



Dear Members,

The 1st PWS Networking day held on July 21 was a great success. Presentations from a variety of people provide plenty of information and points for discussion. Approximately 50 people participated on the day and this meant many opportunities were available for networking and forming connections between members, health and medical professionals and service providers.

Topics that were discussed included PWS research at The Garvan Institute of Medical Research, accommodation and housing options, behaviour management, communication and learning at school, feedback on the International PWS conference and an update on the work of our national body, the PWS Association of Australia.

Thank you for all those contributed and attended the day and I am sure we will hold another one in the future.

At the Networking Day I proposed some questions about the future role of the Association. What are the needs of our members that the Association can meet and secondly what is realistic for our Association to achieve given the profile of our membership and the important role that many of those members have as primary carers of people with PWS?

The Association would welcome your comments and responses to these questions (nsw@pws.org.au). An opportunity to raise and discuss these issues will be provided at the Annual general Meeting of the PWS Association of NSW Inc on August 18.

Please find enclosed notice of the 2007 AGM. This is an important meeting for our Association, providing an opportunity for members to get involved in the organisation in a more official capacity. Voluntary associations rely on many people doing things to support our members and official roles are needed to keep the association viable and active.

At the AGM I will not be seeking re-election as President ending a stint of 4 years. Our current treasurer, Mr. John Sackett, has also advised that he will not be seeking re-election as Treasurer in 2007. During the last 4 years we have experienced a change in how the NSW Association communicates with members, holds meetings and networking events and even the way we collect fees. We have had a dramatic increase in members with a baby with PWS, and a small group of parents with young children with PWS are initiating fund raising activities to raise money for medical research. We are now looking towards the future as we try to understand the needs the Association has to address.

This is a time of great opportunity and I ask that you please consider getting involved in the Association and having a greater impact in the lives of people with PWS. The focus is on the possibilities for our people not the disabilities.

At the AGM will be also hearing from Dr. Lesley Campbell of the The Garvan Institute of Medical Research. Lesley will provide an overview of PWS related research being conducted at The Garvan and the potential for the outcomes of this work to impact the lives of people with PWS.

The Association must fill all its office bearer positions including President, Treasurer, Secretary and Vice-president to remain viable and operational. We will also have an opportunity to elect a new delegate to the PWS Association of Australia. If you have any questions about these roles I would be pleased to discuss them with you. I can be contacted on nsw@pws.org.au or at home on 02-9543 4609.

I hope you can attend the AGM and I look forward to meeting you there.

Kind regards,

Miles Apperley
President
PWS Association of NSW Inc