

**The Association for Glycogen Storage Disease (UK)  
Charity Registration No. 327841**

**REPORT of the GENERAL SECRETARY (PRESIDENT) to the 21<sup>st</sup> AGM  
And Family Conference of the AGSD(UK) on  
Sunday 16<sup>th</sup> October 2005 at the Hilton Milton Keynes Hotel**

The venue in for the 20<sup>th</sup> AGM and Family Conference held October 2004 was in downtown Birmingham at the NOVOTEL. This year there was a joint conference with the AGSD(UK) and the IPA (International Pompes Association) spread over the Saturday and Sunday of the 9<sup>th</sup> & 10<sup>th</sup> October 2004. For the first time there was an informal Conference Dinner on the Saturday evening to which families of all types of GSD and professionals were invited. The aim was to enable families to become aware of common experiences and problems which arise in the caring for any child or adult affected by any form of glycogen storage disease.

At the **2004 AGM** (Chair Hugo Del Mar) the following officers were duly nominated and elected:

General Secretary	Ann Phillips
Treasurer	Sue DelMar
Hon. Secretary	Clive Tonks
Data co-ordinator	Peter Constable
GSD type I co-ordinator	Hugo DelMar
GSD II (Pompe) co-ordinator	Allan Muir
GSD III co-ordinator	Lisa Alexander
GSD IX co-ordinator	NOT FILLED
General Member	NOT FILLED

NOTE: Andrew Wakelin is our non-Executive Committee member for GSD type V (McArdles) co-ordinator. The position of General Member is a way of allowing any paid-up member of the AGSD(UK) a chance to attend Executive Committee meetings over a year and contribute their comments and ideas for particular issues.

\*\*\*\*\*

It is with deep feelings of loss that we learned of the passing away of Tim Arthur shortly before the 2004 Birmingham Conference. Our thoughts are with Ailsa and their children. Tim was the guiding spirit of the very. An update on the forthcoming March 2006 Costa Rica Bike Ride will be given by Allan Muir at this AGM. There are still a few places left if you sign up at this October 2005 Conference.

\*\*\*\*\*

The 2004 Saturday Conference started with a light-hearted presentation with photos of the Charity Bike Ride held in November 2003. Colin McArthur gave an excellent off-the-cuff talk about their adventures in Vietnam. He then outlined new plans for the next bike ride due to take place in March 2006. Contact Allan Muir for further details.

## Activities during the Year from October 2004 to October 2005:

**The Executive Committee met three times during 2005  
on 12 February 2005, 18 June 2005 and 24 September 2005.**

At each meeting there was a discussion about such routine matters as Conference planning, Treasurer and General Secretary reports and updates on contacts and news members from each of the GSD type representatives. The Conference this year took a while to organise. Eventually a venue was found through a Conference location company. Ann Phillips agreed to inspect three possible venues located in the southern part of the country and chose the Hilton Milton Keynes as the most suitable. Next year the AGM and Conference is being hosted by Henry Thompson up in Newcastle (probably at the NOVOTEL) on the weekend of the **14<sup>th</sup> and 15<sup>th</sup> October 2006**. Those of you who have been with us for the past 11 years will remember that Henry organised our 10<sup>th</sup> AGM and it was the first time we actually used a Hotel as



part of our venue. No more Scout Huts!!

An important decision was made to agree to a one year contract with the Muscular Dystrophy Campaign to pay the salary for one day a week (Thursdays) of a MDC employee Helen Fowler whose job is to support and gather information on the UK Pompe families. This is an experiment which if successful could be widened to include support for the other GSD type membership. This is a glimpse into the future as we will most likely have to become an incorporated Charity along the lines being set-up by the Charity Commission.

One role a **General Member** to the Executive Committee could take on would be to provide expertise in raising our profile with the public and possibly take on the Newsletter. There is also a need for someone with legal qualifications to advise us from time to time especially if we have to move towards becoming an incorporated Charity. **If any of the current membership feel they could provide this support could you contact Ann Phillips or any other member of the Executive Committee.**

### General Speakers:

Chris Hendriks, (*Birmingham Children's Hospital*) gave us an excellent overview of all GSD's in a humorous yet informative fashion. This talk helped us to all better understand the problems faced by families affected by all the types of GSD. (See Workshop Reports October 2004)

Ruth Gear from the *Muscular Dystrophy Campaign* (MDC) spoke about MDC connections with our muscle affected GSD patients and said the MDC are hoping to have a greater bond with the AGSD in the future. In particular they would like to assist in lobbying for the early licensing of the Enzyme Replacement Therapy (ERT) for Pompe patients in the UK

The MDC is a charity that represents over 30,000 UK patients and over 60 diseases including the muscle affected glycogen storage diseases such as GSD types II (Pompe), IIIa (Forbes/Cori) and V (McArdle's). Our current AGSD(UK) volunteer representative to the MDC is Mrs. Ann Jacklin who made contact last year with the MDC office in London. Note that Miss Jean Tait was our first representative from 1989 to 1994 and our very first Pompe member.

After the morning coffee break people dispersed to the following:

### 2004 WORKSHOPS on GSD

**Type I** Dr. Catheryne Mah,  
Dr.D. Koebel  
Dr. K. Bhattacharya

### WORKSHOPS (continued)

**Type II** Dr. Mark. Davidson (GENZYME),  
Dr. Ed Wraith (Manchester)  
Professor Tim. Cox  
(Cambridge)  
Ellie Gunary (MPS),  
Dr. Catheryn Mah (USA)  
Dr. Kerry Cresawn (USA)  
Dr. Andrea Amalfitano (USA)

**Type V** Drs. J. Buckley, R. Godfrey and  
Dr. G. Whyte (UK Olympic  
Team Physiologists)  
Dr. R. Quinlivan (Oswestry)

After the Buffet Luncheon the **Workshops** continued until afternoon tea at 1600 followed by Final announcements, a cheque presentation and Closure.



\*The Executive Committee apologises that no Workshop reports on GSD type I and type V appeared on the [www.agsd.org.uk](http://www.agsd.org.uk) in January 2005. We are currently **updating the Website** and hope to post the Workshops for 2004 and 2005 onto the Website in January/February 2006. The 2004 Pompe Workshops were duly posted on the **GSDnet** and the **IPA** website by Allan Muir. Past printed copies are **available on request** from Ann Phillips.

**Three Newsletters were composed and sent out to paid-up members of the AGSD(UK).**

**SPRING 2005 (Vol 5 Issue 10): Editor Ann Phillips**

Details of the 2004 Conference in Birmingham were presented. Two **Workshop Reports** were given from Allan Muir (Pompe) and Andrew Wakelin. **Family News** was reported from Claire Baker, Adam Dowley, Doreen de Vine, Rebecca Fitzroy and Peter Phillips. Wendy Bascal gave us a report on caring for her family (one husband and 3 children) as a mother/wife with GSD type IIIb (no muscle involvement). Ann Phillips travelled to 'Down Under on a five week travel holiday with friends. She was able to make contact with three GSD families in Australia and two families in New Zealand. Ann Jacklin reported on a one day Conference held at Nottingham University in December 2004 entitled "Promoting Genetic Education for Health Professionals – A New Era in Caring". Finally members were encouraged to write to their local MP and ask them to join the All Party Group on Metabolic Diseases headed by Kenneth Brennan MP.

**SUMMER 2005 (Vol 5 Issue 11): Editor Ann Phillips**

This issue featured testimonials to **Professor James Leonard** on his retirement from the NHS and The Institute for Child Health. Three of his patients spoke of their experiences of his total commitment and care and expressed their heartfelt thanks. Hugo summed up the kind of care he gave to all of his patients by recalling how delighted Prof. Leonard was when things went well but how determined he was to improve any situation when things went wrong. Professor Leonard has been closely involved in our Association for GSD ever since we were first formed in 1986. I personally and all of us would like to thank him for his patient support and practical advice that was always available over the phone day or night.

This Issue also contains two articles reproduced from the Gaucher Association's Newsletter which give a brief explanation of the remit of **NSCAG** (the National Specialised Commissioning Advisory Group) and of **NICE** (National Institute of Clinical Excellence) in the provision of funding and access to expensive drugs needed to provide proper and effective care for patients with Rare Disorders.

**WINTER/September 2005 (Vol 5 Issue 12): Editor Sue Del Mar**

This was the pre-Conference issue and gave notice of the AGM, a copy of the Minutes from the 2004 AGM and notice of election of officers. A brief provisional Programme for Sunday 16<sup>th</sup> October was given along with details of speakers and Workshops. The accounts for the year are also presented by our Treasurer Sue Del Mar who also produced this issue 12. Family News featured a picture of Rosie Thompson (GSD type III A) as bridesmaid to her long term friend and school support for Rosie throughout her school years.

## ANNUAL ACCOUNTS FOR ASGD 2004/2005

INCOME		2003/2004		2004/2005		
	£	£	£	£	£	£
	1,360 Subs					1,060.00
		Donations	Interest	Total		
5,249.00	General	6,103.59	665.10	6,768.69		
666.00	McArdles	0.00	217.98	217.98		
781.00	Type III	727.50	79.12	806.62		
3,944.00	Pompés	911.11	1,327.20	2,238.31		
18.00	Type I	1,604.97	26.99	1,631.96		
		9,347.17	2,316.39	11,663.56		11,663.56
10,658.00	<b>Total Donations+Interest</b>					
301.00	gift aid			406.15		
501.77	bike ride int			2477.73		
71074.60	bike ride			8769.23		
	2004 Conference Grants			3555.79		
2,109.50	2003 Conference Merchandise			68		
6,000.00	Cornstarch grants					15,276.90
	<b>Total</b>					
92,006	<b>TOTAL INCOME</b>					<b>28,000.46</b>
	<b>Administration</b>					
		Pompe	General			
43.81	Phone			78.92		
335.69	Postage	64.43		156.52		
1,094.65	printing & artwork	352.50		465.72		
196.29	Stationery	189.77		105.19		
602.20	Office Equipment					
186.15	Com Travel & conference Costs	37.20		626.2		
35.00	Computer Costs	127.19		318		
	Other	7.50		56.99		
2,493.79	<b>TOTAL</b>	778.59		1807.54		
	<b>TOTAL ADMIN</b>					2,586.13
3,738	2004 Conference	1,750.00		5064.44		
	<b>TOTAL CONFERENCE</b>					6,814.44
2,000.00	Cornstarch Grant Type I			1,500.00		
	Cornstarch Grant General			500.00		
110.00	Subs to Orgs			120.00		
24.06	Bank Charges					
12.48	Merchandise			86.41		
10,365.00	Cornstarch Grant					
2,000.00	McArdles Grant					
47.85	McArdles Refreshments			7.80		
						2,214.21
48,730	<b>TOTAL EXPENDITURE</b>					<b>2214.21</b>
						11,614.78
43,275.00						Income less expenditure
60,559.00						Brought forward
						16385.68
103,834.00						103834.07
						<b>TOTAL</b>
						120219.75
395.50						as at 31-05-05
370.39						Lloyds a/c No. 0042991
52,561.29						1217.83
50,506.89						Lloyds Bike Ride a/c No. 0486725
103,834.07						139.62
						COIF Fund a/c No 943100001C
						56877.68
						COIF Bike Ride Fund a/c No 943100002
						61984.62
						<b>TOTAL</b>
						120219.75

No 2

**ACCOUNTS**

**17 MAR 2006**

RECEIVED BY POST TEAM;  
COMPLIANCE DIVISION

**2003/2004**

31,733.83	Pompe's
5,094.24	McArdles
1,647.06	Type III
595.69	Type I
12,096.90	General
50,877.28	Bike ride
1,789.07	2003 Con Grant
<hr/>	
<b>103,834.07</b>	<b>TOTAL</b>

**ALLOCATION****2004/2005**

Pompe's	31,443.55
McArdles	5,304.42
Type III	2,453.68
Type I	727.65
General	18,166.21
Bike ride	62,124.24
2003 Con Grant	
<hr/>	
	<b>120,219.75</b>