneous with other walks...for FPWR
- BCPWSA Summer Gathering – August 15<sup>th</sup> (Leah Price & Heather Beach)
  - some families left
  - 4 families stayed and hung out
  - informal chatting and sharing stories
- Pittsburg Report – lobbying (Carroll Baldwin)
  - Paul is 23.
  - Last year and a half in crisis.
  - at 19 lost support services
  - lobbying to get support...without success
  - gained weight 165→ 371 pounds
  - high blood pressure, sleep apnea, diabetes, other health issues
  - family was in desperation...sought out children's institute in Pittsburg Pennsylvania...has a program specifically for PWS.
  - family receive help to apply from North York Hospital in Toronto
  - Dr. Berrall runs PWS clinic in Canada...Karen Balko and Dr. Berrall provided a letter to support the case...applied to the ministry of health out of country medical services...and got the funding to send him there...\$1000/day
  - Health BC (one branch) helped to support family (a wonderful program...all medical care...pt, ot, psych, dietitian )
  - lost 86 pounds in three months and is stable behavior and medical wise
  - what will family do with him once he comes back to BC? Nothing in BC for the moment. Ontario has centres where they have homes...gave them the names of the ones they visited last year...CLBC called them...Paul is there now...while BC figures out what to do next.
  - People are paying attention and maybe we can raise the profile for PWS in this province.
  - Ontario WAY ahead...group homes, a clinic, a huge support network
- OPWSA Report – (Bev Baldwin)
  - one day conference
  - morning: two key speakers (Dr. Dan Driscoll, Ken Berrall)

Dr. Driscoll – all the pieces of PWS together, bringing everyone up to speed (excellent for the caregivers)

Dr. Berrall – day to day practical clinic

Diagnoses happening within the first year of birth

Talked about his clinic and what they do...model on the Pittsburg institute. –reciprocal agreement...if they need our services...contact them

-afternoon: Karen Balko ran a workshop for service providers who had one or more people with PWS in their care

-leading edge of what the research is saying to do

-key is about educating the servers of our PWS people

-draft protocols

- Information on: BC PWS Clinic – children & spring sessions (Cheryl Gagne)
  - Spring session 0-6 years of age (took place this year)
  - Winter session 7-18 years of age (BCCH has stated this will take place on Dec. 17<sup>th</sup>, 2010)
  - They will likely continue with sessions in the spring for both age groups.
- Pictures to web site – please send us any pictures you have that you may like to see on the web site!
- Reminder: medical alert booklets & bracelets can be purchased from the PWSAUSA. [www.pwsausa.org](http://www.pwsausa.org)
- New items

#### **Dr. James' book** (Alan Price)

-proposed that we purchase some copies as a society to send out to different groups.

(BCPWSA executive will create a list and send them to some places as resources.)

-BCPWSA will also send this information out to our contact list as well as to other associations and email forums(PWSUSA, Janalee Heinemann, OPWSA, FPWR, etc.)

(Cheryl Gagne has added information to our web page.)

(Heather Beach will take these communications.)

#### **Clinic for those over 18**

-it was proposed that someone look into the possibility of a clinic for those over 18 years of age. Hopefully with the Baldwin family moving to find an acceptable adult care facility for their son, this can be partnered with that movement.

#### **How can we get the children (older than 6 and younger than 14) involved in a session???** (Alan Price)

-It was proposed that we add a session during our conferences to include the children aged between 6 and 14 years of age. This has several challenges to it: we would need, volunteers or staff (probably one on one) (We could look into: -grade 12 volunteer hours/university volunteer hours, other community services...); we need an activity; a curriculum and a location. It needs to respond to our society goals of education, advocacy and support. It should also meet our adult session criteria if

possible: one fitness (gross motor), one craft (fine motor) one information session (education) and some connecting activities (social skills). As a spectrum disorder, we do not know in advance the differences that each child will have. We could have a very large variety of skills in all areas...and will need people qualified in dealing with such a variety of children.

Alan Price will look into coordinating this.

**Student research award Terrance James (research)**

We discussed the student research we funded (as she presented this morning).

How did it go over? Was it a worthwhile endeavor? Should we do it again?

-sent out to hospitals as well as clinics

-even the process educates the population about PWS

Cheryl proposed that we offer this student bursary again.

Seconded by Carroll Baldwin.

Passed.

Terrance James will once again promote this and evaluate it.

- BCPWSA – Appointments

- President - Heather
- Secretary - Cheryl
- Treasurer - Catherine

-SPRING Meeting DATE

POTENTIALLY

March 19<sup>th</sup>, 2011

Location to be announced

(we are seeking a less expensive location)

Adjournment motioned by Parise Yun.

Seconded by Margie Sillers.