

getting people moving

ISSUE 7 AUTUMN 2017



Box 500, 44-46 Morningside Road Edinburgh EH10 4BF Registered Charity Number: SC038205 olivia@500miles.co.uk

www.500miles.co.uk

Abbreviations

A few of the terms we use to keep things simple (and save space!)

P&O: prosthetics and orthotics

MoH Malawi: Ministry of Health of Malawi

MoH Zambia: Ministry of Health of Zambia

TATCOT: Tanzania Teaching
College of Orthopaedic Technology

CSPO: Cambodia School of Prosthetics and Orthotics

KCH: Kamuzu Central Hospital

MCH: Mzuzu Central Hospital

UTH P&O: University Teaching Hospital, Lusaka, Zambia

Dear friends of 500 miles

It seems that the wheels turn very slowly from week to week, but looking back over 8 months, as ever, quite a lot has happened.

I visited Malawi in July and spent time with our new managers in Lilongwe and Mzuzu. You'll meet Caroline and Samantha and Charlie in this issue. Both centres remain very busy. Our sensitisation and outreach activity in the north of Malawi has led to a marked increase in production whilst, despite being short staffed in Lilongwe, production levels are being maintained.

My next trip to Malawi will be in January 2018 to recruit our first Malawian manager for our centre in Lilongwe. I hope that engagement with MoH Zambia will turn a corner soon, meaning that a trip to Lusaka will be necessary in 2018 to progress our activity in Zambia.

In our training programme, we are delighted to announce a graduation this month and three new starts.

With Sue Davie, our new trustee and accountant at the helm, our accounts and trustees' report for the year 2016 were approved by OSCR in September. You can read them **on our website.**

As we are still cash-rich from the BIG dinner, fundraising has been on a back burner, but please read about the amazing and heart warming efforts of some of our supporters.

If you missed it, please watch our short video summarising our work in Malawi - available to **watch here on youtube.**



A still from our recent entry for the Scotland-Malawi Partnership's video competition (click image to watch).

It was made for us by Agata Jagodzinska and Michael Grant, the extremely talented duo behind **Raw Film**, as an entry in the Scotland Malawi Partnership's video competition. Thanks to everyone who watched and circulated the video helping us to win one of the four prizes which was collected by trustee, Robin Garrett at the Scotland Malawi Partnership's AGM in October.

Thank you for your ongoing interest in 500 miles and for your wonderful support in every form. Merry Christmas when it comes - and all good wishes for 2018! The next newsletter will come out in May.

Olivia Giles



Could you bike 500 miles?

If you're interested in supporting 500 miles, we're organising a once-in-a-lifetime cycle down the shore of Lake Malawi, in September 2018. With a 250-mile route through 'the warm heart of Africa', it's a chance for you and a partner or friend to cycle 500 miles for 500 miles together - not only visiting our centres in Mzuzu and Lilongwe, but also taking in some of the world's most stunning scenery. If you're up for the challenge, **please do get in touch**.

fundraising



Sue goes 007 for 500 miles

Inspired by the amazing Sue Edwards (pictured above, left), the Inner Wheel Club of Reading Maiden and Erlegh held a swanky James Bond themed casino night. Everybody was enthralled by the glamorous atmosphere created by the decor, Casino Royale cocktails and a real croupier to run the Black Jack.

We were shaken and stirred by the wonderful total of £1,400 – and also by Sue and her husband, Robin, raising another £250 from sponsorship of their own 500 miles walk.

Lilongwe Triathalon

We were lucky to yet again be a beneficiary of the Lilongwe Triathlon – a competition organised by a small team of expats in Malawi. Our two 500 miles teams were not exactly in the



Our team: Mark, Clinstone, Samantha, Alwin

running (or cycling or swimming) for prizes but Charlie from our Mzuzu centre and Mark from our Lilongwe centre presented the prizes and everyone had a wonderful day. We were delighted to accept a donation of £1,753. Many thanks to Abbie Morris and her team!



Tea time with Inner Wheel

District 2 of the Inner Wheel raised a superb £1,168 for 500 miles at its international rally and sumptuous afternoon tea in Moffat in October – which I enjoyed immensely (see left). Meanwhile, the Dumbarton Rotary Club hosted a novel valuation day, which raised a magnificent £1,000.

Marathon efforts

We had three seperate runners in this year's London Marathon: Alastair Morrison with his own deferred place, Barney Johnson (pictured near right) with a regular charity ballot place and Douglas Alexander with a celebrity place. They all completed the course in brilliant times – Alastair achieving a personal best in his 9th marathon – and among them they raised an incredible £12,012.18 including Gift Aid.





Not only that but Janette Elrick (pictured above, far right) raised £2,521.66 including Gift Aid by running the Prague Marathon.

9 years' support in memory of Chris

9 years ago Georgina Yeo opened a Just Giving page in memory of her husband, Chris Hume who had tragically died from cancer at a young age. She chose 500 miles because, in 2007, Chris lost a leg due to the disease but enjoyed some very happy, active months (see photo, right) thanks to a prosthetic leg and excellent NHS support. Chris and Georgina had noticed that 500 miles tries to give the same support to people in Malawi and Zambia. Since 2008, Georgina and her family, especially her mum, Brenda Graham, have organised a variety of fundraising events – like a 20-

mile sponsored walk supported by many of Chris and Georgina's friends and a spectacular BIG dinner at Brenda's house – and have marked family occasions, happy and sad, by donations to this page, including donations to celebrate the birth of Georgina's twin girls with her husband, Edd.

Last month Brenda held a lunch/coffee morning in her house asking for donations and selling her sauces and pickles (as pictured) and raised £200 plus Gift Aid which took the total this family has raised to





£10,115.15, not to mention the Gift Aid of £2,421.51. Brenda wrote to me "I need to set myself a new target"! I hope Chris would have been pleased that many, many people have been helped to walk in his memory.



10k walk gives £1k for 500 miles

In early June, Rhona Smyth, Christine Povey, Trevor Jones, Morna Sloan and Patricia Scotland all took part in the Nordic Walking Grasmere Gallop for 500 miles, hiking 10km over rough ground, using their mobility and training to assist others who struggle with theirs. They raised £1,000 with a lot of Gift Aid on top.



Malawi

We are very proud that two members of staff, Elvas Benadeta Singini and Mark Ndagonera, took two of the top prizes at the Malawi Orthopaedic Association conference in September, putting

P&O on the map in Malawi.

Malawi: Lilongwe

Caroline Cater is a physiotherapist who has brought her experience of working in the English NHS to 500 miles at KCH in Lilongwe where she has been managing our centre solo since March 2017. We're delighted that Caroline will stay with us until the end of May 2018 and assist us with the handover of her job to our first Malawian administrative manager who will be recruited between



Caroline at our centre at KCH.

now and January and will start work in March. This is a major and positive step for the full integration of this busy centre into the Malawian national health service whilst we plan for a suitable Malawian prosthetist/orthotist manager to take over the reins in a few years.

Short staffing has put the Lilongwe centre under pressure in recent months but Caroline has nevertheless led our second sensitisation and outreach to Kasungu District, a part

of central region which is underserved by health and disability services. In August and September this year we visited four separate new locations in Bua and Mziza as well as revisiting the four places in Chamwavi to which we took our first outreach in the district in August 2016. All of these places were chosen because they are close to the main road, but even so, the majority of people living in this area will never before have had a chance to get a prosthetic or orthotic device. The District Health Officer can't assist patients with transport – 2-3 hours on the road to Lilongwe – so we are relying on people to make their own way to us and then we can assist with transport home.

After many false starts over the last four years, we've finally recruited a full time rehabilitation technician in Rabecca Mangani.



The crowds gather, waiting for outreach in Kasungu District.

We kept holding off because we believed that the MoH Malawi would appoint one to us but early this year we decided we couldn't wait any longer.

Rabecca qualified with a 3-year diploma from Kachere Rehabilitation Centre in Blantyre, Malawi and has been trained for us



The Lilongwe team: Mark, Tahona, Ivy, Maliwase, Damaris, Dominic, Alwin, Kambuye, Happy, Peter and Rabecca.

in working with amputees and people with other mobility difficulties by Evelyne Huizinga, who some of you may remember as a previous manager of our Lilongwe centre. We're really delighted that we are now able to support our patients with some physiotherapy and guidance on how to use their devices safely. The majority of Rabecca's specialist training was paid for through and by Pat and

Ron Sutherland of Hawick Rotary Club. Pat, a former physiotherapist herself, was the instigator of this initiative – many thanks Pat!





Above: Rabecca Mangani with a patient. Left: The team meeting HRH The Countess of Wessex at KCH

We didn't quite manage to get HRH The Countess of Wessex into the 500 miles centre, but she kindly took the time to meet and greet Caroline and Maliwase Munthali and Mark Ndagonera when she visited KCH in March.

We have reclaimed, refurbished and furnished the back third of the original 500 miles building at KCH for use as a staff room for breaks and lunch and an office for quiet work away from the workshop. We had always retained a storeroom in this building. The other two thirds remain occupied by KCH as offices.



The team enjoying some downtime in the new staff room.

project updates

Malawi: Mzuzu

Charlie Freeman and Samantha Burgio are a husband and wife from New South Wales, Australia who are sharing the job of managing our centre at MCH in Mzuzu. They arrived in February and very quickly got to grips with the job. Charlie is an exercise physiologist (similar to a physiotherapist) and although, like Caroline, he does not have a lot of time to deliver clinical care, his expertise is a real bonus for the guidance and safety of our patients in Mzuzu where we do not yet have a rehabilitation technician.



Charlie & Samantha on holiday at Victoria Falls.

Charlie also manages our sensitisation and outreach work in remote parts of Mzimba District. This needs high energy and stamina to generate a constant and healthy throughput of cases – and this is what has led to an increase in the number of devices delivered to patients at our centre in Mzuzu, from approximately 50 to 60 per month.





Above: Professional development in action at Mzuzu. Left: Maliwase teaching.



The Mzuzu team: Benadeta, Tiwonge, Maxwell, Eviness and Clinstone.

Samantha's background is in management and administration, latterly of refugee services. She is steadily creating, improving and documenting all of our systems and was the perfect person to take the lead in organising our annual all-staff continuing professional development days which were held in Mzuzu this year.

I have asked Sam and Charlie to share their thoughts about working in Mzuzu in our next edition.





Maxwell, on the course run by Cerebal Palsy Africa.

We are grateful to Cerebral Palsy Africa, a Scottish charity run by Archie Hincliffe, for giving Maxwell Goliath, a place on a two-week course for phsyiotherapists on the specialist treatment of children with Cerebral Palsy. Although Maxwell will not be practising physiotherapy, the course has given him a good insight into alternative treatments, made him more aware of the special needs of this patient group and given him connections with whom to discuss relevant cases.

Zambia

With deep sadness, I report the untimely death through illness of Isaac Zyambo in May. He was the first Zambian whose training was sponsored by 500 miles. Isaac was an exceptionally talented professional who went the extra mile for his patients from the goodness of his heart – because he loved to help people.





Zambia: UTH P&O

Since last November we have been supporting UTH P&O as if a draft memorandum of understanding ("MoU") between MoH Zambia and 500 miles had been signed. The idea was to show our commitment and to demonstrate how our model could help MoH Zambia build the capacity of UTH P&O and so reach more people with disabilities all over Zambia.

Our basic model is that 500 miles will pay for low cost P&O devices for people who cannot afford to buy them, on the basis that (1) the income from these devices is ring fenced for UTH P&O and (2) MoH Zambia buys the low cost stock required to meet the demand for such low cost devices (for which 500 miles in turn will pay) – and MoH Zambia may use the income to buy the stock. From January to July 2017 we have paid or committed to pay for devices for 73 patients who were approved for treatment at UTH P&O, using a simple form system.

However we have had no substantive response to the MoU from MoH Zambia and

it has not bought any low cost stock for well over two years. To try to keep things going, 500 miles has bought two emergency orders of stock, one in March 2016 and one in June 2017 but we're now at the stage where in order to carry on working in Zambia, we need some in-country commitment and engagement. Otherwise our support is simply relieving MoH Zambia of its obligations which would ultimately actually deplete UTH P&O's capacity and self-sufficiency – when what we want to do is build it.



Above, right, bottom right and below: Various patients at Chitokoloki Mission Hospital.



Zambia: Outreach

The draft MoU includes provision for an outreach programme to four initial locations, using UTH P&O to deliver the service. In 2017 500 miles has arranged and sponsored four outreaches by UTH P&O to Mongu Cheshire Home (2 outreaches), St Francis Hospital in Katete and Chitokoloki Mission Hospital. Over 75 patients were treated. For Katete and Chitokoloki, each outreach involves two trips, one to cast and one to fit, as there is no remote workshop - and we even have to fly technicians to Chitokololi.

We would like to have continued with our programme but, with no indication of MoH Zambia engaging with us, there has been no outreach activity since July. We hope to able to recommence this essential work and expand it as people living remotely in Zambia have no other realistic way of accessing a P&O service.



Left and right:
Two patients at Mongu Cheshire Home showing off their prosthetics.



Zambia: Eastern Province

Timothy Miti continues to work well for 500 miles at St Francis Hospital in Katete in Eastern Province. He is carrying out repairs to prosthetic and orthotic devices and fabricating simple orthoses as well as keeping a register of all patients who need P&O services and in particular, those who need devices that can only supplied through outreach from the UTH P&O Department. Timothy has kindly provided the patient stories of Blessing and Jimmy on page 8.



Above and left: Two young outreach patients at St Francis Hospital.

project updates

Training

Mwayi Lewis Munthali graduated from the Cambodia School of Prosthetics & Orthotics (CSPO) with a 3-year diploma in orthopaedic technology on the 13th of this month. He is the first Malawian to take this course and will return with a slightly different approach and skill set which will enhance and compliment that of his colleagues in Lilongwe who have all trained at TATCOT in Tanzania. Mwayi will start work almost as soon as his plane lands as we are desperate for the manpower to meet demand.



Mwayi and his classmates in CSPO celebrate their graduation.



This is partly because Maliwase Munthali has just gone part time in the workshop as she is now studying part time to upgrade her 3-year diploma from TATCOT to a degree through a 3-year blended, distance learning programme run by a German university called Human Study, in conjunction with TATCOT. This is a similar course to the one which is being undertaken by Elvas Benadeta Singini who is based in our Mzuzu centre. Bena is already more than half way through the course and we are very proud of her consistent high scores.





Right: Maliwase outside our centre. Above: Treating a young patient.

Also from Malawi, and following in Mwayi's footsteps, Samuel Mkomera, began his 3-year Diploma at CSPO in March. He has worked with us in Lilongwe as a bench worker since December 2014 and has showed great promise. You'll hear more about Samuel next time.

Our third new start this year is Kein Chabene from Zambia. Kein was originally recruited for us by Sister Cathy who runs the Cheshire Home in Mongu in the far west of Zambia. On her recommendation, 500 miles sponsored Kein to take a 1-year



Kein hard at work in the workshop at CSPO.

course in prosthetics at TATCOT in Tanzania. Kein qualified in August 2012 and returned to Lusaka to work for 500 miles at the Zambian Italian Orthopaedic Hospital for a while. There he received good training on the job from Isaac Zyambo mentioned above.

Kein then became 500 miles' "man on the ground" in Lusaka, working from a container at Beit CURE Hospital, which kindly provided us with a base for him. Kein carried out repairs and fabricated simple orthoses on his own account and in 2015 he began referring more complex cases to UTH with 500 miles sponsorship. As our relationship with UTH developed, Kein became part of the team working at UTH and we were delighted when the Minister for Health in Zambia agreed that he should be taken onto the government payroll as a full time member of staff at UTH.





Kein in Bangalore - enjoying his social life and his studies.

However for his own career progression, Kein needed to upgrade his certificate to a diploma. Mobility India run an upgrade programme which usually takes three years but Kein's work experience plus the results of examinations he took convinced Mobility India to let him upgrade in two years. Kein left for Bangalore in July.

Kein said, "School is going on very well. The teaching system is very good and I am gaining knowledge. I can see that I will be able to deliver something new in my country upon finishing this course. Being far away from my pregnant wife and son is difficult but my wife is encouraging me just to focus on my studies. India is not exactly what I expected. I have had to adjust to the lifestyle and culture – too much curry!"

At home in Lusaka, Kein's wife has just given birth to Faith, a sister to Kein's son, Mark. Going abroad to study is a major commitment involving a lot of sacrifice for the students.

patient stories

Here are the stories of just a few of our patients in the last eight months. The patients on this page were treated at the 500 miles centre at MCH. The first three patients on page 8 were seen at the 500 miles centre at KCH and the last two were outreach patients at St Francis Hospital in Katete in Zambia.

Tiwakomole Zima

Tiwakomole, 70, was Bena's patient at MCH in September. A widow with 5 children and 15 grandchildren, she lives in the village of Njebwa in Mzimba district. In 1991, she was diagnosed with cancer in her left leg so a trans-femoral amputation was



carried out. Nobody in her village knew that a prosthesis was even a possibility, assuming that people do not walk after amputation. She was given crutches, but they had worn out within a year and so she got used to crawling and, when required, was lifted by her relatives.

Tiwakomole was referred to a 500 miles outreach to Edingeni in July, where she was given an appointment at MCH. She came with

her two daughters to stay in our hostel and simply crawled/shuffled to get about. Bena fabricated an above-knee prosthesis for her and, as Tiwakomole had lost the front part of her right foot in a fire as a child (which alone affects a person's balance), a toe filler too.

She went home five days later, able to walk. She will probably always need crutches, but the combination of her prosthesis, toe filler and

crutches should allow her to be independently mobile. Tiwakomole was very happy as she never expected to have another leg. She told us that her life will be easier and that she will be to attend church services - and funerals! Her two daughters were happy too because their days of lifting their mum are over.



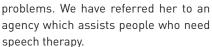


Hendrina Kamanga

Hendrina is 9 years old and the only child in her family. She is in standard 1 at Mzenga Primary School in Nkhata Bay District. She has Cerebral Palsy due to premature birth. When she came to our centre at MCH, she was walking with a crouched gait and putting her toes down first. We made DAFOs (dynamic ankle

foot orthoses - pictured) for her which she used for about 3 months. When she came back for review in August, her gait was much improved. She no longer has a toe strike but she steps with the sole of the foot, close to normal, though still with her knees in valgus.

She goes to school daily because she has enough balance with the DAFOs. She is not doing very well at school due to hearing/speech



Hendrina's parents are very happy with her progress as they didn't think anything could be done about her gait.

> When she comes back for review next time we expect to see her walking quite normally and for the valgus in her knees to reduce.



Vitumbiko Mvula

This story was written by one of our technicians, Maxwell, who comes himself from a family affected by disability. As a result, he is passionate about making people aware of the social and economic consequences of a disability beyond the health issues, not just for the child, but for the whole family.



Vitumbuko comes from Chanthomba village in Mbelwa in northern Malawi. He was the third born in the family of four children. He is in standard 3 at school. He was born with multiple deformities from an unknown cause. His father left his mother a few months after he was born as he found it shameful to have a child with disabilities in his family. As the bread winner, his mother sells firewood for a living, a business from which she is struggling to pay school fees for Vitumbiko's elder sister who is in form two. It seems that the young

girl is being forced to drop out of school which is a shame as she is bright and would like very much to continue. His father is now married to two other wives and although he works at a maize mill, he fails to support Vitumbiko and his brother and sisters financially.

Clinically, Vitumbiko presented with a right side trans radial stump, a left side trans humeral stump, leg length discrepancy and feet with a big toe only. He is an active and bright child. He is able to eat and write using the mouth and his right stump.

We decided to make bilateral extension prostheses to allow him to stand upright, eliminate the leg length discrepancy and improve his gait and confidence.

The result was satisfactory. We compensated for the leg-length discrepancy and he achieved a much better gait using less energy. He was very happy with his new prostheses and was looking forward to going back to school.



patient stories





Moricious Patrick

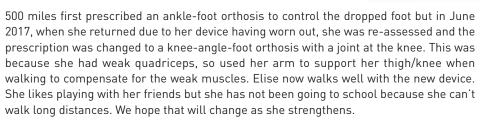
14 year old Moricious was born without a tibia and femur in his right leg. He seemed to grow normally until he should have started to walk but instead he just crawled. Then, since children are adaptable he started walking using his left leg and a crutch. It was not until he was four that Moricious was referred to Queen Elizabeth Central Hospital, where doctors performed a through-knee amputation.

In 2014, he was spotted on an outreach to Mangochi District and was immediately referred to 500 miles for a prosthesis. By this year, that device was completely worn out and because he had grown so much, it was also too short. Moricious says his new prosthesis is more comfortable. Moricious is an ordinary boy who likes playing with his friends, both at school and home, and who likes watching movies – and his device allows him to do that with dignity.

Elise Kawaza

Elise was born in Dowa in 2009 and contracted Malaria as an infant. Although she was treated at

Dowa Hospital, her mother realised that she had acquired a drop foot after she was discharged. In 2010 she was referred to 500 miles by the Malawi Council for the Handicapped (MACOHA).



Binalison Chikuni

Binalison was diagnosed with cancer in his right leg when he was in standard 4 of primary school. He immediately left school, seeking treatment. His leg was amputated below the knee in order to save his life. Life has been difficult to him and his family.

He is 14 now and in February this year he got his first assistive device at 500 miles at KCH after being referred from MACOHA's outreach to Dowa which 500 miles supports with a P&O service. We

trained Binalison to use the artificial leg, but it was difficult – taking practice and perseverance to build up tolerance. After 4 months, he was reviewed at the outreach clinic and was referred back for a new device.

In June we fabricated a better fitting device, which improved his walking. When he got his second leg, he promised that he will go back home and help his family farming. "This year I will cultivate tobacco, maize and soya beans so that I can sell them," he said. Unfortunately he cannot go back to school – but he prefers farming to schooling.



Blessing Thole & Jimmy Mwanza

Blessing and Jimmy were both born in the eastern part of Zambia with congenital deficiency of the tibia, and were referred by the P&O outreach by UTH P&O to St Francis Hospital in Katete (SFH).





Blessing was born in 2014 with a congenital break of the right tibia bone. When he was a year old, he was taken to Chipata Central Hospital where they referred him to Chipata Cheshire Home (CCH), which has links with orthopaedic surgeons who visit SFH. In 2016,

he was seen by Dr. Moyo who suggested a right below knee amputation which was successfully carried out. 7 months later, Blessing's review at SFH showed that his stump was ready for a prosthetic fitting. Several of CCH's wards have received P&O devices over the years through the UTH P&O outreach service, so CCH knew to how to get an artificial limb for Blessing. His parents were very grateful, while Blessing is happy to stand on his two feet!

Jimmy is now 11. He was born with Tibial Hemimelia in both legs which led to below knee amputations when he was 7. Before then

he got about in a wheelchair or by crawling. He received his first legs in 2013 and he received his latest legs in March 2017.

Obviously both boys, and many children like them, are going to need new prostheses as they grow.



How to support us

To support us please see the How to support us page on our website. For online giving, we encourage you to use Virgin Money Giving over Just Giving because it charges considerably less. If you would like to make regular donation we suggest a standing order. You can specify that you would like your gift to go to the One Smile fund which is used only to pay for P&O devices for patients who cannot pay for their own.