AMANDA & RICHARDS KILIMANJARO CLIMB FOR CHARITY MARCH 2016

Our Story

For some time now we have been thinking about what we could do as a big personal challenge that could result in making a difference to others. We have decided, in our wisdom, to climb Mount Kilimanjaro in March 2016 – a 7 day trek to reach the 5895 metre summit of the highest free standing mountain in the world and the tallest mountain in Africa. As Amanda really doesn't like walking (or sharing smelly toilets!) and Richard is afraid of heights, not withstanding the difficulties of altitude sickness and 8-12 hour treks per day, it should indeed be quite a challenge!

We are doing this challenge in order to raise money and in particular awareness of a small independent UK charity very close to our hearts – Invest in ME Research. Why this charity? Well in 2002, Amanda's brother, Paul Kayes, was struck down with M.E. (Myalgic Encephalomyelitis) following a virus. He was very fit, active, had a good job, a loving wife and two children, yet this illness showed no mercy as it gripped his body and as a result, for the last 13 years he has become virtually housebound and most of the time is confined to his bed. His only hope is that a cure for ME is found.

Invest in ME is run on an entirely voluntary basis by sufferers and parents of children suffering from M.E. Every penny they receive goes towards finding the cause and cure for this horrible illness whilst also trying to educate health care organisations and the public.

Their most recent push is to raise funds for Biomedical Research into ME and have already laid foundations for a UK Centre of Excellence for ME Research. We want to help them take a step closer to reaching their goal, so that one day soon, a cure can be found to help Amanda's brother, and other sufferers, to get their lives back. We also want people to understand more about M.E. so its sufferers don't feel so misjudged.

So what exactly is ME

ME is a debilitating illness that affects 250,00 people in the UK (a prevalence higher than HIV or multiple sclerosis) and around 17 million worldwide. 25% of sufferers are severely affected to the point they are effectively house or bed-bound. 10% are children. There is no cure. Even the cause is unknown, as so little research has been funded to date, although it often follows a viral infection. ME is thought to be primarily a neurological disease with symptoms such as extreme physical and mental exhaustion, muscle weakness and paralysis, joint pain, head pain, blurred vision and severe dizziness or blackouts, vertigo, insomnia, respiratory problems, noise and light sensitivities, cognitive impairment, digestive problems and a host of other symptoms.

ME doesn't prey on the weak, it can hit anyone…..strong men, active women, healthy children….at any time. It can last anything from a few months to a lifetime. It can kill. Sufferers feel misunderstood, misjudged and isolated.

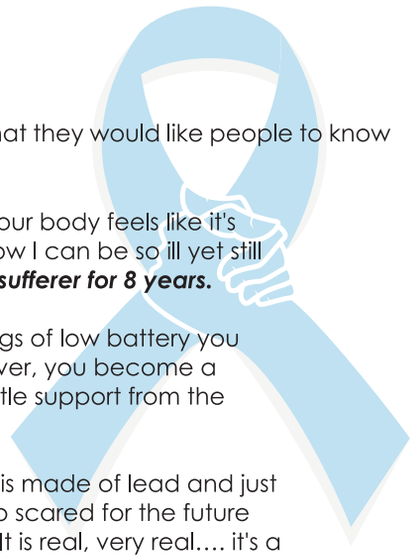
Dr Kilimas, who splits half his clinical time working with patients with HIV and the other half with patients suffering from ME has said " if I had to choose between the two illnesses, I'd rather have HIV". Enough said.

To the right is pictured a young girl called Merryn. She suffers from severe ME, having been struck down with it aged 15. She was an active teenager, loved school and was part of an acting and modelling agency. Now she is bed bound, in constant pain, needs 24 hour care, is unable to walk talk or swallow and has been diagnosed with intestinal failure. Doctors fear for her life, yet Merryn continues to fight and supports other ME sufferers as well as raising awareness through Invest in ME. This is only one story. These people need our help…and to know we care.

Overleaf we have written out some descriptions of what it's like to have ME, in the words of ME sufferers. Please take a moment to read them, then, if you can, help us to make a difference to these people. Please spread the word to raise awareness of ME, so that more people know the truth about this horrific illness and, if you can, donate some money to Invest in ME so that maybe one day soon, we can find a cure.

Thanks very much……Amanda & Rich x

Don't just take our word for it



We asked some ME sufferers to try to put into words what it's like to have ME and what they would like people to know about how they truly feel. This is what they said:

"It's like you have been injected with a deadly poison, where every part of your body feels like it's slowly shutting down. I feel trapped inside my own body, often wondering how I can be so ill yet still be alive, and yet the medical profession has no answers." ***Hayley Green 27, sufferer for 8 years.***

"It's like someone pulls the plug and you are left to function on whatever dregs of low battery you have left. In other words, running on empty. It feels like life as you know it is over, you become a spectator of life and not a participant. It is a very lonely illness to have with little support from the medical profession." ***Nicola Lavin 37, suffering for 14 years.***

"It's like having the worst flu every second of everyday, like your whole body is made of lead and just being able to get out of bed everyday is an accomplishment for me. I feel so scared for the future because the medical profession don't even acknowledge this illness as real. It is real, very real…. it's a living hell." ***Jade Thomson 32, sufferer for 3 years.***

"It's like walking a tightrope over hell, trying always to manage a condition about which no one really cares whilst every morsel of your skin burns and every nerve cell writhes and bounces against every other nerve cell and you just hope like crazy you can hold on. After so long I just feel utterly mentally exhausted. My mantra now is ' we need help, not hope'. I've been 'doing' hope for 45 years. That's why people who have their health and can raise funds for bio-medical research mean so much to every one of us with this condition because they bring that 'help' a step nearer. Their steps lead directly to our steps..." ***Rosie Cox 52, sufferer for 45 years.***

"It can be like being spun fast on a merry-go-round, then being asked to read a paragraph from a book while still nauseous, all done while wearing a lead jacket and divers boots and being hit with sticks by a karate class while suffering a massive hangover having being awake for 3 days, then being told how well you look and all you need to do is to just pull yourself together. I once had my arm in a sling and got treated far better than I do with my ME, and I did not feel I had to justify why my arm was in a sling. ME is a KILLER, not a joke." T***ony Bradstock 58, sufferer for 44 years.***

"I feel so badly let down by the NHS which is wedded to the idea that ME is a psychosocial illness, when 4,000 research papers show there is a physiological basis to ME." ***Anonymous.***

"ME is like a hundred illnesses in one; it viciously attacks every aspect of your physical body, painfully and unrelentingly, and leaves you merely existing through the motions of living, while being completely denied to ever feel remotely alive. I feel ME is something so complex and controlling upon the human physique, one cannot even hope to understand unless one has it. And that is something no one with ME would wish upon another person, for it is a hideous death sentence - it takes lives long before it kills." ***Emma Hodgson 32, sufferer for 21 years, triggered by MMR jab.***

"It's like wading through concrete with weights strapped to your arms and legs, all day, everyday. Even lying in bed can feel like your body is encased in concrete. I feel robbed of the life I hoped to have, the plans I'd made for my farm, for me. I feel like a crap friend most of the time as I can't help people like I used to. And I feel alone, mostly it's just so bloody lonely." ***Sally Crowe 37, sufferer for 3.5 years after contracting Q-Fever in Australia.***

"It's like having a constant headache, overwhelming mental and physical fatigue alongside a central nervous system that feels totally overwhelmed. I often tick off the hours just to make it through the day. I feel devastated that there are so many others suffering like me and little is being done to find a cure. Worst of all I am watching my three daughters grow up without being able to properly share their life experiences. My youngest daughter has never seen me well." ***Luke Remnant 42, sufferer for 7 years.***

We truly hope this leaflet has helped you to understand more about the terrible illness of M.E. and the devastating effect is has on peoples' lives. We also hope it helps you understand why we are passionate about raising money and awareness for Invest in ME. Thank you very much for taking the time to read this.

If you could spare some cash and would like to sponsor us, you can donate via our just giving page: www.justgiving.com/amandakayes - **EVERY PENNY WILL GO TO THE CHARITY** as we are 100% self-funding the Kili trip.

For more information about M.E. or the work of Invest in ME, please visit their website www.investinme.org