

**The McArdle's Workshop:
Andrew Wakelin McArdle's (Type 5) rep to AGSD UK.**

Our 2004 conference went very well at the weekend. The McArdle's workshop had an attendance of 20 people, made up of 9 patients, friends, families and 4 professionals making presentations. Thanks to everyone who organised, presented and participated in the Workshop.

Some firsts...

I think nine is the highest attendance of McArdle's patients we have ever had. (Perhaps the largest number ever gathered in one room anywhere?)

We had two youngsters join us -*Peter Rogers and Craig Hawker*. Craig is the youngest McArdle's patient we have had attend the conference - he will be 11 this week.

We welcomed what I think is our first overseas patient visitor - *Eugene Schaefer* who travelled from Germany.

One of the best parts of the day for all of us was to get together informally and be able to chat and swap experiences, get advice and

ideas, etc. This was stimulated by three excellent presentations from:

Dr John Buckley ~ who talked about the exercise tests being conducted at the Oswestry clinic, the results so far and how they may develop.

Dr Richard Godfrey, Olympic Team Physiologist, - who reported on the data obtained from the "Growth Hormone Response to Exercise study he did with McArdle's patients. And after lunch a very entertaining

Dr Greg Whyte, Olympic Team Physiologist, - spoke about the 2004 Olympics where he explained how exercise for Olympic athletes and for McArdle's patients are on one continuum, *albeit at opposite ends!*

Finally we held an **open forum session**, where we swapped information and had input from Dr .Ros Quinlivan from the Oswestry clinic and the three Drs who had spoken..

On 18 **October 2005** the speaker will be Prof Howell from Perth in Australia has agreed to talk on his work towards a gene therapy for McArdle's . A full report of the presentations will be posted to the AGSD(UK) web site in due course. I will post a note on GSD Net once it is there.