



FABRY'S SUPPORT GROUP INC.

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"To provide support for those affected directly or indirectly by Fabry disease throughout Australia. Increase recognition, awareness and understanding of Fabry disease, its effects and potential solutions." (Mission Statement)

PRESIDENTS REPORT

2007 has been a busy and eventful year. The time always flies from one AGM to another, but when we reflect on the work done by the committee we are always amazed at the achievements and what we have accomplished in a year. Last year was no exception.

Our 2006 Annual General Meeting was held on Sunday 29th October at the home of Megan and Mark Fookes in Willoughby, Sydney. There were about 20 of us and we had a great meeting and social BBQ after. Thanks to the Fookes for their hospitality.

It was at this point that we reviewed the survey results from August as a committee and were particularly heartened by the results. There were many issues identified in the survey and an incredible amount of positive and constructive feedback. Most people found the Fabry's Support Group kept them in touch with what was happening in the Fabry's community and most felt that the group was mainly concerned with the wellbeing of its members. Everyone said they enjoyed receiving the newsletter and there were many areas that they wanted covered in the newsletter from medical advancements, to diet and member profiles. Armed with this information we discussed ways in which we could bring all this information together and it was at this meeting that we first discussed the concept of having a Fabry's Conference in conjunction with our next AGM, an idea was born...

The committee worked tirelessly throughout the year bringing together the conference, with all the other commitments most of us have; family, work, study, and treatment this amounts to an enormous effort. Lots happen behind the scenes and we meet on many occasions to allocate work, share ideas and basically get the conference up and running.

But as we have said the conference was driven from the results of the survey that many of you participated in last year. We looked at the topics you as members wanted and then coordinated the medical professionals to best fit those interests.

We truly hope this conference is the first of many in the years to come and that we can do this to keep Fabry's patients informed and in touch.

However that is not all that happened in 2007; August was a special month for the Australian Fabry community with a visit by one of the world's foremost medical experts in Fabry disease, Dr Christine Eng. Now an Associate Professor in the Department of Molecular and Human Genetics at the Baylor College of Medicine in Houston, Dr Eng has collaborated for many years with Dr Bob Desnick on a number of research projects and clinical trials in Fabry disease. Dr Eng spoke to members in both Sydney and Melbourne in August and the reports from those who attended were very positive.

Whilst the committee of the Fabry's Support Group is made up of those who's life is touched by Fabry's a big thank you must go to Genzyme Pharmaceutical Company and its staff who have worked with us this year to have access to guest speakers and who are kindly sponsoring the Inaugural Fabry's Support Group Conference. A special thanks to Stephen Larsen (now left Genzyme), Lyn Fidler and Anthony Earp who worked with the committee throughout the year.

But like every year there is always more work to be done. I would like to take this opportunity to personally thank members of the committee for their efforts throughout 2006/07.

Lea Chant
President
Fabry's Support Group