

President's Message AGM 2010

Most years I have some difficulty in starting to write this message and this year has been no different. It has taken me until 5 days before the event to actually feel like we as a Committee are ready for this AGM. This past year CleftPALS WA has (mostly) run quite smoothly, until we attempted to book the Annual General Meeting... In summary, we will never hold an AGM on a Saturday again! Finding an available date during May or June on a Sunday that didn't clash with the AFL was impossible, so we decided a Saturday would be OK. The issues then kept coming, including even getting our hands on a projector – a big thank you to the Genetic Support Council of WA, whom have loaned us theirs! Anyway, we are now ready and I am now finally looking forward to the day.

As I just mentioned, this past year has been relatively smooth, with the exception of some issues with the retention of Contact Parents. This is no slight what-so-ever on the Contact Parents, just some systemic problems with availability, timely notification from the hospitals and an expectation (from some professionals and families) that Contact Parents are available at all times. Again, this is not a slight on anyone that may have contributed to those issues, however it is a perfect opportunity for me to remind all our members that Contact Parents are volunteers and they do their best at all times.

As a result of these problems, the Committee recently discussed the Contact Parent procedure and will begin trialing the changes immediately. Obviously, any additional issues will be managed as they arise. The main change to procedure is that **all** Contact Parents will be advised when a baby is in Neonates, so if **any** C.P. has an appointment during the next few days, **that** C.P. can visit the family to give them the file, "Clarence" and sell stock, if required. The family will, however, still be allocated officially according to cleft type. We are trying to ensure we don't get the last minute emergency calls from families requiring stock to go home - this is completely unacceptable and the responsibility should **not** be falling on CleftPALS to ensure a family is ready to go home. We hope all our members and the professionals continue to understand that our commitment to new families has not altered at all. However **we**, as Contact Parents, also have families and commitments - and are volunteers - so we need support too. If we don't get this right, we won't have parents who are willing to put their hands up to be Contact Parents, and that is also unacceptable. Right, that is my whinge over!

In other CleftPALS business over the past year (to end of March), the following has occurred:

- Total Memberships remained static (143 in 2009 versus 141 @ March this year).
- Term Memberships rose from 33 (in 2009) to 37, which is fantastic.
- Babies that CleftPALS contacted dropped this year – see Erica's report.
- We slightly changed the role of Equipment Co-ordinator, making co-ordination of the breast pumps a separate job – not sure if this has been good or bad, but the new Committee will discuss at a future meeting.
- The website is now being completely redone! The Committee finally decided to pay someone to get this finalized, so it might actually happen now...

We remain financially secure and the Morning Teas and other events continue to be well attended, so that is good news.

Nationally, very little has happened this past year. CleftPALS Victoria continued work on the "Give Our Kids A Voice (GOKAV)" campaign, almost solely. I will admit that I have not been the best National Representative for WA this past year, as I have had a number of issues with the meetings not going ahead at the planned time or not going ahead at all. Unfortunately, with

such a small Committee, this regularly happened due to a lack of quorum, which I found quite annoying. Hopefully this coming year will see the National Committee regroup and get back on track, holding the meetings every 6 weeks. I definitely intend doing what I can to contribute to the success of the National group. Kim MacPherson and I are off to Adelaide on 1st July for the National AGM and Conference, so I look forward to reporting on that in the next newsletter.

The next year of CleftPALS will bring us a couple of additional challenges, none bigger than the planning of the next National AGM and Conference. Perth last held this event in 2006 and it was absolutely fantastic. Next year's will be the 3rd National event in this state that I have been involved in. Fortunately, this will also be the 3rd event for Angela and the 2nd for a couple of other Committee members (that are re-standing), so I am very excited about how well planned and, therefore, successful it will be. We had approximately 50 people at the 2006 event - I am hoping to double those numbers this time 'round! We don't have an exact date yet, but, for those of you who do plan well in advance, please "pencil in" the Saturdays during July. We will be discussing and trying to determine a date during the first couple of meetings after the National AGM.

Aside from the National event, I am hoping to personally look at each role to see if procedures need updating/changing/removing. We have recently started following up members who have been "complimentary" and not actually paid yet (usually new families – they receive 2 newsletters for free) and existing members who have not renewed their membership. This change has already resulted in a few new members and renewals, so it will continue to be part of the membership role in the future, where possible. Developing a CleftPALS WA Procedure Manual is something I have wanted to do for at least the past 8 years and I am determined to make a start on it this year!

To finish up, I would like to thank the many Committee Members that have had a go this past year, despite the problems, and will not be returning this year – your input, no matter how big or small, is much appreciated. I would like to specifically mention Katrina, who stepped down from Equipment Co-ordinator mid-term (but is still managing her little team of splint makers), and Pam, our industrious Treasurer of the past few years, who is also stepping back to the General Committee. Thank you both SO MUCH for everything you have done during your time on the Committee – sincerely, without your efforts, CleftPALS WA would not be what it is today!

And, lastly, I will let you all know that I am definitely pulling the pin as President next year. I desperately want to return to the Education role and will also maintain a position on the National Committee. I actually really enjoy being the President, but it is time for a new one people!! We will be looking for additional support, physical and financial, over this coming year, especially due to the National AGM/Conference, so if you are able to contribute, please let me or another Committee member know. Also, if you have any suggestions for speakers, displays or other information you would like at the Conference, let us know sooner rather than later. I look forward to sharing a productive and exciting year with you all.

Presented by Neeva Stephen