

Association for Glycogen Storage Disease (UK) Ltd
Registered Charity number 1132271

TYPE CO-ORDINATORS' MEETING

Saturday 22nd October 2011 at the Holiday Inn, Telford.

MINUTES

Present

Sue Del Mar	(SDM)	Type I Co-ordinator and Trustee
Allan Muir	(AM)	Type II Co-ordinator and Development Director AGSD-UK
Esther James	(EJ)	Type III Co-ordinator
Larissa Lowe	(LL)	Type IV Co-ordinator
Andrew Wakelin	(AW)	Type V Co-ordinator and Chairman AGSD-UK
Wendy Griffiths	(WG)	Administrator AGSD-UK

ACTIONS

1. The Chairman opened the meeting and welcomed everyone to Telford Conference.
2. The Chairman reported that because of other commitments, Christine Evans has resigned as Type IX Co-ordinator. AW had thanked Christine for the work she had done over the last few years. The Trustees would seek a new Co-ordinator. AW
3. AW showed the information cards which have been produced for Type V patients to keep in their wallet or purse, and asked the other Co-ordinators if they would like to have a similar card for their patient types. The other Co-ordinators were very interested, and would consider what they would like on their particular cards. ALL
4. There was a discussion about the Conference and feedback forms. EJ said that we need to set the date for the next Conference as soon as possible, making sure that it does not clash with other GSD events or the school holidays. SDM suggested that we find out when other GSD conferences are. AM suggested May could be a good month. However that is impractical for the financial year. There was a suggestion to have it in London and this generated a debate about funding for the Conference, with AM saying the details must be decided within the next month. He suggested October/November, but not at half term. Reading and the Home Counties for locations were also put forward. AW said we need feedback from all members not just those attending this year's conference. AM to organise survey. AM
5. EJ said she planned to attend that the International Congress on Hepatic GSDs in Lyon, France on Wednesday 4th to Friday 6th April 2012. She also mentioned that the Spanish president was proposing that the EU be asked for funding for all GSD types. EJ
6. The date of the next meeting – to be advised.

The meeting closed at 11am.