

2007 Reading Conference Report of General Secretary to the 23rd Annual General Meeting and Family Conference of the Association for Glycogen Storage Disease (UK)

Charity Registration No. 327841

We have held our annual AGM and Family Conferences in several great northern cities including Newcastle-upon-Tyne (1994), Edinburgh (1996), Manchester (1999) and Bradford (2003). In 2006 we revisited Bradford and enjoyed the friendly facilities of the NOVOTEL for a second time.

Hugo Del Mar opened the 2006 AGM by welcoming 26 families and an equal number of health professionals. Hugo thanked everyone for giving up their Saturday to meet and discuss the latest progress in the management and treatment of glycogen storage diseases.

The following officers were duly nominated and elected to serve for the until the 2007 AGM.

General Secretary	Ann Phillips
Hon. Treasurer	Sue Del Mar
Hon. Secretary	Clive Tonks
GSD type I representative	Hugo Del Mar
GSD type II representative	Allan Muir
GSD type III representative	Robert Wood
GSD type V co-ordinator (non-board member)	Andrew Wakelin
Vacancies :	General Member
	Data-coordinator
	Publicity Officer

All members of the Executive Committee meet 3 times a year to set out the details for future conferences, the latest promising research into treatments and (hopefully) cures for GSDs. These members help run the ongoing business of the AGSD(UK). We are sorely in need of new **General Members** with a willingness to help us progress into becoming an efficient and viable organisation.

Expertise in Management, Charity Law data protection Publicity and fund raising ideas would be an added bonus.

Allan Muir then gave a report on the very successful bike ride in Costa Rica which raised over £38,000. Hugo then closed the and members dispersed to Workshops on Types I, III, Pompe's and McArdles. Written reports can be found on our website www.agsd.org.uk under Workshop Reports for individual types

NEWSLETTER NEWS

The advent of our new and revamped website plus the willingness of hard working mother Rosalind Martin to be our Newsletter editor, means there is a pdf version available to whoever **registers their e-mail address** with our Treasurer (and data-base holder) Sue DelMar. The Newsletter is still available in paper format to those who do not or cannot access the internet and **have registered their postal address and a contact phone number** with Sue.

We have produced three Newsletters the since 2006 Conference.

SPRING 2007 (Vol. 6 Issue 3)

SUMMER 2007 (Vol 6 Issue 4)

WINTER 2007 (Vol.6 Issue 5) (Conference information issue)

Spring and Summer 2007 issues contain: the following highlights.

The progress and growth of the **McArdles clinics** in Oswestry by Andrew Wakelin our GSD type V coordinator. Dr. Ros Quinlivan has written her Report to the AGSD(UK) on the McArdle's Disease Service and a Research Annual Report on the Wolfson Centre for Inherited Neuromuscular Disease. The clinics, which currently are held on a quarterly basis, have become oversubscribed. The doctors (Oswestry, Birmingham and Sheffield) involved have prepared a business case for the National Specialist Commission (NCG) to fund a diagnostic and clinical service for McArdle's disease in the UK. This would mean monthly clinics giving patients better and more frequent access to assessment and management. The most conservative estimate of incidence means that there must be 180+ McArdle patients in the UK, of whom they are seeing about 50 so far and with increasing numbers requesting appointments all the time.

Allan Muir is the new chairperson of the *International Pompe's Association* (IPA). The IPA is a federation of Pompe support groups around the world, which includes many groups that support other GSD types – like the AGSD(UK). Allan reported to our committee that Joan Fletcher (Willink, Manchester) has been appointed the **Pompe Family Support Officer** for all Pompe patients in the UK. Joan will be based at the NCG Centre for Lysosomal Storage Diseases in Manchester. This is a hugely significant step and very exciting for the AGSD(UK). Joan will start working on 1st October 2007 (depending on Police checks etc.) and will be at the 2007 Reading Conference to meet everyone.

Details on the Pompe Pages (www.pompe.org.uk – News)

FAMILY NEWS

Three family friends or members have obtained a place in the London 2007 Marathon and have chosen to support the AGSD(UK). We hope to hear of their their efforts and struggles on our behalf at this year's AGM in Reading. Thank you so much to Gary Baker, Luca Venditto and John Clarke for their hard work and perseverance.

Michael Addison Hugh Martin was born to Roalind Martin (GSD V and our News editor) on Tuesday, 7 November 2006. Rosalind managed to produce our first pdf Newsletter three weeks before little Michael was due. Michael was her excuse for missing the 2006 Bradford conference!! Many congratulations in order and we hope he grows up to be our publicity co-ordinator. .

Geoffrey and Caroline Wood celebrated their Silver Wedding Anniversary. Their son Robert Wood is our GSD type III co-ordinator. Robert just graduated from university in Business Studies and Management. He and his partner Jenny (also newly graduated) will hopefully give some new skills and insight to our Executive Committee

Jane Cargill (GSD V) with five "companions of the road" described their walk of the West Highland Way covering 95 miles between Milngrave to Fort Williams. Her training run consisted of an ascent of Ben Lomond. We look forward to her next challenge of climbing Ben Nevis in September 2007.

Nancy Yetman (GSD Ia) describes having a **liver transplant** to "cure" her GSD. She comes from a family of eight children, five of whom had GSD, 3 died from complication of GSD type 1A. Her story is more than inspiring and will give hope for any GSD people who may have to undergo such a procedure. The Phillips family is especially grateful for allowing her story to be published.

Member Grant Fraser wishes to remind everyone to send him your **used stamps**. Address is: 64 Laichpark Rd, EINBURGH EH14 1XB. Details can be found in the SPRING 2007 newsletter.

Dr. Clive Tonks (Pompe) is on the adult Myozyme infusion programme and describes his first six months on the treatment.

Ann Phillips attended the USA 2007 Conference at Duke University in Durham, North Carolina. Over 150 people came and this year attended Workshops in both the liver affected GSDs (specific therapies for, liver transplant panel) and for the Muscle affected types V and VI etc. A full report will be posted to the December 2007 Newsletter. The Florida team were very welcoming and took Ann on a day outing to a Lemur colony and the first tobacco plantation!!

EXECUTIVE COMMITTEE -met on the three Saturdays of
3rd February, 9th June and 22nd of September.

Congratulations and thank you to Hugo Del Mar, Allan Muir and Andrew Wakelin for getting the new webpage up and running with easily accessible content constantly being amended and added. Hopefully, more past Workshops will become available and perhaps some if not all of the Newsletters produced since 1985 will eventually be available. Andrew has put a lot more information about Type 5 onto the web site (and more to go, when I get time). This has boosted the number of hits we are getting from people's searches on Google, Yahoo, etc. I am getting more enquiries from all around the world. I recently had three new UK patients find us in one week! We can now get very interesting **stats on usage of the web site via Google Analytics** – Andrew will show anyone who is interested show to access them during the Conference.

The Exe Committee is accepting the advice of .Andrew Wakelin to try and produce a quarterly Newsletter starting with December 2007.

For four issues a year we should aim for

Mid December – most of the Conference reports

Mid March

Mid June

Mid September (Conference details)

If all goes to plan the following general dates will be set.

A – Main copy date for articles (D minus 1 month).

B - Date for small, last minute news items (D minus 10days)

C – Date Sue (has the e-mail address list) for distribution (D minus 1 week)

D – Publishing date.

All AGSD(UK members are encouraged to submit information (referenced of course), stories, Photo's etc. However, each piece and/or picture submitted must give clear and written consent to being published in the pdf for registered membership and/or consent to be placed on the more openly accessible www.agsd.org.uk website.

I personally would like to thank all those who have arranged and hosted our past family gatherings starting with first proper AGM in when 5 founding families met at the Del Mars' home in 1985 and Hugh and Greta's Murphy's home in 1986. As our membership grew the Conferences expanded into church halls and scout huts. It was our 10th AGM Conference in Newcastle-upon-tyne where we first made use of a hotel as a base with lectures at Teaching Centre of Newcastle General Hospital. The hosting record lies with Sue Del Mar who has hosted at least 7 of these over the years

Submitted to 23rd AGM on 13 October 2007 by Ann Phillips
General Secretary AGSD(UK)

ASSOCIATION FOR GLYCOGEN STORAGE DISEASE (UK)

Registered Charity 327841

ANNUAL ACCOUNTS FOR YEAR ENDING 31 MAY 2007

Statement of Financial Activities

	£	£	2,006 £	2,006 £
	Unrestricted Funds	Restricted Funds	Unrestricted Funds	Restricted Funds
INCOMING RESOURCES				
Donations	2,142	1,554	966	2,918
Gift Aid	4,260		1,692	
Fund raising	5,872	4,516	18,078	
Conference income	3,500		3,380	
Investment Income	3,944	1,756	3,509	1,658
Subscriptions	980		1,120	
TOTAL INCOMING RESOURCES	20,698	7,826	28,745	4,576
RESOURCES EXPENDED				
Charitable Expenditure		76		470
Conference Expenditure	4,034		6,035	
Website	4,139	2,000		
Fund Raising Expenses	380	26		
Subs to other Charities	70		130	70
Merchandise	485			
Grants	600		20,040	
Management And Administration	1,310	2,220	1,522	4,904
TOTAL RESOURCES EXPENDED	11,018	4,322	27,727	5,444
NET INCOMING RESOURCES	9,680	3,504	1,018	-868
FUND BALANCE BROUGHT FORWARD	81,574	38,798	80,556	39,666
FUND BALANCES CARRIED FORWARD	91,254	42,302	81,574	38,798
ALLOCATION OF FUNDS				
VON GIERKE	1,014		867	
POMPE	27,482		29,056	
CORI	3,927		3,617	
MCARDLE	9,878		5,258	
General	91,254		81,574	
TOTAL	133,555		120,372	