

PRESS RELEASE

McArdle Disease sufferers conquer their Everests in Wales

Monday 2 August

- 10.30 am - Start Llandaff Cathedral Green
- 1pm - Photo opportunity on the steps of the Senedd, Cardiff Bay
- 1.30pm - Reception at Pierhead Building, Cardiff Bay

At 1pm on Monday, 2 August, an international group will complete a grueling 32-day Welsh adventure when they reach the Senedd in Cardiff Bay after walking 210 miles. What makes the journey so remarkable is that they all suffer from **McArdle Disease**, a rare disorder which causes muscle pain and damage. Some patients have been advised that exercise could leave them wheelchair bound by the age of 40.

For people with McArdle Disease everyday activities such as cleaning their teeth, doing the washing-up or drying themselves after a shower can cause significant pain. It can be a real struggle to walk to the local shops, and anaerobic exercise such as heavy lifting can easily lead to muscle breakdown and renal failure.

Rob Gray, 66, from Dundee, who has driven from Scotland to lend his support, has experienced renal failure three times. He says, "Given my experience with McArdle Disease, I have been amazed at what these guys have achieved".

The walkers have taken each careful step on their walk to raise awareness of their condition and show others with the disease what can be done with the right management. Support has grown as they have neared Cardiff, with up to 15 people walking together. On Friday, after they reached the summit of Pen y Fan in the Brecon Beacons, the walkers met the **Mayor of Brecon, David**

Meredith. On Sunday, **Wales's teenage swimming sensation Jazz Carlin** is walking with them from Pontypridd to Llandaff Cathedral.

In the last few days they have been joined by **Charlton Thear, age 13, who has travelled with his family from the Canary Islands.** Charlton hopes learning from older McArdle patients will help him cope better: “The school term meant I could only join ‘Walk over Wales’ for the last three days, but it has been really good for me to have an opportunity to walk with others with McArdle Disease and learn from them about how to cope with it.”

The walkers are expecting mixed emotions on their final leg from Llandaff Cathedral to the Senedd – delight at completing a big personal challenge and sadness that an inspirational event has come to an end. **Andy Williams, 48, from Singapore,** says, “I arrived in Wales unsure what to expect, and anxious about the walk ahead. I’m exhilarated by what this group has accomplished, committed to continuing to challenge the condition and confident that it need not seriously limit me. As Max Boyce once sang, ‘where there’s a will there’s a way’. I’ll leave with tremendous memories of the beauty of the Welsh countryside, and its many, many hills and valleys!”

They have been able to complete the walk by carefully managing their exercise, “Starting slowly each day is absolutely vital”, explained **Stacey Reason, 40, a nurse from Toronto, Canada.** “We know if we exert ourselves too forcefully we will damage our muscles, but by adopting the right pace and technique we need not be severely limited. At the start of the walk I hoped for flat meandering stretches, but I have surprised myself by how much I have enjoyed the hills and mountains of Wales.”

The lessons learned have been shared with McArdle patients across the globe through regular blogs at www.agsd.org.uk. A Facebook Group supporting the event has members on five continents. Followers say they have been inspired. As one McArdle Disease sufferer commented, “Cardiff may be the end point for this trip, but it is just the beginning of a longer journey within the McArdle community.”

For eighteen year-old **Dan Chambers from San Diego, California**, discovering his capabilities in Wales has been a life-changing experience. He says, “Hopefully our online followers will carry our mid-walk tips, techniques and mentalities from this year with them in every step that they take back at their respective homes, leading into next summer. We want to present this opportunity again to others with McArdle in hopes that they’ll be able to experience the glories that the team has shared this month.”

The group intends to return to Wales in July 2011 to share the insights they have gained with a much larger group of McArdle patients.

Andrew Wakelin, 61, from Builth Wells, the group leader and **Chair of the Association of Glycogen Storage Disease** says, “It is fantastic that for the first time ever people with McArdle Disease have walked together for an extended period. We have learned so much about this condition, especially about mountain walking. It is an amazing achievement for us personally, but also we know that we have inspired hundreds of other patients around the world. The ‘Walk over Wales’ has helped change many lives for the better.”

The initiative can be sponsored online at www.agsd.gov.uk

AGSD web resources on McArdle disease:

<http://www.agsd.org.uk/tabid/1137/default.aspx>

Explanation of McArdle disease by Dr Ros Quinlivan

<http://www.agsd.org.uk/tabid/1142/default.aspx>

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