



Australian Cystinosis Support Group

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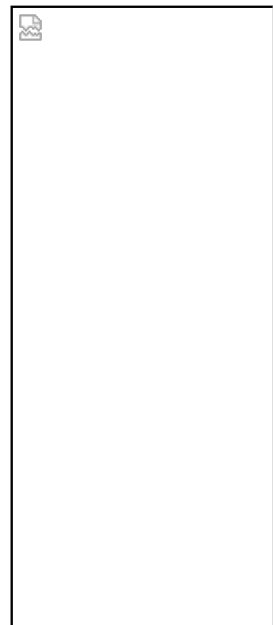
Hello and welcome to 2007

To all our Cystinosis families and friends throughout Australia. Its been rather a long time since we produced a newsletter and much has been happening on the Cystinosis front, As many of you know there was an International Cystinosis Conference in the Netherlands in July 06 and one of our mums from Brisbane Debbie Woodward did a huge amount of fund raising to be able to get to this conference. Debbie unselfishly decided instead of using the funds to take some of her family to the conference she would pay for one of our N.S.W

Doctors Jeff Fletcher to attend the conference with her.

Dr Ian Hewitt from Western Australia happened to be on a holiday in that part of the world so he also attended the conference. Our Australian support group organized for a fair bit of the conference to be videoed to produce a CD/DVD for Cystinosis families as an educational tool. The quoted cost of this project was \$18,000 Euro. Orphan Europe and the U.S,A Cystinosis foundation came to our aid and have helped pay the bulk of this with only \$2000 being our contribution to the project. The CD should be available soon and we will post copies to all families. We would like all doctors and health professionals dealing with Cystinosis to get a copy of this CD so please begin making lists of those you think would benefit by receiving it.

Inside this issue:



1st Australian Cystinosis Conference

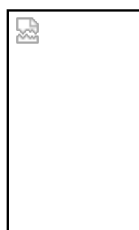
In February 06 we applied for a small grant to hold a Cystinosis conference in W.A. We received \$5,700 from Careers WA. This project grew from a small W.A. conference to an International Cystinosis Conference with families from all over Australia and also a family from New Zealand wishing to attend. Orphan Australia who provide our Cystagon matched the grant from Careers WA and we were off and running to hold the 1st ever Cystinosis conference in the southern hemisphere. The conference was set for September 9th and 10th at the Atrium Hotel Mandurah. Families from S.A, W.A., Q.L.D, TAS,VIC and NZ attended, The grant covered flying and accommodating Dr Paul Roy from N.S.W as our medical professional. It also paid for the conference facilities and most of the meals and also accommodating the child care workers to look after the little ones while the conference was running. All in attendance had a wonderful 2 day conference. We appreciated all those that did talks at the conference and supported this project.

Many thanks!

[Http://australia.cystinosis.com](http://australia.cystinosis.com)

Email address- cystinosis.australia@bigpond.com

A big thank you to Dr Roy



We wish to express a great deal of THANKS to Dr Paul Roy who gave so much of his time and energy at our Australian Cystinosis Conference.

Without his help and support it would not have been possible to hold our conference.

Also a special thanks to Dr Roy's wife Joyce who unselfishly gave up her husband's company so that he could attend our conference.

Sue and Serena Scott
1 Clifton Cres,
Pinjarra,6208, WA

Ph-(08)95312135
Mob- 0407196685