

Minutes BCPWSA Meeting, February 25, 2017

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B.C. Prader-willi Syndrome Association

General meeting

Location: Delta, B.C.

Time: 10:45 - noon

Chaired by: Cheryl Gagne,

Present: Joan Velestuk, Holly Levebvre, Susanne Szabo, Nasrin & Bahar Shams, Erin Hall, Tim Hall, Cindy Armstrong, Jennifer Chan, Glen Thomson, Cindy Thomson, Lindsay O'Hearn, Frances Robinson, Karen Todd, Alan Todd, Susan Todd, Parise Yun, Yvonne Blomer, Rupert Gadd, Heather Beach, Jeff Bumstead, Mandy Young, Laura VanDiemen, Mandy Young, Al Young, Jason MacDonald, Lifang Yan, Lorele Houde, Marianne Szabo, Matt Thompson, Lindy Thompson, Nanping Liu

Secretaries Report

Minutes from Fall 2016 meeting reviewed: Approved by Leah Price, seconded by Parise Yun.

Treasurer's report:

Current balance is \$13,093.50. Significant income sources were: PHSA Grant came in \$1,950.00, a donation from a Family \$867.00. There was no annual skating party this year. There is still a Paypalls balance of \$2,000. A larger detailed report will be available in the Fall.

New Business:

**Report on the Alberta Study: Dr, Haqq is doing a study in Edmonton Alberta. There is no funding for transportation. * Diet Initiative: low carb diet with feelings of fullness vs. high carb foods and how it influences behavior. If anyone happens to pass through Edmonton please contact Dr Haqq to participate.

** Online research studies. 3 or 4 studies through FPWR. Access is online (FPWR website) for registration for these studies. Studies areas are: Cognition and behavior, social behavior, task switching.

** Our association will apply for the family support grant at BCCH. This is usually a \$1,500 grant for conferences and meetings. Canucks Alumni usually gives BCPWSA \$2,000 through the Siller's Family.

** BCPWSA is hoping to change our website and update it to have more secure supports. Our current website support person suggests that we update our registration system. One suggestion is Picatic.com. Heather and Frances and Cheryl will investigate this.

** Conference planning: Not a lot of conference planning at present. We have changed how we do conferences from spring to fall. We are considering doing a half a day workshop e.g. with Marc Laundry. Parise suggested that the association can perhaps do a workshop for service providers that are free of charge to give information to teachers, SEA's etc. regarding PWS. Another suggestion is to piggy back on an autism conference. Maybe learning about PWS can be a session offered at such a conference.

** Susanne Szabo is hosting a June 24th fundraising walk at Centennial beach again this year. Will also try to plan opportunities for gatherings during the summer.

** PWS Oregon has shared information about a campout the second week in August 2017 near Seattle. Look on the PWS Oregon website to get details.

** Question about the ongoing investigation into a PWS dedicated group home in BC. There was no current info on the status of this endeavor. Services in Washington stage was discussed.

Meeting Adjourned: 11:55am Moved by: Parise Yun, Seconded: Mandy Young

Next Meeting: Fall 2017