

One Step at a Time

Walking with McArdle Disease

Stacey L. Reason

*“I learned to accept what is
and embrace what can be... in just 210 miles!”*



Foreword by Dr. Ros Quinlivan
Afterword by Dr. Mark Tarnopolsky

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Walk over Wales

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Afterword by Dr Mark Tarnopolsky, MD, PhD, FRCP(C)



Association for Glycogen Storage Disease (UK)

I'd like to thank:

My parents, Bob and Barbara - for without your love, support and defective PYGM genes, this book would not have been possible.

Jorge, Lauren and Brayley for walking by my side,
without question, for over two decades.

Andrew – your dream captured my imagination, one step at a time.

First published November 2013

Edition 1.1 January 2104

Edition 2 September 2016

Association for Glycogen Storage Disease (UK) Ltd

Old Hambledon Racecourse

Sheardley Lane, Droxford SO32 3QY, UK

ISBN 978-0-9569658-3-7

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2013-2016

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Contributing authors

Many thanks to Dan Chambers, Charlton Thear, Andrew Wakelin and Andy Williams for permission to reproduce the daily blog. They all contributed each day or even wrote the whole blog on some days.

Thanks also to all those who posted comments on the blog pages; we have only been able to use a very small selection.

Photographs

Front cover: Stacey Reason and Andrew Wakelin on the ascent of Glyder Fach, Snowdonia, 2011.

Photograph by Dan Chambers.

Frontispiece: Stacey Reason and Andrew Wakelin set out on Cadair Idris, day 12 of the “Walk over Wales”, 2010. Photograph by Dan Chambers.

Opposite: Andrew Wakelin and Stacey Reason head for a summit, Snowdonia, 2011. Photograph by Dan Chambers.

Muscle biopsy photographs are reproduced by kind permission of Professor Caroline Sewry, Great Ormond Street Hospital, London.

Our thanks to everyone who pooled photographs from “Walk over Wales” and the walking courses, in particular special mention goes to Dan Chambers, Sally Wakelin, Jos van den Einde, Stacey Reason, Andrew Wakelin, Allan Muir and Clive Hicks-Jenkins.

Acknowledgements

The “Walk over Wales” team members wish to express their sincere thanks to the support drivers who made the whole enterprise feasible – Heather Curry, Peter Wakelin, Sally Wakelin and Rob Gray.

A big thank you to all those, too numerous to mention individually, who sponsored the walkers, giving them huge encouragement and raising approx. £14,000 to underwrite the AGSD-UK's work on McArldle Disease.

Thanks to Stephanie von Dressler for the “Walk over Wales” turtle logo.

Thanks also to Ryan Christensen, Kathryn Birch, Barbara Derrick, Allan and Jamie Muir. Finally to Wholebake Ltd for sponsoring some of the walking courses with 9-bars.



LOTTERY FUNDED



Supported by the
EC DG Sanco through
the EUROMAC project
(contract no. 2012 12 14).



Euromac is the registry for people with
McArldle Disease and other rare muscle conditions.
www.euromacregistry.eu



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This book is dedicated to all those who struggle daily with McArdle Disease and particularly to the memory of Jessica Binder who died from complications of an episode of rhabdomyolysis.

Jessica Binder died aged 31, only months after finally being diagnosed with McArdle Disease. Jessica's story holds a mirror to the story of almost all of us with McArdle's, except in the way that it ended tragically.

As a child, Jessica was traumatised when forced to do exercises she couldn't manage in gym class and each Spring when they had to run a mile. It was a huge blow to her self esteem to be treated as someone who was lazy.

Jessica and her family were very frustrated by the difficulties of getting a diagnosis and the many years of trying. She started getting more fixed contractures in high school. In the last few years she had many episodes and in the year before her death was twice admitted to hospital with rhabdomyolysis.

Finally in early 2010 the name was put to what had ailed her since infancy. At last everything made sense regarding her physical limitations. Jessica had always been prescribed muscle relaxants for pain relief, but learned that they may have contributed to the muscle wasting and rhabdomyolysis.

Jessica's mother Pat says "We were just beginning to learn about McArdle's and we really didn't yet have a grip on the difference between aerobic and anaerobic exercise, and how to avoid injury. Only six months after being diagnosed Jessica suffered another massive episode. This time it was to take her life. It started with ½ hour of intense exercise on a stationary bike, severe contractures all over, rhabdomyolysis leading to complete kidney failure with anuria, waiting too long to seek medical help, Creatine Kinase exceeding 200,000, being put onto dialysis, her lungs filling with fluid, going into cardiac arrest, it taking 45 minutes for her heart to start

pumping again, the delay causing her brain to swell and a few days later her death."

Jessica was working on a double major in photography from the University of Wisconsin-Eau Claire and also taking classes to be an alcohol and drug treatment counsellor. She was an artist, loved to read and she was an avid

journal writer since her school years. She loved to swim, especially in the ocean, and would often go to the local fitness centre with her snorkel gear.

For Jessica's funeral her closest friends and family compiled a list of words that best described her: motherly... brave... radiant... compassionate... joyful... good humoured... curious... mischievous... magical... free-spirited... charismatic... daring... a deep thinker... inquisitive... imaginative... adventurous...

... an avid journal writer... possessing a lust for life.

Pat again – "She was a beautiful human being. When viewing her picture you would never guess that she suffered so much with her McArdle Disease. It truly is a disease that doctors don't know about.

"I wish I had in my hands before her final episode the guidance which the AGSD-UK has produced since. Patients and doctors need this information. Also, schools need help to spot this disease – often misunderstood and hard to live life with it. The education of patients, doctors and sports trainers about the disease will be hugely helpful to the McArdle's community.

"We are comforted by the fact that Jessica saved another person's life through organ donation; contributed tissue samples to McArdle's research; and provided the inspiration for guidance on emergencies now being available."



JESSICA LAURA E. BINDER

29 JULY 1979 – 19 OCTOBER 2010

Foreword

McArdle Disease is often not diagnosed until well into adulthood. Individuals struggle for decades not understanding why they suffer from exercise intolerance, fatigue, muscle pain and fixed contractions. Alongside the physical symptoms, feelings of embarrassment and inferiority ensue. Living with a rare and chronic condition can lead to anxiety and depression, particularly if the cause remains undiagnosed.

With diagnosis, comes awareness and information on proper strategies for managing the condition on a daily basis - yet for many, the experience remains a solitary one.

This group grasped the challenge of proving to themselves and to the world that despite the disease they could achieve remarkable things.

The author narrates her personal experience of learning to live with McArdle Disease over a 210 mile walking trek down the length of Wales. What began as a personal journey, soon flourishes into a significant event, catching the imagination of people with McArdle Disease all around the world. Over the course of 32 days, this intrepid group steadily puts one foot in front of the other. Coming to the realisation that this is the way forward, they agreed to start annual 'Walking with McArdle's' residential courses to help others with the condition.

Walking with the group for a day gave me, as a medical professional involved with the care of people with McArdle Disease, a rare opportunity to gain a valuable insight into how people live with this rare condition.

Sharing practical strategies for managing day to day, is vital towards improving quality of life. The lessons that were learnt throughout this journey are discussed and shared.

Dr. Ros Quinlivan MBBS, MD

Consultant in Neuromuscular Disease

MRC Centre for Neuromuscular Diseases

National Hospital for Neurology and Neurosurgery, London

Introduction

How did we get here and
why is it important?

From early childhood you know there is something wrong. You try, but cannot keep up with your friends. They so effortlessly run and play, but your body fails you, your legs stiffen in protest, making it nearly impossible to take another step. Every day, with everything you do, you fall behind... everyone. With no explanation at hand, you are left feeling embarrassed, humiliated, utterly defeated.



Stacey and Dan (third and fourth from left) and Andrew (right) meet at the AGSD US conference, Denver, 2009.

Doctors examine you, but find nothing wrong. Perhaps you are suffering from growing pains, perhaps you aren't trying hard enough, or perhaps you are just simply unfit. So you try harder.

Despite your best efforts, the pattern of trying and failing repeats itself time and again. As you move into your adult years you have become adept at managing your premature

exertional fatigue, stiffening leg muscles and accelerated heart rate. Ready-made excuses for stopping/resting have become deeply ingrained into your subconscious daily routine.

Your life is different.

For most, the journey of discovery is long and frustrating. Diagnosis is bittersweet. Simultaneously, relief and panic wash over you. What does the future hold living with a rare genetic disease?

McArdle Disease is a rare metabolic disorder, more specifically a glycogen storage disease (Type V) caused by a deficiency in the enzyme myophosphorylase. The missing enzyme prevents glycogen stored in the muscle to be converted to glucose for exercising muscles. Symptoms include exercise intolerance with myalgia, early fatigue, weakness of exercising muscles and myoglobinuria, potentially leading to

rhabdomyolysis, renal failure and/or compartment syndrome.

This is a story that begins in the Fall of 2009 when a handful of anxious McArdle patients stepped into an empty conference room in Denver, Colorado. They had taken a bold first step to discover more about the disease that has insidiously taken away so much from them. On behalf of the AGSD-UK (Association for Glycogen Storage Disease UK) Andrew Wakelin (Type V Co-ordinator/McArdle patient) greeted the newcomers with a lifetime of experience. For many it was the first time they had ever met anyone else diagnosed with McArdle Disease. Over the course of two days Andrew led the inquisitive group through various formal and informal discussions – all centred on McArdle Disease.

In the months following the conference, the group maintained contact with one another – forever connected. For the first time in their lives, someone fully understood their daily efforts. What Andrew, Dan and I didn't realise, was that in less than a year we would find ourselves standing on a carboniferous headland known as the Great Orme – about to embark on a journey of a lifetime.

On July 2nd 2010 Andrew Wakelin, Dan Chambers and I set off, one step at a time. We were headed to Cardiff – (338 km) away! Walking the length of Wales was a life-long goal for Andrew – oddly enough, the idea intrigued Dan and me as well. Our trio, soon to become a foursome (joined by Andy Williams), wanted to demonstrate to the world that despite our physical limitations this lofty goal was attainable.

As we made our way across endless fields, deep valleys and foreboding mountains, the hours accumulated both in our hiking boots and perched in



A happy group set off on day 16 of Walk over Wales, half way through.

front of our computers. Our team was dedicated equally to our goal of reaching Cardiff and to that of bringing McArdle Disease to the attention of teachers, youth leaders and the medical community alike. After thirty-two days, 210 miles (338 km) and 35,000ft of ascent, our intrepid group walked soulfully into Cardiff Bay. It may have been the end of Walk over Wales (WoW), but it is where now begins.

With all that we learned about McArdle Disease (and ourselves), I felt compelled to share this story. Living (undiagnosed or diagnosed) with a rare disease can often leave an indelible impression. This book sets out to not only trace my personal journey of living with McArdle's, but more importantly to provide the reader with hope, inspiration and practical advice for managing life day to day.

Of course I continue to struggle with the idiosyncrasies of McArdle Disease. But now, when you see me on the side of the road taking a break, be rest assured I am no longer desperately searching for a makeshift explanation, but rather making the most of what life has to offer and pausing to enjoy the moment!



The 'high level' group, day 6 of the walking course, North Wales, 2013. L to R: Andrew, Siobhan, Niekie, David, Jen and Dan.



Dr Ros Quinlivan (right) joins Andrew and Stacey for a day on the second "Walking with McArdle's" course, Wales, 2011.

Stacey L. Reason

Toronto, Canada
November 2013

McArdle Disease

What causes the disease and how it affects those who suffer from it.

McArdle's is a very rare disorder of muscle metabolism. About 200 people in the UK are diagnosed, but we believe it affects about 1 in 100,000 people, so there are probably around 600 affected people in the UK in total.

Genetic condition

McArdle's is inherited from parents who are carriers and is not infectious. There is no cure, but much can be achieved with good management.

Energy shortage

People with McArdle's experience a serious shortage of energy during the first 10 minutes of any activity, and throughout *all* intensive activity. Care has to be taken, as even activities like chewing, drying after a shower and hanging up clothes can cause muscle symptoms.

Symptoms and risks

McArdle's people appear normal and healthy but activity results in premature fatigue, exaggerated heart rate, pain and muscle spasm.

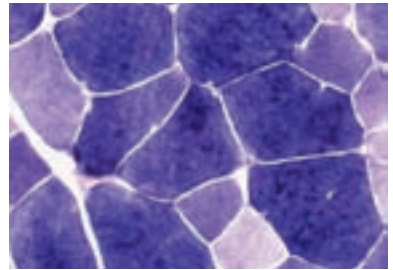
If activity is continued despite the pain, muscles become stiff and swollen and muscle breakdown (rhabdomyolysis) may occur. In severe cases this can lead to life-threatening kidney failure or compartment syndrome requiring urgent surgical intervention.

Longer term risks

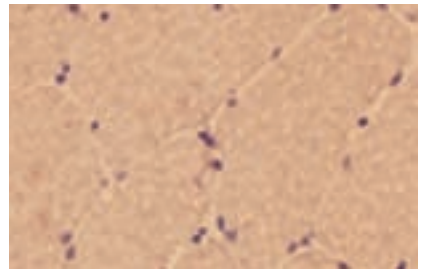
Longer term, the risks are of accumulated muscle damage from repeated over-exertion or alternatively of muscle wastage due to the avoidance of activity. If activity is avoided due to the symptoms this can lead to loss of aerobic fitness which makes it much harder to do anything without quite severe symptoms. It can also result in a wasting away of the muscles.

Adapting activity

To cope with necessary daily activities, people with McArdle's have to break down any intense activity into very short sections of a few seconds. Some activities are avoided and



Normal muscle showing muscle glycogen phosphorylase enzyme.

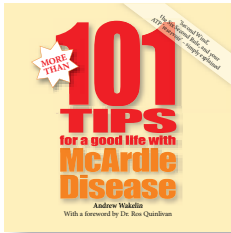


Muscle of a person with McArdle Disease showing absence of the enzyme.

others carried out differently. McArdle's people also need to take plenty of gentle exercise to enhance their aerobic capacity. They should plan for at least 45 minutes of exercise, five times per week. The best way is to build activity into your life.

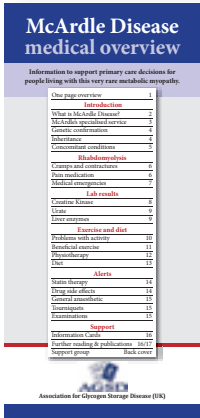
The technical bit

McArdle's is also known as Glycogen Storage Disease Type V. It is inherited in an autosomal recessive fashion. Mutations on the *PYGM* gene on chromosome 11 result in the absence from the muscle cells of an enzyme called myophosphorylase. This enzyme (made up of 842 amino acids) is needed to convert glycogen (fuel stored in the muscle) into energy at the start of activity and throughout intense activity.



101 Tips for living with McArdle's

A handy book for people with McArdle's, "101 Tips for a good life with McArdle Disease". An easy to absorb guide to the many things which can be done to avoid problems and improve fitness. This pocket-sized paperback of 164 pages can be ordered or can be accessed on-line (free) via the AGSD-UK web site. Also available in German and French from the respective patient support groups.



Medical Overview

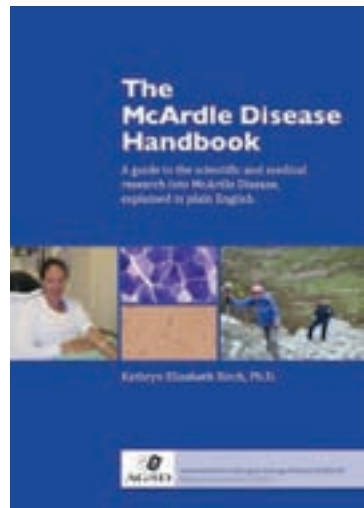
A 20 page booklet providing a quick overview of the medical aspects of the condition. It is intended for any medical professionals who are not familiar with McArdle's. In particular it will assist general practitioners, emergency doctors and consultants in other conditions when they are seeing someone with McArdle's.

Scientific and medical research

For those who want to know more, the AGSD-UK publishes the McArdle Disease Handbook, by

Kathryn Birch Ph.D. This 208 page A4 paperback book is a guide to the scientific and medical research into McArdle Disease, explained in plain English. As well as printed copies to order, the handbook is available for free access on-line.

The handbook is also available in German and Italian (and hopefully further languages in future) from the respective patient support groups of those countries.



McArdle pages – www.agsd.org.uk

Please check out the GSD Type V (McArdle Disease) section of the AGSD-UK web site for more information on McArdle's. New developments in the walking courses and any revisions or extensions to the 'Guidance for Walking' section will be published there.

Walk over Wales

A group of people with McArdle Disease walked 210 miles (338 km) across Wales to raise awareness of the condition.



Walkers Dan, Stacey, Andy and Andrew later joined by Charlton.



Our Walk over Wales turtle logo.

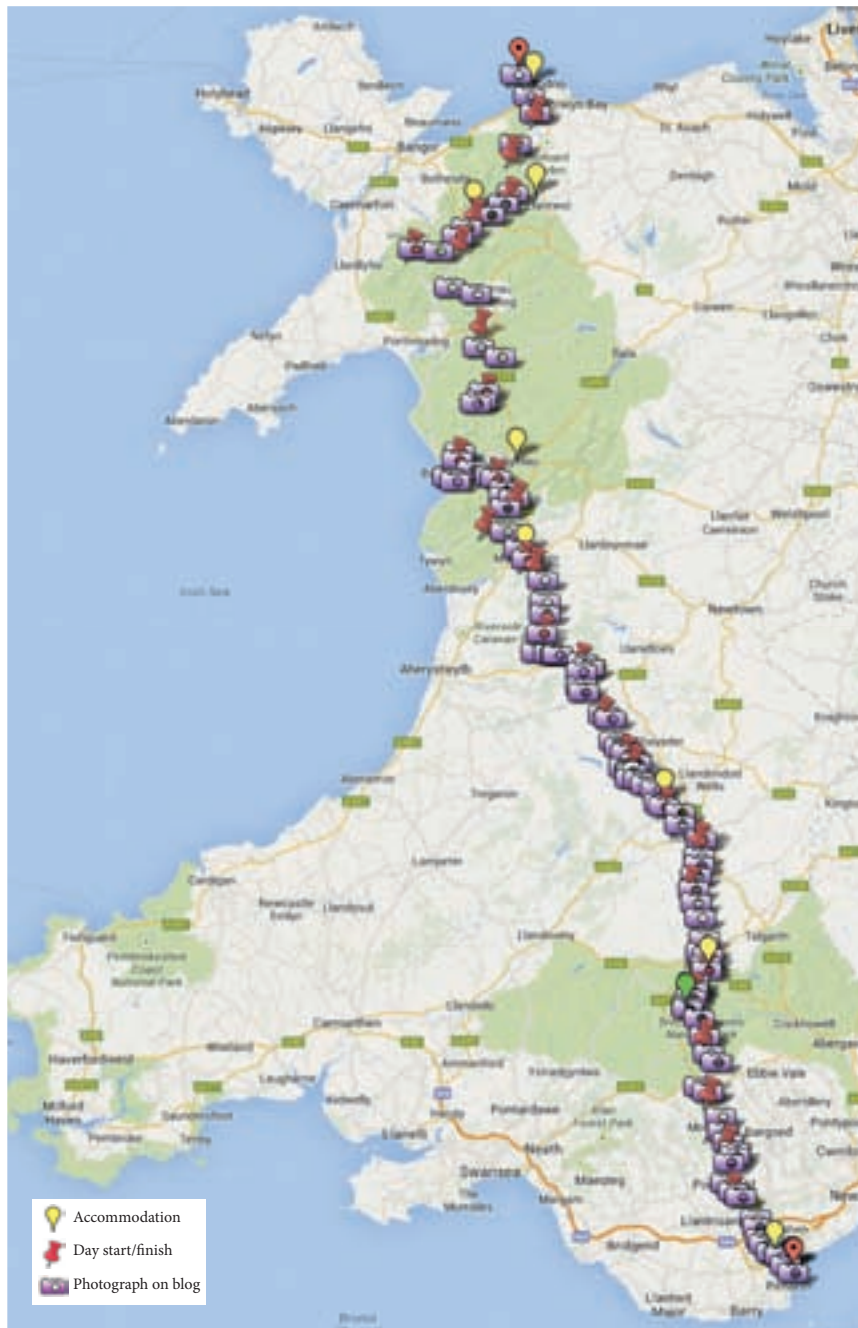
I'm not one to keep a daily journal, but for the next 32 days of "Walk over Wales" (WoW) I did. Not sure of what I was getting myself into, I thought it would be shrewd to chronicle the days' events.

Up until this point in time, my solo athletic experience(s) had been the yardstick against which I measured myself – that was about to change. Doing anything (even walking a few blocks), with anyone (even my family) was always a source of great angst. I wonder – will a month long stroll up and down the hills of Wales help me lessen my lingering disquietude?

Throughout our journey the team posted a daily blog. The intent was to share our story and raise awareness of McArdle Disease. We highlighted the details of each day, documented how the collective group was managing, and shared tips and strategies we discovered along the way.

As you read on you'll find my thought's (perhaps yours as well?) contrasted against the the daily blog.

The route of “Walk over Wales” led from Great Orme on the north coast to Cardiff Bay on the south coast. It travelled through the Snowdonia National Park, the Cambrian Mountains and the Brecon Beacons National Park. 210 miles (338 km), taking in many mountains on the way with approx. 35,000 ft (10,700 m) of ascent.



Map data © Google 2013

Stacey Reason – Canada



The challenging walk to piano lessons (all three blocks, on the flat) was the first memory Stacey had of being ‘different’. She would often be forced to stop part way in response to her racing heart and stiffening leg muscles.

At the age of eight, she had already developed a wide array of excuses to explain her seemingly poor level of fitness. At the time, her favourite excuse was stopping to tie her shoelace.

The physical challenges and utter embarrassment continued into her adult years. Medical doctors insisted she was merely ‘out of shape’. Desperately wanting to increase her fitness, Stacey kept busy. She ran, she rowed, she cycled and played ice hockey. Of course – always at a slower than slow pace.

Fortunately, she figured out the magic that she now knows as ‘second wind’, and never ran into too much trouble.

In 2005, while out for a run, Stacey was struck by a car and sustained a severe head injury. All physical activity had to stop. For two years she was not able to exercise and became very de-conditioned. While visiting her cousin a few years after the accident, Stacey decided to go for a swim. As she made her way across the pool, all of her muscles cramped up. Embarrassed, she slowly made her way back to the edge, and didn’t tell anyone what had happened – there was no apparent explanation. The following day, she was hospitalised, found to have sky high CK and subsequently underwent tests and was diagnosed with McArdle Disease.

Relieved to know she wasn’t lazy, Stacey searched for information about McArdle’s – eventually finding her way on-line to Andrew Wakelin. Happy to learn how best to manage day to day, she eagerly began exercising again, this time more carefully and more slowly.

Since then, Stacey has continued to work hard to regain her pre-accident level of fitness. Along the way there have been challenges, including a few hospitalisations for rhabdomyolysis, myoglobinuria and near renal failure; but overall Stacey continues to improve. Finding the right balance has been the most challenging aspect.

Whilst participating in the “Walk over Wales” was both terrifying and exhilarating, it was an experience that dramatically changed how she lives with McArdle’s day to day. Stacey looks forward to seeing you on the hills of Wales!

It turns out that Stacey has a strong will. It was clear that a chronic muscle condition was not going to prevent her from remaining physically fit and capable of doing the physical activities that most of us only passively watch on TV and dream about.

A few years earlier, when I was on call, I was asked to see Stacey in the emergency room because her plasma creatine kinase (CK) levels were extremely high. She had been swimming and she had developed excruciating pain along the muscles of her back and of her thighs. She told me that her family background was from England. I had read that Dr. Brian McArdle in Guy’s Hospital, London, had described in 1951 a muscle disorder in a man that had pain after physical activity. This is a genetic disorder that can be seen in families. Given her background I thought that this was her diagnosis.

Today Stacey has not allowed this condition to slow her down. Instead this has been a stimulus to prove that the mind and body can overpower such a disorder.

Stacey never gives up. I believe that she will be a role model for many with similar conditions, to encourage them to go upstream and conquer the world.

DR. ARTURO WADGYMAR, MD
NEPHROLOGIST

Dan Chambers – USA



At age 4, Dan remembers lagging behind the rest of his soccer teammates. At 6, he recalls walking up hill to his best friend's house and having to stop and sit on the curb as his muscles felt heavy and stiff. Middle school PE became a nightmare as fatigue increased. He began to bow out of activities, often standing on the sidelines watching his classmates run. Despite his struggles he stayed active and baseball became his sport. While adapting to the sport (with muscles on his mind in every play), running became increasingly strenuous as the bases lengthened to 90 ft (27 m). His baseball career came to an abrupt end when he knocked a line drive to the fence. As he rounded first base at full speed everything slowed down and despite pushing to the max, he appeared as if he was running

in slow motion. He kept pushing until his sliding attempt into 3rd base turned into a stumble and fall. Hunched over, crippled with contractures in his legs, arms and abdomen he realised the gravity of his condition.

These early years were filled with confusion. His desire to play and his work ethic were in stark contrast to his endurance. Simple activities that looked so easy for others were extremely difficult for him. His mom began taking Dan to local doctors looking for reasons for his exercise intolerance. There were numerous misdiagnoses including labels of lazy and “deconditioned”. It took out of state visits to McArde specialists Dr. Ronald Haller in Dallas, Texas and Dr. Alfred Slonim in NYC to confirm the diagnosis of McArde Disease and learn the basics of managing this lifelong disorder and how important it is to listen to his body and not push past fatigue and pain, even in activities of daily living. Though it was extremely helpful to meet with McArde specialists once back home in California he was left alone to figure out how to manoeuvre through life.

He gradually pulled out of all formal sports and activities. Still attempting to be active, he suffered two major injuries ages 16 and 17 while out with friends resulting in hospitalisations with CK levels in the 200,000's. His mom continued to search for help and guidance which led her to an online support group where she began speaking with Andrew Wakelin. In 2009 she took Dan to an AGSD conference in Denver, CO where he was able to meet others with McArde's including Andrew and Stacey. After that meeting, Andrew finalized his plans for Walk over Wales and invited Dan to join.

Walk over Wales proved to be a turning point in his understanding of how to not only live with McArde's but to thrive. This life changing experience was instrumental in the realization of his abilities and turned his focus away from what he couldn't do to what he could do. Dan has since returned to help others to experience Walking in Wales and has participated in additional more challenging walks with Andrew in Snowdonia. In 2013 Dan, Andrew and two other young men with McArde's hiked in the Dolomite mountains which proved to be the most challenging and exhilarating walk yet.

Ironically, having McArde's has allowed Dan to travel to places he would most likely have never got to and challenge himself safely with others who understand while enjoying spectacular scenery. He looks forward to continuing his adventurous walks and sharing his experiences with other McArde-ites.

Andrew Wakelin – Wales



Andrew remembers symptoms of McArdle's from age four. He was always the one out of his siblings who wanted a piggyback and now, almost 60 years later, he still shivers at the thought of leaving his childhood home and having to walk 100 yards uphill immediately from the front gate.

Doctors repeatedly put his “bad legs” down to growing pains, rheumatism or “knock knees” – or were just totally indifferent to the problem. He had two major episodes of rhabdomyolysis – one after a tug-of-war and one after helping to hold up a car whilst a wheel was changed. Despite massive fixed contractures, both instances were treated as “sprains” and he was sent home with pain killers. He was lucky not to go into renal failure. If only a simple CK blood test had been carried

out he might have got onto the path towards diagnosis.

Andrew had kept active with aerobic exercise from his early years and later worked out for himself to avoid anaerobic exercise. He thinks doing a daily newspaper delivery round as a teenager probably did him the world of good – perfect exercise for someone with McArdle's at a time when his muscles were still developing. He also managed family walks and Scout hikes, but had a miserable time in sports and gym lessons at school.

Andrew had gout diagnosed at age 19 with no obvious cause, which might have led to discovering his McArdle's but it was not followed up by his then GP. Then in 1980 at age 30 a social contact with a doctor, who listened carefully to his life story and did a CK test, led to him being referred to a neurologist, a battery of tests, two muscle biopsies and a diagnosis. At last! He was told he was about the 50th case in the world and there was nothing to be done. “Goodbye.”

Having finally got a diagnosis of a real medical condition explaining his lifelong symptoms, Andrew no longer went out for walks, thinking this was what he had to do to protect himself. After about three years he realised he had deteriorated and what little advice he had been given could not be right. Over 18 months he gradually built back up to the point where he could again walk the hills, albeit at his own pace and in his own way. He struggled and wanted to give up at the start of each walk, but from experience he knew that later he would be fine and at the end of the day he would be ready for more while his “normal” friends would be fit to drop.

At age 50 Andrew discovered the UK McArdle Clinic and finally learned the scientific basis for what he had been able to achieve. His diagnosis was confirmed by DNA testing - he has two copies of the common R50X mutation and thus has zero myophosphorylase. With the greater understanding which came from learning the mechanisms of the disease and learning about “second wind” he went on to make better use of what he had learnt by experiment. Using techniques he has developed he has climbed all 188 of the Welsh mountains over 2,000 ft (610 m), and mountains around the world. (He copped out 200 ft (61 m) short of the 19,340 ft (5,895 m) summit of Mount Kilimanjaro blaming altitude sickness rather than his McArdle's.)

When leading the “Walk over Wales” at age 61, Andrew believed that his McArdle's was no worse than it ever had been.

Andy Williams – Singapore



For as long as he can remember Andy has lived with muscle pain/weakness that has sporadically led to a feeling of humiliation and inadequacy, with that humiliation sometimes painfully public. Several times he had been told he was simply lazy or unfit and despite three major instances of rhabdomyolysis he was not diagnosed until the age of 43.

His parents often told him how, even at an early age, he hated walking and after a short distance would complain his legs ached. At school he remembers swimming to have been a particular challenge. His first recollection of humiliation was a junior school lengths competition. He managed to complete the length but not before those on lifeguard duty came to the side of the pool to pay particular attention to the poor weakling who seemed in peril and who was delaying proceedings with what must have been one of the slowest lengths in school history.

Cricket was his favourite sport and he was good enough to represent both his school and university. A reflex catch at short leg takes little exertion. Running between the wickets can, with skill, be controlled by appropriate calling, except of course in very tight situations. In one such, as a junior player, he recalls attempting a third run and coming to a grinding, inexplicable halt mid pitch. Dismissed ‘run out’ he walked back to the pavilion close to tears, unable to explain what had happened or why.

Andy credits cricket with helping him to cope with the disease and to remain reasonably active, but it has seen him hospitalised twice with rhabdomyolysis. On both occasions kidney tests were undertaken but never a simple creatine kinase (CK) test. The days that followed games would also see him wander around with a degree of stiffness most people would associate with far more demanding exercise.

His worst rhabdomyolysis episode followed an introductory gym session in 1986, which led to three days in hospital and all sorts of tests including a kidney biopsy, but again no CK test and no diagnosis.

Andy finally got the answer to that school ‘run out’ thirty years later, when diagnosed in Singapore through a series of coincidences and a very alert cardiologist. With diagnosis came relief and also the opportunity to learn how to cope and indeed improve fitness. Since visiting Dr Alfred Slonim, in New York in 2005, Andy has tried to plan regular exercise into a hectic business travel schedule. Having kept a record of treadmill sessions he has been able to show considerable improvement.

Andy found the “Walk over Wales” to be a tremendous experience in meeting other McArdle people for the first time, and in gaining an enormous sense of achievement. Having hated hills all his life, the revelation of conquering several mountains (and even enjoying the challenge!) encouraged him to strive for further improvement in fitness, and to return to enjoy the beauty of Wales and its mountains.

Approaching 50 Andy has just bought himself a new cricket bat. He plans to recommence playing and hopes to enjoy some competitive cricket in the same team as his 12 year old son George, before George moves on to a level at which Andy could no longer hope to hold his own....

Charlton Thear – Canary Islands



Unusually for a McArdle person, Charlton (known as Charlie) was diagnosed at the age of six. Although living in the Canary Islands at the time, his family are from Newcastle on Tyne in the UK, where his parents, Alison and Terry, managed to secure his diagnosis at the Centre for Life.

From the age of seven Charlie has attended the UK McArdle Clinic where his diagnosis was genetically confirmed. Having learnt what to do and not to do, he has successfully avoided any major incidents or hospitalisations.

Charlie has known Andrew for many years and when he heard about his plans for “Walk over Wales” he was very keen to take part, despite being only 13 at the time. School term got in the way but he managed to walk with the team (joined by

his mum Alison) for the last three days to the finish in Cardiff.

At the time of going to press, Charlie is now 16 and has ticked off three major Welsh peaks, including the highest, Snowdon. He has also completed a major challenge of 7 days of serious hiking in the Dolomites, Italian Alps.

More walkers around the world

Other people with McArdle Disease joined in the spirit of the month by completing a walk wherever they were, as they were not able to join us in person. They all helped to raise awareness and raise money through sponsorship to help the cause. They were:

Dianne Berryman in Australia
Lorraine Baguley in Australia
Marcelo De Luca in Argentina
Margaret Carter in the UK

Margaret deserves special mention as she is one of the worst affected by McArdle's, following a life of hard physical work and a very late diagnosis. She had been a regular user of a mobility scooter and a wheelchair for 10 years prior to her walk for McArdle's in 2010. Walking with her walking frame, Margaret pressed on against the odds to walk some 100 yards. Sensibly her route was to her local pub and back. Margaret even got herself featured in the local paper and raised an amazing £500.



Margaret Carter, supporter extraordinaire!

Our thanks to all these walkers, whose support was really appreciated and helped to keep us going in Wales.

DAY 1

2 JULY

Great Orme's
Head to
Conwy Castle

Following two days of transit, the moment of truth had finally arrived – the first day of our collective journey across Wales was upon us. What were we doing embarking upon such a lofty goal – complete madness.

As our kind hearted support driver manoeuvred through the narrow roads, my anxiety began to swell. Engaging in physical activity with 'others' is not something one with McArdle's does. I had to keep reminding myself that they too would find themselves needing to rest, just as I would – but yet, that nagging sensation of complete panic overwhelmed any and all streams of logical thought I had. I was beginning to feel like the eight year old version of myself who would mentally prepare for the dreaded end of year play day – an event most kids eagerly anticipated all year long. Instead, I fearfully prayed for a natural disaster.

To add to my sense of fear, we had arranged to meet the press for our monumental send-off. Fortunately, they didn't arrive and we were able to slip away unnoticed. The sky was a vacant blue, the air was warm, and the smell of the sea was carried in-land by the strong off-shore winds. Sounds lovely – not exactly; as our first step of many was met by a tremendous headwind. This made the transition into 'second wind' more difficult. This invisible force was the first of many unexpected challenges that lay ahead for us.

Without hesitation, Andrew unapologetically stated his need to stop. What a relief, as I did too – but yet felt embarrassed to say it out loud. As nonsensical as it may seem, uttering aloud the need to rest, felt like an admission of failure, of incompetence – something I didn't want to concede to. After a few minutes we carried on, repeating this pattern as often as needed. It was at this moment I began to realize this journey was different – perhaps even manageable, if only one step at a time.

The impact of having to stop and rest due to McArdle's can be all encompassing. Everyday, without fail, I find myself in a situation whereby I need to stop, or at the very least, slow down and rest. Having lived thirty-six years without a diagnosis, I was perpetually embarrassed with the ambiguity of my seemingly poor level of fitness. This led me to the creation of an expansive collection of creative excuses for rest – my favourite was letting my dog stop and sniff during our daily walk! Naturally, seeing dogs on this first day, I anxiously hoped they would stop for a visit, for an inconspicuous rest before carrying on.

No chance – these Welsh pups are not attuned to the ways of this McArdle walker.

As we turned the bend, the winds were behind us and the rest of the day's walk transpired without incident. We talked, we laughed, we ate – all pretty normal stuff. All that was left was two-hundred and five miles, and a few mountains. And with that thought, a fleeting sense of accomplishment soon vanished in a puff of reality. Breathe – me, the optimistic pessimist, just had to remember to breathe...



Stacey and Heather approach the bridge to Conwy Castle and the end of day one.

Only 205 more miles to go!

• 'Sheffield' to all • McArdle's and the wind • Why everyone should have a cuddly dog • Ice cream at Conwy Castle • 5 miles down

Heather drove us to Great Orme, only to find the road closed. A few minutes of panic when we thought we'd miss the press, but no worries, Heather got us there in due time for our meeting with the press, that didn't show!

Mother Nature greeted us with gale force winds, but we managed a photo opportunity nonetheless. Check out our WoW Banner! In typical friendly Welsh style Andrew instructed us to be sure to greet all passers by... what he didn't tell us was what the local greeting was. So when he greeted a walker by saying

'Sheffield' we thought that is what we were to do. We've since learned that is just a city in the north of England [it slipped out as he explained where DNA testing for McArdle's is carried out].

Back to the issue of the wind. All three of us found it quite challenging to begin our walk directly into a head wind. It meant we had to go extra slowly in order to safely get into second wind (no pun intended).

After we left Great Orme we travelled along a lane that gradually descended around the headland.

The sun was shining and the cloud shadows were dancing across the sea. We made our way to the seashore and walked along the North Wales Coast Path. We stopped in at a cafe to refuel with Bara Brith (Welsh Cake/Bread).

Along our way we were met by many dogs and Stacey was disappointed that they were not as



At Great Orme the wind made our banner a handful.

sociable as her own dog. We discussed the benefits of having a cute and cuddly creature. One, they get you out and walking every day and two, frequent stops (either to visit with other walkers or for a pee break) help with the transition into second wind.

The walk along the estuary was very scenic and peaceful. Across the way we had a wonderful view of Conwy and the Carneddau Mountains where we'll be going over the next two days.

We arrived at Conwy Castle after a 5 mile walk and had an ice cream to celebrate, knowing we only have 205 more miles to go!

Way to go, congrats to all of you on Day 1!
Stacey, I had an ice cream from Murphy's in
your honor!

MIKE MARINO, USA



Walking on hard sand to ease the effort.



WoW, one day done!

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20
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210

DAY
2

3 JULY

Conwy Castle
left behind
at last

The butterflies in my stomach now seemed more like caged elephants. The beauty of Conwy Castle faded quickly as we set off, one step at a time. It was difficult to take in all of the lush scenery, as my old familiar preoccupations returned – anxiety, fear and panic.

How many curious and beautiful things I have missed as a result of being consumed with my body's inborn error of metabolism and all that it affects. My increased heart rate, my stiffening muscles and my deflated ego. Today was no different – I could feel myself heading down this familiar path, fighting to ignore the obvious.

What I failed to realize, for the second day running, is that I was now walking with people who fully understood this predicament.

At the same time we all began to slow down... it was clear and noticeable, and in a few moments we came to an eventual stop. No words were said, we just...stopped. Together we rested and enjoyed the moment. And then, just like that, we carried on.

A moment of relief washed over me...maybe it was finally sinking in. I no longer had to worry or feel embarrassed. Who am I kidding? These primitive responses were not going to fade away that quickly. They have lodged themselves deep in the crevices of my mind. Logic would not prevail – at least not today. But a seed of hope had been planted – a new beginning was emerging.

After lunch came the realization that there were more hills to conquer and further miles to walk. Andrew did classify today as a 'moderate' stretch. I'm not sure I agree. He may be a sadist or an optimist, I still can't tell, but if eight miles is moderate, surely twelve kilometers would be hellish – at least to me! And with the elevation peaking at three hundred and sixty meters, it'll feel like we walked to London.

We agreed to keep our lunch breaks short so as not to risk falling out of 'second wind' – something none of us wanted to do. Getting back into a comfortable stride after each break took effort, so we carried forward 'slow and steady'. As the day progressed and the miles behind us accumulated, the walking became easier. Is this what 'normal' feels like? It is truly remarkable how our bodies adjusted. Enjoying the euphoric feeling of our ever moving bodies while it lasted, we revelled as a group in our 'second wind' – both literally and figuratively.

With the second day coming to a close, and over 13 miles (21 km) under our belt, we were well on our way. Perhaps not far on our way, but we were moving, and in the right direction – south to Cardiff and forward towards a better understanding of McArdle's, and our ever expanding boundaries.



Andrew, Dan and Stacey keen to get going from Conwy.

Just under 34,000 ft (10,400 m) to go...

- How many sheep in Wales? • Conwy Castle finally behind us • 8 miles (13 km), climbed 1,181 ft (360 m) • Slow and steady was the name of the game



Away from the coast and looking down on the Conwy valley, the task ahead seemed enormous.

With our first true day of hilly terrain, Dan found it best to purposely slow down before approaching the hill in order to conserve energy. A great tip for all of us.

As we marched up and down all of the peaks and valleys we ran into more sheep than either Dan or Stacey had ever seen - too many to count. It seemed that every corner we rounded we had sight of Conwy Castle, despite hours of walking. We were happy to finally lose sight of it in the second half of the day.

Today was graded as 'moderate' but Stacey is sure Andrew made a mistake, as she felt it was rather difficult - mostly because Southern Ontario is rather flat. Tomorrow we are heading into our

first big mountain day - 8.5 miles and 830m ascent. Off to bed for a good night's sleep. Dan is sitting on the lounge floor of the B&B playing the landlord's guitar.

McArdle's reminds me daily that it will always be a part of my life. Good luck! Looking forward to hearing more.

RACHEL WALKER, USA

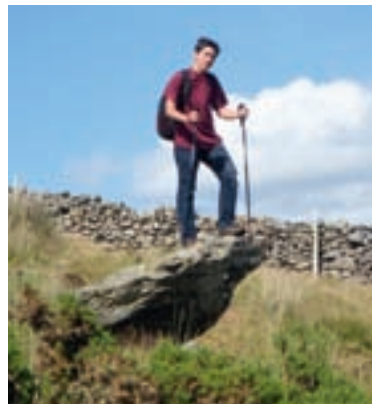
Wishing I could share the beautiful scenery of my homeland with you. I admire all of you.

Hwyl Fawr!

SIONED WILLIAMS, LONDON



Descending to rendezvous with Heather ('we'll have to go back up!').



Dan finds his first 'King of the Castle' spot.

DAY
3

4 JULY

Through the
Carneddau
Mountains

As I settled in to bed the night before, I was feeling tired, homesick and completely overwhelmed. I confessed to Heather (our support driver and my compassionate room-mate) that I might not walk the next morning. In retrospect, I think jet-lag was getting the better of me. Fortunately, I slept great and began the day with a traditional Welsh breakfast. My plate was full with bacon, sausage, fried mushrooms, tomatoes, eggs and toast. Apparently the Welsh breakfast is meant to be bracing and filling, preparing the consumer for a day of hard work in the often difficult Welsh climate and

terrain. Good thing – as today's walk is graded 'hard'.

In traditional British form, the team discussed the day's route over a cup of hot tea. The weather was indeed foreboding, and Andrew was concerned about our planned route over the Carneddau range. His apprehension was justified by a call to Mountain Rescue, so a low lying route was quickly mapped out between sips and stirs.

I had been a little nervous about our first big mountain day, who am I kidding – I was petrified. So the decision to walk an alternate route was not upsetting to me at all – even considering the poor weather.

When we arrived at our starting point, the weather was dismal. It was the kind of day that would keep any sane person indoors. The rain fell heavy, and the wind carried it sideways

– there was no escaping it. Andrew, Dan and I looked at Heather hoping she would confirm our thoughts, and insist upon returning us to the safety of our B&B.

Heather would have none of it and next thing I knew we were walking away from the shelter of the car and into Mother Nature's cold, wet embrace. Within minutes we were soaked. The defining moment was upon me – would my rain gear withstand the harsh weather of North Wales. Fortunately, it did!

I was now regretting my earlier 'rain dance' that kept us off the mountain range. For most people, the wind and rain, would move them along at a steady pace, even accelerate them with the goal of reaching refuge as quickly as possible. For us, that option was a luxury. We hiked for three hours, and only covered a few miles.

I can't begin to tell you how frustrating it is to be held back by your body. Our minds are telling us to pick up the pace, to get out of the rain – but our muscles are telling a completely different story, cooperating just enough to keep moving. And so we plodded along – one step at a time, ensuring not to tip the balance from aerobic to anaerobic.

As one could imagine, those of us with McArdle's tend to be good planners – more out of necessity than anything else. I suppose we've all learned early on the importance of thinking ahead and devising strategies to get from one place to the next – safely and without undue embarrassment.

Our predetermined rendezvous with Heather appeared like a welcome mirage – we hopped in the car and headed for warmth. The remainder of the walk would have to wait.



Dan and Andrew push hard up hill in heavy rain.

Windy, Wet 'orrible Wales (WVoW)

- *Change of plans!* • *Today we tested our rain gear... to the max.*
- *Technique + aerobic capacity = success*

Like a good Scout, Andrew checked the mountain forecast before we set off this morning. It didn't sound promising. But to be certain, Andrew placed a call into Jed (Mountain Rescue contact - OVMRO), he confirmed the decision. So, an alternate route was decided upon. Our plan was to complete the same distance today in order to meet our target mileage.

As Heather dropped us off this morning we were all a bit reluctant to get out of the car - the rain was driving down hard and the wind was utterly wicked. With rain gear on, we set out with a plan to meet Heather a few miles along the route - just in case of emergencies.

Our route was along a high valley (1,300ft) and we were into a strong headwind (30 mph), so by the time we spotted Heather, we promptly jumped into the shelter of the car. Despite the inclement weather we managed to get a few pictures for the blog, without causing any undue harm to our cameras (let's not mention Andrew's water-logged cellphone).

We have found that we are all three very similar in our performance. After 3 days of walking together we realise that apart from building aerobic capacity it is essential to have good technique to avoid injury. We are all learning from each other and will write more about this later in the trip.

Although tomorrow is our 'rest' day, Andrew insists we have to finish today's route.

I believe the word "perseverance" applies here. Wishing you clear skies for the rest of the walk (or at least a little less rain).

JO DICARLO, CALIFORNIA

Great to see you look like you're having fun. You are an inspiration to us all.

DIANNE BERRYMAN, AUSTRALIA

Now we know why Wales is so green and beautiful!

Dan, you still look handsome even though you look like a drenched dog.

TERRI CHAMBERS, SAN DIEGO



A McArdle hazard to crawl under.



A very wet VoW crew very happy to see support driver Heather.

DAY
4

5 JULY

Catching up -
over to the
Ogwen valley

Our thirty-two day journey across Wales was constructed with much needed 'rest days' strategically placed every four to five days. What we didn't account for was the possibility of having to 'make-up' for lost mileage due to inclement weather – a rather remote prospect in Wales I'd say! A difficult decision had to be made – do we rest, knowing we have twenty-eight days of walking ahead of us, or do make up the mileage, knowing we have one hundred and ninety-nine miles to trek in twenty-eight days. And don't forget about the hills still ahead...

One strategy I developed over the years was to try and get ahead of others whenever possible, to always be at the front of the pack while out for a walk. Then, when I needed to rest, I could do so while waiting for stragglers to catch up. Alternatively, I would fall behind and spend the balance of the walk trying to catch up. And if that doesn't sound frustrating enough, when I'd finally get in sight, they would set off and the pattern would repeat itself.

In line with this school of thought, we decided to stay ahead of the curve by taking advantage of a rain-free forecast and complete the previous day's walk along the reservoir to the beautifully situated bunkhouse – Gwern Gof Uchaf – our home away from home for the next three nights.

Andrew, our chief navigator, soon to be named 'Illustrious Leader' has trekked all over the hills of Wales, and knows most of the country like the back of his hand. With that knowledge, Dan and I happily plodded along, while Andrew's exceptional map reading skills kept us on the straight and narrow – more or less!



Our route along this lakeside, then up and over into the Ogwen Valley.

"We are on a path, just not the right path" declared Andrew.

Being lost. I take pride in always knowing where I am because the last thing I want to be concerned with is being lost and having to retrace my footsteps. So, one step at a time, I like to ensure I'm headed in the right direction. Having to walk further than required seems counter-intuitive when at times you struggle to walk just a few hundred meters.

Not sure which direction I'm headed (although it must be south to Cardiff), across a desolate landscape, with rather unimpressive map reading skills. Not an ideal position to be in, but Andrew really seems to know what he's doing, so I blindly follow along.

Fortunately, we were just a stone's throw away from the path. The road to our 'yet to be seen' bunkhouse was now in sight. Tragedy averted, no substantial distances to be retraced. Phew! The thought entered my mind – perhaps I should brush up on my topography and map reading skills.

Another day done – four days finished – twenty-two and a half miles DONE.

I think we're on the right path...

- What flies at 300ft and frightens the bejebes out of you?
- Gwern Gof Uchaf – basic • An experience with varying terrain

It has been so wonderful to hear all of your responses to our daily updates on the blog - thank-you for your support.

Although today was our designated rest day - we had to make up the distance from our rained out day yesterday - so we picked up where we left off, and hiked alongside the reservoir. Along our way we were met by a flock of sheep being herded in to be sheared. It was quite the experience as we were directly in their path. Fortunately only one was left behind!

Most of our route was on good trail today; however we did encounter slippery rocks and tussocks (grassy humps). We all agreed that each time different muscles (due to incline and/or terrain) were used we had to make the transition into second wind with those muscles - thereby slowing us down frequently.

Part way down the hill, our fearless leader



Well matched for McArdle's despite 20 year gaps between us.

'bunkhouse'. Essentially camping, but in a building rather than a tent. Directly outside the front door is a flock of sheep keeping watch - a little different than stepping over the family dog!

The next four days will be met with a number of great ascents through Snowdonia...

BREATHE!



Lifting a metal gate - beware McArdle's!



Descending over rough ground, tomorrow's mountain range in front of us.

Andrew led us down the garden path, the problem was, it was the wrong path. We received a call from Heather wondering if we were on the right track. Although we got slightly off course, the end was in sight.

En route Dan lost his 'rag' - second one thus far... he is now making the trek rag-free.

The last leg of the day was along the roadside. We all heard a rather loud noise approaching from behind and expected a large lorry - but no, it was a couple of Royal Air Force jets on a training run at 300 ft (100 m). Yikes!

For the next three nights we are staying at a

You are all looking wonderful and are an inspiration!

LORI

After the bed-and-breakfast accommodations, your bunk house adventure will be interesting.

JO DICARLO, CALIFORNIA

Today published in the forum of the Spanish Association of people with glycogenosis what you are doing.

MARCELO DE LUCA, ARGENTINA

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DAY
5

6 JULY

Ogwen to
Pen-y-Pass over
the Glyders

‘An easy start in the Ogwen Valley, then a gradual climb up over the Glydderau range. A short day but with a lot of ascent.’ That is how the description of today’s climb read. The words that stood out in my mind were – easy start, gradual climb, short day – sounds quite manageable!

At 0630 my bladder gently nudged me out of a deep sleep. I woke with the sudden recollection of where I was – in a converted

barn, on the top bunk – inches away from the biggest cobweb I’d ever seen. I snuck out the set of double doors as quietly as I could with the intent of sliding back to bed before anyone awoke for another hours’ sleep. Shhhhhh.

The ascent up the Glyder Range was situated right at the foot of our bunkhouse. Which meant our muscles would be working hard straight away. Anticipating the climb ahead, Andrew called today’s plan ‘slow and steady’. According to Sir William, the word ‘Glyder’ derives from the Welsh word ‘Cludair’, meaning a heap of stones. After many hours of push, stumble and gasp the name was considered gaelic for “endless bloody climb on a hill of marbles”.

What I didn’t account for was the direct relationship between elevation gain and my level of anxiety. The higher we climbed, the more panic stricken I became. But at this point in my newfound relationship with Andrew and Dan, I was not about to fully disclose ALL of my weaknesses.

Andrew drew my attention to the path that would take us to the ridge – ‘Holy Mother



Day 5 started in the lee of Tryfan.



Hard going almost from the start.



Crossing a stream in Cwm Tryfan on good stepping stones.



Just a couple of steps and rest, leaning on our poles, on this steep scree slope.

of God, it was a forty-five degree angle path that was no wider than 2 ft (0.6 m) – doesn't this place have codes for 'nerve-wrackingly-steep-easy-to-fall-and-fall-and-fall' paths?

One step at a time, I made my way as quickly as possible up this path to the ridge and more level ground. I did not stop, I did not rest. I did not listen to my aching muscles. I just kept going – flanked by panic to my right and fear on my left. I didn't stop and talk to Andrew. I didn't insist that I couldn't carry on. I just made my way up and away from a terrifying situation as fast as possible – correction, as fast as McArdle's possible.

We were near the top, but not at the top. We had more climbing to do, but the exposed climbing was behind us, at least for now.

The weather had turned for the worse – the winds were strong, the air was cold and I was certain it was snowing – okay, maybe they were just really cold rain drops. By now I was frozen, despite putting on an extra layer. As we clambered over the moon-scape before us, the gravity of the situation began to weigh heavy on my mind. Here I was, three thousand feet above sea level, fighting my way across a rocky terrain with only one choice – to carry on.

At this point I broke down and confessed to Andrew – I was in over my head. The muscles in my



Dan looks back over yesterday's route and north to Conwy.



Andrew and Dan brave the Cantilever on Glyder Fach, in gusts and rain!

legs were screaming for rest. The heaviness of each step was overwhelming – it felt like the weight of the world was resting upon my failing body. But the cold, rain, and limited hours of daylight meant we had to carry on, slow and steady all the way.

We made our way up and over Glyder Fach and Glyder Fawr. I was barely able to make my way thus far, how would I get back down? I kept telling myself, over and over again –

you are healthy, you are strong. My muscles were yelling at me, trying to convince me otherwise. I knew they were right, but I needed them to hang on, just for a little while longer – just until I got off this mountain.

The route down was challenging, made worse by my sore, fatigued muscles. After eight hours of trekking, we met Heather at Pen-y-Pass. Relieved and tired, we collapsed into the warmth of the car.

Following dinner, I began to feel very unwell – cold, nauseous and shivering. About an hour passed, and Andrew made the decision to take me to the hospital. All of the appropriate tests were done (thanks to a letter I carry from my Dr.), and my CK came back just slightly elevated in the few thousands. My muscles certainly told a different story though. After a few litres of IV fluids, I was discharged and back in the comfort of my bunkbed.

What a day – exhausted, scared and alone – and it's just the beginning.



Just focussing on getting down.

Not all the 'Glyders' is gold!

- One giant step for mankind... one small step for McArdle's
- Forecast – rain and high winds with a sprinkle of fear • Conquering the cantilever



It looked a loooooong way down to Pen-y-Pass.

Today we set out from basecamp onto the Glyder Range, past Tryfan. Stacey was clinging onto the ground for dear life. We were met with a particularly steep slope straight away, which meant we had to take particularly small steps in order to avoid anaerobic exercise. Upon completing the first leg, we headed forward on a relatively easy track towards the omnious 45 degree path up to the mountain range.

Already the view was quite intimidating, I mean spectacular.

Once we made it up the very narrow path (if you can call it that) we stopped for lunch, where the 'Isle of Man' girls shared their lunch with Dan. We had a choice to make - carry on with the intended route, or bail. We carried on ascending to the cantilever.

Despite rather intense wind gusts, Dan and Andrew fearlessly conquered the rock for a photo op (courtesy of Stacey). We now had to make our way to the highest peak of this range - Glyder Fawr - a mile away along the ridge.

Although the incline was minimal, the trek was challenging - as the path was poorly defined and over a combination of loose scree and boulders. Once at the top, we promptly searched for the next cairn that would lead us down the mountain (too cold for a snap shot).

At this point Stacey's legs felt quite sore and shaky (McArdle's related?), and untimely enough,



Cheerful to be getting excellent care.

the weather started to gust in. Despite Stacey's pain, we had to get down. So we compensated by taking the "slow and steady approach" in order to avoid the "quick scramble and stop".

A few hours later, following supper, Stacey felt particularly unwell - sore muscles, nausea and shivering. The decision was made to go to the hospital and have her CK checked. The CK came back minimally elevated - so the conclusion was that Stacey was dehydrated.

The lesson we all learned is that not all that ails you is due to McArdle's. Thanks to Gwynedd Hospital for their prompt, friendly and superlative service!

Keep moving, one step and one day at a time,
everyone is cheering, proud of, and behind you
and the whole Wales gang!

MARIO, NEW YORK

Congrats guys. Stacey, that is one picture I do not
want to see any more of. Hugs.

JOHN REED, CANADA

Amazing! Truly you are an inspiration, and
shining examples of what can be achieved in
spite of McArdle's.

CHERYL ELLIS, ENGLAND



DAY
6
7 JULY
Over the Snowdon massif

The pain in my legs reminded me of my poor decisions from the previous day – I would NOT be walking today. For that matter, perhaps nor would Andrew or Dan – the weather was quite dismal.

Six months prior to arriving in Wales, I sent an enthusiastic email back to Andrew stating that I wanted to join him on his pilgrimage across Wales. Really? Had I committed to five weeks trekking up and down the hills of Wales?

I began walking, I walked everyday. I carried my pack, I walked up hills, I walked down hills. I walked with my dog, I walked with

my friends. One step at a time. I didn't pass up an opportunity to walk. I thought I was ready, I was certain I was prepared.

Andrew sent a very detailed itinerary to the team about a month before departure. It included map references, mileage, elevation gain, grade, terrain and comments. But the substantiveness of the landscape didn't sink in until I found myself lost against the backdrop of the mountains and their magnificent proportions.

Pre-diagnosis I had conquered a few mountains. In particular, I summited Mt. Washington via Tuckerman's Ravine (8.5 miles and 4,300 ft (1,310 m) of ascent) to the 6,288 ft (1,916 m) peak. It was challenging, I struggled, I took my time – but I made it up and down without incident.

But Snowdonia was different. The peaks boasted striking rock formations and treeless tundras, and terrain that dropped away precipitously on one side or the other (sometimes both) to the valleys below. I was beginning to understand – exposed routes with vertical drop-offs heightened my angst, propelling me forward at a dangerous pace.

I would have to deal with this, and fast – as we had 175 miles to go.

Confirming my previous thoughts, McArdle's was not the problem, elevation was not the concern. Anxiety to sheer drop-offs coupled with an inappropriate coping strategy was the stumbling block. The pattern looked a bit like this – stressor (exposed paths), led to increased anxiety and tense muscles, followed by an urgent need to escape the threat (moving faster than my body can supply energy to my already stressed muscles).



On the Miner's Track, with Y Lliwedd in the background.

Learning how to mitigate these (and other) variables that can impact McArdle's was an important lesson for us all.

Andrew and Dan conquered Snowdon, while Heather and I conquered the grocery store. Their tales were exhilarating, their pictures terrifying. I am so pleased the weather cooperated (more or less) and they were able to summit the highest peak in Wales.

For me, the decision to re-join the boys will have to wait until the morning. Although it was my intent to walk every step of the 210 miles (338 km), the need to listen to my body was a priority. I kept telling myself, the road is long, the journey has just begun!

And then there were two...

- *Safety first!* • *Revisions, revisions, revisions...* • *Hang on for dear life*
- *Who's leading who?* • *Don't panic*

The morning of day 6 approached quite quickly, as the previous night was a late one. We were greeted with rain and heavy fog – not an ideal day to summit Snowdon. So we headed off to the cafe down the road to update the blog and check the weather forecast. A late start was decided on, as the weather was to clear by afternoon.

Today, Snowdon would be met only by Andrew and Dan – as Stacey's muscles were quite sore – remember, safety first. At 1:50 they headed up the Miner's Track in foul conditions, with the plan to turn around if it got any worse.

For the first 20 minutes the rain persisted, but then settled down – so they carried onwards and upwards. The trek up was nice but rather windy. Andrew asked walkers coming down what the conditions were like at the top – all said something different – not too helpful. So the route would have to be decided moment to moment.

Andrew and Dan were met with unbelievable wind at the summit – 25mph winds gusting up to 50mph! The pictures appear as though they are in the midst of a snow storm – extremely poor visibility. Dan had a moment of panic as he wrestled with his pack – this led to an unfortunate strain of his upper arms. We can climb mountains, but struggle with our packs – ohh the subtleties of McArdle's [sigh]!

On the way down, Dan had to lead Andrew for a short bit, as Andrew could not see through his fogged up glasses – the blind leading the blind. Just when frustration was setting in, the skies began to clear and the view was spectacular – thank-goodness for the late start!

Once off the mountain, we all enjoyed another fabulous meal – courtesy of Heather and drank, drank, drank – water that is!!

Thought du Jour... *"Right now I feel as though I don't have McArdle's"* (Dan on the way down Snowdon, the highest mountain in Wales).

That giant challenge on this day.
Forward gladiators.

MARCELO, ARGENTINA

My goodness! I can't imagine what it must be like to climb a mountain under these conditions - McArdle's or not.

JO DI CARLO, CALIFORNIA



With Heather, seeing Andrew and Dan off in the rain.



Gusts to 50 mph and no visibility on the summit.



Descending into a beautiful evening. Down at 9.30 pm!

DAY
7

8 JULY

Through the
Moelwyn slate
quarries

Frustrated. Sidelined. Sore. I am beginning to feel like the weakest link. Which I know logically isn't true, but when are emotions ever logical? Heather's intuition kicked in straight away. She reminded us that our goal was to get to Cardiff, happy and safe. Even if that meant adjusting our route from time to time.

Heather and I kept busy throughout the day – we dropped off the boys (today they were tackling the Moelwyn Mountains), I wrote the previous day's blog, we transferred luggage to our next base – 'Tan-y-Fron' in Dolgellau,

and finished off with picking up Andrew and Dan up at the end of their nine mile trek.

Keeping busy and feeling productive helped me keep everything in perspective. I had come to Wales for the express purpose of walking, one step at a time, from the Great Orme to Cardiff, and now I found myself benched – an all too familiar feeling.



Happy at the prospect of leaving the bunkhouse.

Prior to my diagnosis, I can't count how many times I have passed up an opportunity to do something, for fear that I wouldn't be able to keep up. I've avoided team sports and play days, golf tournaments and group fitness classes – for how else would I explain my tragically poor level of fitness. Watching from afar, albeit for a different reason, brought that familiar feeling to the forefront.

Perhaps this was part of my journey, to not only accept my diagnosis of McArdle Disease, but a more global affirmation of self. It was at this point I decided to accept the challenge and participate when and how I could.

That evening, we had a long discussion about our expectations for the walk. Our collective goal was to make it to Cardiff, together. Given the numbers of variables we'd encountered thus far, flexibility was going to be the key to our success. And so the decision was made – slow and steady all the way to Cardiff!



Making our way through the long abandoned slate workings of Cwmorthin.

Upon reflection...

- *Continuing to recover* • *Can you say BULL!*
- *Slow and steady all the way*

For two days since climbing the 'Glyders' Stacey has felt quite sore. Upon reflection, the CK test was premature and had likely not peaked – so rest and plenty of fluids is the name of the game. It is important to note that the 'Glyders' ascent was met with challenging terrain; exposed, steep paths and high winds/rain. None of which is favourable for someone with a fear of heights.

The sending-off crew was out in full force this morning. The footpath was surrounded by numerous calves and one VERY large bull – note how big he was in the pictures!

Shortly after starting out Dan was feeling rather fatigued, but no pain. After a short break and something to eat he felt much better and was ready to go. Sometimes it is difficult to distinguish between what is related to McArdle's and what is just par for the course... we are certainly learning a lot as we go. The ground was quite boggy and made the trek slow going and very wet – good thing Dan has 'perfect' footwear!

On the way up Andrew and Dan were passed by a couple (very typical for us); a little while later they were passed by the same couple making their way down (again, quite typical). The couple joked that they'd had time for a meal and a bottle wine at the top! This very clearly demonstrates how we have to manage with McArdle's – slow and steady – all the way.

Thought du Jour ~ We realise we may have to adapt in order to work around McArdle's by missing some peaks and revising our route, as the main objective is to get to Cardiff. Essentially there have been a number of variables along the



Yesterday's route over Snowdon lost in the clouds.

way that have lengthened our days. They vary from – weather, challenging terrain, diminished visibility, poor paths, fear, photo-ops, fatigue and trying to find wi-fi to work on the blog.

Slow and steady, all the way to Cardiff!

Having to adjust, revise, adapt is just part of having McArdle's... it may not be what you planned for or expected but you find another way!

TERRI CHAMBERS, SAN DIEGO

Fantastic photos. I'm off walking but I don't think my Australian winter will be anywhere near as challenging as your Welsh summer.

DIANNE BERRYMAN, AUSTRALIA



Stacey sees Andrew and Dan off...



through a field with a very large bull!

0
20
40
60
80
100
120
140
160
180
200
210

DAY
8

9 JULY

Minfordd to
the heart of the
Rhinogs

Last night I crawled into my double bed, pulled a warm duvet up to my chin and slept undisturbed in the privacy of my own room – heaven.

Our B&B is situated on the outskirts of Dolgellau, against the backdrop of a gentle, rolling hillside – a stark contrast to the Ogwen Valley. We are staying here for the next week before moving on to Machynlleth. For now, I will enjoy the beauty that surrounds me, as the softly falling rain echos peace and tranquility.

As Andrew and Dan set off, one step at a time in a persistent drizzle this morning, Heather and I wondered how long they would last. The wet



Feeling a lot better.

weather was relentless. Even though Dan was revelling in his newfound relationship with the rain, it was clear that Andrew was getting a bit weary of it. Needless to say, they packed it in early, in exchange for a warm shower and dry clothes.

Today was Heather's last day. For the past week, she drove us out to, and back from, some of the most remote places I'd ever been. She fed us, cleaned up after us and nurtured us. What were we going to do without her? Next in line was Peter, Andrew's brother. Peter would be taking over as support driver on Monday, and Andy (a fellow McArdlite) a couple of days thereafter. Four boys and me – oh dear!

I would soon learn, that despite spending a week as the sole female; Andrew, Dan, Peter and Andy were quite pleasant – for guys!



A few posed shots for the press!

It's raining again...

- Rain – 5, Sunlight – 1 • Nuclear fallout • Soggy boggy footsteps!
- Second wind saves the day once again.



Dan loves the rain, even when starting out in it.

Sunlight in Wales? No such thing. Six consecutive days of rain!...Plunging in occasional ankle-deep water across buggy stretches of mud: shoes saturated to the max.; though the Trawsfynydd Power Station provided a radiant warmth for drying†.....

After four “hard” days (labeled according to the mileage and elevation estimation on the itinerary), day eight presented Dan and Andrew with a less challenging walk. Although rain continued to pour down and the terrain was scattered with patches of soggy mud, our route



The wild ponies were not so wild.

was reasonably level with the exception of a few moderate ups and downs. This allowed for a relative breather while we were still able to continue on in progress towards Cardiff.

With the avoidance of extensive climbs we are able to maintain a stable second wind: traveling with a more consistent pace with fewer stops needed. This allowed us to best utilise our aerobic capacity. The abundance of inconsistency, confusion and simply unknown information surrounding this disorder often clouds the little bit of information that is concrete. The importance of second wind and sensitive use of immediate ATP cannot be over-estimated.

Thought du Jour ~ “I’m really a fair-weather walker and five days of walking in the rain is a bit of a shock to the system.” – Andrew

“Weather’s weather.” – Dan

† By the way, that is a joke, it’s been decommissioned for about 20 years.

Andrew, I thought you were the most sane of individuals. But who in their right mind walks the length of Wales in the rain when they own a perfectly good 4WD? I will continue to follow you with a large amount of admiration.

ALAN CRAIG, UK

Glad to hear Dr Quinlivan walked with you. My mam Alison said when I join you there will be *four* generations of McArDle-ites.

CHARLTON THEAR, CANARY ISLANDS



Crossing the dam of the Trawsfynydd Reservoir.

DAY
9

10 JULY

Our first real
rest day

Today is a REST day. Today we are going to REST. For the first time in over a week, we are in a position to sleep in, laze about and see Wales from a tourists' vantage point. No hiking boots, rain gear, backpacks or poles. I think I will wear my flip-flops!

Following breakfast, we took advantage of some free time and got caught up with the blog, uploading our pictures and communicating with the media. The administrative details were beginning to consume two to three hours each day, complicated further by the challenge of finding a consistent internet connection.

At this point in the walk, we had a strong following of ten people – most of which were related to Dan, and we certainly did not want to disappoint them.

As Dan was our official photographer, he was responsible for sorting through the pictures each day, choosing the best ones and composing captions. I often wrote the blog (with input from Andrew and Dan), and Andrew maintained all correspondence with the media. Our process was beginning to solidify and our roles were starting to take form.

I thought I was going to have all sorts of free time in the evenings, so I packed a couple of books, and loaded a memory stick with eighteen movies. So far, I hadn't cracked a book, or watched a single film. Between walking – one step at a time, cooking/cleaning up, planning routes, blogging and sharing a few laughs, there was no downtime. The reality of what we were doing was really beginning to sink in.

Walk over Wales was not just our journey, we wanted to share our experience with the world. We wanted to record our successes and challenges, what worked and

what didn't. Most of all, we wanted to demonstrate that people with McArdele Disease CAN lead a normal, healthy productive life.

Now that we had caught up with our paperwork, we decided to visit Barmouth. The town is on the west coast of North Wales – nestled between a mountain range and the sea on the mouth of the river Mawddach. The beach extends as far as the eye



Fishing boat in the harbour at Barmouth.

can see, while palm trees sway in the gentle sea breeze. Andrew and I meandered through the town, grabbed a quick bite to eat, then made a quick trip to the grocery store. Back at the B&B, Dan took advantage of the opportunity to unwind and relax.

On the way back, we spotted an ideal dinner venue set on the banks of the Mawddach Estuary – George III Hotel. I recommend the Grilled Goat Cheese and Ratatouille Tartlet.

Tomorrow is a special day, as Dr. Quinlivan will be joining us on the trails.

Finally – a real rest day

- *We're all exhausted from all of this resting!* • *Beware of Stinging Nettles*
- *Barmouth (Abermaw)*



Dan and Stacey outside the George III hotel, Penmaenpool, with the old toll bridge in the background.

After 8 busy days, the team is enjoying a day of R&R. Following a lovely breakfast and some administrative house-keeping we headed into Abermaw for a leisurely seaside stroll. We think we've spotted a different restaurant to have dinner at tonight.

Of note – Stinging Nettles actually sting!

Thought du Jour ~ Is there a 3rd wind? [Dan jokes]. However, we do all feel so much better at the end of a day's walk.



Well done. Keep up the good work. Hope weather better for you tomorrow. Have some of our heat... we'll blow it in your direction.

MARTIN AND CHRISTINE WAKELIN, UK



A day on the beach.



Summertime in Abermaw (Barmouth).

DAY
10

11 JULY

Through
the Rhinog
mountains

We had a fair way to drive to get to our starting point for the day. We adapted the route for a few reasons. To provide me with a comfortable transition day while I found my walking legs. Also, the weather was variable – particularly in the mountains, and we wanted to be able to easily converse with Dr. Quinlivan.

Shortly after we arrived we spotted her car in the distance. She made the two hour drive on a Sunday to walk with us – WoW.

Following a round of introductions and a few photos, we eagerly set off on the trail. As per usual, the track undulated up and down, veering to the left and swaying to the right. The path was so waterlogged – tadpoles were making it their home.

We carefully stepped from rock to dry bed, being careful not to strain any muscles unnecessarily. Our hiking poles facilitated this balancing act, allowing us to maneuver through the soggy terrain more comfortably.

The time passed quickly as the ebb and flow of our conversation had a singular focus – McArdle's. Dr. Quinlivan gracefully addressed all of the questions we posed – as if it were the first time she'd ever discussed this rare disease. We just couldn't get enough, one comment led to the next, and before we knew it, it was time for lunch. Perhaps now would be a good time to let Dr. Quinlivan enjoy the beautiful landscape of dense forests and open moorland that surrounded us. Our apologies.

Dan spotted a large boulder that looked like an ideal spot for lunch. As it turned out, this ended up being the turning point marking the half-way point for the day.

We took advantage of Dr. Quinlivan's expertise and inquired about my previous day's 'bout with rhabdomyolysis. She felt that my state of panic would have led me to tense up, causing my muscles to function more anaerobically, resulting in muscle breakdown. Something I plan to avoid from this point forward.

On our return trek back to the cars, Dr. Quinlivan noticed she was leading the group. She abruptly stepped back and urged one of us to take the lead, thereby setting a more reasonable pace for us to manage, one step at a time. Her level of insight, both academically and practically, is commendable.

The day concluded at Coed y Brenin Forest Visitor Center over cream tea. I've been told, the Brit's answer to everything is 'have a cup of tea – you'll feel better'. They're not too far off the mark! It was an absolute pleasure to meet Dr. Quinlivan and have the opportunity to share and learn even more about McArdle's. Thank-you!



Dr. Ros Quinlivan visited us for the day and walked with us.

Talkin' the walk...

- Dr. Ros Quinlivan joins the team for the day's walk
- Stacey is back in the game
- Is that sunshine we see?
- Saved by the pole



Stacey, Dr. Ros Quinlivan and Andrew fly the flag.

Today we were joined by Dr. Ros Quinlivan (UK's leading consultant in McArdle's). It was a very pleasant day – we 'talked the walk!' The day provided Dr. Quinlivan with an opportunity to witness 'second wind' and the need for frequent stops first hand. At one point along the trail she recognised that she was leading the group and suggested that one of us lead – so as to more appropriately set the pace. Throughout the day we shared anecdotes and asked many questions – Dr. Quinlivan was very gracious and answered ALL of our questions with compassion and care.

One interesting topic that we discussed was how to successfully transition into second wind. We have all experienced times whereby we've felt as though we haven't been able to get into second wind at all, most likely because we have set out too quickly. It is essential that we always start out slowly, in order to boost our fat metabolism (in

lieu of not being able to utilise stored glycogen).

Parts of the path today were terribly boggy – so much so, we were stepping through puddles of tadpoles. In an effort to step around one particular puddle, Dan artistically side-stepped forwards and backwards around his pole in an attempt to not fall into the soggy grass. Dan saved himself at the expense of his pole! Thank goodness Andrew has extras.

Sunshine, finally! If even for just part of the day.

We ended the day in true British form, by sharing a pot of tea with Dr. Quinlivan at the Coed y Brenin Forest Visitor Centre. Thank-you Dr. Quinlivan – we thoroughly enjoyed the day.

Andrew, Stacey, and Dan represent 3 generations of McArdle-ites. Awesome!

MARK CHAMBERS, SAN DIEGO



All using walking poles, including Dr. Quinlivan.



In Bwlch Drws-Ardudwy



Muddy paths, but the weather was good.

DAY
11

12 JULY

Barmouth and
the foothills of
Cadair Idris

Last night Peter joined the team. My first impression was 'this is NOT Heather'. What will this charming man think when I ask him for a pre-walk hug? He is a very attractive guy, with strong features and a firm voice. No, I don't think 'hugging' is his thing.

Given that the team had been together now for nearly two weeks, I had earned a reputation of being rather touchy-feely. What can I say, a big warm embrace is comforting. Peter soon learned the drill, and before I knew it, he was the one asking for a hug.

Peter and Clive have the sweetest Jack Russell Terrier named Jack. We met the three of them this morning high upon the hills overlooking Barmouth. Our route began on a narrow road that steadily eased its way down to the railway viaduct below. Getting started today would be fairly easy, as the demand on our working muscles was relatively low.

Being a dog owner, I've learned that dogs are opportunists. Jack was not unique in this manner. He took turns bribing each of us to play fetch with him, one step at a time, all the way to the sea. First Dan, then me, back to Peter, then Clive.

He worked hard on Andrew, but eventually gave up and turned his attention back to the rest of us. Jack (Peter and Clive too) were a pleasant addition to the team, if only for the morning.

When we arrived at the Barmouth Bridge, Peter, Clive and Jack bid us adieu. One of the challenges of being the 'support driver' is that you need to be at the end point with the car, so off they went to diligently fulfil their responsibilities.

The views of the Afon Mawddach River to our left and Cardigan Bay to the right were breath-taking. I enjoyed a quiet moment absorbing the serenity of the sea, as this

would be our last view of the coast until Cardiff. After paying the seventy pence toll, Andrew, Dan and I set off on the landward side of the wooden viaduct, across the estuary, and up into the foothills of Cadair Idris.

When it was possible, we arranged to meet with our 'support driver' at a half-way point. This provided all of us with the opportunity to walk lesser or greater distances (depending on how we were feeling that day). Given the ease of this morning's walk – we all carried on. Shortly thereafter, our pace dramatically decreased as the trail began to wind up and up and up.

We walked through forest and open meadow, past Welsh Blacks (cutest cows ever) and lambs. The sun was shining and our mood was relaxed. It really was a perfect day. The open land gave way to some brilliant views of our next endeavour – Cadair Idris – the haunted mountain.



Day 11 for us, day 1 for Jack – he's ready for the off.

Last glimpse of the Irish Sea

- *The day the sun shone* • *Farmland, seaside, estuary, meadow, forest and mountain*
- *Four legs good – two legs bad!*



With Peter and Clive approaching the railway viaduct at Barmouth.



Clive and Jack join the walkers.

Our walk today was absolutely glorious! We began on a hillside several miles above Barmouth. Peter (our new support driver), Clive and Jack meandered down to the seaside with us. We stopped for lunch on the Barmouth viaduct, before crossing the estuary.

From here, Peter, Clive and Jack returned to the car, while the three of us continued on. We strolled along the estuary for a couple of miles, before heading into the forest – a welcome reprieve from the heat of the sun.

We met Peter at a pre-determined checkpoint (optional bail out point), but all decided to carry on for a few more miles to the end point. At this point the grade changed – mostly uphill. Of interest – we walked for over 7 miles – downhill and on the flat, so we were all feeling very good. But as soon as the grade changed, we all struggled

and had to stop frequently – until our uphill muscles moved into second wind. Fortunately, our walking poles helped to ease the transition – four legs are better than two!

The last section of the walk was mainly across rolling meadows, with a view of Cadair Idris in the background. Absolutely breathtaking.

Thought du Jour ~ Andrew, your car doors are so sophisticated, they're like you – they lock up over 5 miles/hour.

It will be hard to leave such a lovely place.
JO DI CARLO, CALIFORNIA

The pictures help let us all feel like we are there with you. Hang in there. Keep up the great work.
BETH SCZEMPKA, USA



It's not all easy going!



A great day all round – company, route, weather and scenery.

DAY
12

13 JULY

Over Cadair
Idris to
Minffordd

I'm not used to starting my day with a press photographer snapping pictures. Par for the course I suppose when you decide to walk across a country. When you think of the 'press', don't you conjure up images of flashing camera's and mass hysteria? One guy, in a late model sedan, reeled into the car park at Ty-nant, jumped out of his car for all of 20 sec – shot two, maybe three pictures and off he went. I didn't even have time to apply any lip gloss.

After a quick trip to the loo, we were on our way to explore Cadair Idris. Legend has it that the mountain is haunted. Anyone who spends the night on its slopes will either awake a madman or a poet. Fortunately for us, we didn't have any plans to sleep here tonight.

Today's walk, unlike yesterday's, was a steady slog all the way up. A blanket of cloud rests upon the shoulders of Cadair's ridge, leaving the sky grey and the air cool – a welcome reprieve as we plodded our way up towards the lowest point on the ridge. As Andrew, Dan and I slowly ascended, one step at a time, Jack raced up and down, and side to side. Clearly, he did not have McArdlé's.

The final stretch of track up to the ridge zig zagged as the ground steepened – yikes. Clive positioned himself to my right, teetering on the precipice of the trail (at least that is how I recall it), which provided me with enough courage to move forward in a slow, controlled manner. Once over the ridge, and away from terrifying (beautiful) views we stopped for a quick lunch break.

The route to the summit headed east along an obvious pathway, rising steadily through the low lying cloud. This is where we parted ways – Peter, Clive, Jack and I retraced our footsteps down the windy mountainside, back to the car park; while Andrew and Dan made their way onwards and upwards. I had learned my limits, and now was not the time to aggressively challenge them. I had too many miles ahead of me.

We decided to indulge in a hot cup of tea and some sweets. We went back to Dogellau, and found our way to the TH Coffee Shop – a converted hardware shop. As seating was limited, we were joined by two locals. These gals had wild stories to tell. They insisted on sharing their cake with us, but only if we shared ours with them. At eighty-seven and ninety-two years young they certainly kept us entertained for the afternoon.

Now warm and content, we raced off to collect Andrew and Dan before darkness fell. The last thing Team WoW needed was a madman or a poet!

Back at the B&B, Andy arrived eager to join the Team and hit the trails. Andy, his brother Paul (and children), joined Peter, Clive, Andrew, Dan and I at George III Hotel for a fabulous meal. Our small group had suddenly grown, even just for a day. Knackered and in need of a good night's rest, we all headed off to bed. We were a third of the way down the length of Wales. Not too shabby!



Contemplating the heights to come.

Scratch that... the rain is back!

- *Feeling better on Day 12 compared to Day 1 or 2*
- *Andy arrives from Singapore*
- *Rain, mist, wind*
- *Up hill, we are typically walking at 1/4 to 1/3 the speed of others*



Joined by Clive, ascending the Pony Path.



Considering all the route options.

We set out this morning at around 10 am under a blanket of cloud. As we glanced up at Cadair Idris the peak was hidden by the mist. Shortly after we made it to the ridge, the rain began to fall. Following lunch, Andrew and Dan carried on to the peak, while Stacey, Peter and Clive made their way back down the 'known' path. A tough decision for Stacey, but a necessary one in order to avoid anxiety, tense muscles and potential further muscle damage.

As we made our way up the mountain, we were passed by many enthusiastic walkers. We figure our uphill pace is approximately 1/4 to 1/3 the speed of the average walker. Slow and steady all the way.

After walking for 12 days, Dan and Andrew have noticed that they are able to walk further distances and climb higher elevations before having to stop and rest – something they were unable to do for the first few days. Stacey has not experienced this to the same degree, as she had a three day break last week.

Andy arrived from Singapore this afternoon and is joined by his brother and two children. They all plan to join tomorrow's walk. Welcome Andy!

Thought du Jour ~ Ninety-nine % of the time when there are southerly winds, it doesn't rain.
– Alfred. Guess what Alfred – the wind is southerly and it's been raining since noon.



Dan strikes a pose in the mist.

All quite amazing, and so inspiring. Finding useful what you're learning practically about McArdele's too. Keep posting folks.

And well done!
CHERYL ELLIS, UK



Another summit view lost in the clouds.

DAY
13

14 JULY

Down the
Tal-y-Llyn
valley

The Talylyln Railway running from Tywyn to Nant Gwernol, just above Abergnolwyn, is popular with visitors to the area. Time permitting, we hoped to take a ride on the narrow gauge railway. But first we had to get there. Andrew, Dan and I met Andy and his brother at a car park, seven miles back from our finishing point for the day. The skies were threatening rain – what else is new?

There are a couple of firsts today. Andy is walking with us for the first time. Should be manageable. However, Andy is joined by his brother Paul and his two children, Henry and Alice (none of which have McArdle's). My first thought is uh oh! How will I ever manage to keep up? At this stage of the walk I've safely figured out Andrew and Dan, but non-McArdle walkers? This is going to be disastrous.

As we made our way up the first hill our tight knit group began to unravel – and fast. Leading the way was Paul, followed by Henry and Alice – no surprise there. Andy would then race up the track – literally run up the hill, only to stop, rest and recover. Andrew, Dan and I were gobsmacked, as we steadily pulled up the rear. Slow and steady, one step at a time.

Through rain and forest, sun and paved road, we plodded along. The path wound its way back down the hillside, dropping us on the shores of a glacial ribbon lake. Apparently Tal-y-Llyn Lake is the flattest lake in Wales. At least that's what Andrew believes. Now I did some research and there is no geographical mention of 'flat lakes', but for what it's worth, I kind of agree with him.

By mid day we had arrived at the finishing point feeling strong and energised. We had a choice to make – take a ride on the first railway in the world to be preserved as a heritage railway by volunteers, or plod on and knock off some of the following day's long trek. In keeping with McArdle logic, we settled for option B. Peter ferried Paul, Henry and Alice back to their car, while Andrew, Dan, Andy and I tackled the steepest lane-way ever.

By strategically using our poles (making them shorter for the uphill) and zig-zagging our way to the top (in order to reduce the angle/distance ratio), we tackled the final mile – despite being passed by an elderly couple part way up the hill. Sigh.

No matter, we were now in a fine position for our morning's walk.



Andy's brother Paul, plus Henry and Alice in bin liners, walked with us for the day.

Long steep slopes

- *An easy day at last* • *Andy finds another use for his walking pole*
- *Dan goes for a swim* • *Zig-zagging!* • *Extra mileage*

The team was joined this morning by Andy, his brother Paul and Paul's two children. Despite the rain (and lack of rain gear – bin bags don't count!) – they seemed to have a great time. Let's hope they dry off before they return home.

After starting on the flat, we began trekking up a rather steep slope for about a ½ mile, ascending 360 ft (100 m). With frequent stops, we successfully made our way to the top. Throughout the climb we all compared notes about our different strategies. For example, one strategy was to progress very slowly and continue all the way, whereas another was to walk quickly, then stop and rest. It has been so valuable for the four of us to walk together to share our experiences and learn from one another.

We arrived in Abergynolwyn alongside a riverbed. Dan spotted an ideal photo opportunity and jumped into the river, film camera and all! Before long, most of us joined him for a refreshing dip... up to our ankles at least!

In order to get a head start on tomorrow's walk, we decided to forge ahead. The next mile was up another very steep slope and would be a very difficult walk first thing in the morning. Here we employed Andrew's patented 'zig-zag' method up the road. It proved to be very helpful, as it reduced the angle and intensity of the climb.

Andy was a few paces ahead of the rest of us, but suddenly came down toward us in a bit of a



The rain kept on all the way along Tal-y-Llyn lake.

fluster. He had used his pole to poke a wasp nest (which he realised after the fact). Fortunately, no one was stung and no wasps were injured. New rule of the road – poles are to be used **ONLY** for walking!

It goes without saying, but, it is raining again – quite heavily at times. On the up side – no need for showering or laundry!

Thought du Jour ~ “I think this is a McArdle's convoy!” (As we sit in stop and start traffic.)

Love seeing your photos every night, cannot wait to be there. Please book the sunshine!
CHARLTON THEAR, CANARY ISLANDS



Zig-zag technique up the very steep final section.



End of the day on a high, literally!

DAY
14

15 JULY

Hills and forest
Abergynolwyn
to Machynlleth

Andrew's car struggled to climb the hill we had conquered at the end of the day yesterday, confirming the magnitude of our ascent. Once at the top we adjusted our poles, checked the map and arranged our gear. Before setting off, Peter provided us with a brief history of the abandoned slate quarries and derelict buildings we'd pass along the way. Today promised to deliver some fabulous photos.

Powered by one of our last homemade meals, courtesy of Alfred, we set off for Machynlleth – sometimes referred to colloquially as Mach. Our route would take us through dense forests, across open

meadows, down paved roads and to the far side of forestry operations. I suppose this was the most direct route, but was it the easiest? We'd soon find out.

An hour or so into our walk we arrived at a fork in the road (this would not be the last time this happened). The map was telling us to go in one direction, the trail – another. Eeny meeny miny mo – which way should we go. Off we went and back we came, thirty additional minutes – make that 210.5 miles.

Certain of our direction, Andrew led us deep into the darkness of a dense forest. One step at a time, I couldn't help but wonder, where the hell was I going? As my apprehension grew, Andy's blood sugar dropped. Fortunately we had Kendal Mint Cake on hand, a glucose based confectionary



Thank goodness we did that steep climb yesterday afternoon.



Stacey bravely leads Andy into the scary darkness of the dense pine forest.

known to mountaineers and explorers for its high energy content.

By the time we ascended to the ridge above, it was time to refuel and have lunch. It was also a great place to more properly determine where the heck we were. Lunch was followed by a second wrong turn. Being lost in the woods was getting old. It was then Andrew coined the phrase “We are not lost, we just don’t know where we are”. If he didn’t know where he was, I most certainly had no idea where I was. Now I thought, would be a good time to PANIC.

Needless to say, we found our way to Machynlleth – the path was long, our feet were damp and our gear was a little more worn than when we set out in the a.m. What’s important though is that we were prepared. We carried maps and a compass. We had multiple cell phones, first aid kits, and emergency snacks. Our support driver knew our route and we did not panic – thanks to our ‘illustrious leader’.

There surely was an easier route, but the challenges we faced today made the reward of achieving them that much sweeter. Tonight we celebrated at a posh restaurant – the ‘Mawddach Restaurant’. Stunning views of all we had accomplished were just outside the window.



Andy's first summit.



Why do they keep smiling?



Well, we're here and we ought to be there. I think.



Mud: sometimes 12 inches deep.

I think our map is lost in the MUD...

- Knee high mud • We break open the first aid kit
- Sometimes all you can do is laugh • Kendal Mint Cake



Mud too deep to risk stepping in (caused by forestry machinery).



Track or stream, Dan is not bothered.



Emergency repairs with gaffer tape.

Dan Dan the gaffer tape man. Not only his rain poncho but now also his right boot are held together with large quantities of black tape. This is how the day began!

A beautiful walk through a slate quarry carried us through to 'second wind'. Despite the fact our trek was on the uphill right out of the gate, we were feeling great... until... Andrew pulled out the map and a decision had to be made – which way do we go?

The map indicated our route was to veer left – faithfully we did just that. About 45 minutes up a rather steep incline, Andrew began to question our decision – we were headed NW, but should've been travelling SE. Back we went! In the midst of our mis-guided journey was a rescue mission...a 50ft retracement as the map fell from Andrew's jacket on a narrow steep section.

Ahhhh...I don't know where we are! [Andrew]
A very narrow path was found and up we

went, heading towards the thick of a conifer forest. Now this wasn't any old forest, it was dark and ominous – Blairwitch like (see photo on page 48). After heading into the blanket of darkness, Andy became a little light headed. Kendal mint cake [emergency energy bar resembling a brick of sugar] provided by Stacey got things back on an even keel. Stacey tried some and immediately “felt a cavity coming on”.

Stagger, stagger, squelch. Before lunch all of us had soggy shoes as we squelched our way up through a fir lined bog, up and further up until we reached cloud cover. The sun came out briefly, only very briefly. After lunch we took the road less travelled by – it was the wrong road, so another backtrack along the ridge to the highest point before dipping back into the forest.

We stumbled upon a stream or rather a footpath...or perhaps a stream masquerading as a foot path followed by a swamp performing the

same trick – this was serious sludge – 6 inches deep all across the “footpath”. In places we had to use fallen timber to bridge the worst parts.

In the near distance we could hear forestry vehicles – little did we know we’d be stumbling directly upon them. At this point we had been walking for 5½ hours and our boots were SOAKED. Once we sorted out which direction we had to go – there were 5 possible choices – we took our first step with Andy leading the way – SPLAT! Andy’s Caterpillar boots gave up the ghost and shed a sole. Fortunately, Dan came to the rescue with tape to bandage things up – a rudimentary fix to get through the day. The mud was surreal – at best 3 inches deep, at worst 12 inches deep. For the next 45 minutes we trod as carefully as we could across our man-made bridges, stepping into the muck only when necessary. Of note: the difficult terrain could have led to serious muscle injury – we were careful so as to manoeuvre through with great caution.



We finished at the clock tower in Machynlleth .



Really tough going in thick heather with only a hint of a path.



Is this art? McArdle’s art?

Once on the ‘other-side’ we peacefully meandered down the mountain into Machynlleth – smiling all the way. Today was a good day – it didn’t rain (at least not until the evening!), and we maintained our sense of humour throughout.



Yes, there is a path under there somewhere.

Absolutely WOW. Wish I was there, but at the same time thinking could I do what you just did today. Congrats ALL.

JOHN REED

The photos and the blogs are great!
Keep going and keep smiling!

CAROL PEARCE, WALES

It’s brilliant to see you all taking on such challenges and seeing the funny side of it too! Bet the laundry at the B&B took a hammering that day! Keep smiling you lovely people – thinking of you lots!

HEATHER CURRY

(WEEK 1 SUPPORT DRIVER)

DAY
15

16 JULY

Rest?
Machynlleth to
Aberhosan

The weight of the heavy falling rain whipped against my bedroom window, waking me from a deep, comfortable sleep. Joining the boys, I sleepily made my way to the dining room, one step at a time, to bid a fond farewell to our host 'Alfed' before setting off to Machynlleth.

Despite being an official rest day, we had a busy twelve hours ahead of us. First was the move, then some work on the blog and photos, followed by a looming deadline for a press release. The afternoon was reserved for a short walk before driving out to

Aberhosan and a dinner engagement with ceramicist Meri Wells.

Despite having walked nearly halfway across Wales, some of us struggled today on the relatively flat, unimpressive walk along the shoulder of the road. We took it slow, patiently waiting for 'second wind' to take over. Was it the late afternoon hour that was responsible for our sluggish start? How daft! One thing is for certain, with the number of collective hours spent in our hiking boots over the past two weeks, we all concurred – long walks are more favourable to short ones when it comes to McArdle's. And with that, Peter whisked us off the gravel shoulder and onto Meri's house.

The stretch of road between Machynlleth and Aberhosan, that diverges from the A489 provided a visual palate of various shades and textures of green. The road twisted and turned as it softly grazed the rolling hillside. This evening was already proving to be magical.

Peter introduced us to his very dear friend Meri Wells. What an honour. We spent the better part of an hour wandering around her seventeenth century farmhouse – ducking through doorways, finding hidden entrance-ways and reveling in the sheer lopsidedness of

each and every wall. Meri took us to the tin shed she works in, and up into her gallery on the second floor of her home. Her ceramic creatures are extraordinary salt glazed beings that possess a part human, part animal otherworldliness.

When Meri learned of my periodic sense of anxiety, she showed me a particular collection of ceramic figures, entitled "The Worriers". She described how all her creatures

embody emotions and tensions that lie under the surface of all human beings and relationships. The Worrier's job was to provide it's owner with a sense of freedom from angst. One now has a home in my dining room.

Andrew, Dan, Andy, Peter and I left Meri's house feeling rested and enlightened. Meri showed us a different way of being in the world; of living in the moment, and being one with the world around her. I feel truly blessed to have met such a wonderful, creative, strong woman.



Artist and ceramicist Meri Wells welcomed us to her 17th century home.

Rest day privileges

- Relocated • Press Release • More Walking on a rest day!
- Great Evening

Having relocated to Machynlleth we were privileged, in the evening, to visit the home of ceramicist Meri Wells, in Aberhosan. Her beautiful 17th century, secluded home and studio, filled with art and artefacts were a real treat, while the feast she had prepared was most welcome, washed down with a nice red. Andy and Stacey both acquired small Meri Wells originals and were sorely tempted by some of her superb large fired works, while Dan tried to capture the essence of the setting on film. To see some of what we saw visit www.meriwells.co.uk.

Peter Telfer visited and filmed Andrew speaking about McArdle's, and then the whole group walking up Meri's driveway demonstrating our diagonal ascents. Great sympathetic direction from Peter meant a fun session and we look forward to the finished product. Brilliant that he made time to join us and will edit the material for us www.pixelfoundry.co.uk.

We also found time to knock a mile and a half off tomorrow's journey, which includes plenty of uphill sloggling, and crafted a press release, which will hopefully gain more coverage.



Andrew interviewed at a table made from a slate sign.



Meri has repaired the house, some outbuildings still to do.

Dan if you drink the beer before, the bottle has no weight and you cannot repair your boot. :-)

Andrew please send me an autograph, soon you'll be the star of the TV. Every day I fall more in love with Wales and those green fields.

I can not stop looking at the blog and giving all my support.

MARCELO, ARGENTINA



At every turn were unexpected characters.

DAY
16

17 JULY

Machynlleth to
Nant-y-Moch
Reservoir

According to the Met Office, July in Wales is supposed to be in the top tenth percentile for sunshine throughout the year. And yet, it is RAINING again. I was wearing multiple layers (to keep warm), and a rain jacket, rain pants and a hat. I even had a cover on my backpack. I was dry, but drowning in my waterproofs!

The morning route led us along lane-ways, trails and cow pastures. We climbed up and down stiles and were constantly second guessing which direction to go. Is it right or is it left? Just as the rain gave way, we located the correct path. Off came the layers of rain gear. I managed to find room in my pack for everything, barely – now all I had to do was carry it for the remaining eight miles. I secretly hoped that one of the guys would take pity on me, and offer to lighten my load. Then it donned on me – they have McArdle's too. Oh boy!

It was nice for a change to bathe in the warmth of the Welsh sun – even if only for a short break before continuing our trek through the Cambrian Mountains. The land is predominantly covered by peat and overlain with moor grass. It is an empty, beautiful area where you are likely to meet few other people over the course of a day. English travel writers affectionately refer to the area as the 'Desert of Wales' – not because it is arid, but rather because it is largely uninhabited by humans. I guess I won't find anyone else to carry my pack!

The balance of the walk was peaceful and quiet. We marched along, one step at a time, in single file – deep in our own thoughts. The silence was all around us, it was practically deafening. At one point I found myself at the back of the pack. As if by position alone, I began to feel myself slipping further and further behind the group. Up in front is where I am most comfortable I thought, I'll have to be sure not to let myself end up back here again.

Just as I was beginning to feel like I'd walked far enough, Peter came into sight. I must have looked exhausted, as he offered to carry my pack. I really wanted to maintain my



Plymlymon calls us in across the vast expanse of the 'Desert of Wales'.

pride and say no – but the mere thought of walking the last half mile pack-free sounded way too good. Before, I could utter the words 'yes, please', I had unfastened the straps of my rucksack, releasing the weight of the world onto the boggy terrain before me.

With a newfound spring in my step, we made our way back to the car, then we drove past the Nant-y-Moch hydro electric reservoir and home to Machynlleth.

We're not lost, we just don't know where we are!

- *On the missing list!!* • 7 hours 15 minutes
- *Beautiful scenery and inevitably Dan takes a dip* • **SUNSHINE**

We set off in the rain and after walking for a long time with several detours we hit Glyndwr's Way and followed it simply because we knew where it ended, though not where we joined it. We weren't lost, we just weren't certain where we were!

Once we returned to the correct path, we came upon a farmer herding his sheep, who seemed to know everything about us! Peter had expected us earlier, and had clearly stopped for a chat, leading the farmer to comment in a lilting Welsh accent. "Ah you four must be the ones on the missing list". He then spent a good deal of time explaining our route for the rest of the day.

Finally at just before 2pm, as we stopped for 20 minutes for lunch, to our surprise the sun came out!!

Steep, steep, long, long, slog, slog, slow and steady was the order of the post lunch session – worth it upon reflection, as once we got to the top the views were stunning. It opened up into a vast green landscape and we got our first views of tomorrow's peak, Pum Lumun (tomorrow will not be Andy or Stacey's favourite day of the walk, a rain dance may be in order tonight.)

As we neared the end of today's journey we came to a stream, initially there seemed no way over it, or round it. Thankfully before we waded through the river, Andrew consulted the map and spotted a foot bridge. Dan was clearly



Unpronounceable to anyone but a Welshman.

disappointed by this, as after we had crossed the bridge, he dropped his pole into the stream and shortly thereafter fell in after it.

A long day but another day of achievement, and thankfully a day with sunshine.

What I find really useful in your blog is the practical stuff. That sort of experience and knowledge will be priceless, worth its weight in gold.

CHERYL ELLIS, UK



A long steep climb up through forestry.



Crossing the stream at the top of Nant-y-Moch reservoir.

DAY
17

18 JULY

Nant-y-Moch
to
Pont Rhygaled

While Andrew fastidiously worked out an alternate route, Andy and I secretly applauded Mother Nature's deliverance of rain and thick mist. Of course we knew we'd still have to deal with the inclement weather; but at least it would be from the safety of a low-lying route. Pumlumon would have to wait for another day.

Besides, we were all becoming experts on walking in the rain by now. I think Dan was even getting used to the feeling of sopping wet denim against his skin. The biggest hurdle centered around bathroom breaks. Going to the loo in the wide open expanse is something I've had to become accustomed to. But, dropping my drawers in torrential downpours has proven to be more challenging. Trying to precariously balance, out of sight, and in such a way so as to not overly strain my quadriceps was no easy feat.

Today presented us with a variety of extraneous variables. The weather was poor – rain and low-lying cloud. The winds were strong and the ground was water-logged. I don't expect the path would have been any easier to find in the absence of these taxing conditions. But seriously, how many times can you get lost in the rain? Again, perhaps a silly question to ask if you're hiking in the remote hills of Wales.

Our 'illustrious leader' continued to direct us up the hillside. Not an easy route. Every step was arduous, we had to carefully choose each step, ensuring not to twist an ankle, damage our muscles or lose a pole. Slowly, but surely we make our way up, one step at a time, continually fighting the primitive desire to move quickly out of the weather.

If given the chance to walk up or down a hill – Andrew seems to always choose the high road. I should have known. It took some time, but we made it – and sure enough, there was the path. Why is he always right?

Cwm Clyd Isaf welcomed us with a warm loving embrace. The beautiful house in the valley would be our home base for the following eight nights. Peter said his goodbyes, while Sally (Andrew's baby sister), prepared dinner. Dan, Andy and I were thoroughly enjoying the hospitality of the Wakelin siblings.



One of the feeder streams coming from Plymlymon into Nant-y-Moch.

Wash, rinse, repeat...

- Lost again • Rain dance = success • Rain, heavy rain • Mist, thick mist.
- Hello • Arrived at Cwm Clyd Isaf



Zig-zag after too long a snack break sheltering from the rain in the car.



Lovely scenes despite the wet.

Today we were to ascend Pumlumon, but mother nature had other plans – or perhaps Stacey and Andy's rain dance to avoid the peak worked. The morning was met with heavy rain and thick mist. Back to the drawing board for Andrew – a new route had to be worked out.

Peter dropped us off where we left off yesterday (note, we drove 3 miles down the road, just to walk back – now that is what you call dedication). Into a head wind we strode, uphill. It was slow-going but steady.

Off to the left we veered onto a track – leading up and into the forest. Half way up, we stopped for a quick lunch break. The weather was cooperating at this point so we carried on, leaving our dear support driver behind in the mist.

The track continued for quite some time – a very pleasant treat, despite the continuous incline. Just as we settled into a comfortable pace, the track came to an abrupt halt. We turned around 360 degrees, and did not find an obvious path. After consulting the map, we were no clearer, but decided to move onwards and upwards.

It seemed as though every other step we took landed us in a foot of water – par for the course I suppose. As we made our way along, one confused step after another, we heard a voice coming from within the thick of the forest. HEELLLLOOO. We never did see who was calling out to us.

This was the most difficult leg of the day, as the terrain was very uneven, causing us to take very steep, cautious steps. In order to avoid

muscle injury, frequent rest stops were taken, despite the heavy rain.

The path was finally found – of course at the top of the ridge. We made our way down the road and to our waiting car that whisked us off to Cwm Clyd Isaf – Andrew's beautiful home.

Well done to all who are walking. I did my 'little' sponsored walk last week, felt quite proud of myself. Will keep an eye on you all from now on.
MARGARET CARTER, KIDDERMINSTER, UK



Meeting the support car, totally soaked but still smiling.

DAY
18

19 JULY

Over remote
moorland to
Cwm Ystwyth

At the beginning of this journey, I was anxious and afraid. I was not the kind of person that took risks – any risks. If there was a chance of failure, I stayed away. I comfortably led my life this way for as long as I can recollect.

There's something about living with a disease that remains nameless and faceless for the better part of three decades. I still vividly remember the overwhelming feeling of utter embarrassment as my leg muscles would begin to stiffen and my heart would race out of control forcing me to stop dead in my tracks. Who was I to

know my skeletal muscles were desperately searching for energy, unable to convert glycogen to glucose.

Some doctors told me my hips were over-rotated, while others instructed me to take beta-blockers to manage my idiopathic exercise-induced tachycardia.

Regardless, the consensus seemed to be that I was unfit, lazy and out of shape. How could this be? I tried everything – I ran, I rowed, I walked, I cycled. I took fitness classes, I practiced yoga. And yet, the problem never went away. At the beginning of every walk, of every activity, my muscles would fatigue and my heart would race – each and every day.

And so, I avoided engaging in activity with others, what was the point. I just couldn't keep up. I'd walk unaccompanied to meet colleagues for lunch and would exercise alone. Anything else was too risky. Problem solved.

But here I am, hiking through Wales – doing something I desperately avoided for years. I no longer was afraid or embarrassed. Walking with Andrew, Dan and Andy, one step at a time, has enabled me to understand that I can do anything I set my mind to. McArdle Disease is, and always will be, a part of my life; but it is not my life.

So today I happily trod up and down the hills of Wales with my newfound developing courage and acceptance of this rare metabolic disease. I hope I can hang onto this feeling forever. Could you?

Despite my life-altering realisation, old habits die hard. Upon finishing the day's walk, the overwhelming urge to forge ahead and lessen tomorrow's mileage got the better of us. We happily set off down the road to knock off a couple extra miles. Gotta try to stay ahead!

The day's efforts were rewarded with a hearty dinner. After which we treated ourselves to a drink at the oldest pub in Powys and possibly Wales – The Red Lion Inn at Llanafan Fawr (c.1188).

Despite the late hour and my ever-growing fatigue, I am feeling stronger than ever. Andrew's dream has become the catalyst for our collective understanding of how much we can achieve.



Dan strides out, taking the lead as navigator.

A tale of two valleys

- Valley, peak, valley, peak, valley... 'nuf said!
- Wales never looked so beautiful with the sun on the hills
- Poleless
- The long way 'round
- We didn't get lost today



A perfect McArdle's start – an easy, level track down the Wye Valley - not for long!

After a sharp left into the car park, we crossed the river Wye – a question we've been asking ourselves for days now. The very obvious path headed into the forest alongside the riverbed. Although we had many alternate path choices, we continued on with Dan at the helm, one correct heading after another. He then directed us up a path off to the right...you guessed it – up another hill.

To our dismay, the path narrowed and was covered by long grass and tussocks – which made trekking very challenging. Off in the distance we spotted the gate that we had to pass through – only problem was there was a bull and a herd of cattle in the way. Now, for many the 100m dash would be feasible, but we made a reasonable 'McArdle's' decision and went around.

We shared our lunch with a swarm of gnats, needless to say, half a sandwich later and off we went down into the next valley. Of course, at this point in the day we are typically VERY excited... but not today... as we were informed there was

another hill to get over.

The next climb was a soaker – but the end was near. When we arrived at the car park, we opted to carry on down the road a couple of miles (to lessen tomorrow's trek).

Dan decided to experiment today and go poleless – the verdict is that the poles are really valuable – as they help distribute the load and effort. Towards the end of the day Dan dug his poles out of his rucksack to aid him getting over the last hill.

Thought du Jour ~ Wye oh Why!

I guess you know by now, you are carrying McArdle sufferers from all over the world on your backs. We may not be trekking the walk physically with you but we are following you every step of the way. We would all love to be with you. Great going.

LORRAINE BAGULEY, AUSTRALIA



Taking a breather on a long, steep ascent.



Trying not to get wet feet on this rare dry day!

DAY
19

20 JULY

Cwm Ystwyth
to Garreg
Ddu reservoir

I wonder if we weren't too focused on our journey, forgetting to take caution during the remaining sixteen hours of the day. While getting prepared to set off for the day, Dan strained his abdominal muscles. This is always a concern, as sometimes it can be difficult to determine the degree of muscle damage. Dan made the decision to join us for the day as today's walk was an easy route along the old Elan Valley Railway, with the recourse to opt-out at any time.

The rain was relentless, but so was our determination. We carried on, one step at a time, with the knowledge that tomorrow was a rest day. Besides, you can't get wetter then wet.

The Elan Valley is situated in the county of Powys and consists of seventy square miles of moorland, bog, woodland, river and reservoir. The dams and reservoirs of the Elan Estate provide enormous quantities of water to the city of Birmingham, approximately 118 kms away. I was comforted with the knowledge that at least Sally knew our whereabouts in this otherwise desolate landscape.

The huge skies eventually cleared and we caught a fleeting glimpse of the sun. Now would be a good time for a quick break. Sally joined us for our final rest stop – before planning to meet up with us at the Visitors Centre. We managed to get through the gate before Sally called out to us – the car had given up and refused to start.

Andrew attempted to call his mechanic – no cell service, Sally then tried with the same result. Thankfully my international roaming package picked up one bar (provided you were standing in just the right spot), just enough to place a call. Three hours later with empty lunch bags and lifeless cell phones, help arrived in the form of one guy and his van.

Despite the rain, mechanical failure and long delay, the Elan Valley, with its deeply incised valleys and remote landscape, left us speechless. The west-east route across this isolated part of Wales can only be described as breathtakingly majestic and gracefully alluring.

You just never know where beauty will find you. Fortunately, we will be back tomorrow to complete the final two miles along these beautiful reservoirs and impressive dams.



Despite all the rain, the Elan Valley reservoirs were all rather depleted.



Stacey takes a nap on a sculptural bench beside the trail.

Breakdown: McAnical not McArdle

- *It rained... we walked... we got wet... car broke down... we quit!*
- *All in all – a great winter's day in the Elan Valley*



Three ready for the off while Dan deals with his blisters.



Old railway line through "Devil's Gulch".

Having conquered Snowdon and Cadair Idris, Dan got a cramp in his abdominal muscles at the house early this morning. We contemplated bringing forward the rest day – in hindsight we should have, but for other reasons.

We started in light drizzle up a long incline, and as we climbed the rain got harder – we have come to realise though that there is only so wet you can get!

Along the Elan Valley reservoirs the views were quite stunning and the rain has made everything green and lush. We met a group doing their Duke of Edinburgh Gold award – 80 km in four days, plus carrying their kit. On the post-lunch downhill trek we even kept pace with them – briefly.

As we descended one side of the reservoir we noticed driver Sally on the other bank waving frantically – we assumed she had broken down – we found out shortly afterwards, at the next meeting point, that she had simply seen the sun... En route we passed through Devil's Gulch and many spectacular views.

After departing for our final meeting point, and the last few miles, Sally called after us, this time the car had given way and refused to start. We tried coaxing it, but to no avail – in fact for 20

minutes the alarm refused to be silenced

We waited, disappointed, in the rain (for a few hours) and eventually the cavalry arrived, the car was temporarily started, so we decided to head to the warmth of base camp. We will be back on our rest day tomorrow to finish the day properly.

I am becoming addicted to your blogs and photos. I don't know what we will do when the walk is over. Thank you Andrew, we McArdle-ites now know anything is possible if we listen to our bodies.

LORRAINE BAGULEY, AUSTRALIA



Craig Goch dam, early 20th century water supply network.

DAY
20

0 JULY

Garreg Ddu to
the Elan Valley
Visitor Centre

It almost seems pointless to check the weather forecast. At some point in the day it IS going to rain. Today looked promising though. Andrew's back garden was bathed in streams of sunshine. Thirty minutes later, we were back in the Welsh Lake District to complete the remaining two miles. Just as we stepped out of the car the heavens opened up – splat!

Dan taught us that 'weather is just weather', whether we like it or not. We had just under two weeks left to get to Cardiff, rain or shine. Oddly enough, I think we were all beginning to enjoy the challenge

the elements presented us. I certainly don't think I would have drank as much tea had the days been warmer though.

After touring the Elan Visitors Centre, we made our way back to Andrew's house to re-group. Andy, Sally and I fancied going to the Royal Welsh Show, leaving Andrew and Dan to attend to more serious matters of this and that.

Over six and a half million people have passed through the gates of the Royal Welsh Show since it permanently moved to Builth Wells in 1963. And now we could count ourselves amongst the many. Unsure of what we were getting ourselves into, we jumped on the bus with an open mind. What I didn't quite grasp was that the show was an agricultural show, and therefore has a concentrated focus on farming.

Nevertheless, we happily wandered, one step at a time, into and out of vendor stands selling manure spreaders, Wellington boots and bull semen. We sampled sausages and cider, ice cream and chips. Just another day in the midlands. The

afternoon passed with a casual lack of concern, until Andy spotted the BBC Radio Wales booth broadcasting live with Roy Noble.

Donned in our 'Walk over Wales' t-shirts, we approached his assistant with the excitement of prepubescent teens. Either keen to hear our story or anxious to see us on our way, Roy agreed to a quick interview about our pilgrimage from Great Orme to



Andy and Stacey got a spot on Roy Noble's national radio show at the 'Royal Welsh'.

Cardiff. A job well done I'd say – wait till Andrew hears about this.

With dinner in hand, we casually made our way back to Cwm Clyd Isaf, eager to tell Andrew and Dan all about our adventures, including our national radio broadcast.

As Dan prepared Welsh Cakes (under Sally's supervision), Andy and I rambled on about the fascinating afternoon we had. It took awhile to convince Andrew we really were on BBC Radio Wales. In fact, he went online straight away to confirm our tall tales.

All in all we had a good day. It may have rained, but we didn't get lost. I wonder – would a new pair of 'wellies' fit in my suitcase?

Rest day walk... Royal Welsh Show...Radio Wales

- Sunny skies pre-walk – rain during – sunny skies post walk • Car park trauma
- Royal Welsh Show – otters, pole climbing and BBC Radio Wales.



Raining again!

Over breakfast, we basked in the warmth of the morning summer sun that was streaming in through the kitchen window. Shortly thereafter we headed back to the Elan Valley to complete the two miles we missed yesterday – due to car troubles. With a spring in our step, we jumped out of Andrew's Renault, and started down the path... 10 minutes later the heavens opened up... back to WoW reality! We were very fortunate to have walked through this elaborate reservoir system suppling the English midlands – despite the rain.

Fortunately, we only had a couple of miles to knock off before reaching the Elan Visitors' Centre and a cup of tea. Back at Andrew's house, the sun made a repeat performance – of course we weren't walking at this point!

In the afternoon Andy, Sally and Stacey took advantage of the rest day to visit the Royal Welsh Show, which was an eclectic mix of rural life meets flea market meets livestock. Our first challenge was managing the short incline from the 'park and ride' spot, we were directed towards, to the waiting coach. Despite our morning walk we were forced to stop at least twice as the bus driver waited patiently; luckily our WoW T-shirts offered an explanation. Sigh, the frustration.

Once inside the showground, we came first upon a fly fishing casting competition, though we weren't able to discern what a winning technique looked like. From there we witnessed one of the most bizarre exhibits imaginable – a somewhat "eccentric" lady of a certain age, eating yoghurts while two otters roamed freely inside her voluminous sweatshirt – quite what was the intention was unclear. Onward to the pole



All hail to the Illustrious Leader.

climbers who raced up telegraph poles higher than some small buildings – stamina most impressive but not a pursuit we will be taking up.

Roy Noble of BBC Radio Wales was broadcasting live, so Andy and Stacey leapt at the opportunity to WoW Wales. Somewhat to our surprise, our request to be interviewed was greeted with an immediate yes, and so we made out national radio debut speaking about WoW and our efforts to raise awareness of McArdle's. Roy gave us ample opportunity to get our message across and we are indebted to him.

All in all we had a wonderful day taking in some of the shows and meandering through the many trade stands. Back at home base, Andrew kept busy, while Dan enthusiastically prepared garlic bread and Welsh Cakes for dinner. This will be accompanied by pork and leek sausages and a selection of olives acquired at the show; all to be washed down with a flagon of Herefordshire cider from the same tent.



Dan picks wild raspberries beside the trail.

We are so intrigued by your walk across Wales.

We are so thankful that all of you are raising awareness of McArdle's around the world! We send a special aloha to Dan.

JAMIE, HAWAII

DAY
21

22 JULY

Elan Valley
to Cwm
Clyd Isaf

After a good night's sleep and a rather delightful lay-in, it was time to get moving. Today's walk would cover nine miles, many hills, and bring us directly back to Andrew's house via Alt y Clych.

If I could choose one word to describe today it would be 'exhilarating.' We walked for seven hours and didn't see a single soul (sheep and RAF jets excluded). The barren landscape challenged us both physically and geographically, as we made our way through the tussocks, one step at a time, from cairn to cairn.

After climbing for what seemed like an eternity, we finally located the trig point atop Y Gamriw. The view from the 604 meter peak was all encompassing. A pleasant reward for our exhausting efforts. This was one of those days you hate to love. With each passing mile, the landscape transformed, presenting an ever evolving spectacle of colour and form. And yet, there were so many more miles to go.

As we descended down a ridge, Andrew told us of his walk up there in 2006 when he had such pain in his arms and felt so breathless that he had a lie down on the top. Three days later he had a heart attack. Andrew was aerobically fit and the damage to his heart was not too severe. After treatment he has made a good recovery (as evidenced by his ability to walk across a country). He now aptly names the ridge "Heart Attack Ridge" and has repeated that walk several times since.

We all took a deep breath before carrying on down into the valley – Sally would be meeting us to ensure we were all in fine form – particularly after the amount of cider some of us consumed the previous night. During our brief rest stop, Andrew pointed out the path we would be taking back to his place. Straight up another hill (insert another sigh).

By this time, we were definitely in 'second wind' and so the hills were less of a challenge for us. Not having any deadlines meant we could set a pace of slower than slow, maybe even slower than that! We stopped frequently, admired the views and took plenty of pictures.

Just a few weeks ago, I would have doubted my ability to trek through these hills and the difficult terrain. I would have panicked at the thought of walking with others, having to keep up with the group pace. Yet I find myself exhilarated and confident. I am happy to be here and I am enjoying the challenge.

Our last hill of the day was Alt y Clych. We approached it from the north side up a long, steady track. Andrew eagerly led us to the edge for a view of his home in the valley below. As Dan teetered on the perimeter, Andy and I immediately took three large steps back.

I can't decide if the trek down the steep hillside was made better or worse by the large, coarse ferns that dominated the landscape. On the one hand, the bracken would provide a soft landing spot, should I trip and fall – on the other, one of these fronds would likely cause me to trip and fall. Surely if the sheep can make their way through these dense thickets, I can too!

Back on level ground, Sally met us with cream tea – how delightful!



Earlier we had been on Y Gamriw, at back.

Hallelujah

- Sun glorious sun • Mama and babe • Humbled • Cider is the solution
- Barnes Wallis • Climb every mountain • 7 1/2 hour slog.

The early morning low cloud soon gave way to sunshine, and as we settled over breakfast, Dan and Andy were in fine fettle after sampling the local cider last night. We left base camp anticipating clouds building as we reached our start point, but were buoyed to start in bright sunshine – sunscreen compulsory.

We set off for what turned out to be a 3 hour climb from reservoir side to mountain peak, past the redundant reservoir that was used as a practice site in WWII for the famous Barnes Wallis bouncing bomb, up and up we climbed to the 604 metre peak “Y Gamriw”, where we lunched sheltered by a cairn as the RAF flew up the valley, beneath us.

Lunch over, we trekked on over boggy terrain comfortable in the knowledge that Andrew is totally familiar with each “off piste” step of these hills around his home.

We quietly passed a family of sheep, which posed helpfully for pictures and then headed on to the tops of Drum Ddu, Craig Chwefri, and finally Alt y Clych. At times, on steep slopes we slowed almost to a stop, taking care to slow ourselves down to avoid pain – which enabled us to reduce the number of times we physically needed to stop today.

Hallelujah we thought, as we finally reached the peak of Alt y Clych, overlooking Andrew’s beautiful house below, appropriate as the song of the same title covered by Jeff Buckley, has become something of a walk anthem, much to Andrew’s chagrin.

Today had been almost rain free until sleet greeted us on the final climb to Alt y Clych. Wet again, we reached the front door of Andrew’s home to be greeted by fresh scones, cream and jam and hot tea prepared by Sally, which helped revive us. To complete the welcome, we were humbled to read Cheryl’s great posting to the McArdle’s Facebook Group page – thank you Cheryl!!!

Thought du Jour ~ Hallelujah – humbled by the magnificence of the hills and all of YOUR love and support.



We climbed up out of the Elan Valley.



Under used paths can be overgrown - here with bracken.



Still smiling after the second big ascent of the day.

I can't imagine how you remain motivated to head out into the wet every day and face those hills! Your hard work and blogging are inspiring.

JENNY COYNE, AUSTRALIA

After this experience might you be less likely to “overdo” it while walking with others and be able to walk at your pace with confidence?

TERRI CHAMBERS, SAN DIEGO

DAY
22

23 JULY

Cwm Clyd Isaf
down the Wye
to Builth Wells

Well on our way to Cardiff, the gears were beginning to shift. For me at least, the journey began as a personal one. But, as time passed and hills were conquered, the realisation settled in – I was only a small part of this journey. We were walking for everyone else with McArdle's. Our struggles and our successes were their's too.

In order to convey this message to the masses, we diligently recorded each day's travels. Andrew had set up a 'blog' on the AGSD UK website for ease of communication. Our aim was to share our thoughts and feelings, the conditions of the day (route, distance, elevation, weather, etc.) and the challenges/successes we had. At first readership was low, but as the days passed, the number of followers increased.

I never imagined how powerful this experience would be. We heard from people all over the world. One step at a time, our team of four was growing, the support was palpable. It was then we realised this was only the beginning.

We finished our seven (and a half) mile walk today in fairly short-order. There were no hills, except for the gentle slope up Andrew's lane-way, the path was well marked and the sun was shining. It was decided (surprisingly so) that today was boring – we missed the hills and the rain! Perhaps even the excitement of temporarily not knowing where we were.

This left ample time to attend to more important matters – the McArdle community. We wanted to reach out to more people, to empower them in the same way we had empowered one another. And so we enlisted the creative genius of Mark Zuckerberg, and the power of social media.



I'm sure they won't mind if I give them a friendly cuddle.

muscle disease, but the ties that will keep us together run much deeper. These past few weeks have changed my life.

Now having covered all of the bases; blogging, Facebook, press releases, and radio interviews we began to think about future plans. How could we maintain this forward momentum? The decision was made – our walk would be the first of many.

Happy and content with our developing direction we closed the books, turned off our computers and shared a relaxing evening with each other. Despite the short time together, we'd developed lifelong relationships. The common thread that ran through us may be a rare

Flat, dry and over by 3pm – feels like a rest day

- 7.5 miles along the Wye Valley
- Early finish, no hills, no rain – something missing!



Today we walked from Andrew's house rather than driving.

We must be progressing, as today's walk seemed like a stroll in the park, even starting on the long uphill slope of Andrew's drive presented few problems. With no hills to conquer and no rain to endure we are left feeling slightly flat, even though we did manage to outpace a family out for a stroll, much like today's terrain.

Good to finish early though as we have plenty of plans to execute with the intent of increasing publicity for the Walk as we near Cardiff.

With minds freed from focusing simply on the next step, our creativity has been given free rein. Expect a new WoW Facebook Group – we aim to have at least 500 followers by Cardiff. We've decided the Walk may have to be re-titled the Inaugural Walk over Wales, with minds pondering whether a shorter version, perhaps a week, could become an annual McArdle's event.

For us there is no question that climbing hills with fellow McArdle walkers makes what might otherwise seem unappealing, a whole new and enjoyable experience. The pressure of slowing everyone down has lifted, and the need to excuse every stop has disappeared – hill climbing is suddenly enjoyable – to the extent that an extra walk up Andrew's mountain is being contemplated for our next rest day.

What you're doing is inspirational. Today I thought... how even God rested on the 7th day.

CHRIS CHAMBERS, USA

A well deserved leisurely stroll. After all the hills I'm sure this was like a "walk in the park".

JO DI CARLO, CALIFORNIA



Fields, tracks, lanes, paths - almost all level today.



Misty views of the Wye Valley.



Trying out a fly-fishermen's access to the river.



This stone bridge is heavy. What has Dan seen?

DAY
23

24 JULY

Builth Wells to
Upper Chapel
Road

I'd be lying if I didn't say I was nervous about walking with two Doctor's today, Andrew's local GP and her husband. These aren't just any Doctor's though – they are a husband and wife team that run ultra marathons – ONE HUNDRED miles (160 km). What they can do in under twenty-four hours, took us about fifteen days. Perhaps we could have pushed that to ten days – maybe.

I know I shouldn't be worried – they're Doctor's, and they know we all have McArde's. But boy, do old patterns die hard. We met them in a car park, just outside of Builth. As we waited for them to arrive I warmed up by doing laps around Andrew's car – if I timed it perfectly, I might be able to get into 'second wind' just as they pulled in.

Sally joined us for the beginning leg of the walk. Hard to imagine, but we got slightly turned around as we headed out of Builth. Back on track again, we kept a steady pace, talking, laughing and enjoying the views.

The ascent was gradual, and quite manageable. But somehow I got caught up talking to one of the Doctor's and before I knew it, we were approaching the ridge. I turned back to see where the rest of the group was, only to notice they had fallen way behind. I was pleased to be up in front, but realised at that moment I'd pushed on too fast – my legs were starting to speak up.

Shortly thereafter we paused for lunch – it's amazing how much better everything tastes after a few hours of climbing. I ate so fast, I don't think I even stopped to catch my breath. While the others were finishing their lunch, Dan and I had fun taking silly photos of one another pretending to hang off a false cliff.

Now at the top, the path led us across open country. The skies were grey and the wind was blowing, but we were dry – where did the rain go?

It was a pleasure to share our experiences with these two compassionate GP's. As we approached the road, Sally wheeled up to return them to their car. We decided to continue down the road, one step at a time, and get in another mile.



Leaving Builth Wells with Stephanie, Mike and Bella.



Saying thanks and goodbye to the Drs. Warrick.

Ran 100 miles in 22 hours...

- *Not any of us, of course!*
- *Back to climbing – exhilarating*
- *3 stages of the McArdle's walk*
- *GP joiners*
- *Cloudy, but dry – well a slight mist*

At 10:00 am the WoW Team met Drs Stephanie and Mike Warrick in Builth Wells, before meeting the press and proceeding with the day's walk. Following a photo shoot, we were off, accompanied by Andrew's GP and her husband (also a GP). After a brief stretch on the flat, we were feeling fine and moving at a good pace, one that Stephanie and Mike were able to keep up with... at least so we thought, until Mike shared his experience of running 100 miles (160 km) in 22 hours! Impressive.

As we strolled across the open countryside, Mike and Stephanie listened with great interest as we shared some of our McArdle experiences. We discussed the difficulties children have in obtaining a diagnosis. As we continued along, Mike was impressed with our stamina as we slowly, but steadily climbed over 430m – an ever improving ability we have noticed.

In fact we have noticed a distinct improvement in our capabilities over the past few weeks. When we began on 2nd July – we doubted our ability and were comforted in the knowledge that we could take a day off at any time. Within a few days to a week, our thoughts had progressed and we were now thinking we just might make it all the way to Cardiff. Now that we are in the final stretch, we are feeling great – and are now seeking hills to climb!

The weather cooperated with us today – the clouds hovered above, but only a slight mist fell...



Dan and Stacey. Don't ask!

Thought du Jour ~ “The more we do, the more we can do.”

“Never doubt that a small group of thoughtful, committed people can change the world. Indeed it is the only thing that ever has.” Just found that on a postcard and thought of you.

CHERYL ELLIS, UK

I work with Dan's mom. I'm looking over her shoulder to see your adventures and progress. I admire everyone's patience and endurance. Do I need to have McArdle's to join your group?

ERIKA, USA



It's OK, we were the other side of the road!



A long haul out of the Wye Valley.

DAY
24

25 JULY

All the way
to Brecon

Before we even took our first step, we tossed around the idea of doing extra mileage. Three days from now, we were gearing up for a demanding day over Pen y Fan – the highest peak in the Brecon Beacons. The more Andrew studied the map, the more he feared it may be too much. So between now and then, we were confident we could make some headway and reduce that day's mileage.

Our route today took us from Upper Chapel to Lower Chapel – a straightforward six miles. Despite the easygoing path, Andrew had a difficult time getting started this a.m. – one of those seemingly

inexplicable mysteries of McArdle's. He'd had a good breakfast, a sound night's sleep; we started on the flat – huh – some days this disease just doesn't make sense.

So we walked slowly, stopped when necessary and within thirty minutes or so, were able to set off at our usual blistering pace (insert sarcasm).

It was obvious that the landscape was changing – the further south we travelled, the softer the hills became. They rolled effortlessly, one into the other. By the time we caught up with Sally, a few hours had passed. I imagine she would've loved to join us – but her 'support driver' duties kept her behind the wheel and on the constant look-out for our next rendezvous.

Without any worry of being exposed to vertical drop-offs, the walks were becoming easier and easier (for me) – until we arrived at the top of a field and turned a corner. The path we were on was a public right of way. However, it travelled through a farmer's field – one that contained a herd of bullocks, without any option of circumnavigating them. Out-running a bull was not an option for us – our plan had to be a bit more elaborate.

One step at a time, Andrew inched his way through the field as twenty-eight pairs of eyes glared with a transparent spirit of inquiry. Andy, Dan and I bravely followed a good distance behind him. To this day, I'm not entirely sure what the 'plan' was, but we made it through – unscathed!

Tiptoeing past a herd of bullocks was nerve-wracking enough, but climbing through a thick wall of stinging nettles was tricky, but in the end worth it. Fortunately, the chemical laced leaves gave way to a lush green field and blue skies. We took a few minutes to relax and soak in the sunshine – yes, sunshine. I even took a moment to teach the boys Virabhadrasana II. Om.

Time to move on, Sally was waiting for us at the ten mile mark. Given the early hour and our unwavering energy levels, we decided to finish the day at the Brecon Visitors Center – two miles away. Twelve miles was a new record for us – a celebratory drink was waiting for us at 'The Griffin'. Cheers!



Stacey strikes a yoga pose in the middle of... grass.

Exceeding expectations

- *Two days in one* • *Never mind the bullocks!* • *Brecon or bust* • *Ominous presence*
- *Finally a cold drink at the end of the day* • *2011 - 1 week*



Pen y Fan taunts us on the horizon all day.

Today we started very slowly and kept our support driver Sally close by in case we wanted to opt out at any stage. In the end, we found our groove, and twice pushed on beyond the “day’s end” to reach Brecon - Tuesday’s leg of the walk.

The final leg of the day took us along a stream and into town through dappled woods, a welcome reprieve from the warmth of the mid-day sun.

We trekked 12 miles through countryside that at times took our breath away, it was a real treat and our main challenges came, not from the walking, but from the farming hazards. A field of cows became more of a worry when Andrew uttered the immortal words: “I don’t want to worry you, but they are all bullocks”. He did though, lead us gallantly through the field. We weren’t scared for a moment!

At each turn it seemed that the peak of Pen y Fan (our final major climb) was almost taunting us - an ominous, brooding, presence in the distance, which now is the only major obstacle between us and Cardiff, Dan’s exuberance excepted.



Our illustrious leader gingerly eases them out of the way.



Nothing but a gentle stroll really.

We are now collectively feeling pretty comfortable with the terrain and had talked yesterday about pushing on to Brecon. Upon meeting Sally at 3pm, it quickly became clear that with only a couple of miles to go we should do just that - our reward came when Andrew detoured for liquid refreshments on the way home.

With the sun setting in the background, we began planning for next year - as Marcelo said in his recent comment, ‘this does not stop at Cardiff’. We now want to share the experience we have so enjoyed - watch this space for plans for 2011 and get that treadmill out!!!!!!!

12 miles? I feel tired just looking at that figure. Amazing stuff guys! Loving your blog and pics.
JENNY COYNE, AUSTRALIA

Sounds like you all are gaining steam rather than losing. Hard to believe Cardiff is so near. Thanks for giving hope to others of what is possible.

TERRI CHAMBERS, SAN DIEGO



Phew, we reach Brecon visitor centre – two days in one.

DAY
25

26 JULY

Two peaks
from Cwm
Clyd Isaf

Who needs REST – not us! Despite being a proper ‘rest day’ we had an appetite for more. A day without walking now seemed incomplete. We had our sights set on the hills surrounding Andrew’s house – Alt y Clych and Banc Craigol. We had already summited the first hill, so I fancied climbing the later of the two. But first, we had to take care of paperwork – work first, play after – that was the rule!

In the meantime, Rob arrived. He would take over from Sally, and be our fourth and final support driver for the journey. Over lunch we shared stories – Rob shared with us his experiences and challenges with McArdle’s. With two diagnosed siblings, and having been a patient of Dr. McArdle, Rob had plenty to tell.

With full bellies and paperwork complete, we grabbed our boots and ran out the door – Dan decided to summit Alt y Clych again, while the rest of us (Andrew excluded) opted for the opposing hill.

Andy and I reached the peak within moments of one another and let out a collective sigh – we made it. Not only to the top of this hill, but three quarters of the way to Cardiff. Although, we still had to make our way through the Beacons and one more mountain.

For now it was time to say goodbye to Cwm Clyd Isaf – we were moving on to the Canal Barn Bunkhouse – oh dear!

Shortly after six o’clock we arrived in Brecon to unload our gear and check out our new home. The list of bunkhouse amenities included: central heating, a drying room, a large covered annex to wash down boots and unlimited hot water. What

about the concierge, in-room dining, heated pool and wireless internet? I suppose my 8x12 room and single bunk-bed will have to do! We dumped our belongings and headed into town for dinner.

The Boar’s Head seemed like a reasonable place to eat – very pub-like! Until, one step at a time, we passed through a double set of doors leading to another world. Andrew, Sally and Rob decided to call it a night after dinner; while Dan, Andy and I were drawn in by the madcap scene all around us.

It must be said – what happens at the Boar’s Head, stays at the Boar’s Head, but be rest assured – we all left that night with our eyes wide shut.



Rob, Stacey and Andy point to Dan on top of Alt y Clych.

Twin peaks (on a rest day)

• *Alt y Clych, Banc Craigol – rest day madness* • *Rob joins* • *Dr. Brian McArdle*
• *On to Brecon* • *Sunny again!!!*



The view from Banc Craigol over Cwm Clyd and onwards in the direction we are due to walk.

We arise bright and early and proceed to take our time producing press release 3, design by committee is always tricky, but in this case it seemed to work – slow and steady!!! Once again it was a nice sunny day...

Rob (week four support driver) joined us from Dundee this morning and we learnt that he was diagnosed at the age of 20, after suffering renal failure. He met Dr. Brian McArdle in the '60s and appeared in *The Lancet* at that time.

In the afternoon, still in the third stage of the WoW, we decided to throw in a couple of extra climbs. While Dan headed off to summit Alt y Clych, Andy, Rob, Sally and Stacey slowly climbed Banc Craigol – Andrew, who can walk these hills any time, suggested madness was setting in – but the views from the top rewarded the effort.

This evening, the ever growing WoW Team is off to Brecon for the next four nights.

Wednesday's trek up Pen y Fan will be joined by our very supportive family and friends.

Thought du Jour ~ "I don't believe it" – Andrew. (See the Facebook group – 'Walk over Wales for McArdle Disease' for a full understanding of this reference...)

You guys are managing to capture in words all of the ups and downs of this journey, so much so, that I feel the excitement (and sadness) that you are almost at the finishing line.

KIM VELOCCI, CANADA

Good luck to you all, sounds like a really successful journey so far, and well done for getting all the press coverage. I hope that the last week of your walk goes really well.

KATHRYN BIRCH, UK



The rustic sign for Andrew's rustic house.



Oak trees on the climb up Banc Craigol.

DAY
26

27 JULY

Getting ahead
into the Brecon
Beacons

Spending the past four weeks with Andrew, Dan and Andy has been a tremendous experience. We set out to achieve the most formidable challenge any of us have ever attempted. We didn't just walk across Wales, we shared an incredible journey – one that enabled us to explore the limits of our boundaries and share with the world all that we had learned.

In just a few short hours, our tight knit group would be joined by my husband – Jorge, and Andy's family (five non-McArdle walkers). Excited as I was, a part of me was concerned how the upcoming day's walks would be transformed – us against them. Would my ridiculously slow pace still leave me feeling self-conscious as our family members effortlessly meandered by our sides?

At this point in our journey, I was well on my way to a place of acceptance and understanding. I now believed I could achieve most anything – albeit at a slower pace. What I had to work on though, was the pervasive feelings of inadequacy. I had to stop comparing myself to 'normal' people. One step at a time, I am getting closer and closer to achieving that goal.

For the last time, just the four of us laced up our hiking boots, slung our packs over our shoulders and walked towards the base of Pen y Fan. As we waited under the shade of an old growth tree for Rob to pick us up, we quietly reflected on the past few weeks and all that we had accomplished – of course Jeff Buckley's 'Hallelujah' was playing in the background.

With time to spare, Andrew, Dan and I set off to visit Hay-on-Wye while Rob collected Jorge from the train station. Andy elected to stay behind and settle in for an afternoon nap. The world renowned 'Town of Books', a popular destination for bibliophiles, did not disappoint. With over thirty book stores to visit, we enjoyed a leisurely afternoon.

The day culminated with a lovely dinner – all thirteen of us, together celebrating.



Setting out from the canal side bunkhouse.



A perfect McArdle's start – along the (level) canal towpath through Brecon.

The day before Pen y Fan

• *The Boar's Head* • *A walk in the park* • *Family arrive*

The Boar's Head in Brecon is certainly a pub full of character and characters. We had a thoroughly enjoyable evening, watching people, some playing bar quoits, others involved in an odd 4 person version of musical chairs, or dog sliding and listening to the juke box. Of course, Hallelujah was played, as was the Wurzels classic – I am a cider drinker – surprisingly this was a bar standard as one of the locals is known for his consumption of the west country treat. A few pints of Ramblers Ruin were reward for the rest day ascents – that's right...we are now climbing hills on our rest day.

As it's difficult to leave before your songs come on the juke box, and the pub did not close until 1 a.m., we ended up staying a little later than we had envisaged, so lucky we had only a short day today walking from our excellent bunk house accommodation to the lower slopes of Pen Y Fan.

It looked a little less ominous up close (we think) until Andrew pointed out that we could not see the peak – what we could see was a minor top along the way – ah well... energy levels are very high presently, and we all feel that the walk has got us in better shape than for some time – the task will be to avoid de-conditioning when we return to day to day life. The time to focus solely on this one task has been a luxury and a superb way to unwind.

We have discussed next year in a little more detail and plan to choose a week in mid July – ideally we will base ourselves in one location for the week and we should be able to accommodate a variety of levels of walking ability, with the intent being simply to share the experience we



Andy and Dan try short stretches on a climb.

have enjoyed with as many McArdle patients as are interested. We intend to provide details of proposed dates by the end of this walk so people can mark it in their calendars and begin to think about planning to join and training for the walk.

An earlier night needed tonight to ensure we are in top shape for Pen y Fan tomorrow.

Your courage and strengths are admired by many. We are so proud of all of you!

ADRIANA, USA

You have given those with McArdle's a great deal of hope – knowing that they too can do things they never thought possible.

JO DI CARLO, CALIFORNIA



The rest of the world is catching up with our techniques - at the outdoor bookshop.

On the foothills of Pen y Fan.

DAY
27

28 JULY

Brecon to
Taf Fechan
Forest



Joined by family, friends and colleagues – our large party ready for the off.

Our last big mountain day struck me as bittersweet. I was so pleased with all that we had accomplished. Four lone McArdle-ites braving the hills of Wales, not to mention our wavering confidence and obsolete glycogen stores. Yet I found myself saddened with the prospect of arriving in Cardiff – and home to our less sympathetic lifestyles.

Having this opportunity to spend our days selfishly focused on nothing but ourselves and the walk has been a once in a lifetime experience, a true luxury. The pace we set and the methods we implemented became normalised within our insulated foursome. And feeling normal is not familiar to us – so it felt great!

The question now, was how do we carry this momentum forward. To be able to comfortably walk with others, to carry out our daily activities and do so safely and with ease. Zig-zagging through my neighbourhood is not exactly common practice!

Perhaps today would be a reasonable test. In total we were joined by eight non-McArdle walkers. They ranged in age from ten to seventy-seven. Some male, some female. But they all had one thing in common – access to skeletal glycogen.

The climb was gentle, but persistent – we paced ourselves, slow and steady. One step at a time, our large group began to spread out across the ever increasing incline – we were pulling up the rear. Oddly enough, I wasn't too bothered by it. Then again, we were surrounded by loved ones.

Relative to the hills we had climbed early in the walk, this one seemed easier. The terrain wasn't as tough, but the distance and elevation certainly were comparable. It would seem as though our bodies were responding positively to our increased level of fitness. Across the board, we all noticed a marked improvement.

Following a homemade dinner, we set off to a local pub to work on our final press release. There were only a few days left before arriving in Cardiff, and the final leg of this journey.



Straight up out of the car park. Stacey finds a safe place to test her fear of heights. Walking poles for the McArdle-ites.

Done, Done, Done...last BIG climb

- Pen y Fan no longer ominous • 77 year old leads the way • Rain, wind, climbs, sun
- Steep, lots of drops • Reinforcements • Paparazzi Pete • Calming words from Jorge



Summit party, Pen y Fan.

Under blue skies we set off up Pen y Fan, some of us more uneasy about what lay ahead than others. The physical challenge would, at the outset of our journey, have been a potential concern – that is no longer the case – but fear of height remains!!! And today certainly challenged us.

We were joined today by Sue Del Mar, co-founder of AGSD-UK; Allan Muir, one of the Trustees of AGSD-UK and his son Jamie, who has GSD Type II (Pompe), both of whom kindly walked up backwards on some tough stretches of the climb to capture our techniques on camera.

Stacey's husband Jorge hot off the plane from Toronto, and Andy's father Glyn, who set a fierce pace throughout the day, and children Megan 12 and George 10 also joined us for the climb to the top of this 2,883 ft peak. While Andrew's brother Peter, and his Jack Russell Jack, who must have covered half of the Brecon Beacons, provided further moral support. Of course they had to amuse themselves, and fight the constant urge to speed ahead, which they all achieved. It was interesting to observe Glyn, a carrier of McArdle's,

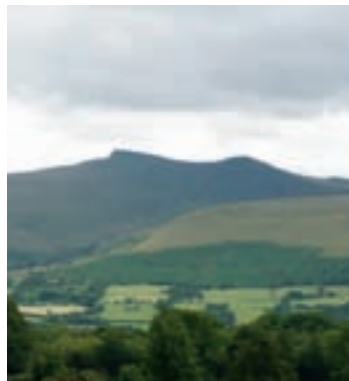
trek up the mountain side, he very clearly had no problems on what was a challenging walk. On one of our frequent rest stops up the hill, we were quickly passed by a group carrying a kayak up the mountain – we were less intrigued at the time with the reason why, but more so by the fact that they overtook us so readily!

As we reached the higher slopes the winds picked up, the skies darkened and nervous tension rose, but by taking it slowly and steadily none of us experienced any McArdle's related issues. The techniques we have learnt stood us in good stead for this last ascent of our journey to Cardiff. Once we had negotiated the steep slopes at the top, the rest of the walk was comfortable, allowing us to freely discuss our final press release and to talk more about next year.

At the finish today Peter carefully staged The Team for a photo shoot and our inevitable arrival in Cardiff. To wrap up the evening the WoW Team made their way to 'The Gremlin' – a wifi hot spot... funny enough we met up with the Mayor of Brecon – photo shoot tomorrow!

Thought du Jour ~ "It will be long... it will be hard... there will be no withdrawal." – Winston Churchill 1940 (compliments of a bloke's t-shirt we passed on the way up Pen y Fan).

Woo hoo!!! Way to go WOW Team! You've conquered the challenges all the way to the last BIG climb. If there's a will there's a way.
Great job by all!
ERIKA, USA



Three generations of the Williams family. Our objective, Pen y Fan. A welcome treat on the drive back to Brecon.

DAY
28

29 JULY

Taf Fechan to
Merthyr Tydfil

Tonight was our last night in Brecon before moving onto a proper hotel in Cardiff. Which meant – the end was upon us. We all were beginning to feel a little anxious about parting ways. You know the feeling you get when the clock is winding down – you’re trying to live in the moment, yet at the same time imprint every last memory. That’s what it was like.

We had a long walk ahead of us, it was on easy terrain and mostly downhill. Three weeks ago, this would have been my ideal walk. A well laid out path, no dramatic ups or downs and no possibility of getting lost. Now, the mere idea of this just seemed BORING. In fact, I think there were more blisters and aching shins today than on any of the previous days’ walks.

Navigating my way through the wilderness, and possibly getting turned around, has always scared me to death. Getting lost and having to walk further (or getting lost and having to walk further quickly) was not in my repertory. I’ll say it again – I always played it safe.

But walking with Andrew, Dan and Andy was so easy, there was never any pressure to keep up, to move quicker, to walk further. And so, as I began to feel ‘normal’, for the first time ever, my fear of walking in the back country began to fade. I was learning to appreciate the remoteness of the hills and the inherent beauty of the great outdoors. Formal trails with well marked signage no longer provided comfort, but instead felt restrictive.

So there we were, slogging along a ten mile trail to Merthyr Tydfil. It was as though I could feel time passing us by – all too quickly now I thought. Enough, I had to

remind my self – over and over – just stay in the moment, enjoy today.

Our last evening in Brecon was a memorable one. Mayor Dave joined us at ‘The Gremlin’ for a drink before we set off, one step at a time, down the street to our favourite watering hole – the Boar’s Head. The usual gang was in attendance – ‘Cider Monkey’, ‘Pint & a Half Guy’ and Sadie the German Shepherd.

Tonight we weren’t thinking about the end, we were rejoicing in the moment. We passed the time

A lot of our route is now on disused railways that used to export coal.

reminiscing on the climbs we made, the weather we endured and the fun we had. We were now mountain climbers and long-distance walkers!

After the Lord Mayor's show...

• Long, flat, unchallenging, tarmac... • What have we become?!



We say goodbye to the mountains, all downhill now.

After the exhilaration of yesterday's achievement, today's walk was more of a mundane slog along roads and a well-marked, and indeed road-like track. A few weeks ago we would have looked at a 10 mile walk along such terrain as an accomplishment – today under cloudy skies, blisters were our biggest enemy.

Even the bullocks were on the other side of a secure fence today.

Scenic though it was, it did not match the routes we trudged along on previous days. Fortunately, Jorge, Andy's children and niece Grace, provided some entertainment along the way. 10 year old George proved conclusively that he does not have Type V by running up and back, and probably covering an extra mile in the process.

Plans are afoot to change the planned route for Saturday – as it is currently set at 12 miles. After today's long and tedious walk, we thought it would be a good idea to walk a few miles tomorrow (our final rest day) in order to balance out the days.

The WoW Team is looking forward to

meeting Charlton (a 13 year old McArldle patient from the Canary Islands) on Saturday – when he joins the team to walk for the three day journey into Cardiff.

Thought du Jour ~ Savouring every last morsel of time as we make our way into Cardiff... May you always enjoy the moments as much as we have on this remarkable journey of discovery.

On Sunday August 1st. WoW version Argentina. 10km from my house to the embassy of the UK.

In support of my friends who walk in Wales.

MARCELO, ARGENTINA

Walking poles \$20; walking shoes \$100; backpack \$50; a month long "Walk Over Wales" with fellow McArldle-ites PRICELESS!

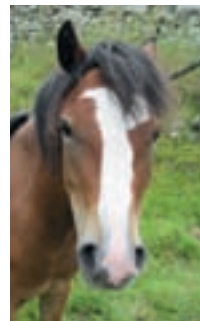
JO DI CARLO, USA

Not only have you, the WoW team, accomplished a magnificent goal, we, the 'others' have been with you every day in spirit. We cannot be prouder or more in awe of you for this accomplishment.

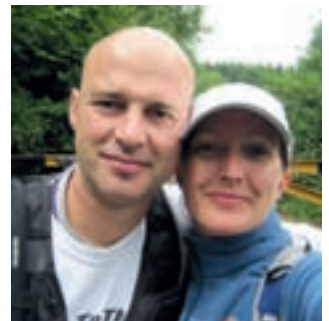
JANET JOHNSTON, CANADA



Still great scenery but getting a bit more urban.



Hello!



Together again.

DAY
29

30 JULY

Merthyr Tydfil
to Pont y
Gwaith

Tomorrow's walk was slated to be twelve miles long – perhaps too much for Charlton's first day. With bags packed and a full day ahead of us, we elected to walk six of tomorrow's twelve miles. Just one caveat – we wanted to do some climbing. It would seem as though a paradigm shift had occurred – we were transformed.

Having traversed through the Brecon Beacons, the route from Myrthyr on to Pontypridd was remarkably different. The mountainous landscape gave way to a flat, over-populated trail. Excited by our metamorphosis, Andrew studied the map carefully to find a suitable high level route.

The road weaved up and out of the industrial cityscape to a vast expanse of nothingness. Intrigued by the views, we leapt out of the car to get a closer look. There were sheep (of course) and wild ponies wandering through mounds of debris and commercial waste – not to mention an array of animal carcasses laying about. It felt like we had left Wales and landed in a post-apocalyptic wasteland.

Back to the Taft trail (our original route) we went. With our mountain climbing days behind us, we set off through an over-stuffed parking lot – the streets were abuzz with cars, buses, motorcycles and bicycles. Gone were the sheep, lambs and comforting hues of purple heather that blanketed the countryside.

Although the landscape was unimpressive, we reminded ourselves there was still twenty-five miles to go. Besides, weren't these the kind of trails we longed for just a few weeks ago? It's amazing how our (perhaps just my) point of view had transformed. Walking in a supportive and understanding environment had the ability to displace any and all reservations.

One step at a time, we made our way along the paved trail. With each falling rain drop, I reflected upon the thousands of steps we'd taken on this pilgrimage across Wales. In isolation both were unimportant, but collectively they contributed to something greater. In our case, that 'something' was how much we really can do (despite having McArdle's).

Before I knew it, we had completed the six miles and were headed to our final destination – Cardiff. Shortly after we checked into the Churchill Hotel, we met up with Charlton – our youngest walker, and his family. Now there were six of us (including Rob our support driver), from four continents – walkers from around the world – amazing.



The official photo with Mayor Dave complete with chain of office!



The Taft Trail went through some fairly scary underpasses.

More rest day walking

- Mayor Dave • Cider Monkey • Chicken Land • Taff Trail • Gently falling rain
- Best cup of tea ever • Charlton arrives!



29 days, not long now. We should make it OK to Cardiff.

On Thursday evening the WoW Team met up with Dave Meredith, Mayor of Brecon, at 'The Gremlin' pub for a photo op. The Mayor was very intrigued with our journey, as we discussed our trek thus far. Mayor Dave ensured that Dan was of age by checking his ID – Dan followed up with a heartfelt hug.

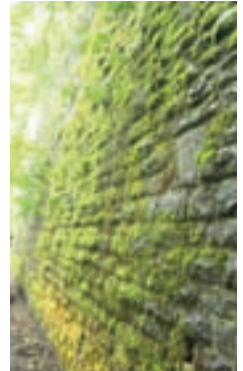
To conclude our stay in Brecon, we made a return visit to the 'Boar's Head' pub, where we were enlightened by our new friend Andrew of Brecon – otherwise known as 'Cider-Monkey'. The WoW Team enjoyed a day's end beverage and a wide variety of songs on the jukebox. As we made our way back to the bunkhouse, we happened upon 'Chickenland' – of course we indulged in a late night snack!

The sun rose quickly this morning, as we packed up from the bunkhouse in order to head out on the 'Taff Trail'. Despite the fact that today was a scheduled 'rest day', we collectively decided that it would be a good idea to knock off some miles today, with the intent of shortening Saturday's route – Charlton's first day.

Within an hour of walking the rain began to gently fall – a phenomenon The WoW Team is quite familiar with. The difference being, today's rain was pleasant and refreshing – a welcome reprieve from the near drenchings we've used to.

To end the walk, we finished at a quaint tea shop by the Taff River. As Rob shuttled Andrew back to his car, Andy, Dan, Stacey and Jorge enjoyed a pot of tea and caramel biscuits – preferably enjoyed warm.

As the team arrived at the Churchill Hotel in



The surroundings alternate from natural to industrial.

Cardiff, we were welcomed by Charlton and his family. Charlton had needed to finish his school term before he could join us. We presented Charlton with his WoW t-shirt and look forward to walking with him and his mother Alison over the next few days.

Congratulations to Marcelo, who has been inspired to walk from his home to the UK Consulate in Argentina on Sunday – 10 km in total! We can't wait to hear from you Marcelo.

I have thought of you every day. I wish you a hugely successful end to your trip and thank you for the most amazing effort on behalf of all McArdle's people.

SIONED WILLIAMS, UK

Welcome Charlton and Alison. I'm sure you'll be made to feel very much at home, and hope you draw as much from this experience as the rest of the team seem to have done!

CHERYL ELLIS, UK



The valleys have a lot of terraced housing, even up slopes.

DAY
30

31 JULY

Pont y Gwaith
to Pontypridd

Without any challenges along the route to distract us, we were all feeling a tad bit woebegone. Despite our heavy-hearts we were thrilled to be walking with Charlton and his mum.

Our walk today began at the quaint tea shop we finished at the day before. Not wanting to miss even one square inch along the route, Dan and I ran back down the hill (not easily passable by car) and stopped directly in front of the cafe. Pleased with ourselves for making the extra effort, we proceeded slowly back up the hill to join the others. It was important that we started the day *exactly* where

we'd left off yesterday afternoon. Well, perhaps not for me, as I had already missed a few days earlier on, following my anxiety induced episode of rhabdomyolysis. However, Dan had not missed one step of this entire journey. Impressive.

Off we went. Having walked for miles upon miles together, the four of us had progressed substantially in our fitness. Starting on the flat generally presented no difficulties for us at this stage. But now that we were joined by Charlton, we had to be more attentive – after all, it was only his first day. So slowly, one step at a time, we all continued on the journey to Cardiff.

Being a popular walking/cycling path, the Taff Trail was well marked as it followed the course of the River Taff. We walked along an abandoned branch of the Taff Vale Railway, through residential streets and for a short while – back into the trees. Boy did I ever miss the seemingly contrary forces of North Wales. Peace and solitude set against an unforgiving terrain and the ever changing elements.

The straightforward route provided ample opportunity for us to get to know Charlton and his mum. We shared our experiences with him, and in turn he described how McArdle's had affected him. It was fascinating to speak with both Charlton and his mum, yet another story about McArdle's – different; but very much the same.



Debate about how much more to do today.



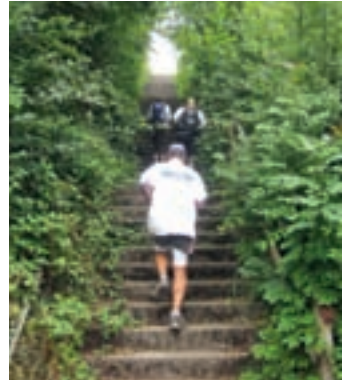
The Taff Trail is a really good path, mainly on old railway lines.

Welcome Charlton

- Charlton's first day • An extra mile • No rain – well a drop or two
- Stairs, stairs, stairs • Where is the path? • Three cheers for Marcelo • Sigh!



A big welcome to Charlton and Alison joining the team



Steps for fun? Can this be true?

Today we headed further down the Taff Trail to the town of Pontypridd, and finished by doing a mile of tomorrow's intended route, reaching the local cemetery. For once there was no rain, but unfortunately Charlton did not manage to bring the Tenerife sunshine with him. We kept a good pace throughout the day and discussed technique and the importance of regular moderate exercise.

An odd day for Stacey on the stairs – reaching the top of two flights at the hotel this morning, her muscles complained, but a couple of hours into our walk 70 steps up a steep bank were added just for fun without even passing for breath.

In order to give Charlton the authentic WoW experience, we headed up what was once a footpath but was now crowded with brambles. We braved the nondescript path, as we wanted to head off the main road and back into the serenity of the woods. Dan fought hard to make a reasonable pathway through the thorns, but in the end we admitted defeat (thorny scratches aplenty), and retraced our steps to the busy road.

As we near the finish it is with mixed emotions – joy at what we have achieved, but sadness that this fantastic journey is coming to its end – at least for this year. Each of us has enjoyed each step (well maybe there were a few we could have passed on) and will leave with a sense of achievement and equally a sense that there is even more we can achieve...

Tomorrow we will be joined in spirit by our friend Marcelo – as he walks in support of WoW, from his home in Argentina to the UK Embassy.

30 days! 70 steps! 3 cheers! Weather is fair!
Almost there!

MARK CHAMBERS, SAN DIEGO

This group of folks, who started out as relative strangers, have become 'friends' to me precisely because they have shared all they have learnt. And I too feel I have grown. Let's keep helping each other, learning and growing.

CHERYL ELLIS, UK



All deep in thought? There seemed to be a diversion of a diversion. No longer the youngest, but Dan can still have fun.

DAY
31

1 AUGUST

Pontypridd
to Llandaff
Cathedral

The average person takes approximately 2000 steps to walk one mile. That would mean we had taken 394,000 steps to get to this far. Not including the countless 'extra' steps we'd taken – not because we were lost, but as a consequence of not being sure of where we were. That just leaves 26,000 to go!

It was difficult to stay in the moment today. Our minds kept fast-forwarding to this evening – our last supper. I wanted time to slow down, perhaps even standstill – at least until I could mentally catch up. It was hard to believe we were on the eve of this larger than

life odyssey.

Before arriving in Manchester five weeks ago, I questioned my decision to participate in this event on a daily basis – if not hourly. I kept reminding myself 'you can do this – at the very least, give it a go'. I wavered between feeling confident in my decision and terrified with the unknown. My family and friends rallied around me, gently pushing me in the direction I knew I wanted to go.

But something happened while I was here. I came to a life-altering realisation. I learned that despite having McArdle's, I can achieve remarkable things. I think we all learned something about ourselves. It would have been impossible not to.

With plans well underway for next summer, I wanted a firm commitment from my new walking companions that we would all return next year – hiking boots in tow. So I raised my right hand, extended my pinky finger and motioned for a group proclamation of our promise. We all clasped pinky's and repeated the phrase 'pinky swear'. Done deal!

When we arrived at Llandaff Cathedral the sun was hanging lazily in the clear afternoon sky. With mid-afternoon weariness setting in, there was no time to loll about – we had work to do prior to meeting everyone for our pre-celebratory dinner. Back to the hotel and our computers. Besides, there'd be plenty of time to relax this evening.

I snuck away for a few minutes to formulate my thoughts. How was I going to articulate all that I wanted to say

tonight in just a few brief sentences. Fears had been conquered, strangers became the best of friends, and vital life lessons had been learned. Sincerity will lead the way...just don't forget to breathe (I often had to remind myself of this).

So, one step at a time, we all made our way down to the hotel dining room. Andrew, Dan, Andy, Charlton and I were joined by many – husbands, brothers, sisters, mothers and fathers – tonight we were one. Good food, happy tears, kind words and warm laughter carried us through the evening – a night I will never forget.



And then there were five! And the sun came out.

So that's what summer walking feels like!!!

- Sun at last • A scenic walk along the Taff • A costume wedding • Castell Coch
- Llandaf Cathedral • Our penultimate day

And now the end is near..... after today just four short 'Wakelin' miles will stand between us and our objective in Cardiff.

When we started our journey we were wishing the miles away. Now we'd all like to add a few more mountains, a couple more reservoirs, a barrel more laughs and plenty more miles.

Today though was a great day for walking – with the arrival of August, summer finally joined us. The sun shone all day, as we wandered down the Taff Trail leaving Pontypridd, heading into the beautiful countryside along earthen tracks, through woods, and up some decent slopes. The hills gave us the opportunity to demonstrate a few techniques to Charlton, and by the end of the day we were all moving at a rapid pace along the final level path to Llandaf Cathedral.

Along the way we passed Castell Coch – a recent creation, and happened across a costume wedding complete with a beautiful white vintage car; our second wedding in two days, the first at the hotel was a little more raucous.

The walk from the castle was all downhill into the outskirts of Cardiff. As the path neared the Taff River, Dan could not resist a dip (whole body soaking), and finished the walk just as drenched as we have been on most days – end of walk exuberance a plenty, and perhaps the 4th stage of the Walk over Wales – delirium!!

Now for Team WoW's last supper (sob, sob) and an early night in preparation for the media frenzy tomorrow will bring!!!

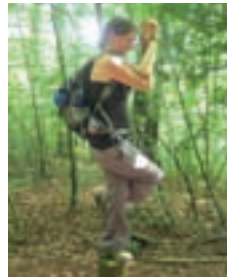
Thought du Jour ~ With tears of happiness in our eyes, we temporarily bid adieu to our new friends – our collective journey has just begun. Thank you friends far and near for always believing in us in all ways.

Tomorrow should be very emotional. I will need a box of tissues by the computer... waaaaa. You now all have lifelong friends on different continents and you WILL see (and walk with) one another again and hopefully many more Type V's. You can not only live with but thrive with McArdle's! What you all have accomplished is nothing short of amazing. Can't find the right adjective! Very proud of you all.
Finish strong!

TERRI CHAMBERS, SAN DIEGO



We'll only be able to put our fingers up one more time.



Stacey's yoga on a pole.



Dan can't resist a final dip.



No Andy, we forgot to book a chauffeur driven Roller.



A crazy idea started a year before is actually coming true!

DAY
32

2 AUGUST

Llandaff
Cathedral to
the Sennedd

I woke early this morning, wanting to assimilate all that had transpired over the past five weeks. It was hard to believe I'd be packing my bags for the last time. As I carefully organized my belongings, tears began to roll down my face. The enormity of all we had accomplished was beginning to take hold.

I'd better have a cup of tea!

Breakfast was quiet, none of us really knew what to say – what could we say. Words were not enough. Instead I decided to leave the boys with a memento of our time together. Since a fortunate stroke of serendipity had brought us all together, I thought a lucky Canadian Loonie would

be fitting. Dan immediately put his under the insole of his shoe, Andy tucked his away in his wallet, and Andrew said “What am I going to do with this?” My bets are, he still has it, safely stowed away.

We made our way back to the Cathedral in plenty of time to meet ITV Wales and complete the last four miles. Just like the first few, the sun was shining and the gentle breeze carried ashore the fresh sea air. However this morning, I no longer carried with me that old nagging sensation that had been with me for so many years. I walked with confidence and ease.

As we approached Cardiff Bay we slowed down to let our family and friends walk on ahead. In quietude, we took our last few steps, side by side. Just for a moment, time stood still, and the world around us faded away. It was just the five of us.

Ahead lay the steps to the Sennedd and our final destination. Our family and friends were enthusiastically cheering, as ITV Wales filmed the final leg of this extraordinary journey.

I wanted so much to tell Andrew, Dan, Andy and Charlton how much they meant to me. I wanted to express my gratitude, and acknowledge the profound impact this experience had on me. But I didn't – instead I just walked. How could I express all that I was feeling. For once, words failed me.



Charlie's youngest brother, Jimmy, gets in on the act.



Andrew tries to get key messages across on ITV News.



“End of term” feeling knowing the end was now so close.



Andy and Stacey get their thoughts on camera.



This last day was, literally, a stroll in the park.



ITV News Wales follows us in to Cardiff Bay and our finish at the Sennedd (Welsh parliament).

And just like that we were here, 210 miles (338 km) from where we began.

Back at the hotel, we got busy working on our LAST blog. As we sipped champagne, we reflected back on how far we had come – not just in distance, but towards a greater understanding of how best to manage this rare metabolic disorder.

The single most important event of my life had come to a close. With bags packed, the blog uploaded and train ticket in hand, I waited on the steps of the Churchill Hotel with Jorge and Dan for our taxi to arrive. Saying good-bye to Andrew and Andy would not be easy. Perhaps a hug would make it better.

I extended my neck to it's full range to get a look out the back window of the cab as the driver sped off down the road. Within minutes my friends had disappeared out of view.

As Winston Churchill once said, “Now this is not the end. It is not even the beginning of the end. But it is, perhaps, the end of the beginning” And so, I will march forward to my new life, **one step at a time!**



Our journey begins.....

- *The final supper* • *ITV News Wales* • *Barely concealed emotions*
- *This trip ends, but the journey continues* • *Summer has arrived*



The steps of the Sennedd, surrounded by celebrating family and friends.

Dinner last night for the team, along with Sally, Rob, the whole family Thear, big brother Martin and his wife Christine – a tear jerking affair with words of thanks from Stacey, Dan and Andy for all of Andrew's supreme efforts in bringing this all together.

This morning we were joined by family and friends, filmed at the start by ITV Wales for today's news at 6pm (there is a link on the AGSD-UK web site). In turn Andrew, Stacey and Dan fought their emotions as they spoke to the camera – it's been that kind of journey, but hopefully we will have said enough to get the message across clearly – if we can do it, so can many other Type V's with the right guidance.

The morning's walk was pleasant, a football came in handy, Dan had no opportunity to get wet – Cardiff Bay was deemed, even by Dan, to be a bridge too far, and before we knew it was 1pm and we had arrived at our final destination (this time around!!).

Dan kissed the ground, the crowds cheered



Family members of all ages gave us great support.



So close now, getting a bit emotional.



We all needed a little quiet reflection before setting off.



Reception at the Pierhead Building, Welsh Assembly.



Five triumphant walkers pose for the cameras.



That's it, done, signing off now.

and more interviews followed for Andy (similarly struggling to hold it together), and Alison.

A reception at the Pierhead Building, allowed time for reflection, and to meet Andrew's Welsh Assembly Member, and leader of the Liberal Democrats in Wales, Kirsty Williams.

It was great to have so much support today including from Allan, Jamie and Barbara Muir who drove from Hampshire again to help us complete the last few miles – our thanks to all.

Thanks also to everyone who has read the blog, left comments and shared this journey with us – for us it has been a rich experience just to be here and walk, but your support has made us part of something much bigger and more meaningful.

To all who have walked elsewhere – well done – to Marcelo thank you for planting a seed, which we will nourish and which will first bear fruit next summer, back here in Wales.

We are looking forward to 2011, and hope that other Type 5's will want to join us – we know a few of you do already... Andrew will be there to lead; Andy, Stacey and Dan are all committed to the reunion, and hopefully Charlton will join us as well. We hope to firm things up soon and will publish on the Facebook Group.

It's been a blast..... *au revoir mes amis.*

Thought du jour – What are we going to do with our lives now?

Hi Team, Looking at your final photo, you have achieved something most Type 5's would not have thought possible, but here you are at the end of a amazing journey. The friendship you have developed will never be broken. We are all grateful to you.

LORRAINE BAGULEY, AUSTRALIA

Well done on completing this huge walk. It was a real pleasure to accompany you on the Built to Upper Chapel section and we could see just how fit you had become. You have really challenged the presumptions that your disease must limit your fitness. You have savoured the joy that comes with time in the mountains and valleys of Wales, something that very few people dare to try. Hope you have raised lots of money and undoubtedly you will have increased awareness of McArdle's. You have certainly taught us lots!

STEPHANIE & MIKE WARRICK
(ANDREW'S GPs)



Dan and Charlie share the last map reading.

It was nice to get to know all of you through this blog and your pictures. I have been a part of many causes in the past, but never have I felt so connected emotionally. I wish you all the best as your own individual journey continues and may you rest easy knowing that you have had such a positive impact on those around you – with Type V and without. Slow and steady everyone as you deal with Day 33 – the dreaded “morning after”.

KIM VELOCCI



Dan's looks unsure whether his T-shirt is OK in a cathedral.

Your journey is an inspiration. I was crying just looking at the pictures and thinking that you have so much to be proud of.

NANCY

Having climbed with Andrew over many years, I know something of the courage and determination it takes to be a hill walker with McArdle's. A fit walker, free of the disease, would have found this ambitious trip daunting. The effort of will required to keep going each day, for a month, with blistered feet, tired legs and the usual aches and pains caused by climbing and descending, (and let's be honest, who doesn't also have days when they have a headache and just want to stay in bed!); and to keep on going right through the spine of Wales, mostly in the rain and careful not to avoid the summits (oh goodness no!), mean this long distance walk would have proved a challenge to anyone. However, overlay all these difficulties with the exercise induced pain that is McArdle's and what you have all just done as a group, with such obvious humour and friendship, is truly remarkable and you need to be very rightly proud of yourselves. You can be sure that everyone who knows you is.

ALAN CRAIG, UK



Tears and hugs in front of the TV camera.

Press coverage

A small sample of the press coverage we received as we walked over Wales. Most of the papers covered our exploits as we passed their area.



We make the news stands!



Walkers reach halfway point

A party of walkers has reached the halfway point of their 210-mile walk across Wales. The group, led by a man with a rare genetic mutation called McArdle's disease, has walked 105 miles so far. They are now walking the Gower Peninsula, from the Gower Head, in Llanelli, to the National Library in Cardiff.

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A party of walking wonders wander through Wales

A PARTY of inspirational walkers have announced the details of a new route to walk the length of Wales. The route will start in Llanelli and end in Cardiff, covering a total distance of 210 miles.

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Llandudno to Cardiff walk will raise awareness of McArdle's Walkers of the world back muscle disease sufferer

McArdle's disease is a rare genetic mutation that causes muscle pain and weakness. It is named after the man who discovered it, James McArdle. The disease is caused by a defect in the PFKFB3 gene, which is responsible for producing an enzyme called phosphofruktidase-2 (PFKFB2). This enzyme is essential for the production of energy in the muscles.

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Dan kisses the ground at the finish, on ITV Wales 6pm News.

Epilogue to Walk over Wales



Given that the prime directive for McArdle Disease is to engage in regular gentle aerobic exercise, the way forward became very obvious – this journey would be shared with others – we would walk and learn together!

In the years following Walk over Wales, the team has been joined by McArdle walkers from around the globe – Australia, Canada, America, England, Scotland, Wales, Spain, Ireland, Germany, Singapore, the Canary Islands and the Netherlands. Together, year after year, walk after walk, we marvel in our newfound abilities and lifelong friendships. Determined and purposeful, slow and steady we are changing the world one step at a time!

On a personal note, Walk over Wales taught me some important lessons about life. Walking 210 miles (338 km) seemed impossible, yet we did it – I did it. We found our way and forged our own path. I arrived at the finish in South Wales a new person – a more self-assured version of my previous self.

For most of my life, I interacted with the world in a less than confident manner. The answer to every question was unfailingly ‘I can’t do that’.

Until my diagnosis (age 36) I felt inferior and incompetent. Diagnosis brought relief and understanding, but trying to erase a lifetime of negative thoughts wasn’t easy.

WoW enabled me to accomplish what I perceived to be impossible, meet others that are similarly affected, and take those important first steps towards acceptance and ultimately a fulfilling life.

Today, my journey continues – when I find myself feeling a little bruised and defeated, I reflect back on the mountains I conquered, the miles I triumphed over and the friendships that emerged.

Stacey L. Reason

Moving forward

Development of a course for people with McArdle's to learn how to exercise safely and extend their boundaries.



The first "Walking with McArdle's" course, Snowdonia, 2011.

Upon completing 210 miles (338 km) and countless hills, the people who participated in the 'Walk over Wales' in July 2010 realised that walking as a McArdle's group was enjoyable and confidence boosting. This positive experience led to the development of a walking course – Walking with McArdle's.

The focus of these courses is to provide individuals with an opportunity to meet other affected people and share experiences, whilst gaining practical knowledge on how best to manage day-to-day life with McArdle's.

Anyone with a confirmed diagnosis of McArdle Disease can participate. However,

The objectives of the walking courses are to:

- Develop good management of the person's McArdle's.
- Improve aerobic fitness.
- Teach a range of techniques and approaches to improve performance and minimise the risk of injury.
- Identify and eliminate any bad habits that have developed.
- Extend each person's personal boundaries.
- Boost each person's confidence.
- Make walking enjoyable and establish it as a habit.

individuals must be able to achieve ‘second wind’ in order to fully participate on the walks.

Through informal discussion and practical experience, the week-long courses aim to develop the best techniques for walking with McArdle’s. Strategies for achieving ‘second wind’ and learning to use walking poles are two of the topics discussed. With improved aerobic fitness, the risk of muscle injury is lessened – in turn, individuals will gain confidence in their abilities and increase their motivation to undertake regular exercise.

The walks are carefully planned to suit the capabilities of all members in the group. Opt-out points are planned along the way, so that everyone can confidently join the walk for whatever distance best suits them.



Gabi Johann and Stacey Reason at Bosherton Lakes, Pembrokeshire National Park, 2012.

THE COURSES

By the time of this second edition the courses have been run for 6 years and people from 14 countries have participated. It is hoped that this will continue to develop and grow. Look out for the video on the AGSD-UK Youtube channel.

In 2011 the team ran two walking courses in the Snowdonia National Park. The walk routes ranged from level walks around lakes, through valleys and along the coast, to hill walks from gentle to strenuous. Each of the participants experienced moments of anxiety and concern with the idea of walking longer distances and climbing hills, but as the hours and days passed, everyone’s anxiety softened.

By keeping a slow and steady pace, the team climbed two Welsh mountains. With newfound confidence, everyone finished their course feeling positive and better equipped to manage the day-to-day frustrations of living with McArdle’s.

These first weeks served as a rich learning opportunity, enabling the group to



Walks are planned for an easy start on the flat.

better plan for future sessions. A recurring theme identified by all who participate is how valuable it is to spend time walking and talking with others that understand.

Each year since the team has offered courses, some again in Snowdonia and some

I've never felt so strong, physically capable, hopeful and inspired. There is such benefit in sharing our knowledge and experience.

All that and fun too!

SIOBHAN MURRAY, USA



A more challenging path in the Aberglaslyn Pass.

in the Pembrokeshire National Park. In 2013 they ran a course on Martha's Vineyard off the east coast of America. Courses have been run by Dr Andrea Martinuzzi in Italy. And a challenge event was held in the Dolomites.

With each walking course, more and more people are realising the potential of their abilities. A universal awareness, on the part of all participants, of being able to achieve much more than they ever imagined, has empowered McArdle-ites from around the



Fanastic views along the Pembrokeshire coast.

I have learnt more about my McArdle's this week than I did in 30 years from my diagnosis.

GABI JOHANN, GERMANY

ON AN CHALLENGE EVENT IN THE DOLOMITES
It was like 'Boot Camp'. It was the toughest thing I have done, physically and psychologically.

DAN CHAMBERS, USA

beyond Wales the plan is to encourage this development around the world. Canada and Germany are in our sights, but who knows where else walking courses might be organised.

We plan to develop organiser's notes and course materials. Hopefully, expertise will develop, potential leaders will emerge and groups in other countries will take up this highly therapeutic and enjoyable approach to helping people with McArdle's.

...great on all fronts - health wise, fun and meeting McArdle-ites. A memorable moment was climbing Cnicht and having a group of children race past, while being with McArdle's people made it seem normal to be going at a slow pace!

WILLIAM O'NEILL, IRELAND

I wouldn't have attempted anything like this except with other McArdle people. At the top of the hill I thought was I heading for heaven. I am thrilled with what I achieved this week.

LORRAINE BAGULEY, AUSTRALIA



Seven McArdle people (ages 15 to 63) summited Y Garn.

Afterword

I am absolutely delighted that Stacey has taken the time to write down her experiences with McArdle Disease and exercise, for it is both educational as well as inspirational.

Too many of our patients have been given a therapeutic, nihilistic view of their disorder and adopt a sedentary lifestyle that leads to isolation and a lowering of their threshold for symptoms and rhabdomyolysis.

Unfortunately, this becomes a self-fulfilling prophecy and even daily activities such as peeling potatoes or climbing stairs can trigger events.

Given that McArdle people experience muscle cramps and occasionally rhabdomyolysis with exercise, it would seem to be logical to avoid exercise; however, the body adapts to exercise by up-regulating alternative pathways (fat and amino acid oxidation and blood glucose use) that can bypass the metabolic defect in McArdle Disease (myophosphorylase deficiency).

Carefully conducted exercise has been shown in several studies to reduce symptoms of McArdle Disease by up-regulating alternative energy systems and Stacey's book highlights how slowly progressive and careful training can allow patients with McArdle Disease to attain fitness levels and performance that is truly impressive.

We have had McArdle people return to our clinic after six months of regular exercise and claim that their McArdle Disease is "cured". Most are shocked that the activity that previously triggered their disease is well tolerated after a period of careful exercise and dietary manipulation. Although regular exercise will reduce the likelihood of rhabdomyolysis, McArdle people should avoid exercise on days when their muscles are sore and fatigued and/or they have dark urine. Furthermore, rapid increases in intensity or duration must be avoided to reduce the risk of rhabdomyolysis.

Overall, Stacey's story is inspirational to both patients and physicians and shows how McArdle people can complete activities that even able-bodied people would find difficult.

Congratulations Stacey and friends, you are inspirational.

Dr. Mark Tarnopolsky MD, PhD, FRCP(C)

Professor of Pediatrics and Medicine,

Division Head of Neuromuscular and Neurometabolic Disorders,

McMaster University, Hamilton, Ontario, Canada

One Step at a Time

With each step your heart beats faster, your legs grow heavier and realisation sets in – you have to stop! For those of you with McArdle Disease, and for those that have walked alongside it, this ritual is all too familiar.

‘One Step at a Time’ traces the route, thoughts and emotions of a McArdle patient on a life-altering journey of discovery and growth. Her understanding irrevocably evolves when she walks over two hundred miles to meet it.

Today, walking with others has become a regular event. McArdle groups are getting together around the world to walk, share and learn from one another in a supportive and safe environment.

‘One Step at a Time’ provides a truly awakening narrative for patients, families and health professionals alike.

“Inspired by the daily blog of ‘Walk over Wales’, at age 64 I travelled across the world for the learning, support and friendships of a walking course. I achieved more than I ever thought I could. Now others can similarly gain from this inspirational and informative book.”

– **Lorraine Baguley, Australia**

“Invaluable! Stacey’s book will inform, inspire and encourage future McArdle generations.”

– **David Thompson, UK**

“My walking course in Wales provided an opportunity to increase my knowledge, challenge myself, and experience first-hand the bond people with McArdle Disease share. ‘One Step at a Time’ provides similar insights for patients, friends, and family.”

– **Rachel Walker, USA**



Walk over Wales



Walking courses


AGSD
www.agsd.org.uk

UK: £12.00

