

# 24th Annual General Meeting and Family Conference of the Association for Glycogen Storage Disease (UK)

Charity Registration No. 327841

## Report of General Secretary to the 2008 Reading Conference

The October 2007 Family Conference was held at the Novotel on 13 October 2007. Chairman Hugo DelMar opened the 23rd AGM thanking everyone for giving up their Saturday to meet and discuss the latest progress in the management and treatment of glycogen storage diseases. Over 70 families and health professionals attended including a family from Isreal. Hugo announced the launch of much improved AGSD(UK) website which was linked to PayPal. This allows subscriptions and donations to the association, to be paid via the website. In the past a large part of our administration expenses came from postage and printing paper copies of our Newsletter three times a year. Hugo thanked the London Marathon runners, Gary Baker, James Clarke and Luca Venditto, who had raised over £12,000 for the association. He paid special tribute to Sue Del Mar for her efforts in organising this and other conferences and thanked Genzyme for their continued sponsorship.

our membership of articles, activities, pictures etc and family news we may struggle to do so. OThe following officers were duly nominated and elected to serve for the until the 2008 AGM.

General Secretary	Ann Phillips
Hon. Treasurer	Sue DelMar
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

**Again no one volunteered for the vacant posts.** All members of the Executive Committee meet 3 times a year in LONDON 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 Members** with a willingness to help us progress into becoming an efficient and viable organisation.

Those who have read Clive Tonks' Personal Reminiscences of the October 2007 Reading conference in the Spring 2008 Newsletter will remember a fire alarm drill at midnight. Hopefully this year you will all have an uninterrupted rest. The NOVOTEL management was contacted by the Conference organiser and they sent the following statement: " We are examining what happened during the fire alarm to ensure that if there is ever a real fire will be able to deal with it efficiently and effectively. Thank you for your comments."

Hugo then closed the formal AGM 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](http://www.agsd.org.uk) under Workshop Reports for individual types.

There were two main issues of the AGSD(UK) Newsletter in SPRING and SUMMER plus the pre-2008 Conference Newsletter. The Board would still like to be able to publish at least quarterly but until we have more members on the Committee plus active submissions from ur editor Rosalind is excellent and can accomodate all formats!!

### Spring 2008 Volume 6, Issue 5:

Allan Muir reported on developments the Pompes enzyme replacement therapy LOTS trials and the establishment of the UK government NSCAG Lysosomal Disorders Centres. These are modelled on the original four UK Gaucher centers set up in the early 80's. Dr.Weinstein's **Type 1 Workshop report** from the 2007 Conference

includes the new Cornstarch trials, current management of GSD types 1a and 1b and Type III developments. Katherine Wright reports on the World Muscle Society International Congress and ensuing developments in her McArdles research at RJAH Orthopaedic Centre for Inherited Neuromuscular Disease (CIND) in Oswestry UK.

**SUMMER 2008- Volume 6 Issue 6:**

This issue reported on the **Workshop on GSD Type III** given jointly by Professor Smit (Holland) and Dr. Weinstein (Florida). There are two reports on developments in **GSD type V or McArdles** : Dr. R Quinlivan reported on her work with the McArdles Disease Service at the Wolfson CIND and Rachel Wright describes her work in developing cell culture models of McArdles derived from special mutations from wild type mice and McArdles' affected sheep (Dr. Howell in Australia). Dr. Ratna Puri (New Delhi) wrote a vivid description of her participation in a **Liver Glycogen Storage Disorders Course** held in Manchester between 17<sup>th</sup> – 18<sup>th</sup> April 2008.

Dr. Puri was sponsored by the AGSD(UK) to attend in order to help improve the management of the many GSD patients in India.

**The Executive Committee met in person** two times on 23<sup>rd</sup> February and 7<sup>th</sup> June in and one **teleconference** meeting(arranged by our Chair Hugo DelMar) on 31 September 2008. A1000 thanks to our intrepid Secretary, Dr. Clive Tonks, who skilfully and quickly produced the minutes of all three meetings. The minutes are electronically available on request by any AGSD(UK) member from Dr. Tonks.

Hugo and Andrew reported further improvements to links and content of the AGSD(UK) webpage. The Committee have begun to discuss the possibility of employing an Information Officer. Allan and Andrew agreed to develop a job description and aims for such a post which initially could be funded for a year.

Long term funding would be a problem.

Finally I wish to apologise for my lack of participation in the work of the AGSD(UK) this past year because of my son Peter Phillips ultimately fatal 3 liver transplants.

I do express my deepest appreciation to the other members of the Committee including the Chair Hugo DelMar, Secretary Clive Tonks, Treasurer Sue DeMar , Andrew Wakelin, Allan Muir and Ailsa Arthur.

Submitted to 24th AGM on 27 September 2008 by Ann Phillips,  
General Secretary AGSD(UK)

## ASSOCIATION FOR GLYCOGEN STORAGE DISEASE (UK)

Registered Charity 327841

**ANNUAL ACCOUNTS FOR YEAR ENDING 31 MAY 2008**

Statement of Financial Activities	2008	2008	2007	2007
	£	£	£	£
	Unrestricted	Restricted	Unrestricted	Restricted
	Funds	Funds	Funds	Funds
<b>INCOMING RESOURCES</b>				
Donations	1,546	8,992	2,141	1,554
Gift Aid			4,260	
Fund raising	3,262	859	5,872	4,516
Conference income	3,946		3,500	
Investment Income	5,138	2,473	3,944	1,756
Subscriptions	600		980	
<b>TOTAL INCOMING RESOURCES</b>	<b>14,492</b>	<b>12,324</b>	<b>20,697</b>	<b>7,826</b>
<b>RESOURCES EXPENDED</b>				
Charitable Expenditure		45		76
Conference Expenditure	5,608		4,034	
Website	430		4,139	2,000
Fund Raising Expenses	10	25	380	26
Subs to other Charities	120		70	
Merchandise			485	
Grants		515	600	
Management And Administration	1,253	375	1,310	2,220
<b>TOTAL RESOURCES EXPENDED</b>	<b>7,421</b>	<b>960</b>	<b>11,018</b>	<b>4,322</b>
<b>NET INCOMING RESOURCES</b>	<b>7,071</b>	<b>11,364</b>	<b>9,679</b>	<b>3,504</b>
<b>FUND BALANCE BROUGHT FORWARD</b>	<b>91,253</b>	<b>42,302</b>	<b>81,574</b>	<b>38,798</b>
<b>FUND BALANCES CARRIED FORWARD</b>	<b>98,324</b>	<b>53,666</b>	<b>91,253</b>	<b>42,302</b>
<b>ALLOCATION OF FUNDS</b>				
VON GIERKE	1,809		1,014	
POMPE	29,787		27,482	
CORI	9,441		3,927	
MCARDLE	6,971		9,878	
General	103,982		91,254	
<b>TOTAL</b>	<b>151,990</b>		<b>133,555</b>	