

B.C.P.W.S.A. FALL 2009 Meeting - AGENDA

- Joan Velestuk, Terrance James, Gina Griffiths, Bev Baldwin, Carroll Baldwin, Betty McKay, Brett, Sillers, Susan McKay, Moon Yun, Parise Yun, Audrey Bouvet, Ken Bouvet, Tanya Johnson, Tamara Croft, Leah Price, Alan Price, Bev Ross, Tasha Campbell, Glen Thomson, Cindy Thomson, Catherine Nickerson, Heather Beach, Matt Thompson, Jeff Bumstead, Lindy Thompson, Joanne Taylor, Cheryl Gagne
- Spring 2009 Minutes approved by: Gina Griffiths
Seconded : Joan Velestuk
- Treasurer's Report (Catherine Nickerson) \$15,422.00
\$9,000 (allotted to camp and available)
(Money from Richard Brodeur 2009 not yet in.)
- Membership Fee Reminder (Catherine Nickerson)
-\$25 family membership due by December 31st, 2009
(for 2010 Membership in good standing)
- UBC Scientific Study Funding & Information (Terrance James & Joanne Taylor)
 - Dr. Gibson looking for participants to partake in a study on PWS and PWS-like disorders
 - information attached
 - 30 year study
 - through UBC
 - interested families should contact Dr. Gibson directly
 - Student Research Award : applicant Whitney Quong accepted and received \$1250.00 and \$250.00 later for presenting at a future meeting
 - recommended to have Dr. James communicate to Dr. Gibson and query payment process
 - Cheryl Gagne will send an official letter to the rewarded applicant: Whitney Quong
- PWS Clinic in Alberta (Joanne Taylor)
 - Dr. Andrea Hagg from Duke University is relocating to Alberta in July
 - Is hoping to have a PWS clinic in Edmonton, Alberta
 - As more information becomes available it will be posted on the Web site
- MLAs & MPs (Joanne Taylor)
 - invited three MLAs (including Kevin Falcon, Ida Chong)
 - Ida Chong responded that she was unable to attend
 - no response from others (Kevin Falcon responded after the conference)
 - we encourage you to write your MLA
 - sample letters will be posted on the web site

- Fundraising update:
 - Richard Brodeur Gold Tournament – (Bev Baldwin)
 - many donations came in - Thank you
 - did very well financially despite the economy
 - Richard Brodeur 2010 (not a guarantee)
 - Thank you letter to send (Cheryl Gagne)
 - Thank you Bev for your time and commitment
 - Poinsetta Fundrasier (Joanne Taylor)
 - if anyone is interested see Joanne Taylor
 - One Small Step 2010 (Joanne Taylor)
 - Tanya Johnson will speak on this
 - Lulu Lemon Grassroots Funds (Cheryl Gagne)
 - we have been applied to this
 - Fundraising Run available in Vancouver (Cindy will look into this)
- Summer Camp Funding (Joanne Taylor)
 - \$9000.00 funds available to access for camp or support worker for camp
- Rare Disease Foundation Meeting Report (Heather Beach)
 - getting together and pooling resources
 - general meeting for people to come together and share resources
 - many medical in nature but some developmental
 - very well versed people in ways to lobby the government for funding and research
 - next meeting is in October (anyone can attend these meetings)
- Summer Gathering 2009 – report (Heather Beach)
 - camping trip
 - three families went
 - very fun and informal
 - next day a gathering at Park
 - eight families attended
- BCPWSA – Vision and summary
 - Cheryl Gagne
- BCPWSA – Elections / Appointments
 - President – Heather Beach nominated
 - Heather Beach by acclamation
 - (Alan Price, Bev & Carroll Baldwin to support)
 - Secretary – Cheryl Gagne by acclamation
 - Treasurer - Catherine Nickerson by acclamation
- Spring Meeting Date
 - to be determined by executive (no spring conference)

- FPWR – survey – (Joanne Taylor)
-handed out survey
- Adjournment
-Meeting adjourned by: Lindy Thompson
Seconded by: Leah Price