



January 2012

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Mount Kilimanjaro – Done and Dusted!



I am VERY pleased to announce that Mount Kilimanjaro is done and dusted! How amazing the experience was! It is very difficult to summarize this incredible journey, so instead I have decided to include the daily blog updates in the newsletter, along with some photographs. I do hope you enjoy reading all about our adventure!

I would like to take this opportunity to say a BIG thank you on behalf of the CMN team for supporting us in our challenge! As a team, we have raised over £70,000 for the Caring Matters Now Support Group. The funds will enable the support group to continue financially supporting the CMN research at Great Ormond Street Hospital, raising awareness of the condition within the medical field and providing the much needed support to those affected by CMN.

I would also like to take this opportunity on behalf of the CMN trustees, Dr Kinsler and the CMN members to thank the 18 CMN trekkers for their total support and dedication in raising over £70,000. Your determination, grit, strength and motivation is a real inspiration to us all. It was an absolute honour to be able to climb Mount Kilimanjaro with you all.

Finally, thank you to Mark Kalch and Dr Jim Blackburn for leading us up Mount Kilimanjaro. Your professionalism and friendship enabled us to reach our full potential!

Sow a thought, reap an action. Sow an action, reap a habit. Sow a habit, reap character. Sow a character, reap a destiny.

Jodi Unsworth

It's finally here....gulp by Kirsten Payne

I've just chatted to Jodi and Mia on the phone and I swear only dogs could hear us, those girls are EXCITED!

9 month's worth of training and the big day is finally here. And I can't wait. So while the rest of the group jump on the fun bus to travel from "Up North" to Heathrow, I have a few more hours to lie happily in my bed, have a few showers and re-wrestle stuff in to my bag.

A wise man once said "Life is not a journey to the grave with the intention of arriving safely in a pretty and well preserved body, but rather to skid in broadside, thoroughly used up, totally worn out, and loudly proclaiming, "Wow – what a ride!"



Day 1 by David Taylor

Climbing Kilimanjaro, treacherous, taxing, frightening and very dangerous at times. Yes, the 4x4 journey to Londrossi Gate was all of these, and more. Puncture aside and a poor load involved in a one-car accident, the journey seemed to pass fairly quickly. This was because our driver was trying to reach the gate before the aforementioned puncture resulted in a flat tyre and set about trying to break land speed records. They almost succeeded too until we needed to disembark for repairs. And we didn't have a car-jack. Salvation came our way minutes later when some of our fellow Trekkers stopped to help. A short pit-stop later and some failed attempts to photograph some monkeys, we found our way to Landrossi Gate and signed for our permits. We were delayed due to the land rover breaking down but reached the start of the Lemosho route. And immediately sat down for our first break of the day. And Lunch – result! Soon we were off however, following our Tanzanian guide, Batuel, up the lush slopes. The slopes became even more lushes after an hour or so when a downpour damped out boot but not our spirits- the camaraderie of the previous few days seemingly followed us up the mountain.

There were a few cheers and handclaps as we reached our first destination- Big Tree Camp. Potentially one of the most welcoming things I've ever seen, Big Tree Camp welcomed us like an Oasis in the desert. Provisions were basic but seemed like luxury given the exertions we had put in of the previous 4 hours. The porters were feverishly setting up camp on our arrival and they completed their task while we unpacked our sleeping bags and provisions for the night. One quick wash later and we are now in the mess tent awaiting dinner, which has arrived and takes priority I'm afraid.

Must dash... So Far? So well...



Day 2 - Mvua Inanyesha by David Taylor

And so it came to pass that the Heavens opened and it rained for 40 days and 40 nights. Well, not quite. But I fully expected to find Noah and his wife with their wooden menagerie at camp. The day started off in disastrous circumstances. It seems the labels on the "sun" Vaseline and the "bum" Vaseline had somehow worked their way loose. After some failed gingerly attempts at lip applications, someone in our party (name protected) now has a double supply of the bum variety. Sufficed to say Stu is not happy.

It is a curious fact of nature that water will find its natural case of least resistance. It is another curious fact that "waterproof" clothing does not necessarily need to be waterproof.

Cue much shivery and mild hypothermia. But things, as well as our little party, settled and we've progressed to destination number 2. Shura camp. The summit itself rises above us, inviting us to the challenge. Spirits remain high despite our day, and it was incredibly encouraging to hear laughs and shouts up our winding trail.

There is no doubt in my mind that I am part of an amazing group of people who seem so determined as I am to beat this mountain. In fact, without getting too sentimental here, I would be upset not to be close to these beautiful people in the future. In fact, even our doctor Jim and guide www.markkalch.com slot quite easily into our team. Good friends and good times indeed.

Day 3 - What would Brian do... by David Taylor

Things we have learned so far:
1. "waterproof" is a lie. 2. Vaseline should make their own labels. 3. If asking a porter for a thermarest, ensure it is seen before tipping the guy \$20. Maybe he's just showing you to your tent. 4. Most importantly "waterproof" is a lie.

Today's walk was in contrast to yesterday's rain-soaked day. We were

given the opportunity to appreciate our surroundings as our train snaked through the landscape. Most of our group climbed to Shira Cathedral to admire the spectacular views.

We have been blessed with the best view so far. Kibo rises seemingly meters from our humble campsite behind us. Our group was beginning to suffer earlier today with some sore heads and nausea, but we seem to be coping after a quick nap and quicker washy-washy. Our doc, Jim, continues his open door policy and holds clinics for the sick, elderly and infirm. Group leader www.markkalch.com continues to provide encouragement and tales of croc wrestling and wallaby bashing. We are awaiting his next exciting instalment at Yabby Creek with baited breath. The temperature has fallen tonight and it's getting more and more difficult to recognise people, as they are in several layers of clothing and fancy head wear. And we have low level led lights struggling to cope in the darkness. But we do have pancakes! In fact, the quality of our food had surprised us all and we have been treated to fine delights since we arrived on our hill. Team spirit remains high and we continue to look out for and encourage our buddies, which is nice. I just hope Brian would approve. After all we are "the best group".

Later,

Day 4 - A Doctors Dilemma by Dr Jim Blackburn

A departure tonight, from David's light-hearted take on events to give you a flavour of the trip from the expedition doctor's point of view. I'm Jim, the doctor who, as it turns out, has the privilege of accompanying this happy and go lucky mixed bag of scousers, scots and a few other assorted northern types on this epic adventure. Along with www.markkalch.com, aka Bear (as in Bear Grylls), aka captin RAB, aka Rab C Nesbitt, it's my job to keep the team happy, healthy and fit for the days ahead.

My work started before the trip, contacting

the group giving basic health advice and assessing those who have pre-existing conditions. During the days here, I'm watching every member closely throughout meals, walks and evenings to keep abreast of any emerging problems or worries. I also have "evening clinic" after dinner – so far, fortunately only lightly attended and I keep an open door (open zip) policy so the team can approach me at any time if they or a buddy look to be having problems. After a generally pretty successful couple of days, today it's fair to say has been a hard day. It started early for me, around 5.40am to pack my tent, review notes from yesterday and watch sunrise reflect off Kibo. By 6.30am I was revising my first patient, who after several days of nausea and increasingly breathless over night, we decided could not continue to ascend. This is a tough decision to make and inevitably hard for the team to hear but necessary for the safety of the individual involved. The dilemma at altitude is always to balance a person desire to summit, with their physical, psychological and emotional well-being. I heard this evening; the person involved is recovering well at the hotel. The remainder of the day we steadily gained altitude from 3850 meters on the high altitude tundra of Shira Plain to 4500 meters at Lava Towers, passing through the barren, rocky zone before finally descending to Barranco at 3900 meters. This "walk high – sleep low" strategy is deliberate, giving the body exposure to air that is around a third less in oxygen than at sea level, before descending to safe altitude where we can acclimatise to the extreme conditions we're exposing our bodies to. Everyone has now has altitude sickness symptoms and all are on Diamox – mostly confined to frontal headaches, but also many are feeling the effects of fatigue and muscular aches and pains after a truly tough day walking. Other conditions have popped up along the way- nose bleeds (again





very common this high up), travellers diarrhoea and even a potentially very serious eye infection gave kept me busy during the day, so that while the group rests or has lunch I'm normally found running many consultations and making running repairs to keep everyone moving gradually towards our goal. Other issues – briefly: cold (is getting down to -6 tonight), dehydration (I pity the team as I spend all day reminding people to drink more), nutrition (poor appetite is rife at altitude) and fatigue provision all figure highly in my evening medical briefs. As I grow closer to this extraordinary group of characters who I increasing class as friends rather than clients, I'm troubled; the doctors dilemma up here is that as the summit attempt gets closer and we gain height, the extreme environment means I may yet have to send other people down, ending their dream trip and leaving them disappointed, frustrated or worse still, hospitalised. I sincerely hope not to do this, and so far the group as a whole have done themselves proud, proving they ate fit, determined, resilient and keen to beat this mountain together. Tomorrow, we visit the fearsome and exposed Berranco Wall with its notorious 300 meter cliff next to the path... For this team, it may as well be a walk in the park.

Day 5 by Richard Fenwick

Today has been a day of mixed emotions (more of that later). We awoke to see the 200m Barranco Wall rising up behind our camp. A few of us had seen it last night, so weren't too surprised – those of the group who hadn't seen it were a little 'worried'.

The usual morning routine was interrupted by a few extra trips to the toilet tent and the distressing news that one of our group would be leaving due to an eye infection – not beaten by the mountain tho!

Goodbyes were said, then we began the ascent of the Wall. I think it's fair to say we all found it tough going, but eventually we reached the top. A few hours later we all arrived at the next camp, almost losing smothering of the group due to a near catastrophic pole

failure!

A new camp (Karanga – Peanut) beckons and another acclimatisation walk under our belts...as I write, dinner is arriving so I'll keep the rest of this brief.

MIXED

EMOTIONS...

BAD- losing one more team member.
GOOD- being close enough to the summit to almost touch it. Plus, France beat England in rugby.

I was asked this morning, where would I rather be for my 17th wedding anniversary- with the absence of my wife and children, I cannot think of a finer group of people to be with. Although, www.markkalch.com needs to lighten up on the name calling!
Richard Fenwick

Day 6 by Tom Roberts and Josh Smith

Good-day (ref Bear)
Sooooo... The day started at Karanga camp 400m!

We were rudely awoken well before morning 6.30am by some of our fellow tent buddies moaning about lack of sleep and temperature of the night while we were snug as a bug in a rug (ref Si) in our sleeping bags. Next was breakie, which was sound and outside, so that we could appreciate our surroundings which were pretty spectacular!

8.30am or in Bear's terms 8.30am-9.00am we started to ascend. The first section was made earlier due to the acclimatisation walk yesterday. As we continued, one of us gained weight in the rucksack department (ref David Taylor).

Once to the top of the 1st section, the mountain was in touching distance but first we had to make it to 4600m Barafu Hut camp which was still a good few hours away!

The terrain was deceiving as it looked flat from a distance however dipped and dived, and was quite challenging in sections.

Eventually we made it to Barafu Hut camp, where the camping setup was great as there was no animals within

throwing distance- as the last few nights we thought we were still in the rain forest due to the snoring! (ref Nick, Andy, Olivia and Jenny W). After settling down, then having lunch, we were briefed about the night ahead by www.markgoodday.com and www.jimtherugdealer.com as you know his zip is always open. In closing, its time to rest and re-coupe for the tough test ahead. We would also like not to forget the other 3 people who started this journey with us. so let's do it for them (Jen D, Mark and Steve). But more importantly for ourselves and for Jodi's charity and families involved. So let's get ready to "smash its head in!"

Day 7 - Summit Night by Rick Parry

Inevitably the big night saw me sound asleep at 11pm for the first time on the trek.

Thus started an extraordinary 24 hours of which everyone will have their very personal highs and lows, emotionally and physically. I'm sure everyone had a moment when they thought they weren't going to make it. But the story of this remarkable night wasn't about individuals, it was about the team.

Part of my life has involved building high performing teams and I'm fortunate to have seen some great successes. Tom will immediately think of Istanbul in 2005. And when you build a truly great team, ordinary people do extraordinary things. Mark Bunett, creator of the Apprentice and Survivor, started with a series called Eco Challenge, an absurdly difficult Triathlon that took place in burning deserts and deep ravines. Almost by accident Mark included a rule which said that all 4 team members had to cross the line together. And, this surprise, the focus of the programme learned the psychology of the team dynamics rather than the physical challenge.

Mark concluded that when there was

negativity and tension, teams consumed energy at 5 times the rate as those where there was unity and mutual support. The significant of this is that summit night wasn't about 15 individuals getting to the top. It was about a team of 19 conquering Kili. Everyone played their part and everyone must take an equal share of the credit. Although it was a considerable surprise to our guide Mark, I'm sure it was no surprise to any of us that all 15 reached the summit together. It really couldn't have been any other way. A word about Mark and Jim. Good leaders lead by example and create an environment in which team members can give their best. Mark – you're a good leader mate. Even if you're usual cheery "well you're probably not going to die" was tested a little on summit night.

Jim – undoubtedly put the team first and in so doing sacrificed his own chances of getting to the top – something he was desperate to do. He also played a major role in supporting my Guinness Book of Records application for being the first man to summit Kili with a tampon stuck up his nose. Even Mark hasn't tried this. I think.

When you're faced a challenge like this it's always useful to promise some advice for those who may follow you. All marketers know that the basic principles of marketing are known as the 4 P's. Well I have devised the 3 P's of mountaineering: Pole, Pole and Porters.

The latter, if shouted loudly and confidently enough, is guaranteed to bring the cavalcade to an instant halt. This is especially useful at times of acute breathlessness.

To conclude I'm going to modify a quote from John Wooden, arguably the greatest basketball coach ever.

"To summit Kili it is not sufficient to be WILLING to do it. You have to be EAGER to do it".



Family Activity Weekend

Fri 21st Sept – Sun 23rd Sept 2012



Due to popular demand we are making plans for another activity weekend to be held in 2012.

Dates are Friday 21st to Sunday 23rd September 2012 at Boreatton Park situated in 240 acres of Shropshire countryside.

Back in July we held our first ever activity weekend and it really was a superb weekend. Take a look at the photos and video footage on the website <http://caringmattersnow.co.uk/news-family-activity-weekend.html>

By attending an activity weekend like this it could potentially make a huge difference to a person's self esteem and confidence in dealing with a condition such as CMN.

The activities would allow children and parents to bond and enjoy quality time together and by attending the activity weekend we hope long term friendships will be developed and flourish.

Being given the opportunity to talk to someone who may have or is encountering the same experiences, whether positive or negative of living life with CMN can benefit those affected immensely and would prevent the feeling of isolation.

We have yet again secured a great deal of **£119 per person**. This price includes: Food, Accommodation, Activities, Evening entertainment.

Caring Matters Now is so convinced at the positive outcome of attending this weekend that we will subsidise each person with CMN. **That's one FREE place per family!** (subject to availability, so be quick).

To confirm your place please complete the enclosed booking form and return it by 24th February with a non refundable cheque deposit (made payable to Caring Matters Now) of £24 per person to Lucy Hardwidge, CMN, PO Box 732, Cambridge, CB1 0QF.

CMN research at Great Ormond Street Hospital (GOSH)/Institute of Child Health (ICH)

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Check out the PGL website:

<http://www.pgl.co.uk>

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Funding Update

FUNDRAISING PACK



Want to help us to continue the research programme & provide vital support to families? Then why not request a fundraising pack and join in the fun of raising money for a very worthwhile cause.

Please email Lucy at

lucyh@caringmattersnow.co.uk

to receive a pack.

Or download from the website

www.caringmattersnow.co.uk

Thank you to all our members, their family and to their friends who have made this past year at Caring Matters Now another great success. Fundraising efforts well exceeded our target of £40,000 -- £60,000 was raised this past year! The list of fundraising events our members organized this year was truly impressive.

The funds have been used this year to continue supporting Dr. Kinsler's research at GOSH and without your fundraising efforts, this could not have been achieved. We were pleased to be able to specifically provide £16,000 for Dr. Kinsler's Genetics study project. This work forms an important part of the research into the determination of the root cause of CMN.

In addition to the research aims, the focus of Caring Matters Now as a charity remains providing support to members who are affected by CMN. It was a milestone year for us as for the first time; we 'grew' big enough as a charity to justify the hiring of a Development Officer. With Lucy Hardwidge on board this past year, we had someone dedicated to answering phones, emails, coordinating volunteers, organizing the family day events, writing press releases and newsletters, developing merchandise and a host of other activities. It goes without saying that we have welcomed her professionalism and organizational skills as the list of events grow.

We held a training day for all our support volunteers, three well attended family day events in Glasgow, London and Liverpool and for the first time, also organized a memorable activity weekend in Boreatton Park, Shropshire. Earlier in the year, we also sent Jodi Unsworth to the Nevus Outreach conference in Dallas, Texas where she made many new international contacts in the Nevus community and helped raise the profile of Caring Matters Now.

We at Caring Matters Now are very excited about all the new projects we have been able to undertake as the charity grows in size and scope. We could not do it without your support. So a big thank you to you all and hope we can count on you again to carry the momentum through 2012. Happy New Year and happy fundraising!