

getting people moving

ISSUE 9 DECEMBER 2020



Abbreviations

The terms we use to keep things simple!

CSPO: Cambodia School of Prosthetics and Orthotics

KCH: Kamuzu Central Hospital, Malawi

MCH: Mzuzu Central Hospital, Malawi

MoH Malawi: Ministry of Health

of Malawi

P&O: Prosthetic(s) and Orthotic(s)

Dear friends of 500 miles

So much has changed in the world since our last newsletter, issued at the end of February - but life goes on!

Whilst we in the UK are now caught up in a second wave of Coronavirus, in Malawi and Zambia daily life has pretty much returned to normal. Both of our centres in Malawi have been delivering a full normal service since the beginning of October and we have now resumed outreach activity to try to catch up on the backlog of patients who need replacement P&O devices as well as treating new patients requiring a device for the first time.

We are always talking about the life-changing P&O devices we supply to patients, or fund for them, so in this issue we are taking a little space to explain, with the help of infographics, what each of the four most commonly prescribed P&O devices are, how they work, what they cost to produce and the difference they make to our patients' lives - because life goes on!

However, you will also read how the scale of Coronavirus has had a major impact on our quality improvement programme and our training and fundraising plans.

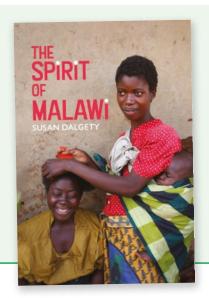
Coronavirus has certainly underscored that health is a great leveller – we all have a vulnerable human body. Unless we recognise the need to support **all** governments world-wide to "treat" this virus, it will continue to plague us all, both physically and economically. But should our recognition of the need for global collaboration in the fight against Coronavirus not extend to all basic healthcare, and not just where self-interest kicks in?

Thank you very much for realising that the need for help in Malawi and Zambia is just as great as it is at home, and for continuing to support our work financially over this difficult time for fundraising for international development work. Life goes on – and our patients depend on your generosity as much as ever!



The Spirit of Malawi available for pre-order

The publication of The Spirit of Malawi by 500 miles trustee, Susan Dalgety, has been delayed but will now be released mid-February. It tells the story of Malawi, including the turbulent events of recent months and their impact, through the voices of Malawi's people from all walks of life. **Pre-order it online now at Waterstones.**



Find us on facebook

Thanks to Susan Dalgety, 500 miles is now on **Facebook**

@500milesAfrica! We are really grateful to Susan for making regular posts so that you can keep up with our news, see videos of our patients and find out about upcoming events

Project updates

Malawi

Sandra Sexton, our quality improvement consultant, has already created and installed most of a bespoke quality management system at each of our centres in Lilongwe and Mzuzu. It is a lasting framework which is intended to sustain the quality of the service being provided from the P&O centres for the long term. 2020 should have seen the completion of this initiative through three visits by Sandy to each of our centres, principally for training but also to design and embed the final parts of the system. Obviously, Sandy has been unable to travel to Malawi but thankfully Johnson & Johnson, who are funding about 70% of the costs of phase 2 of the programme, are willing to be patient.

Throughout the 5-month period from May to September, both of our centres in Malawi operated under strict Coronavirus restrictions and





safety precautions. These included working to a rota system so that we always had one rota ready to step up should someone in the other team appear to have contracted the virus. Fortunately, that never happened – touching wood for the future – but, because we didn't know how long the restrictions would last and we didn't want to deplete our reserves without delivering our primary purpose for an indefinite period, our staff who are paid by 500 miles went onto half pay whilst they were working half time. We are grateful to them for their commitment through that difficult period.

Malawi: Lilongwe

At the start of the Coronavirus restrictions, we anticipated a significant drop in patient attendance but, as time went by, we were surprised by the increasing number of patients who found a way to get to our centre at KCH. Perhaps unsurprisingly, a large proportion of those patients were existing prosthetic users rather than orthotic users. We had assumed that our stock for a year would last for closer to 18 months, but we have in fact had to place an emergency order of components and materials, principally for making prosthetics.

Please see our updated website for a summary of our **project at KCH, Lilongwe.** The highlights are the return of Evelyne Huizinga from The Netherlands as



The team at Lilongwe in good spirits

our manager and our physical move, with the blessing of MoH Malawi and of KCH, into the rehabilitation section of the new Lilongwe institute of Orthopaedics and Neurosurgery (LION) when it is completed. We have just been informed that could be as early as the end of 2021. We will keep you posted on that development.

Above: the centre at Mzuzu.

Right: Bena with her beautiful twins



Malawi: Mzuzu

On 1st July 2021, fiscal and administrative responsibility for the 500 miles P&O Centre at MCH in Mzuzu will pass to MCH and Benadeta Singini will take over from Samantha Burgio and Charlie Freeman as its manager. **As you can read more fully on our website**, this centre was built by 500 miles during 2012 and opened that November. In the 8 years since, we have developed it into a busy clinic, fully integrated with MCH and staffed by Malawians we have recruited and trained, and who (apart from one technician) have been taken onto the MoH Malawi payroll. The northern region of Malawi now enjoys a comprehensive, quality P&O service as part of the Malawi national health service.

We are delighted to announce that Benadeta gave birth to twin daughters, Rachel and Lerner, on the 28th of October. The babies were premature but they and their mum are well. Benadeta updated her profile on our website in September. She said that 2019 had been an eventful year because she got married and graduated with her degree in P&O – but 2020 has been eventful too and it doesn't look like she will be getting much of a rest in 2021!

When Benadeta returns from maternity leave, we should get a clearer picture of the extent to which 500 miles will be permitted by the director of MCH to continue to support the P&O department of his hospital.

Training & website updates

Training

As part of the update of our website, a few of the 20 Africans whose 23 qualifications in $P\&0\,500$ miles has sponsored, have updated their profiles – Benadata, Timothy, Samuel, Kein, Maxwell and Tiwonge. We will highlight any others that are updated in future editions.













Benadata

Timothy

Samuel

Kein

Maxwell

Tiwonge

see more at: 500miles.co.uk/projects/training



Timothy

Timothy from Zambia continues with his 3-year diploma in P&O at Mobility India on Bangalore, funded by The Shoe Zone Trust, but at the time of writing, he has not been able to go home to Zambia for a break since he left in July 2019. Our worry is that if he goes home, with unpredictable quarantine and visa restrictions, he might not be able to return to

India on schedule, and we don't want to risk interrupting his studies. We are still hoping for a travel opportunity around Christmas but maybe June, at the end of his second year, is more realistic.

Alwin

Alwin Kawonga from Malawi has faced the biggest disappointment because his residential 3-year diploma course in P&O with the Cambodian



School of Prosthetics and Orthotics was suspended days before he was due to fly to Phnom Penh in March to begin his studies, the first year of which is being funded by St Columba's Church of Scotland in London. The course has been reinstated online but we are waiting for a residential opportunity to open up so that he can enjoy the full life-enhancing experience of living and studying abroad.

Website updated

Thanks to lockdown, 500 miles' website has had an overhaul and been restored to respectability after a random hack.

As well as patient stories, training profiles and fundraising updates, you can also read a list of our most commonly prescribed devices and their production cost – offering an insight into what your support can do for people in Africa.

see more at: 500miles.co.uk



Know your P&O Devices

Throughout the period of restrictions, we were amazed at the number of existing patients who continued to make their way to our centre at KCH, Lilongwe under their own steam. Here are the stories of four of them which we are also using to explain and illustrate the four P&O devices which are most commonly prescribed in Malawi and Zambia - a trans tibial prosthesis, a trans-femoral prosthesis, an ankle foot orthosis and a knee ankle foot orthosis. These devices, with a small selection of other devices, are now shown with their full cost of production on our website.

If you are stuck for an idea for a Christmas present for "the person who has everything", perhaps making a donation to cover one of these devices in their name would fit the bill!

Trans-tibial prosthesis: Brian Beaton

Brian was born with an underdeveloped, fractured tibia. He spent the first 3 months of his life in hospital. When he should have been starting to stand, his mother noticed that he was unable to bear weight through his left leg but she just kept him at home. Fortunately,



when Brian was 3½, she took him to Beit CURE Hospital where the surgeons decided to amputate his left leg through the tibia so that he could wear a trans-tibial prosthesis and referred him to 500 miles.

Brian got his first trans-tibial prosthesis in November 2017 at 4 $\frac{1}{2}$ and the second one in February 2019 when he was 6. In August this year, Brian's mother brought him back to 500 miles from their home in Mulanje because his prosthesis had become too small and worn out. Maliwase Munthali, his prosthetist, fitted him with a new device on which he walks perfectly (as you can see from the video on our website).

Brian is now 7 and in grade 4 of primary school. Luckily by the time he started school, he could already walk with his prosthesis. His classmates have never seen



him without it and most of them will not even notice it because he walks perfectly and can play normally and even run with his friends, so avoiding stigma and mocking.

Cost £175 – a reasonable price for access to an education?

Ankle foot orthosis: Blessings Amidu

5-year-old Blessings lives with his parents in Dedza, a couple of hours drive south of Lilongwe. When he was two, he contracted Malaria. Although he recovered, his parents noticed that he couldn't walk as well as he used to and had difficulty keeping up with his friends when playing. They saw that he was walking on tip toe on

his left side. You can see this in the photo of Blessings barefoot.

His parents took him for physiotherapy and from there he was referred him to 500 miles in July for an ankle foot orthosis to keep the ankle in a neutral position.

At 500 miles Blessings was assessed by

Mwayi Munthali and diagnosed as having Cerebral Palsy which has resulted in an equinus deformity. This means that he lacks the flexibility to pull the front of the foot up towards the front of his leg. An ankle foot orthosis compensates for that by holding the ankle in a neutral position, letting him stand with his weight more balanced across both feet and walk with the whole surface of the foot touching the ground when a step is taken on it.





A cast was made for Blessing's ankle foot orthosis. When it was fitted and worn inside his shoe, the result was good – but we could still see the equinus weakness so we recommended continuing physiotherapy to improve the walking pattern. With practice Blessings should achieve a normal gait and be able to keep up with his friends again.

Cost £50 - good value for a normal childhood?



Know your P&O Devices

Trans-femoral prosthesis: Edward Jamison



Edward was born in 1991 without any disability. He is married with two children. He lives in Dowa, near Lilongwe and farms to feed his family.

In 2008, he was bitten by a poisonous snake whilst he was sleeping. He was rushed to KCH where the doctors performed a trans-femoral amputation to save his life because his leg was developing gangrene.

After he was discharged, he used



crutches to get about for four years before he was referred to 500 miles at KCH for a trans-femoral prosthesis by Dowa District Hospital in 2012. The device allowed Edward to resume his normal daily activities and to earn his livelihood through farming. Since then, Edward has returned to 500 miles many times to have his device repaired but when he visited us in July this year, his device was deemed beyond repair and so his prosthetist, Peter Chilewani, took a cast for a new trans-femoral prosthesis which he fitted on the 30th of July. Peter reports that Edward was delighted with his new device.

Cost £351 - a small price for physical and financial autonomy?

see pictures and videos of our patients at: 500miles.co.uk/patient-stories

Knee ankle foot orthosis: Gladys Kagwadala

Gladys was born in April 2008, the younger child of Mr and Mrs Kagwadala. They said that she always looked very strong and happy and dreamed of becoming a nurse when she grew up. But in 2014, when Gladys was 6, her toes started developing wounds which were difficult to heal. She was diagnosed with septic wounds on the toes and a "Darco Shoe" which accommodates and protects the toes was

provided by Beit CURE. Because the Darco shoe had a thick sole, in 2018, Gladys was referred to 500miles for a shoe raise to compensate for the leg length discrepancy.

However, during this treatment Gladys's knee on her left side became very weak and swollen and was causing her discomfort. When Gladys walked or even when she was

just standing, her knee was falling into a valgus position (angled inwards). Over time the knee became very unstable and so in June this year, after a fresh referral from Beit CURE, 500 miles began orthotic management.

500 miles prescribed a knee ankle foot orthosis to straighten and support the knee. The device was quickly fabricated and Gladys immediately walked well





Knee Ankle foot Orthosis (KAFO)
Made using polypropylene technology to international standards

The plastic thigh and leg/foot shells fit intimately around the thigh, ankle and foot. This supports or corrects the thigh, knee, ankle and foot positions.

Orthotic Knee joints are placed at either side of the human knee. A KAFO is usually used to stabilise an unstable or painful knee. Knee joints can lock when the user stands and can be unlocked for sitting.

Straps are placed in certain positions to ensure the correct forces are applied to the body. The straps also hold the KAFO securely onto the leg and are made of Velcro and webbing and attached by rivets to the plastic shell.

Actual full cost of production at

with the support of the device. Gladys's prosthetist, Peter Chilewani, said she is very happy with it. She no longer wears the Darco shoe. This will not be the end of the story for Gladys, but we should be able to keep this 12-year-old girl mobile.

Cost £259 - a worthwhile investment in this future nurse?

Fundraising stories

Celebrating our supporters

We are obviously disappointed that the large fundraiser we had planned for 2021/22 has had to be shelved, so we make no apology for celebrating again the magnificent physical feats of **Babs Ross** and **Pamela Spencer**.

Pamela walked 500 miles for 500 miles during lockdown raising £2,227.30 and Babs ran a marathon in Shetland at the end of September raising £1,285.00

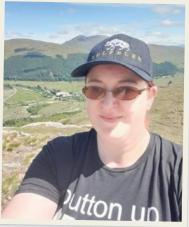
Thank you very much to everyone who supported their fundraising appeals.



Heroic efforts from our supporters! Left: Babs wraps up her marathon. Below: Pamela completes her 500 miles for 500 miles







Nichola's NC500

You may have noticed **on our updated website** that Nichola is going to walk the 516 miles of the North Coast 500 in 28 days in May 2022. 500 miles is among four charities which will benefit. Nichola has been training since 2019 and has already lost 9 and 1/2 stones in preparation but she still has some major surgery (delayed), more pounds and more training miles to go!

A huge thanks to you all

Thank you to everyone who regularly supports us. This year, we are especially grateful to those who donated the savings they realised they had made on haircuts and eating out etc in this year of restrictions and quieter living. You know who you are!

Could you be inspired by Pamela, Babs or Nichola to take up a 500 miles challenge of your own, perhaps as a new year's resolution for 2021?

How to support us

If you would like to support us please see the **How to support us page on our website**. You can donate through PayPal, Virgin Money Giving and Just Giving. For online giving, we encourage you to use Virgin Money Giving over Just Giving as it charges considerably less.

