

B.C.P.W.S.A. SPRING 2015 Meeting - MINUTES

May 01, 2015

5:00 – 7:00pm Vancouver, B.C

- **Attendance-** Heather Beach, Alan Price, Leah Price, Cheryl Gagne, Jennifer Chan, Mandy Young, Lindsay O’Hearn, Frances Robinson
- **Introductions and information sharing:**
- Heather shared that she would like to try the Easter Seals camp again this year. Cost of \$500. Heather wrote a letter to the Legion about donating funds to send a child to Easter Seals camp. This camp is not covered by Autism funding.
- Jennifer has a daughter who is 10. Jennifer tells us that her daughter skin picks and does ask a lot of questions. Food seeking is not that pronounced at the moment. Jennifer has purchased NAC from the health food store and will soon try to see if this will help with the skin picking. Mom reports some aggression.
- Frances shared that her daughter now has an Autism Diagnosis. Food seeking has picked up some.
- Cheryl has no real changes in PWS. Her daughter was diagnosed with Chilblaine’s a vascular disease sometimes associated with PWS.
- Mandy and her daughter are going to Edmonton to participate in Dr. Haqq’s study on the relationship between PWS and Autism. Mandy’s daughter is now on the modified Ketogenic diet. It is working well. The diet entails eating very low carbs. She still eats Yogurt. The rule is that carbs must be less than the total fat and protein. If protein is higher by itself than the carbs, that is even better. They use MCT oil and many nuts. They have changed over to this diet since February. Mandy has noticed that her daughter will ask for less food. Behaviour seems better also. 50 – 60 g of carbs, 80-90 g fat, 60- 65 g protein per day. Mandy has applied to participate in a study with PWS who are on the Ketogenic diet and is hoping to participate. Mandy reports that the medical community is resistant in allowing her to do the Ketogenic diet.
- Leah shared that her daughter is about to get her scoliosis brace. Brace 23 hours a day until she is grown. Her daughter is in puberty and once puberty commenced, there is only two more inches of growth.
- Lindsay is telling us that her daughter is no longer on the Bipap machine. One more sleep study in one month to give her the final clearance.
- **Fall 2014 Minutes** approval – Cheryl & Mandy

- **Treasurer's Report** (Cheryl Gagne)
BCPWSA finances : \$11,182 at present. Cheryl raised \$2,000 with the annual skating party. Thank you Cheryl and friends. In October the association received a cheque from the Blomers.

We will again apply for the Family Support Grant form BCCH to help to offset the cost of our fall conference.

- **Fall BCPWSA Conference:**
Our regular venue for the conference is not available for October. We will need to explore other options. One idea is the use the venue on North Road which we have used in the past.
Heather mentioned that she has approached someone from the Neufeld institute to talk about Attachment Parenting at our conference. Leah also mentioned that a SLP who works with her family, may be able to do a workshop on social communication. Leah will approach him to see if he will be available for the conference. We discussed offering payment if necessary.
- **Fundraising Updates:**
Possible new sources of Funding: Maya Dimapilis a PWS parent has approached Heather to say that she was approached by someone who is interested in helping BCPWSA in his fundraising efforts. One idea discussed is to earmark this money for a specific purpose. We are exploring perhaps sending everyone to Zajak Ranch or exploring options for respite funding for parents.
- **One Small Step Walk**
Will be held this year on September 5th at 1pm Centennial Beach, Delta. Frances will forward registration information to the members.
- **Summer gathering**
Lindsay will book her communal room and swimming pool for a summer gathering. Possible date in July. Details to follow.

Motion to close meeting: Lea Price and Lindsay seconded.

Meeting adjourned at 7:20pm

UPCOMING DATES:

Summer gathering: TBA Possibly July. Surrey

One Small Step Walkathon: September 05, 2015 Centennial Beach, Delta

TBA Fall BCPWSA Conference Venue TBA

Adjourned.