

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

**Minutes of Annual General Meeting held 20 August 2008 at Ibis Hotel  
Thornleigh**

**Attendees: Louisa & Sean Boyle, Cassandra Whitley, Sharyn Robinson, Miles  
Apperley and Dr Ellie Smith.**

**Apologies: Janene Lowe, Kristin Ranucci, Michael Wright**

**Minutes: Sean Boyle**

**1. Minutes of 2007 AGM were read**

**Action: Miles to chase up last year's list of action items and email to Louisa  
so we can keep as a matter of reference.**

**2. President's Report**

Louisa read the key activities/updates for the last 12 months within the association  
which included:

Growth Hormone being approved – huge effort and dedication from Barry  
Greensmith to make this a reality. Paperwork through Pharmaceutical Board  
expected to be completed soon and hormone available through PBS later this year.

Asia Pacific Conference in Wellington – a successful conference that had some  
excellent content for parent's and carer's.

New office bearer's elected – Sharyn Robinson as Treasurer; Susi Trevena into new  
fundraising role; Kristin Ranucci into Resources role and Louisa Boyle as President.  
A big thankyou for their time and effort over the years to Miles Apperley and John  
Sackett who retired from their positions as President and Treasurer respectively.

Fundraising activities – a very successful year of fundraising for \$'s to go to Garvan  
Institute for their research into appetite regulation. Families in NSW raised close to  
\$140,000 in an 18 month period!!

**3. Treasurer's Report**

Sharyn distributed her financial report for 2007-2008. A copy will be available on  
the PWS Assoc. NSW website once updated.

**Action: There are some outstanding subscription fees outstanding. Also  
each member pays a levy to the National association which needs to be paid  
annually. Sharyn to investigate.**

**Accounts need to be audited within one month of AGM – Sharyn to organize  
an auditor and then they can be sent to Department of Fair Trading.**

#### **4. Business Arising**

##### Website

NSW Association website to be updated. Content on the website is not current and we need a point of contact who can update the site with meeting minutes, newsletters, events/activities.

Sean Boyle volunteered to manage site. He has access to a software program that is easy to apply and user friendly. It does cost \$140 to install. Members agreed that it was a reasonable cost for a valuable tool.

**Action. Sean to contact John Sackett to find out about current software licences etc.**

##### 2008-2009 events/activities

Westmead Day has been postponed until March 09. What other events would be of value to families? Suggestion was put forward to organize a workshop with Peter Davies. The PWS Downunder n'letter features information about Peter's workshop (Fighting Fit, Fighting Fat") being held in locations across NZ. A key speaker at the conference in Wellington, it would be very beneficial to have more focused time with Peter, Director of the Children's Nutrition Research Centre, Royal Children's Hospital in Brisbane.

**Action Point (AP): Louisa to investigate this opportunity with Peter for sometime mid to late 2009. Association to cover costs of travel and accommodation for Peter.**

##### PWS Comprehensive Database

Dr Elly Smith from the Children's Hospital at Westmead discussed the database currently in development. Dr Smith has been investigating developing such a tool for some time as she believes a database, which would contain basic medical details on people living with PWS would be valuable as an informational and research tool. Elly showed us a sample questionnaire that could be used for parents/carers to fill out. Due to privacy and ethics regulations the approval process is quite complex and could take some time.

When there are more details about the database, the association can assist by communicate to it's members about it's existence and how they can contact Dr Elly Smith if they wish to be included in the database.

##### Brain and Mind Research Institute – Potential Fundraising Opportunity

Dr Elly Smith raised that Dr Stewart Einfeld, a child psychiatrist at the Brain and Mind Research Institute in Sydney had a real interest in the behavioural phenotype in PWS. Further research into this area is key and could help us understand why particular behaviours are specific to PWS and strategies to better manage this. Elly believes approx. \$20,000 would be needed to fund this research.

**Action: Elly to contact Dr Einfeld to organize a meeting/walk through of the institute with interested parents. Elly to contact Louisa with more info.**

### **Election of Office Bearers**

The retiring office bearer's were:

Louisa Boyle: **President**  
Janene Lowe: **Secretary**  
Michael Wright: **Vice President**  
Sharyn Robinson: **Treasurer**

The following members were nominated and elected unopposed as office bearer's for the association for 2008 -2009.

Louisa Boyle: Elected President 2008-2009. Nominated Dr E Smith. Seconded M Apperley.

Sharyn Robinson: Elected Treasurer 2008-2009. Nominated L Boyle. Seconded M Apperley.

Janene Lowe: Elected Secretary 2008-2009. Nominated L Boyle Seconded S Robinson.

Cassandra Whitley: Elected Vice President. Nominated S Robinson Seconded S Boyle

**Thankyou to Michael Wright who took on the role of VP over 2007/2008 and his support (along with his wife Brigitte) over the 12 months.**

### **Appointment of State Delegate to PWS Association of Australia**

- Louisa Boyle. Nominated State Delegate for period of 2 years. Nominated M Apperley. Seconded S Boyle

### **Other Business**

Purchase of new nutrition literature was raised by Louisa. A new book highlighted in PWS Downunder n'letter June edition is Healthy Eating by Jackie Walters which has a key focus on healthy eating when living with PWS. Members at meeting agreed, to purchase a couple of copies to have available in the resources for members of NSW association to access.

Action: K Ranucci to organize copy. List of current resources to be available on website once updated.

**Meeting closed at 8.45pm.**