

B.C.P.W.S.A. FALL 2015 Annual General Meeting - MINUTES

-Introductions –Heather Beach, Cheryl Gagne, Mary Gjertsen, Lindsay O’Hearn, Alan Price, Leah Price, Mandy Young, Al Young, Frances Robinson, Tim Hall, Erin Hall, Parise Yun, Susie Wang, Ray Velestuk, Joan Velestuk, Starla Hanna, Cindy Armstrong,

- **Spring 2014 Minutes**
 - Passed by Leah Price
 - Seconded by Mandy Young
- **Treasurer’s Report (Cheryl Gagne)**
 - Present balance \$11, 533.02
 - Good Financial Situation at present with some successful fundraising efforts.
- **Membership Fee Reminder (Cheryl Gagne)**
 - \$25 family membership due by December 31st, 2015 in order to be a member in good standing for 2016. Fees help us with costs, website upkeep, new family information sharing and conferences.
- **Reports/Updates**
 - Heather shared how Pharmanac, an amino acid, has stopped her son’s skin picking. She states that it is not to be taken with dairy. It can be purchased on Amazon. Pharmanac is the preferred brand as this is an individually packed and the product does not oxidize as a result.
- **International PWS Organization Conference in Toronto in July 2016.**

BCPWSA would like to send two people to this conference. BCPWSA would like a vote from its members to be able to send two people. Mandy Young would like to go. Price for the trip is still unknown and will need to be researched.

***Motion:** BCPWSA will put forth \$3,000 for two or more BCPWSA Members in Good Standing to attend the IPWSO Conference in Toronto, Canada in July, 2016. Those members will then be presenters at the fall BCPWSA conference. Motion Forwarded by: Mandy Young Seconded by: Leah Price Motion Carried.
- Mandy Young is to be on a panel at the IPWSO regarding their Ketogenic Diet for their knowledge.
- **The Beloranib Stage 3 drug trails:** Heather reported that parents of the test subjects are reporting promising results. Food seeking behaviours have diminished and there appears to be less hunger. Unfortunately one person in the study has died. No cause of death has been established and no link has been established between the drug and the death. The FDA has allowed for the study to continue but with some additional medical tests and safeguards. Dr. Chanoine has said that

Zafgen has expressed interest in Canadian patients for the study. With this death, it is uncertain what will now happen.

- **Adult group home discussion.** Joanne Taylor has been attempting to put an adult group home in place. Joanne has not been able to be present today. CLBC has not been very forthcoming and nothing definitive has been decided. A person has bequeathed her farm for a group home which will then be developed around the needs of people with PWS. E.g. separate kitchens, a farm setting with animals. This home is envisioned for the Kelowna/Kamloops area.
- **Fundraising updates: (Cheryl Gagne)**
 - Cheryl's skating party in Kelowna raises usually \$2,000. Thank you to Cheryl Gagne and Catherine Nickerson.
 - Everyone is always welcome to donate and to do Fundraising efforts for the BCPWSA.
 - Mandy and Al Young also discussed their fundraising efforts on behalf of the One Small Step fundraiser.
 - We have also received some other random donations from members and friends of members and from the Family Institute.
- **Next BCPWSA Conference:** 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.)
- **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 Cindy Armstrong

Meeting Adjourned 3:24pm