

“LAZY, UNFIT” kids may have rare muscle disorder...

Andrew Wakelin (now 61, from Wales) lagged far behind, hiking as a Scout aged 12, pushing against the pain in his legs. The Scout Leader pushed him on in annoyance as Wakelin held back the rest of the hikers who pressed ahead. He couldn't move his legs quickly enough and fell forward bursting into tears, bewildered by his failure.

Despite being untroubled by the bowling and hitting the ball well with a third run clearly on, aged 11, batsman Andy Williams (now 48, from Singapore), inexplicably slowed to a crawl in mid pitch and failed to make his ground. Tears filled his eyes as he trudged back to the pavilion totally confused by what had happened.

Aged 32, Stacey Reason (now 40, from Toronto, Canada) sat terrified, contemplating how she'd manage to muster the physical energy needed to power her oar through the water in sync with her eight team members. With the end in sight and muscles failing, she slumped back, with only seconds remaining, knowing she had failed to keep up, blaming herself for the team's failure to achieve a first place finish.

Dan Chambers (now 18, from San Diego, California) spent the early years of his childhood endeavouring to find a diagnosis with the diligent help of his mom. Countless visits to local doctors proved to be misleading and intensely discouraging. The doctors labelled him to be simply “de-conditioned” and “out of shape”. Confusion mounted.

“Looking in the mirror in my childhood, I gazed upon a skinny and avid baseball player,” he said. “The doctor's claims simply made no sense.”

Chambers received a diagnosis of McArdle Disease aged 12. Such diagnoses are rare for patients with this disorder, as most are diagnosed decades into their life, as was the case for Wakelin, Williams and Reason who were diagnosed, respectively aged 30, 43 and 37, with the same rare muscle condition.

They have come together in these last few weeks and have been walking the hills and valleys of Wales since 2nd July.

“We are sure there are kids in Wales, and of course worldwide, finding life difficult, embarrassed by their ‘failure’ in sport, or simply their inability to keep up with their mates on a bike.” Wakelin said. “Some may be unfit, but like us, some may have McArdle Disease. Early diagnosis is so beneficial as there are many things people can do to help to avoid serious muscle damage, which can lead to renal failure.”

Their “Walk over Wales” is both to raise awareness of this disease, but also to demonstrate to others with the condition what can be achieved despite it.

So far they have completed over 160 miles, and while Reason required a brief hospital visit as a consequence of the condition, they have otherwise suffered no ill effects aside from the odd stiffness. Indeed, each feels significantly stronger toward the end of the walk than they did at the beginning.

The condition means that they must start each day slowly to avoid damaging muscle tissue, and each slope must be approached in the same deliberate slow and steady manner. So far the main peaks they have conquered include Snowdon and Cadair Idris, on Wednesday 28 July, the group led by Wakelin, from Builth Wells will face their last big challenge when they ascend Pen y Fan.

On 31 July the walkers will be joined by Charlton Thear, 13, from the Canary Islands, who will walk the last few days into Cardiff, where they will complete their 30-day, 210-mile, ‘Walk Over Wales’ from Llandudno to Cardiff Bay on 2nd August. Rob Gray, 66 from Dundee, who also has the disease has driven down from Scotland to help with logistics over the final week – he was diagnosed aged 20 having suffered renal failure, caused by muscle breakdown, after working on a construction site.

Family and friends will begin to join the Walk over Wales (WoW) team in the next few days to augment the tremendous support they are receiving from a

worldwide audience reading their daily blog, at www.agsd.org.uk, and more recently joining their Facebook Group, Walk over Wales for McArdle Disease, for the last few days into Cardiff.

McArdle is a rare metabolic disorder that means heavy exercise is painful and can cause muscles to seize up and break down - even leading to kidney failure. Many sufferers think long-distance hiking must be impossible for them. The walkers want to raise awareness of the condition, which often goes undiagnosed, and raise money for the research charity, the Association for Glycogen Storage Disease.

“Kids and young people with undiagnosed McArdle Disease are often at risk of bullying by peers and PE teachers when they say they can’t do things,” Wakelin said. “If we can help more kids to get diagnosed by drawing attention to the disease and show them what they can achieve, all of us will be really happy. And we’ll have done it while walking right across one of the most beautiful countries in the world.”

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Background notes

The Walk Over Wales is the brainchild of Andrew Wakelin, who lives right in the middle of Wales near Builth Wells. He loves walking, but it can be tough for him, as it is for other sufferers of the disease. He planned the route for the whole hike, which started on 2 July at Great Orme Head near Llandudno.

Growing up, Andrew couldn't do cross-country runs and was once hospitalised after trying a tug of war, but he carried on walking - even climbing Mount Kilimanjaro in his thirties. It turns out that he was doing just the right thing for his illness, doing slow, steady walking to keep his muscles from wasting away. Nowadays, the regime Andrew worked out for himself is recommended to newly diagnosed younger patients.

Andrew is the UK coordinator for the association that supports McArdle sufferers. He says, 'It's always been my ambition to walk over Wales, and I was planning a quiet solo challenge, taking a month to cover the mountains from one end of the country to the other. But then it all changed! I can't believe that when they heard what I was doing so many other McArdle sufferers and supporters wanted to come to Wales to join in.'

Andrew says, 'I never knew why I couldn't keep up with my friends as a youngster, and I probably did a lot of damage to myself trying. I was 30 before my McArdle Disease was diagnosed, which is typical. We know more about the condition now and can give young sufferers good advice, so it's really important that children get diagnosed early and learn how to avoid damaging themselves. I hope our walk will raise awareness, as well as collecting some sponsorship money for the McArdle charity... and of course boosting our own confidence and giving us a real sense of achievement.'