

B.C.P.W.S.A. FALL 2016 Annual General Meeting - MINUTES

-Introductions –Heather Beach, Cheryl Gagne, Lindsay O’Hearn, Mandy Young, Frances Robinson, Parise Yun, Joan Velestuk,

- **Spring 2016 Minutes**
Passed by Cheryl Gagne
Seconded by Mandy Young

- **Treasurer’s Report (Cheryl Gagne)**
Present balance \$10, 779.87
The Association’s finances are healthy at present as a result of some successful fundraising efforts.

- **Fundraising:**
We again have secured a grant from the Children’s Hospital Family Support Group Committee. Total amount is \$1,950.00. This grant allows the Association to spend money on e.g. \$350 for comfort, \$500 for speakers, \$600 room rental fees, and \$500 website and child care.
Cheryl is hoping for a fundraising endeavour later in the season and not at Christmas.

CHIMP foundation: Charitable Impact Foundation; Discussed how if we became a registered foundation with them, people would be able to log on and donate through this Foundation to give directly to PWS.

- **Ontario Conference Update:**
Conference attendees discussed how eye opening and amazing it was to see all those specialists invested in PWS. All agreed that they gained much valued information. Mandy participated in the diet panel on the last day talking about Ketogenic Diet Initiative. A lot of controversy about the diet remains.
Scientific Day at the conference: Zafgen’s drug’s clinical trial outcomes were discussed. The findings were that the drug was not causing clots but that there was a thrombosis problem. The FDA is very concerned about this and the study was cancelled as a result. A possible solution is to add a blood thinner. According to the FDA this will mean the study has to move back to Phase 2. Zafgen may continue with this study in the future.

Another promising therapy is Diazoxide. This medication is already on the market and used for insulinoma. It is also affordable. A very small study of 13 PWS took place. Findings were that 90% of participants showed improvement and 30% showed significant improvement of hyperphasia. Weight loss was reported. Another finding was that participants reported a 62% reduction in aggressive

behavior. A future study is planned for 80 – 90 PSW person to focus on dose ranging.

Rhythm pharmaceuticals: Drug: Septal RM 493: Trials of obese people and PSW POMC disorder were done. This condition is very rare and mimics PWS. Dramatic results were reported. Less hunger, and improvements in eating habits. A future study with PWS is possible.

The IPSWO website contains more information on some of the Parent Days presentations. Click on the far right button, conference sections and you can see the taped versions of the presentations. Very helpful, please have a look.

- **For our own 2017 Conference:**

Discussed getting some child care for the siblings so more people could come to conference. Cheryl may explore grade 11 and 12 students who need volunteer hours. We do need to know ahead of time firm numbers for child care and then we can pay for child care personnel.

Ideas on how to draw more parents of adults with PWS. We need to know what is useful for them and what they are struggling with.

Speakers:

Discussed trying to bring PWS experts from the US to come to our conference. We are hoping that perhaps Dr. Miller will be able to come. Dr. Elizabeth Ruth a Psychiatrist from Vanderbilt University is another possibility. (Suggestion to look on the FPWR website to see previous conference presentations on video.)

She presents on topic Adult 101. Medications and treatments for Anxiety and depression.

Another possibility is Linda Gourash: Presented on behavioural intervention and was very useful at conference. She focused on adults and depression, anxiety.

We are hoping for a very big conference in the spring with noteworthy speakers. We will have a downtown location as a draw for the speakers. Conference rooms: \$400 – \$600 for the room. For the babysitting room we always need one hotel room.

Catering costs (which is mandatory when renting a room is at least \$35 pp). Finding a location that has PWS adult activities within walking distance is good.

Explore maybe renting a school with its facilities.

Also exploring including the 6 – 13 year old PWS being included. Some logistical issues with that still to be worked out

Dates: Between April and June and will completely depend on speaker availability

- **BCPWSA Website:**
Looking at retooling and improving website security: Vanessa Dobson can move us to a Wordpress website for a onetime \$1000 and \$1500 charge. We will table that conversation for a different time. Cheryl may look at building a Weebly website.

- **Supplements:**
Cheryl suggested exploring giving PWS persons 5 HTP abut 1000mg. Seems to help. Also Omega 3 is still recommended at 2000mg levels. Borage oil

- **Membership Fee Reminder**
-\$25 family membership due by December 31st, 2016 in order to be a member in good standing for 2017

- **BCPWSA – Elections / Appointments**
 - President - Heather Beach by acclamation
 - Vice-President – Mandy Young by acclamation
 - Secretary – Frances Robinson by acclamation
 - Treasurer - Cheryl Gagné by acclamation
 - Member at Large – Lindsay O’Hearn by acclamation
 - Member at Large – Parise Yun by acclamation

- **SPRING Meeting DATE – TBA**
Location: TBA

-Adjournment

-Moved by Heater Beach

-Seconded by Mandy Young

Meeting Adjourned 12:45pm