

## Provisional Programme

### General Topics

#### Fundraising Update

- |                                  |                   |
|----------------------------------|-------------------|
| London Marathon                  | Guy's Abseil      |
| Pompe to Pompeii Cycle Challenge |                   |
| London Marathon Silver Bond      | Brighton Marathon |
| Raffle – win a car               | Winter Wander     |

#### GSD Film

- Progress and Preview

#### Patient Experiences

### Pompe Workshop

#### Pompe Workshop Presentations:

- |   |                          |
|---|--------------------------|
| LSD Health Technology Assessment            | UK Physiotherapy study   |
| Erasmus Exercise Study                      | UK Immune Response Study |
| EMBASSY study                               | Gene Therapy update      |
| Respiratory Muscle Strength Training (RMST) |                          |
| Improving ERT: Genzyme - BioMarin           | - Amicus                 |

#### Topics for small discussion groups could include:

- |                                     |                                   |
|-------------------------------------|-----------------------------------|
| Exercise                            | Nutrition                         |
| Home infusions/canulation           | Genetic Testing – carrier testing |
| Immune responses and adverse events | Population and Newborn Screening  |
| Patient Registries/surveys          | Clinical Trials                   |
| Pompe infant development            |                                   |

### Hepatic GSD Workshops (Types I, III, IV, IX)

#### Topics for Small Discussion Groups could include

- |   |                                     |
|---|-------------------------------------|
| Healthy eating                          | Menu analysis                       |
| Understanding the goals of treatment    | Tasting cornstarch                  |
| Conception/ fertility /pregnancy        | Exercise                            |
| Me and my genes                         | Building and breaking down glycogen |
| How do I treat a hypoglycaemic episode? |                                     |

### McArdle Workshop

#### Discussions led by Andrew Wakelin

## Advance Conference Registration

The Hotel is easily accessible by road from the M6 and the M54, and by train from Telford Central railway station, which is one and a half miles away from the Hotel.

Although you will not be able to check into your rooms until 2pm, we would encourage you to arrive during the morning, as this will give you time for networking, to get to know other members and to meet up again with old friends.

The Conference will start on the Saturday at midday with registration and lunch, and during the afternoon there will be the usual eclectic mix of speakers, workshops, etc. The day will finish with the Conference Dinner, which will take place at 7.30pm.

The Conference continues on Sunday morning, and finishes at 1.15pm with the Chairman's closing remarks, before a buffet lunch is provided. Again, if you wish to stay for the afternoon, there will be opportunities for networking.

### Speakers

Invited Speakers are not required to officially register, and all meals will be provided, but it would be helpful to know your requirements in terms of dietary requirements and conference dinner. Please use the Professionals' registration form to provide this information.

### Accommodation

We have reserved a number of rooms at the Holiday Inn, and AGSD (UK) will subsidise the cost of accommodation for members of the association.

### Residential and Day Delegate Package

Please indicate in the appropriate place on the form whether you will be registering as a residential delegate or a day delegate.



# AGSD-UK Patient and Family Conference

October 22<sup>nd</sup> and 23<sup>rd</sup> 2011

## Residential Packages and Day-delegate Rates

### Patient and Family Residential Package

For <b>one</b> person staying overnight: Includes conference fees, Sunday breakfast, lunches on Saturday and Sunday, all refreshments and <b>conference dinner</b>	£80.00
Additional adults (sixteen or over) sharing this room: Includes conference fees, Sunday breakfast, lunch on Saturday and Sunday, all refreshments and <b>conference dinner</b>	£30.00 per person
Children under sixteen	FREE

Bursaries are available to help patients and families with these costs.

Please apply to the charity office if you require financial support to attend this conference.

### Patient and Family Day Delegate Costs

For <b>one</b> person attending each day (not staying overnight) Includes conference fees, lunch and refreshments.	£10.00 per day
<b>Conference Dinner</b>	
Adults	£10.00 per person
Children under sixteen	FREE

### Health Professional Residential Package

For <b>one</b> person staying overnight: Includes conference fees, Sunday breakfast, lunch on Saturday and Sunday, all refreshments and <b>conference dinner</b>	£150.00
Additional persons sharing this room: Includes conference fees, Sunday breakfast, lunch on Saturday and Sunday, all refreshments and <b>conference dinner</b>	£60.00 per person

### Health-Professional Day Delegate Costs

For one person attending each day (not staying overnight) Includes conference fees, lunch on Saturday and Sunday, and refreshments	£30.00 per day
Conference Dinner on Saturday evening	£25.00 per person

## Family Member Registration Form

Surname	First name	Special dietary requirements	Wheelchair? (Tick)	Date of birth (if under 18)	GSD Type

Please indicate your requirements by entering numbers in the boxes below:

**Residential** (includes breakfast, lunches and dinner)

**TO PAY**

- Rooms at £80 per room £ \_\_\_\_\_
- Additional delegates at £30 per person aged sixteen or over £ \_\_\_\_\_
- Children under sixteen (FREE)
- Children attending the conference dinner (FREE)

**TOTAL**    £                     

**Day Delegate** (includes lunch)

**TO PAY**

- Day delegates attending on Saturday at £10 each £ \_\_\_\_\_
- Day delegates attending conference dinner at £10 each £ \_\_\_\_\_
- Day delegates attending on Sunday at £10 each £ \_\_\_\_\_

**TOTAL**    £                     

**Crèche**

- Children using the Saturday crèche (free of charge)
- Children using the Sunday crèche (free of charge)

**Please calculate your total amount due and complete the payment section**

## Health Professional Registration Form

Name(s)

Organisation

Address

Post code

Telephone

Contact Email

**Please indicate your requirements by entering numbers in the boxes below:**

		<b>TO PAY</b>
<b>Residential</b> (includes breakfast, lunches and dinner)		
<input type="checkbox"/>	Rooms at £150 per room	£ _____
<input type="checkbox"/>	Additional people sharing a room at £60 per person	£ _____
<b>TOTAL</b>		£ <u>_____</u>

<b>Day Delegate</b> (includes lunch)		
<input type="checkbox"/>	Day delegates attending on Saturday at £15 per person	£ _____
<input type="checkbox"/>	Attending conference dinner at £25 per person	£ _____
<input type="checkbox"/>	Day delegates attending on Sunday at £15 per person	£ _____
<b>TOTAL</b>		£ <u>_____</u>

**Please calculate your total amount due and complete the payment section**

Special dietary requirements? \_\_\_\_\_

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## Payment

Please calculate your contribution from the charges quoted on previous sections. For health professionals we can invoice your organisation directly, otherwise you should pay the full amount by cheque, or by BACS electronic transfer (online or telephone payment)

Amount brought forward from Registration form:	£ _____
Member's Discount - Please deduct £10 if you are a paid-up member of the AGSD-UK:	<b>less</b> £ _____
Amount to be Paid by Invoice / Cheque / BACS transfer (delete as appropriate):	£ _____

Cheques should be made payable to "AGSD-UK Ltd", and sent to

Wendy Griffiths,  
 Administrator,  
 AGSD UK Ltd.,  
 Old Hambledon Racecourse,  
 Sheardley Lane, Droxford,  
 Hampshire, SO32 3QY

Bank details for BACS transfers:

Account name:	AGSD (UK) Ltd
Account Number:	00020992
Sort code:	40-52-40
Reference:	Conf2011 <your name>

Health professionals address details for invoice (Home or organisation address) if different from above:

Name	<input style="width: 100%;" type="text"/>
Organisation	<input style="width: 100%;" type="text"/>
Address	<input style="width: 100%; height: 80px;" type="text"/>
Post code	<input style="width: 60%;" type="text"/>
Telephone	<input style="width: 100%;" type="text"/>
Email	<input style="width: 100%;" type="text"/>