

BCPWSA

Sept. 16, 2006

Dear Association members and families living with Prader-Willi Syndrome in British Columbia:

Since the Spring letter our Association has had one meeting, volunteered at the Richard Brodeur Celebrity Golf Tournament as one of the beneficiary charities of the tournament and had one social gathering.

At the Spring meeting (minutes posted on our website at www.bcpwsa.com), we had two speakers, one on Special Olympics and one on the creation of an I.E.P. for a child with Prader-Willi Syndrome. We also planned the golf tournament activities and fundraising and discussed the results of the survey that we sent out in the spring letter. Based on these results, The B.C.P.W.S.A. fall 2006 and spring 2007 meetings will both have workshops available with a variety of speakers of interest.

The fall meeting and workshops will take place in Kelowna, B.C. on Saturday October 21st from 9am to 5pm. We have three presenters and topics of interest: ***Managing Challenging Behaviour***, ***Living with a Sibling who has a Disability and how Parents can Support their Typical Children*** and ***Community Living and Wills and Estate Planning***. Please see the attached information leaflet and registration form for more information on these workshops. We have also enclosed information from a hotel offering a special rate for our members. Based on the surveys, we know that these topics are of interest to your families and we hope that you will be able to attend. There is no charge for any current family member of the B.C.P.W.S.A. to attend these workshops. A boxed lunch will be provided for \$10 for those interested. There are also several restaurants located nearby.

The spring 2007 meeting will be located at the B.C. Children's Hospital in Vancouver and workshops will be planned with the collaboration of the executive of the B.C.P.W.S.A. and Sheilagh Kelton of the B.C. Children's Endocrinology Clinic. Many topics for that date will be medical related and focus on the expertise of the doctors and specialists from B.C. Children's Hospital who are familiar with Prader-Willi Syndrome. As we continue organization and planning of that particular conference, we welcome your suggestions and ideas.

We are still awaiting the final results of specific funds raised for our association on behalf of Richard Brodeur and his Celebrity Golf Tournament. It is with some of these monies

that we are able to bring you qualified speakers and presenters of interest this fall and the upcoming spring. A special “thank you” to Bev Baldwin for all his work on this activity.

The summer gathering was held in Langley this year and attended by a handful of families, both new to the syndrome and experienced veterans. The weather was great, the pool enjoyed and the informal conversation and fun much appreciated. This annual event will continue next summer. A special “thank you” to Lindy Thompson and her family for hosting this event.

Please remember that the B.C.P.W.S.A. has a web site that is updated regularly with information applicable for B.C. residents. You can access the website at: www.bcpwsa.com . Anyone interested in becoming a member of the B.C.P.W.S.A. can access the website and follow the directions indicated for new membership.

The B.C. P.W.S.A. is working to provide information and create a connected community of affected people.

Thank you!

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