

THE MAIN event

20th - 21st May 2023
Burleigh Court, Loughborough

Whatever your GSD, join us for:

- Updates on latest research & treatment options
- Tips for living well
- New therapeutic activities to try
- Time to share experiences & make new friends
- Chance to hear from leading experts
- Fun for children and families
- For more information contact info@agsd.org.uk

PROGRAMME

SATURDAY 20TH MAY

12.15 - 1.00pm Arrival, event registration and informal welcome from volunteer coordinators for muscle, Pompe and hepatic GSDs in the breakout area

Ben Parker
Pompe

Andrew Wakelin
McArdle & other muscle GSD

Ailsa Arthur
Hepatic

1.00 - 1.45pm Lunch
1.30pm Crèche Opens
2.00pm Opening remarks and introductions
2.05 - 2.50pm Our GSD stories - *Flo and Tim Osborne, Ben Parker, Bronte Thomas*
3.00 - 3.45pm Sessions with clinical experts:

Pompe
New Treatment Options in Pompe: Next Generation Enzyme Replacement Therapies.
Professor Mark Roberts Consultant Neurologist Greater Manchester Neurosciences Centre

McArdle & other muscle
Current research into McArdle and other muscle GSDs
Professor Ros Quinlivan, MRC Centre for Neuromuscular Disease, UCL Institute of Neurology

Hepatic
Developments in the management of hepatic GSDs
Charlotte Dawson Consultant in Metabolic Medicine University Hospital Birmingham

3.45 - 4.00pm Tea break
4.00 - 5.00pm Themed diet/exercise discussion groups:

Pompe
Dr Philip Hennis Senior Lecturer in Sport and Exercise Physiology Nottingham Trent University
Mark Richardson Research Physiotherapist Newcastle University

McArdle & other muscle
Nicoline Løkken PhD-student researcher, Copenhagen Neuromuscular Centre
Peter Finnegan, Highly Specialist Neuromuscular Physiotherapist - McArdle Disease and other related disorders

Hepatic
Claire Bordoli PhD student Exercise and GSD Nottingham Trent University
Joanna Gribben Principal Metabolic Dietitian, Evelina London Children's Hospital

6.30pm **Harp recital by Sioned Williams** internationally renowned harpist living with McArdle's
7.00pm Drinks reception
7.30pm Dinner, entertainment and raffle with great prizes!



SUNDAY 21ST MAY

9.15am Sessions with clinical, research and industry experts

Pompe

Research and developments in gene therapy

Jordi Diaz Manera, Professor of Neuromuscular Disorders, Translational Medicine and Genetics Newcastle University

McArdle & other muscle

Demonstration and discussion of key aspects relating to exercise and activity with McArdle

Peter Finnegan, Highly Specialist Neuromuscular Physiotherapist - McArdle Disease and other related disorders

Hepatic

Research and developments in gene therapy

Jordanna Mora Senior Director, Patient Advocacy, *BEAM Therapeutics*
Grania Crowley Lead, Patient Advocacy and Public Affairs Ultragenyx

10.00am Brief comfort break

10.15am **Rhythm and music rev-up *Talking Drums***

10.45am Coffee

11.15am - 12.00pm **Concurrent living well sessions I**

OPTION A Promoting your wellbeing

Facilitators: *Ben Parker* AGSD-UK volunteer coordinator, *Andrew Wakelin*, Volunteer Coordinator McArdle and other muscle AGSD-UK

OPTION B Tailoring nursery, childcare and education provision

Facilitators: *Watermead Day Nursery* Loughborough; *Elizabeth Davenport* AGSD-UK Specialist Care Advisor

OPTION C Getting the most from your services

Facilitator: *Srividya Sreekantam* Consultant Paediatric Metabolic Medicine, *Rachel Gould* Lead Nurse Birmingham Women & Children's Hospital

12.15am - 1.00pm **Concurrent living well sessions II**

OPTION D Relaxing with art

Facilitators: *Rachel Thomas* Artist and AGSD-UK Trustee

OPTION E Managing transitions to adult life

Facilitators: *Kate Everest* Student Support Manager Loughborough University; *Liz Morris* Lead specialist nurse Lysosomal Disorders Service Addenbrooks Hospital

OPTION F Employment and your rights

Facilitators: *Elizabeth Davenport* AGSD-UK specialist care advisor; *Zainib Hussain*, AGSD-UK Benefits advisor

1.00pm Lunch and depart

