

B.C.P.W.S.A. SPRING 2014 Meeting - MINUTES

April 27, 2014

1:00-4:00 - Burnaby, B.C

- Attendance-** Heather Beach, Alan Price, Leah Price, Glen Thomson, Cindy Thomson, Mandy Young, Lindsay O’Hearn, Maya Dimapilis, Frances Robinson

- Introductions and information sharing:**
- Heather shared how her son’s autism dx. has allowed for them to use the funding to send Silas to camp. Discussion that Easter Seal’s camp has a weekend where family can go with the new camper to familiarize themselves with the camp. Week long camps cost \$500. One can pay for an aide to go with your child. Squamish location.
- Lindsay O’Hearn shared her daughter’s physio experiences on their goal towards walking.
- Maya new member: Hear daughter Sadie is 7 year old and has PWS. Spoke about the benefits of having Psych Ed assessments done and how the information has been helpful in school and otherwise.
- Lea Price discussed her son’s positive experience in military school in Ontario. The structure of the school has been positive for her son. Amya loves being an only child. Still not hyperphasic. Family can now focus more attention on Amya’s needs.
- Cindy Thompson shared her Kindergarten experiences Megan. Going well but there are lots of illnesses keeping her home at times. Some positives with Megan: She leaves food on her plate. Shared that Megan is in Sparks and that is going well. Megan does food seek. Cindy tries to Menu plan and that seems to help a bit. Started skin picking. Cindy mentioned that PWS children should technically get a sleep study every year. Should especially get a sleep study after GH is commenced as sleep patterns could change.

- Fall 2013 Minutes** approval – Cindy & Mandy

- Treasurer’s Report** (Heather for Cheryl Gagne)
BCPWSA is in better financial shape this year than last year primarily due to cheaper costs for last year’s fall conference, Cheryl’s skating party donations and \$2,000 Canucks Alumni donation. Attendees did have to pay to attend the fall conference which helped offset the cost. Family Support Grant form BCCH also helped to cover food cost at the conference. One fundraising idea is that Scotia bank has a way for employees to pick a certain charity to donation. This may be good to mention to employees of the bank that members may know.
– Report Attached

☒ **Fundraising Updates:**

*Skating Party: Cheryl hosted her annual skating party and it raised over \$2,000 this year.

*Toonie-Toonie Party: Leah Price's daughter asked for a Toonie for a gift and a Toonie for PWS research.

*Discussed some fundraising ideas: Ruffling off a nice prize e.g. Canucks tickets. Mandy may know how to get two tickets for raffling.

*Also discuss how to be successful at crowd source fundraising our organization would have to be more specific about the goal/purpose of our fundraising. Perhaps BCPWSA can look into defining goals for fundraising and then raise funds for that specific purpose. E.g. retreats for moms or dads and a family retreats.

☒ **Moms retreat:**

Heather is wondering if there may be an opportunity for mom's to go away together. Suggested locations such as a cabin on Sunshine Coast or perhaps Whistler. Cindy had some ideas. Reagan's Reach may also be an option. Hospitality done through Disability Resource Society may give us access to free access to hotel rooms. Another possibility would be a retreat in Harrison Hot Springs if Brent and Holly can look into getting discounted accommodations.

☒ **FPWR Fall Gala:**

Cindy Thompson shared about the planning for the Gala. Will take place on October 3, 2014. Location River Way Golf course in Burnaby near OSS walk. There will be a Silent Auction, 50/50 draw, singer, possibility of a pianist and dinner dancing. Keegan & Tanya Johnson will be attending. Keegan will be the key note speaker.

Cindy welcomes any silent auction items. Current items include Art, Canucks tx, facial gift certificates. Cost of each ticket will be in the range of \$125 however this is still to be determined. There is capacity for 220 attendees. Minimum 120 people must come for all costs to be covered. The success of this gala will hinge on getting people other than the PWS families to buy the tickets. Marketing this even to employers of especially big companies and others who will be willing to buy tickets will be important.

☒ **Fall BCPWSA Conference:**

Our conference will be the day after the gala on October 4th. Heather is exploring a Metrotown area location. One potential problem is that catering is really expensive in hotels vs. our regular YWCA location where bringing in your own catered food is allowed. Still finalizing possible speakers. Keegan will present on FPWR present research. FPWR may also sponsor possible speakers: Melanie Sylverman who is a nutritionist from California or Dr. Van Boss – Ortho Scoliosis expert funded by FPWR are possibilities. Still working on child minding and other activities for the adult PWS attendees. One possibility is to go bowling if

conference is in the Metrotown location. No bowling locations in our usual Downtown location. Volunteer recruitment for child minding and adult activity group leaders will need to be done. Puzzle exchange will be a part of the conference also. Information will be made available at the same time as the conference registration.

The groups brainstormed some suggestions for possible speakers: One interesting topic is on the different PWS treatment approaches in other countries. This will need to be a research project for some interested volunteer. Contacting the International Organisation will be helpful in this endeavour.

We will need feedback and suggestions from the membership for ideas on presentations and speakers at future conferences.

☒ Resources:

Discussed the need for members to share with each other the good resources they have found in their communities. Also good activities they have found for their children to participate in:

- *Bursary: North Shore Disability Association has a bursary that can be used for camps.
- *Caregiver tax credit available for parents who are caretaking their adult children.
- *Learn To Skate: 1 on 1 skating through special Olympics.
- *Leah has brought some puzzles. Suggested that parents bring the puzzles their children don't want to use anymore to future meetings to participate in an exchange.
- * Good Workshops: ABA in Richmond: Dealing with problem behavior. \$50.
- *Helpful website: UC Davis: Centre for Developmental Disab. Lots of information: An Article on perseverance as an example:
- *PWSUSA Health Care Guidelines published: Good for educating new health care providers and other helpers new to PWS.
- *Some questions about the flight discount information. Mandy will email info to Frances for website publishing.
- *Free movies: Program Access to Entertainment helps with cost for accompaniment of your child to the movies. Kid pays, person accompanying the child is free.
- *Recreation Victoria is a card that has discounted entry rates for certain activities.
- *PNE can also give you access faster to rides etc. Register at PNE. BC Transit has some discount programs.

☒ One Small Step Walk

Will be hosted in Delta this year by Susanne Szabo. Frances will forward registration information to the members

☒ Summer gathering

Lindsay will book her communal room and swimming pool for a summer gathering. Details to follow.

Motion to close meeting: Lea Price and Lindsay seconded.

Meeting adjourned at 3:45pm

UPCOMING DATES:

Summer gathering: July 6th, 2014, Surrey

One Small Step Walkathon: August 10th, Centennial Beach, Delta

October 3rd: FPWR Gala

Oct 4th: Fall BCPWSA Conference The Hilton at Metrotown, Burnaby

Adjourned.

The British Columbia Prader-Willi Syndrome Association

Statement of Financial Position
(Unaudited)

As at January 20, 2014, with comparative figures for 2013

	2014	2013
ASSETS		
Current assets:		
Cash	\$8,800	\$6,575
LIABILITIES AND FUND BALANCES		
Current liabilities:		
Deferred revenue	\$300	\$1,079
Fund balances:		
Operating fund	8,500	5,496
	\$8,800	\$6,575

Approved on behalf of the Board:

Heather Beach, President

Cheryl Gagne, Treasurer

The British Columbia Prader-Willi Syndrome Association

Statement of Operations and Fund Balances
(Unaudited)

As at January 20, 2014, with comparative figures for 2013

	2014	2013
Revenue:		
Donations - other charities	\$2,779	\$5,908
Donations - tax receipted donations	3,128	1,975
Conference fees	495	495
Memberships	550	625
	<u>6,952</u>	<u>9,003</u>
Expenses:		
Interest and bank charges	107	92
Office supplies and sundry	421	543
Professional and consulting fees	-	228
Fundraising	356	397
Education and training	1,985	2,189
Travel	300	722
Research and grants	779	4,158
	<u>3,948</u>	<u>8,329</u>
Excess of revenue over expenses	<u>3,004</u>	<u>674</u>
Fund balance, beginning of year	5,496	4,822
Fund balance, end of year	<u>\$8,500</u>	<u>\$5,496</u>