

PRESIDENTS REPORT 2007

Welcome to the PWS Association of NSW Annual General Meeting for 2007. Thank you for making the effort to come out this afternoon and participate in this important meeting. I am particularly pleased to welcome Professor Lesley Campbell from the The Garvan Institute of Medical Research. Lesley will be giving a presentation to us on aspects of research being undertaken at The Garvan that is relevant to PWS.

Over the course of the last 12 months the office bearers of the Association have met several times in order to keep the wheels turning and plan a few activities. It was hoped that we could build some momentum on activities and opportunities for members to network with each other and thereby build contacts. I think we achieved that aim.

In October 2006 several members participated in a PWS Information day at Westmead Children's hospital. This initiative of

WCH organised by Susie Burrell was very successful and provided an opportunity for a brief talk about the Association to the attendees. The day attracted some of our members from far and wide and it was good to catch up with them.

In November 2006 the Association hosted a visit to Sydney by Pam Eissen, President of the International PWS Organisation. Pam had a whistle stop visit to Australia and the day she was in Sydney managed to meet families involved in the PWS specific residential project and some health professionals. A dinner was organized at a restaurant in Sydney and a number of parents and carers of people with PWS of all ages were able to come and meet Pam and share their experiences. It was a terrific opportunity to listen and share with a person who has a true heart for all people with PWS and to hear of the work of IPWSO.

After a break last year, we organised the PWS picnic day early in May for families of children with PWS. This was a great success with over 20 families attending and the age of children with PWS

ranging from a few weeks through to early teens. It was a beautiful day at Bobbin Head and I had a lot of very positive feedback from those who attend from all over Sydney and Newcastle.

By far the biggest event we have had in the last 12 months and for the last few years for that matter was the PWS Networking Day in July. Over 50 people participated on the day and provided many opportunities for networking and forming connections between members, health and medical professionals and service providers. A broad range of topics were discussed but really only represented the “tip of the ice burg” when it comes to caring for our people with PWS. The day was a great success and I am sure the Association will try and organise more of these 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 the Association to achieve given the profile of our membership. Earlier at this meeting I took the privilege to accept these ideas and have

them recorded so that in the future the Association can meet and consider these ideas and needs and plan how they might be met for the benefit of the members.

I hope the incoming Office Bearers of the Association will work with these ideas and tackle the challenge of meeting the needs of all the members of our Association both young and old.

One of the issues to consider is that many families now making contact with the Association for the first time have a baby i.e. less than 12 months. The number of family's in this situation has increased over the last 10 years principally because of the more widespread availability of improved DNA methylation analysis coupled with growing awareness of the syndrome amongst pediatricians.

From discussions at the Networking Day I am pleased to advise that we will have a librarian or information officer in the future.

Kristin Ranucci has agreed to take on a role that will hopefully see

the Association's collection of books, videos and DVDs better utilized. Kristin will advertise the resources available and keep a track of them as they are circulated around the members. She will also be on the look out for new materials that we can purchase and make available for our members. I am pleased that Kristin has taken up this role and please be on the look out for notices from her in the future. Unfortunately she was not able to be here this afternoon.

Some of our members will be familiar with Kristin and her husband Mark who initiated fund raising earlier this year for The Garvan Institute for PWS related research. Other members have also taken up the challenge to raise funds for The Garvan through a variety of means. "Team Prader" created by Susi Travena and her work Colleagues at Amex have made some outstanding progress with their target of raising at least \$150 000 for The Garvan. I am sure they will achieve this target and on behalf of would like to both thank and congratulate Susi for her efforts so far.

Although not official activities of the Association, we have supported these initiatives by promoting them through our membership and we welcome feedback on the progress made to date.

As mentioned in my Bulletin distributed with the notice for the AGM I will not be seeking re-election as President this year. I will of course remain a member of the Association and will be keen to participate in any activities that may be planned in the future.

I would like to thank the outgoing office bearers of the Association. Janene Lowe our secretary has done a fantastic job, often taking the first calls from parents of children who are newly diagnosed and handling many email and normal mail announcements. While Janene could not come today she has advised me that she is willing to be re-nominated as Secretary for the forth-coming year. Thank you to John Sackett for attending to the Treasurers role and sorting our new memberships for another year. John has indicated that he will not be seeking re-election as Treasurer this year. Finally my thanks to Maurie Spaccavento our retiring Vice –President.

Most of however I would like to thank the members who have participated in our activities over the last 12 months. I hope they were of value to you and I know that your participation has been the reason they were so successful.

Miles Apperley

President

PWS Association of NSW Inc

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