

**Prader Willi Syndrome Association of NSW (Aust) Inc.  
ABN 67639909678**

**Minutes of meeting held 26 March 2008 at Ibis Hotel Thornleigh**

**Attendees: Janene Lowe, Sharyn Robinson, Kristin Ranucci, Susi Trevena, John Sackett, Birgitte Knudsen (standing in for her husband Michael Wright) and Louisa Boyle**

**Apologies: Miles Apperley**

**Minutes: Louisa Boyle**

### **Welcome to New Members**

Janene Lowe, as association secretary welcomed new members to the committee Louisa Boyle, Sharyn Robinson and Kristin Ranucci. Louisa will be taking on role of President, Sharyn is taking on role of treasurer and Kristin will be taking over Librarian role. Janene also passed on the associations' thanks and appreciation to Miles Apperley and John Sackett who have recently announced their retirement from their roles as Association President & Treasurer respectively. We thank them for all their effort and commitment over their many years involved in the committee.

### **Growth Hormone in Australia**

Janene advised that Barry Greensmith has received from the secretary of the PBAC a confirmation that the PBAC has accepted the submission for growth hormone to belong on the Pharmaceutical Benefits Scheme. At this stage we understand that specific criteria will still need to be met as children reach adolescents (ie. Using bone density growth as indicator) and more on this to follow.

Very pleasing news for all parents and caregivers! The next battle for the same to apply for adults with PWS will soon begin!

### **Membership Fees**

It was discussed that going forward, it is more efficient to receive renewal of fees via internet banking. Those who cannot access internet banking to pay via cheque or money order.

Also agreed to keep fees at same amount being \$30 annually and \$15 concession rate.

It was agreed that the new committee members Sharyn Robinson and Kristin Ranucci will take on role of new signatories for all Association Westpac Accounts.

**Action Point (AP): Sharyn to organize next mailout to members calling for fee payment and in that to include associations' relevant bank details.**

**AP: Sharyn and Kristin to complete paperwork to confirm them as new signatories (documents provided by John Sackett).**

### **Communication to Members**

In the next association newsletter, Janene advised that it would be appropriate time to acknowledge the great fundraising efforts particularly over the last 12 months by people like Susi, Kristin, Louisa and many others. To date a total sum of \$137,000 has been raised which has ensured the PWS research project at the Garvan Institute will continue. The committee was also notified that an anonymous donor has donated a large sum which ensures the project can continue for the next 3 years and at that point the team at Garvan will be eligible to apply for funding grant through the Federal Government.

**AP: Susi to draft a brief comms. around fundraising to date and send to Louisa for inclusion in next newsletter.**

Also noted other items to be included in next newsletter:

- Welcome to New members
- Thank recently retired members
- Announce next International PWS conference to be held in Taiwan in April 2010 to allow for planning
- Upcoming events – ie. Networking Day at Westmead in Sept. and Picnic Day for last Sunday in May
- Kristin also advised that telephone/ internet discounts exist for those who hold health care card/receive carers allowance. Include reminder in n'letter.

**AP: Any further ideas/newsworthy items pls send to Louisa (Louisa.boyle@optusnet.com.au) who is preparing newsletter.**

**AP: Janene to send newsletter template to Louisa.**

#### **Networking Day at Westmead – 5 September 2008**

Susi Burrell from the clinic at Westmead Hospital is organizing this information day for parents/caregivers. She is calling for relevant & practical topics that can be covered.

Suggestions raised:

- Dental care – practical tips on day to day oral hygiene from a dentist
- General nutrition tips
- Bio exercise
- Behavioural Psychologist – for eg. Feature a guest speaker who has worked with kids/adults with PWS.

**AP: Any further suggestions send to Susi Trevena who will be contacting Susi Burrell.**

A suggestion was to organize a dinner for parents/caregivers to attend after the networking day (Friday night), at a venue relatively close to Westmead to encourage attendance.

**AP: Susi/Kristin to provide possible venue options. Louisa to include note on this in the upcoming newsletter.**

### **General Networking Day – Follow up to Conference**

Committee agreed that another networking day in addition to Westmead is not realistic for 2008. Next general networking day will be held in 2009.

### **Picnic Day**

Agreed that last years picnic day was successful and worthwhile to continue. Same venue as last year agreed due to location and close availability of amenities (Bobbin Head). Intended date is Sunday 25 May and Louisa to include in newsletter. Kristin suggested including a fun activity this year like a clown who can organize face painting, games etc. as something fun for kids.

**AP: Kristin/Louisa to look into “clown for hire” businesses in area. Find out price etc.**

### **Library Role**

Janene to hand over all DVD's, videos and literature to Kristin. The aim is to have a workable list of all items available, publicized in a central location for all members to get quick and easy access to. For example store this info. on the NSW PWS Association website.

**AP: Kristin to itemize each of these and collate a list.**

On the topic of the website, a suggestion was raised to really maximize the use of this forum. When families are just getting a diagnosis it would be really valuable to be able to jump on the site and get some helpful information and access useful links to help them on their journey. For example in some PWS association websites in Australia and overseas families often feature a profile of their child, sharing special milestones etc.

**AP: Janene, Louisa and Simone Jones (mum in Newcastle) to get together and start to map the processes after you get a diagnosis and the organisations/support to turn to.**

### **Fundraising Role**

After great fundraising results, important to keep momentum so Janene has raised motion to create a fundraising position within the committee. Louisa seconded this and committee agreed on fundraising role.

Janene nominated Susi Trevena as best person to take on role. Susi accepted and Louisa seconded nomination. Committee agreed on Susi as Fundraising officer for the association. Due to limited time, ideas for future fundraising projects to be brainstormed in upcoming meetings.

**AP. Louisa to include this update in newsletter.**

### **Incorporation/Structure of Association**

#### **Legal Requirements**

John Sackett has confirmed the following requirements of association:

- Three meetings to be held as a minimum annually. Annual General Meeting (AGM) is in addition to this.
- Public Officer/Treasurer essential
- A minimum of 3 members (corum) to hold meeting
- Audited accounts should be available at the AGM and the A/C's need to be sent with appropriate form to the Dept of Fair Trading within one month of the AGM.
- AGM to be held by August each year so accounts can be submitted to ATO in line with end of financial year.

### **General Business**

1) John raised that sales of entertainment books to go to association.

2) Janene flagged some ideas for future projects to be noted: Creating packs for parents/carers to use for key transitions:

- New diagnosis
- Preschool
- Starting primary school
- Starting high school
- Adulthood – residential home etc.

3) Susi suggested refresh for NSW PWS assoc. logo. Her neighbour is a graphic designer and has offered to update for free. Will include some ideas in next newsletter.

4) Kristin suggested approaching Woolworths on their \$5,000 Fresh Food Kids Community Grants' program which they provide to local groups who have a focus around health/nutrition. Kristin to investigate.

5) Teleconferencing – Louisa to organize teleconference number for future meetings. Will check with Barry Greensmith/Helen Anderson for use of PWS Australian's Association' number.