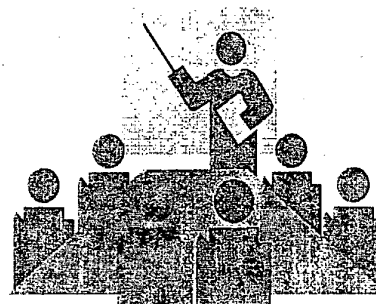


THE ASSOCIATION FOR GLYCOGEN STORAGE DISEASE(UK)
PRESIDENT'S REPORT to the 19th AGM and CONFERENCE
held on 11th October 2003 at the NOVOTEL in BRADFORD-

Much discussion has gone on in AGSD(UK) Executive Committee (ExCom) meetings as to whether we should hold our annual AGM/Family conference in the same place every year. The majority of your ExCom have consistently voted to change the venue so that people from various areas of the United Kingdom have a reasonable chance of attending at least one conference say every 3 years. If you have views on this subject would you jot them down and E-mail them to our hard working Hon Secretary Clive Tonks at cmttonks@aol.com or pass them to members of the Committee at our 2003 AGM in the northern city of Bradford.

The venue for the **2002 AGM and Family Conference** was in the midlands at the Nottingham Gateway Hotel.. The Gateway Hotel had excellent Conference facilities with comfortable hotel rooms. Again thankyou to Ann and John Jacklin and their family for a smooth running day. A special commendation to the Jacklin daughters Elizabeth Haney and Debbie Hooley who organised the excellent creche. Some 40 families came to Nottingham including a large contingent for the extended Pompe's weekend, Ryszard and Monika Damska (Polish Association for GSD), Janka and Thomas Matral (Hungary), and Tony Andersson and his son Robert (Sweden). The 2002 AGM was opened as usual and the Officers and Executive Committee members elected as follows:

| | |
|-------------------|-----------------|
| President | Ann Phillips |
| Treasurer | Sue DelMar |
| Hon. Secretary | Clive Tonks |
| Data co-ordinator | Peter Constable |
| General member | Tim Arthur |
| GSD type I | Hugo DelMar |
| GSD II | Allan Muir |
| GSD III | Ailsa Arthur |
| GSD V | Nicholas Owston |
| GSD IX | Sally Miles |



Under 'Matters Arising -Item 7 AGM 2002 Agenda: "Proposed changes to the Constitution" the AGM was addressed by Nick Owston (legal advisor) on the proposed changes to the AGSD(UK) Constitution (Original filed with the Charity Commission on 23 June 1988) These changes were read , voted on and passed unopposed.

The AGM was followed by Workshops* on GSD types I, II, III and V with speakers including Dr. David Weinstein – type I (Boston, USA), Professor Hopwood- type II (Australia), Dr. Helen Mundy type III (London) and Dr. Ros Quinlivan type V (Oswestry).

*The Workshop Reports are posted on our website and can be found under Workshops.
Printed copies are available on request.

MEETINGS, CONFERENCE ATTENDED on your behalf.

Ann Phillips is still your representative to the Genetic Interest Group (GIG) and is on the GIG Trustee Committee which meets every other month in London. She is currently into her second of three years stint year on the Human Genetics Commission's People's Panel. We were represented at a big Liver Trust meeting in January 2003 designed to raise awareness of liver disease in the UK. The Rare Disorders Alliance is being revived and formally organized. This is a UK umbrella group which is striving to raise awareness of people and families affected in the UK by what the EU classifies as a rare Disorder (less than 10 in 5000 population affected) which in the broad picture covers some 2 million people in the EU. If anyone would like to be our representative on this body could you let Ann Phillips know. Networking with other groups include CLIMB, the Ehlers-Danlos Support Group (meeting in Leeds on 'Social and Ethnic Differences in Attitudes and Consent to Prenatal Testing.'), Jenny Denham from the 'Portwine Foundation'



ExeCom meets at Eurostar Headquarters courtesy of Eurostar and Hugo DelMar.
Pictures show Hon Sec. Clive Tonks guarding the food and drink.
Then Hugo, Peter Constabe and Tim Arthur taking refreshments after a 3 hour session!!
Photographer present was A. Phillips

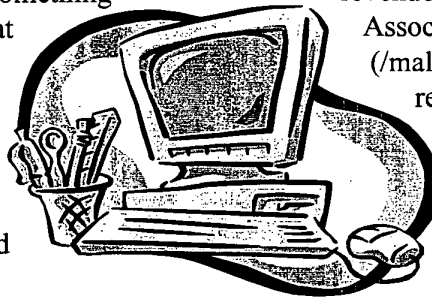
AGSD(UK) WEBSITE

Our GSD I representative Hugo DelMar has agreed to keep our website up to date. If you have any queries or spot something amiss please alert him at hugo@delmar.tv

Our domain name **agsd.org.uk** was renewed for 2 more years thanks to our Webmaster Patrick McEvoy who does the tricky technical stuff and designed the latest version of the website.

For those who have looked at the webpage regularly there was a little button at the bottom of the front page which when pressed gave the accumulated statistics for our webpage. Unfortunately this is no longer available for free

A summary for hits from 04/15/2003 to 05/09/2003 per day are **Total hits 68,35; total visitors 16,359; hourly average is 4.53; Daily average 108.82; Weekly average 761; Busiest day** in this time was 09/04 (378); the **Busiest month** was 09/2001 with 5,308



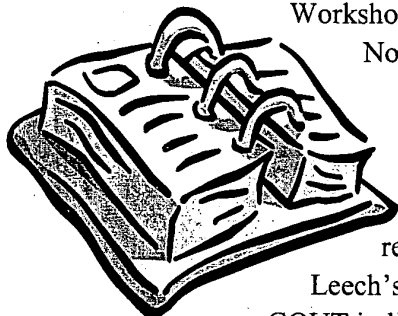
Your ExCom has discussed adding an advertising site to our webpage to bring in revenue. For example, the Gaucher Association is linked to a USA site (/mall.html) and they have so far received about \$200 per year.

EVERY online purchase made begins at which has the appropriate link to the merchant site. There is no additional cost to the purchaser and there are no forms or other requirements. The charity (eg National Gaucher Foundation) gets paid just for being a referral source for a sale. The entire process is automated. The merchant sites record that it was the last page visited before the user arrived at their own pages, and the NGF gets a commission for each sale. The commission rate varies between 1% to 5%, depending upon the merchant site. If anyone has some ideas about valid and legitimate sites please contact Hugo..

NEWSLETTERS for 2003:

Sue DelMar and Ann Phillips have jointly produced the last three issues . Ann does the outer four cover pages and fills the insides with newsy bits from the Families, notices of donations, events etc..

SPRING (JANUARY/FEBRUARY) 2003:



Workshop Reports from 2002 Conference; The Vietnam Bike ride in November 2003; latest glucose testing kit; Alan Walker's Charity Bike Ride; Example emergency letter to medical staff for parents/Patient; Family news.

SUMMER (JUNE/JULY) 2003

Tributes to Nicholas Owston; Harp Concert; Details and registration form about Conference 2003 in Bradford; Christian Leech's story; A possible McArdle's diet programme; Managing GOUT in liver affected GSD types.

WINTER (SEPTEMBER/OCTOBER) 2003:

Nominations for Officers and GSD type representatives; Preliminary Programme for Saturday 11 October 2003; Presiden't Report to 19th AGM in Bradford;

EXECUTIVE COMMITTEE: The ExCom met four times on 12th October 2002, 22 February 2003, 14th June 2003 and 20 September 2003. Up to this year the ExCom has met 3 times a year including one on the Friday before the annual AGM which did not give much time for discussion nor to finalise things for the conference the next day .. As our Hon. Sec said 'I feel we are neglecting our guests' who come a day early to meet informally on the Friday evening. By meeting a month before the AGM/Conference we hope to avoid this discourtesy and send out a proper notice of election etc even though it means an extra trip for the purposes.

Topics discussed at the ExCom meetings include a Report from the President and Treasurer, individual reports from the various GSD type representatives and ongoing discussions on Liability Insurance, raising Funds, etc.

Sally Miles in her role of **GSD type IX representative** reported to the Exe Com in February 2003 concerning no provision for a GSD IX workshop. She says: "I would value thoughts on type IX workshops at conference. I have been concerned that low turnout of type IX's at conference does not warrant a Consultant/Specialist putting in a lot of time preparing work to present to such small numbers. No detriment to the type IX's, (but) I feel as that this type this is not quite so severe people seem to get a lot of information from their Consultants. They also seem happy to contact other type IX's for occasional supportive chats as and when needed. My only thoughts are that conference tends to be a good place to raise awareness and to offer support across the types".

Submitted to 2003 AGM by Ann Phillips President/co-founder AGSD(UK)

