

PROGRAMME**Information Session for McArdle Patients at RLHIM****Wednesday 22nd July 2015 12pm-5pm****RLHIM, London****Organised by Dr Ayfer Kahraman, Clinical Specialist Physiotherapists, Ms Suzanne Booth, Clinical Nurse Specialist, Dr Jatin Pattni, Clinical Psychologist, and Ms Kit Kaalund Hansen, Dietitian on behalf of Dr Ros Quinlivan and the Specialist McArdle Clinical Service**

12:00-12:15 Welcome and Introduction – Ayfer Kahraman/Suzanne Booth

12:15-13:00 General Overview McArdle Disease, physiology - Richard Godfrey

13:00-13:30 Physiotherapy and Exercise –Ayfer Kahraman

- Aerobic Vs Anaerobic, “second wind”, six second rule
- Top tips for exercise

13:30 – 14:00 Lunch

14:00-14:30 Dietician – Kit Kaalund Hansen

- Supplements, diets

14:30 – 15:00 Living with McArdle Disease – Suzanne Booth

- Work and support
- Family – pregnancy, genetics, relationships
- Emergency situations

15:00-15:15 Tea/Coffee

15:15-15:45 Psychologist – Jatin Pattni

- Coping with a diagnosis of a chronic illness
- Depression, chronic fatigue, memory
- Strategies

15:45 – 16:15 Sources of Support – David Thompson and Suzanne Booth

- AGSD Overview, literature, walking course, online forums
- McArdle Nurse, Physio, Psychologist, Dietician – Management clinic
- MDUK

16:15-16.30 Summary, General Question & Answer Session, Evaluation and Close