

March 10, 2006

Dear parent or caregiver:

You are receiving this letter because someone in your family has Prader-Willi Syndrome. The British Columbia Prader-Willi Syndrome Association is trying to contact all families in British Columbia with a diagnosis of PWS.

We are currently trying to reconnect with families and locate new families affected by Prader-Willi Syndrome. Current members include families from all across the province, including: the Central Interior, the North Shore, Vancouver Island, the Fraser Valleys and the Lower Mainland. Involved families have children ranging from just over a year old and well into their early adulthood. It is a great forum for families to meet and exchange information with other families experiencing similar challenges. It is especially beneficial for families of younger children to meet and learn from families who have many experiences and much knowledge to share.

We would like to let you know that the B.C.P.W.S.A. now has a web site that is updated regularly with information applicable for B.C. residents. You can access the website at: www.bcpwsa.com April 22, 2006 is our next B.C.P.W.S.A. gathering. It will be held in at 12778 – 66th Avenue, in Surrey B.C from 1:00 p.m. to 5:00 p.m. These biannual meetings are free to all B.C. P.W.S.A. members. The agenda for this upcoming meeting is posted on the website. Some planned speakers included in this meeting are members of the Special Olympics and a representative from the Surrey School District speaking about I.E.P. development for school age children with Prader-Willi Syndrome.

Anyone interested in becoming a member can access the website and follow the directions indicated for new membership or fill out the attached membership information and mail it to Lindy Thompson. For current members, annual membership payment of \$15 is now due on or by March 15 each year. Please mail your check to Lindy Thompson as indicated below.

The B.C. P.W.S.A. is working to provide information and create a connected community of affected people. This summer we plan to have another social gathering involving our families. Many new changes are happening regarding medical treatment of children with PWS. Several families have shared this information at our meetings. Workshops and guest speakers that are of interest to families living with PWS will be present at our biannual meetings. Funds may be made available for those unable to attend due to financial difficulties.

If you are not interested in becoming a member, we hope you will still provide us with information for our B.C.P.W.S.A. database. Please fill out the attached form and return it in the enclosed envelope.

If you know of any other families that are affected by Prader-Willi Syndrome, please forward this information to them.

Thank you!

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