

B.C.P.W.S.A. FALL 2012 Annual General Meeting - MINUTES

-Introductions –Cheryl Gagne, Marc Gagne, Joan Velestuk, Ray Velestruk, Carroll Baldwin, Bev Baldwin, Catherine Nickerson, Cindy Armstrong, Matt Thompson, Lindy Thompson, Alan Price, Leah Price, Glen Thomson, Cindy Thomson, Terry James, Al Young, Mandy Young, Parise Yun, Holly Lefebvre, Lorile Lefebvre, Brent Lefebvre, Debra Munro, Susan McKay, Marisa Piccolo, Gina Griffiths, Darlene Sims, Heather Beach, Carrie Anne, Michelle Erickson, Karla Lockwood, Tonia Knight, Bev Ross, Jeff Beach, Lara Musa .

-Spring 2012 Minutes

-Passed by Bev Baldwin

-Seconded by Heather Beach

-Treasurer's Report (Catherine Nickerson)

-finances presented and attached to agenda

-Membership Fee Reminder (Catherine Nickerson)

-\$25 family membership due by December 31st , 2012

(for 2013 Membership in good standing)

-change to exclusively electronic communications (cost, environment)

-Fundraising updates:

- Canucks for Kids Grant Application update (Cheryl Gagne)
 - Cheryl & Catherine have applied for this, application documents available upon request
- Gaming Grant update (Cheryl Gagne)
 - Cheryl & Catherine have applied for this, application documents available upon request
- Canucks Alumni donation (Cheryl Gagne)
 - Thanks to Gerry Sillers for advocating for our group and once again encouraging this association to donate to our group.
- Other – Skating party (Cheryl Gagne & Catherine Nickerson)
 - anyone having ideas for fundraising or wanting to take on a skating party or like event can contact Cheryl or Catherine for organization ideas on how to make this happen
 - (Bev Baldwin) – suggested the croup contact: Legions, the Lions, the Kiwanis, Eagles, Rotary groups (the executive will inquire into this)

-Reports:

- FPWR One Small Step Walkathon 2012/2013 – (Cindy Thomson)
 - happened on August 26th in Burnaby
 - \$17,500 raised (with 100% of funds going towards research with the Foundation for Prader-Willi Research)

- happened on September 19th in Ladner
 - over \$20,000 raised (with 100% of funds going towards research with the Foundation for Prader-Willi Research)
 - anyone interested in helping with this walk or hosting a walk to support the FPWR can contact Cindy Thomson
 - pictures will be posted on the BCPWSA website
- Thank you ladies for supporting Prader-Willi Syndrome Research!

- Information on Studies - (Heather Beach)
 - Dr. Gibson – body composition and eating study (simple procedure, scan)
 - Dr. Haqq – three studies in Edmonton (1)-types of meals, (2)-peptide BDNF and levels in the blood related to eating behaviours and cognitive functions, (3)- autonomic nervous functions and distribution of fats and level of hormones) (Dr. Haqq is now funded and can finance the flights and accommodations.) For more information or details contact Heather Beach.
 - Dr. Chanoine -thyroid levels for TSH
- Upcoming Conferences – DDA Building Connectivity (November 10th)
 - Development Delays Association
 - free for members
 - Information provided by the BCPWSA for the members.
 - Several work shops to choose from (see brochure)
 - deadline to registration is October 19th
- Information from CORD (Heather Beach)
 - Information provided by the BCPWSA for the members.
 - Orphan Drug Framework changes (introduction of a national policy)
- Baldwin family update (Bev & Carroll Baldwin)
 - Recap:
 - Pittsburd Institute→ Ontario Prader-Willi Home with support from Dr. Berrall, →Group Home in B.C.
 - (the ups and down of weight, health, behaviour, mental challenges)
 - Hillside Centre in Kamloops for a full assessment(doing well, there for psychiatric assessment, under care of Dr. Robin Friedlander, focusing on the mental problems of Prader-Willi Syndrome, having some successes)
 - Paul cannot be discharged until he has an acceptable location to go into
 - Baldwin's advocating for syndrome specific residency (many families of PWS are interested) and will keep us informed on their progress.
 - Input from families of adults and youth should contact the Baldwins if interested in participating in communications. bbaldwin@ciera.ca
 - Long term plan: Paul is not the only one with these needs, just the first one.
 - If you have not responded to the Baldwin's email requesting support, please do contact the Baldwins. bbaldwin@ciera.ca
 - A committee will likely be formed over the next month to discuss the potential of a Prader-Willi specific group home.

- BCPWSA – Elections / Appointments

- President - Heather Beach by acclamation
- Vice-President – Mandy Young by acclamation
- Secretary – Francis Robinson by acclamation
- Treasurer - Cheryl Gagné by acclamation

-SPRING Meeting DATE – April 6th, 2013

Location to be announced

-Adjournment

-Moved to Ray Velestuk.

-Seconded by Parise Yun.