



Patient Liaison Panel

Supporting the McArdle Disease Service

October 2019



Aims of the panel

- To inform and advise the medical team from patient perspective
- Bringing the experience of themselves and other patients
- Review information and education materials
- Consult on service delivery
- Consult on research projects and innovations



Membership of Panel

- Yasar Ayub
- Nick Jones
- Wendy Lewis
- Richard Nash
- David Thompson
- Andrew Wakelin
AGSD-UK co-ordinator
- Sonia Worthy

GSD7 – Tarui:

- Kelly Flitterman
AGSD-UK co-ordinator



Service support 2019

- Diagnosed people in UK now 321
- We direct many patients to the service
- Supported recruitment of participants for trials
- Situation report on development of ketosis



Clinic support 2019

- Service Level Agreement signed with UCLH and the Clinic
- An expert patient to support a group session at each clinic, led by Jatin, for an hour at lunchtime
- Team being recruited, DBS checked and trained
- Awaiting clinic schedule to accommodate the 1 hour slot
- Need a new way to make contact with new patients, as form being missed



AGSD-UK activities

- Walking Course in July, Brecon Beacons, 9th year, 12 McArdle-ites 1,500ft ascent to summit of Pen-y-Fan.
- Children & Parents Event, 5th year
- This year people from Australia, England, Germany, The Netherlands, Scotland, USA and Wales
- November, IamGSD jointly hosted international workshop at CNMD on the future of nutrition for McArdle's



Forthcoming activity

- Train team for group session support
- Commence support work under SLA
- Assist with induction of new staff
- Invite staff to visit walking course, Children & Parents event and conference