

ACCOUNTS

No 6

327841

11 APR 2007

RECEIVED BY POST TEAM,
COMPLIANCE DIVISION

**REPORT of General Secretary to the 22nd Annual General Meeting and
Family Conference of the Association for Glycogen Storage Disease (UK)**

For 2006
Charity Registration No. 327841

Exciting things have been happening since we last met at the Milton Keynes Hilton on Sunday 16th October 2005.

The big news is the announcement that The European Commission granted a marketing authorisation, valid throughout the European Union, for **Myozyme** on 29 March 2006. **Myozyme** is the Enzyme Replacement Therapy for Pompe Disease, or GSD II.

Myozyme is now funded by the Department of Health through its specialist commissioning body, **NSCAG**, and the treatment is available in one of the 3 paediatric and 4 adult expert centres in Manchester, Cambridge and London. These centres for Lysosomal Storage Diseases (LSDs) were established in April 2005 and are the expert centres for the Diagnosis, Management and Treatment of Pompe Disease. The NSCAG centres currently have funding until 2008

In Scotland and Wales funding is still a problem although there is currently one infant funded in Scotland and one teenage girl in Wales who has been granted a 6-month trial period on therapy. Our only known patient known in Northern Ireland will be treated in Manchester.

In June 2006 THE AGSD (UK) Executive Committee met and voted unanimously to accept the MDC offer to accommodate a family support officer for the UK Pompe community in their Clapham office. The MDC worked closely with the AGSD (UK) for many months last year to research the current care situation with UK Pompe families and to understand their expectations from the new therapy. The new staff member will work alongside the MDC information officer who undertook that research. The MDC also has a new Research Officer who has expressed a keen interest in Pompe Disease and has attended Pompe meetings and events.

Genzyme have approved the decision and has offered to fund the project, this will enable us to recruit an experienced nurse/care-worker/social worker full time. Funding is expected to last at least three years and will be ongoing if successful.

Negotiations with the MDC are still ongoing and we are awaiting the approval of the MDC Board of trustees before contracts can be signed. We hope to start recruiting in late November 2006



The 21st 2005 AGSD(UK) Family Conference and AGM was held at the Milton Keynes Hilton. It was organised at a distance by Ann Phillips with the help of a Professional Conference company called Capital Conferences Ltd. – 'Free venue Finding and Booking service'. The final total cost of the 2005 Conference in Milton Keynes was £6000 but a grant from Genzyme reduced this to £1670.

At the AGM (chaired by Hugo Del Mar) the following Executive Committee officers were duly nominated and elected:

<u>POSITION</u>	<u>NAME</u>
General Secretary	Ann Phillips
Treasurer	Sue Del Mar
Secretary	Clive Tonks
Data-Coordinator	Peter Constable
GSD type I Co-ordinator	Hugo Del Mar
GSD type II Co-ordinator	Allan Muir
GSD type III Co-ordinator	Lisa Alexandra (<i>resigned 2005</i>)

The **GSD type V** Co-ordinator Andrew Wakelin may from time to time attend committee meetings but is not a trustee/Executive Committee member. The positions of **type GSD IX co-ordinator, General Member and Publicity** remain vacant.

The rest of the morning and afternoon was taken up by very full Workshops as follows:

GSD type I: Dr. Brian Peterson (Florida USA) spoke separately to GSD I and III families about his promising research using undifferentiated adult stem cells to correct GSD defects using gene therapy techniques. His Workshop Report is available on request from A Phillips. (There are copies available today at the registration desk).

GSD type II (Pompe) had a long programme of speakers. A full report of what was said can be found from the Pompe link on www.agsd.org.uk or on www.worldpompe.org.

GSD type III Workshop was given by Professor Peter Smit (Holland) wherein he outlined plans to coordinate current information about management and treatment. A new emphasis for future research will be into the long-term effects of GSD IIIa (muscle and liver) on patients. Professor Smit also spoke to

GSD type V workshop was taken by Dr. Ros Quinlivan (RJ&AH Oswestry NHS Trust) She spoke about Professor John Howell's work in Australia using sheep affected by McArdles and gave an update on the progress of the McArdle's clinics held four times a year in Oswestry. A report of the Workshop can be found in the SPRING 2006 (Volume 6 Issue 1) of our Newsletters.



ANNUAL ACCOUNTS FOR ASGD 2005/2006

INCOME		2004/2005		2005/2006		
	£	£	£	£	£	£
	1060.00	Subs				1120.00
	6769.00	General	Donations	Interest	Total	
	218.00	McArdles	965.75	808.78		
	807.00	Type III	204.25	213.27		
	2238.00	Pompés	986.60	131.08		
	1632.00	Type I	1620.00	1282.30		
			107.90	31.86		
	11664.00		3884.50	2467.29	6351.79	
		Total Donations+Interest				6351.79
	406.00	gift aid			445.64	
		Bike Ride Gift Aid			1245.82	
	2478.00	bike ride int			2699.44	
	8769.00	CR bike ride			39179.46	
	3556.00	2004 Conference Grants				
		2005 Conference Grant			3380.00	
	68.00	Conference			920.30	
						47870.66
		Total				
	92006.00	TOTAL INCOME				56342.46
EXPENDITURE						
		Administration				
			Pompe	General	McArdle	
		Postage	272.15	390.19		
		printing & artwork	352.50	820.47		
		Stationery	88.72	145.24		
		Salary MDC	3786.67			
		Corn Travel & conference Costs	249.72	118.78	153.60	
		Other		46.90		
	6271.34	TOTAL	4749.76	1521.58	153.60	
		TOTAL ADMIN				6424.94
		Pompe Article for Newsletter	470.00			470.00
		McArdle refreshments			39.90	39.90
	6814.00	2004 Conference				
		2005 Conference		6454.56		6454.56
		2006 Conference		500.00		500.00
	1620.00	Cornstarch Grant General				
	110.00	Subs to Orgs	70.00	130.00		200.00
	86.00	Merchandise				
	2000.00	McArdles Grant from Bike Ride A/C				20000.00
		CR Bike Ride				21100.73
	48730.00	TOTAL EXPENDITURE				55190.13
	43275.00			Income less expenditure		152.32
	60559.00			Brought forward		120219.75
	103834.00			TOTAL		120372.07
				as at 31-05-06		
	1217.83			Lloyds a/c No. 0042991		124.69
	139.62			Lloyds Bike Ride a/c No. 0486725		78.73
	56877.68			COIF Fund a/c No 943100001C		56099.15
	61984.62			COIF Bike Ride Fund a/c No 943100002C		64069.50
	120219.75			TOTAL		120372.07

*Accountant and Joint
Account
Amy Walker
Accountant*

2004-2005

31443.55 Pompe's
5304.42 McArdles
2453.68 Type III
727.65 Type I
18166.21 General
62124.24 Bike ride

120219.75 TOTAL

ALLOCATION

2005-2006

Pompe's
McArdles
Type III
Type I
General
Bike ride

29056.09
5527.93
3571.37
867.41
17201.04
64148.23

120372.07



ASSOCIATION FOR GLYCOGEN STORAGE DISEASE (UK)

Registered Charity 327841

ANNUAL ACCOUNTS FOR YEAR ENDING 31 MAY 2006

Statement of Financial Activities

	£ Unrestricted Funds	£ Restricted Funds
INCOMING RESOURCES		
Donations	966	
Type I		107
Type II		1,620
Type III		987
Type V		204
Gift Aid	446	
Gift Aid Bike Ride Fund		1,246
Costa Rica Bike Ride		39,179
2005 Conference Grant	3,380	
2005 Conference Income	920	
Investment Income	809	
Type I		32
Type II		1,282
Type III		131
Type V		213
Bike Ride Fund		2,700
Subscriptions	1,120	
TOTAL INCOMING RESOURCES	7,641	47,701
RESOURCES EXPENDED		
Charitable Expenditure		
Type II		470
Type V Grant from bike ride account		20,040
2005 Conference Expenditure	6,454	
2006 Conference Expenditure	500	
Costa Rica Bike Ride Expenses		21,100
Subs to other Charities	130	70
Management And Administration	1,522	
Type II		4,750
Type V		154
TOTAL RESOURCES EXPENDED	8,606	46,584
NET INCOMING RESOURCES	-965	1,117
FUND BALANCE BROUGHT FORWARD	18,166	102,054
FUND BALANCES CARRIED FORWARD	17,201	103,171
ALLOCATION OF FUNDS		
VON GIERKE	867	
POMPE	29,056	
CORI	3,572	
MCARDLE	5,528	
GENERAL	17,201	
BIKE RIDE	64,148	
TOTAL	120,372	

Activities during October 2005 to October 2006.

In 2005 the AGSD(UK) was delighted to be able to make a contribution of £20,000 towards a research project being run by Professor Glenn Morris and Dr Ros Quinlivan at the **Centre for Inherited Neuromuscular Disease** at the Robert Jones and Agnes Hunt Orthopaedic Hospital, Oswestry. Kathryn Wright, a PhD student working on the project, is reporting on progress during the 2006 McArdle's workshop.

Peter Constable our data Co-ordinator has received notice from the Flora London Marathon that the **AGSD(UK) has been designated a Silver Bond Holder** for the Flora London Marathon 2007. Peter will be the requirements of such a Bond and asking for sponsored volunteers to run for the AGSD(UK)

The Executive Committee of the AGSD(UK) met three times on 11 February 2006, 24 June 2006 and 5 September 2006. Discussion at all three meetings included:

Plans for the 2006 Conference and future Conferences.

A decision was made to produce an *electronic version of our Newsletter* as the cost of postage and overseas mailing was beginning to affect our administration budget. To this end enquiries were made and one of our long standing members Rosalind Martin has accepted the role of Newsletter editor. Due to technical difficulties well understood by anyone owning a PC the Summer Newsletter came out in September 2006 in time for our Conference. Please note:

The *SPRING 2006 and SUMMER 2006 Newsletters* are available in pdf format. Please ensure you have given Sue Del Mar your e-mail address and/or have written it into the official Registration book we keep for Charity Commission attendance records.

A new general Leaflet should be available in 2007. This will be accompanied by additional information specific to GSD type as requested.

We are actively seeking a new webmaster and internet service. It is hoped the new site will also generate income for the AGSD(UK) so your support will be very welcome when things are up and running. The aim is to bring both websites (AGSD and Pompe) together. A sub-committee has been formed to look into the possibilities. The AGSD(UK) will benefit greatly from a new professional image as the members of the Executive Committee review and update our charity's status, form and procedures.

We would like to ask you our **members to volunteer for one year** to come onto our Executive Committee. The posts vacant include:

- Data-coordinator
- Publicity
- GSD type III representative
- General Member

Executive Committee meetings are held 3 times a year in London at the Eurostar office in Waterloo station (venue generously arranged by Hugo Del Mar). From the above you can see the discussions and decisions we make on your behalf.

Two Newsletters were composed and posted or e-mailed to paid-up members of the AGSD(UK) in 2006.

SPRING 2006 (Vol. 6 Issue 1)

Details of the 16 October 2005 Family Conference and Workshop speakers were presented. The Workshop reports for Type I GSD were not included with the Spring Newsletter as they were intended to go out as a separate posting along with those for GSD Type II (Pompe), GSD type III and type V (McArdles). Unfortunately the Workshop report given by Dr. Byron Peterson GSD type I though written up by Sue Del Mar was not posted or put onto the webpage this year for technical reasons. The Pompe's Workshop is available on the Pompe – link to our webpage. The type III Workshop is available in the form of a slide presentation by Professor Peter Smit from the Netherlands. The type V Workshop was reported under "McArdle's News@ in the SPRING 2006 NEWSLETTER. Other items were the celebration of the good news about the availability of Myozyme for the treatment of Pompe disease by the European Regulatory Committee. Family news came from Sioned Williams (type V), Clare Baker (type I) and the Muir family.

Helen Fowler of the Muscular Dystrophy Campaign reported on her work from July 2005 to February 2006 where she had spent one day a week supporting the AGSD(UK) Pompe's group. The main part of her work was conducting a survey of UK Pompe members with the aim of better understanding the needs of the UK Pompe the community. The report is called '*People living with late onset Pompe disease in the UK*' and is available from Allan Muir. Helen also investigated major medical alert products in the UK. This has led to the Medi - Alert presentation you will hear at the 2006 Conference.

Other articles include an item called '**Ten Years Ago**' about a weekend away that was held for GSD type I and III families near Milton Keynes. The venue was arranged by the Shall family and the GSD families were registered and organised by Ann Massimo. Dr Philip Lee and a team of volunteer doctors and other professionals presented a marvellous set of programmes separately for adults and children. Funding was provided by grants from the DoH section 64 Grant plus donations from Sherwood Medical and Hospital Supplies.

SUMMER 2006 (Vol. 6 Issue 2)

contains details of the 16 October 2006 Family Conference and AGM including a registration form, a map of how to get to the Novotel in Bradford, the required announcement of re-election of officers and the minutes of the 26th Annual General meeting in Milton Keynes. An item of special interest is the moving account by Mr. Hubert Boyle called '**78 Years of McArdle's**'. On page 5 is Word search puzzle which contains words associated with GSD (compliments if our new editor Ros Martin).

Submitted to 22nd AGM on 14 October 2006 by Ann Phillips
President/General Secretary AGSD(UK)