

**CHAIRMAN'S REPORT to the 18<sup>th</sup> AGM & FAMILY CONFERENCE**  
of the Association for Glycogen Storage Disease (UK)  
**12th OCTOBER 2002 NOTTINGHAM GATEWAY HOTEL-NOTTINGHAM**

Thanks to the last minute organisation of our treasurer Sue DelMar and her family, the 17<sup>th</sup> AGM and Family Conference was held in Birmingham at the Hotel.Campanile. There were some 70 attendees including 27 UK families, four visitors from Europe and the USA The younger children were looked after in a handy nearby Nursery. The vice President and helpers took the older children to nearby Seaworld whilst the parents attended the afternoon sessions

In the 2001 AGM officers were re-elected.for the year. The big change was that Kevin O'Donnell resigned his position as GSD type II representative and retired to the less hectic life of an ordinary member. Allan Muir became our new GSD type II representative. Shelia Redford/Tatre resigned as Secretary and Dr. Clive Tonks bravely volunteered to produce an Agenda and notes for both the AMG and the forthcoming Executive Committee meetings. Wendy Bascal resigned the position of GSD type III representative and Ailsa Arthur agreed to take up the post. The AGM was followed by individual workshops.:

**GENERAL SPEAKER:** Alastair Kent- Director of GIG [The Genetic Interest Group]

**WORKSHOPS:**

GSD Type I & III: The Birmingham GSD clinic team including  
Dr. Ann Green, Dr. Jose Cabrera, Dr. Robert J.Cram,  
Dr. Patrick McKiernan and dietitian Jill Johnson.

GSD Type II: Dr. Ans van der Ploeg and Marloes Hagemon (The Netherlands)

GSD Type V The McArdle's clinic team

GSD Liver affected GSD's Afternoon Question & Answer

Session by Dr. Philip Lee (LONDON)

A full report of the conference and Workshops\*was given in the February 2002 Newsletter  
Summaries of the Workshops were also posted onto our new website [www.agsd.org.uk](http://www.agsd.org.uk) and are still available. from Ann Phillips (SAE A4)

**The AGSD(UK) WEBSITE**

First we wish thank Kevin O'Donnell for setting up our original site and developing the GSDnet which he still runs.The new AGSD(UK) website came into action in August 2001 The year 2001 to 2002 has seen further development of the website, which has been a great success. A statistics facility has allowed us to track and monitor users. The most interesting statistics show that the website has had nearly 50,000 hits & 11,000 visitors, to date, since 18/8/2001. Also we have had visitors from at least 79 different countries. The addition of dynamic content has improved the site making it more interactive and making updating of the website much easier for committee members.

The AGSD(UK) Home page contains key links to GSD types, a "How we can help", Workshop Reports from 2000 and 2001 conferences, links to other sites, such as the USA site , all the past Pompe's reports and the GSDnet, a 'Join us,' a Guest Book, and a rather inactive monthly voting poll do to lack of questions!!

Any suggestions are welcome- send your questions and 5 point answer choices to <[askus@butterfly-net.co.uk](mailto:askus@butterfly-net.co.uk)>

## **NEWSLETTERS**

Three Newsletters (Vol 5 Issues 1,2 and 3) were produced for February/SPRING 2002, July/SUMMER 2002 and September WINTER 2002 (Nottingham 2002 Conference Issue)

## **CONTENTS:**



### **FEBRUARY/SPRING 2002**

*(Vol.5 Issue 1) - editor Peter Phillips*

The Workshop Reports from Birmingham 2001 Conference

Difficulties of travelling with a child with GSD type I a by Alexandra Green

Special Needs Information and Statementing Process by Nicola Phillips

First announcement of the November 2003 Vietnam Bike Ride

### **JULY/SUMMER 2002**

*(Vol.5 Issue 2) editor Ann Phillips*

*Genetic Knowledge Parks-*  
government sponsored research into Genetics etc.

'A Pompe's update' by Allan Muir GSD type II representative

CLIMB Newbury Conference of 19 May 2002  
A report by Allen Muir

Alan Watkins Le-Jog Bike Ride adventures  
'Raising Awareness of AGSD(UK)' articles by Sally Miles (GSD IX), Ann Jacklin (GSD IIc) and Dr. Clive Tonks (Secretary AGSD(UK)).

Changes in the NHS and how the role of your GP is changing.



### **SEPTEMBER/Winter 2002**

*(Vol.5 No.3) editor Editor Sue DelMat*

Conference 2002 in Nottingham -details of Registration, venue and proposed Agenda

Minutes of the Birmingham 2001 AGM

GSD News

Treasurer's Report for 2001 to 2002

### **EXECUTIVE COMMITTEE**

has met three times :

19 October 2001 in Birmingham, and 10<sup>th</sup> February 2001 and 9<sup>th</sup> JUNE 2001 in London.

*Subjects for discussion* included:

The planning venue, date and time for the 18<sup>th</sup> AGM 2002 family conference to be held in Nottingham October 2002

Tim Arthur's proposal for raising core funding for the AGSD(UK) by a sponsored Bike Ride called the "**Vietnam Bike Ride**" challenge" scheduled for 7<sup>th</sup> to 16<sup>th</sup> November 2003.

Further development of the new WEBSITE [www.agsd.org.uk](http://www.agsd.org.uk).

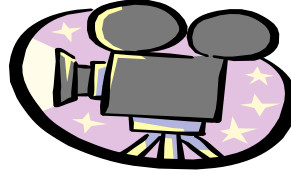
Upgrading Newsletters and producing individual GSD type leaflets

A review of the Constitution by an appointed subcommittee ready for the 2002 Nottingham AGM vote.

The continuing need to raise core funding through donations, sponsorship etc. to pay for the annual Family conference, the Newsletters and running costs.

Regular reports from the representatives for GSD types I, II, III, V and IX.

SPresident's Report and Treasurer's report.



### **MEETINGS & CONFERENCES ,EVENTS**

Alexandra and Richard Green organised and donated the cost for producing a CD version of the 1998 GOS video called "Dietary management of Glycogen Storage Diseases". See A. Phillips for a copy (cost is still £10)..

Ann Phillips was again appointed a *Trustee to GIG*. During the year she represented the interests of GSD at 6 meetings. Topics considered included Genetics and Insurance, government Consultation documents on Retained Organs and on the Commissioning of Specialist Services

Links were made and meetings attended with the Rare Disorders Alliance, CLIMB, the Muscular Dystrophy Campaign and the British Liver Foundation.

Ann Jacklin attended the 3<sup>rd</sup> Scientific Lysosomal Storage Disorders Congress held 20 – 23 June 2002 in Paris. Her report is in the September 2002 Conference Newsletter.

Ann Phillips attended the first meeting of the newly formed consultative Panel of the Human Genetics Commission. The topic for discussion was the pros and cons of having genetics testing kits sold directly to the public through Chemists, private clinics and the Internet..

Allan Muir reported on the CLIMB conference held in Newbury.in May 2002. Part of his report is in the Summer 2002 Vol 5. Issue 2 Newsletter. He encourages those who can to attend future CLIMB meetings as many of the presentations can have relevance to families living with glycogen storage diseases.



**Report submitted by Chair Ann Phillips on the activities of AGSD(UK)  
from Saturday 21st October 2001 to Saturday 12<sup>th</sup> October 2002**