

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

TYPE CO-ORDINATORS' MEETING
Saturday 16th April, 2011 at St. Fagan's Museum, Cardiff

MINUTES

Present

Andrew Wakelin (AW) Chairman AGSD (UK) and Type V Co-ordinator
Allan Muir (AM) Development Director AGSD (UK) and Type II Co-ordinator
Wendy Griffiths (WG) Administrator AGSD (UK)
Larissa Lowe (LL) Representing Type IV patients and families
Esther James (EJ) Type III Co-ordinator
Ben Parker (BP)

ACTIONS

1. The meeting opened and introductions were given.
2. Development Plan AW outlined the AGSD's Development Plan, and it was agreed that everyone would be emailed a copy of it. WG
3. Rebranding AM explained that there are plans to rebrand the Association, and showed those present the first drafts and ideas for the new logo. The difference between "Glisten" and Glysten" was discussed. The designers thought that the first option was the best from the point of view of people unfamiliar with the Association, but AW said that it should be the second option, to keep the "Y" for Glycogen. AW suggested "Glycogen UK", but BP said that if you do not use GSD then it loses its purpose. AM said that it needs to be a "one word brand" – something to stick in people's minds. BP and LL thought it should be left as AGSD (UK). EJ said she did not like the "Playing Cards" and AW agreed, saying our new professional image should lead away from the Playing Cards logo. There was general agreement to keep the "Y" in Glysten.
AM will present the designs and the meeting's thoughts to the next meeting of the Trustees. AM
4. Type Co-ordinators' Reviews and Statements
Type II: AM mentioned the campaign in Scotland, and spoke about a drug that is due to be trialled in Manchester.
AM spoke about medication, and said that chaperone therapy has not so far worked successfully on Type II patients, but trials are due to start soon, using it as a combination therapy with Myozyme.
AM said that doctors and consultants should tell newly-diagnosed Pompe patients about AGSD (UK) at their first appointment, as there is often a four week void between diagnosis and referral to the clinic. This support would alleviate worry and stress for them in the early days.
AM said that he had attended Rare Disease Days in Scotland and Wales recently.

TYPE CO-ORDINATORS' MEETING MINUTES

(cont'd)

ACTIONS

Type III: EJ said that Dr. Weinstein is helping to set up a GSD clinic in Cardiff in June. There are now published "GSD III Management Guidelines." EJ reported that many paediatric patients do not transition well into adult services and many try to cope with the disease alone until a crisis hits later in life. AM reported that the UK LSD Collaboration are currently assessing transition and there may be useful lessons learned when their report is published.

EJ said that a new clinic is being set up in Cardiff, and that she is aware of seven other Type III patients in South Wales. She added that there is a Type III lady in Southern Ireland who was aware of 20 families affected and who wanted to set up a local GSD support group.

The BIMDG is holding a symposium on June 30/July 1 which EJ has been invited to attend. Others may also like to attend but there is a £15 joining fee for the group and a registration fee for the event.

EJ

Type IV: LL spoke about trials and said that with the most common form of Andersen Disease, infants die at an early age. The patient group therefore consists of adult-onset patients and there are very few of them. AM suggested that it may be said that Type Co-ordinators often know best where the research is taking place and when it is happening.

LL told how it was 8 years from her first symptoms to receiving a diagnosis and a gastroenterologist had originally misdiagnosed her as having an eating disorder. She has tried an anaplerotic diet without success. Dr Elaine Murphy at the National Hospital (Queen Square, London) has been helpful and other useful contacts would be Prof. Joanne Martin and Emeritus Prof. Jeremy Powell Tuck, both at the Queen Mary Hospital, London.

LL said she is happy for people to be put in touch with her when she becomes Type IV Co-ordinator, and she is happy to talk to them about the condition.

Type V: AW said that the McArdle's Clinic now has national funding and is relocated to London, and there is also a Type VII Clinic proposed for an initial 4 patients. He said there are 90 patients registered at the McArdle's Clinic, the largest such group in the world. No medication is available for the condition, but exercise is recommended.

After the success of the "Walk over Wales" for McArdle's last year, AW is running two one-week courses in Wales this June/July, each for eight people with the condition.

TYPE CO-ORDINATORS' MEETING MINUTES
(cont'd)

ACTIONS

AW finished by saying that the McArdle's Handbook is not quite ready and is the work of Kathryn Wright who studied McArdle's Disease for her PhD.

5. Membership

AM said that he hopes that people who have left the AGSD-UK will return as a result of our improving image, and that the membership will grow. LL asked if we are registered with the Data Protection Act, and the answer was yes. It was explained Type Co-ordinators can access their particular "Types" membership database. AW explained the difference between being "registered" and being a "member".

6. Communications

The website was discussed, and there was concern that some of the information could be improved. It was suggested that we might commission someone to update and correct it, especially the medical details on it, which might not presently be up to date.

There was a discussion about the value of Facebook, GSDNet, etc. within different age groups. There was a debate about whether it should be emailed or sent as a hard copy.

AW said that when the database is finally sorted, he hoped that an attractive newsletter would go to all those registered with the AGSD-UK twice a year, and the Pompe Bulletin may be incorporated within.

Single page updates for each GSD type, could, of course, be published whenever necessary. LL thought that it should be relevant to all readers, but AM argued that most people would find something of interest within the pages.

The need for a telephone helpline was discussed, and it was decided that this would not be practical.

AM showed a range of publications from other patient organisations; where relevant information is already published (e.g. guide to wheelchairs) we should refer to them where appropriate and publish our own 1/3rd A4 leaflets in each GSD Type.

7. Projects

AM spoke about his submission for a bid of £25,000 from Sanofi-Aventis to organise a complete review of patient numbers and care for those living with GSD.

EJ suggested that Patient Experiences should be put on the website.

TYPE CO-ORDINATORS' MEETING MINUTES

(cont'd)

ACTIONS

AM said that he is hoping for money to film the Pompe to Pompeii Cycle Challenge, and has written to four companies to ask for funding.
AW said that an information leaflet for each GSD Type should be a priority.

8. Conference

The outline of the conference and possible speakers were discussed, such as Elaine Murphy, Dr. Weinstein, Jo Martin and Duncan Cole. Also maybe, a Type I dietician from Great Ormond Street.
BP and LL suggested some patient stories, perhaps in the form of patient presentations (limited to ten minutes each). Other suggestions were workshops about peg-fed babies, coping with diagnosis, equal opportunities and disability benefits under UK legislation. These could take the form of discussion groups in different break-out rooms.

AW said we need to work out timings for the networking sessions.

AW/WG

EJ said that she and Rob would be prepared to chair a workshop for Type III.

EJ/ROB

EJ suggested that a parent or sibling might be willing to give a presentation of their experiences.

It was agreed that the Association would, subject to Trustee approval, pay for the Friday night's hotel accommodation on the Friday evening to allow time for a Type Coordinators' meeting on Friday or Saturday.

9. Date of next meeting

It was agreed that these Type Co-ordinators' meetings would take place twice a year, and that the next one will take place during the Conference in Telford, possibly on the Friday evening or Saturday morning.

Meeting closed at 4.40pm.