

### getting people moving

AUTUMN 2023 ISSUE 12



#### Dear friends of 500 miles

Thank you for your continued interest in the charity and for your generous support through One Smile and otherwise. We are well into our 16th year - and I know that some of you have been with us since the very beginning!

I visited Lilongwe, Malawi in February this year for the first time since Covid 19 travel restrictions were lifted. It was good to be reminded of the day to day service being routinely provided at the 500 miles P&O Centre at KCH from which we have operated since September 2010, but also to see our new home taking shape as part of the rehabilitation building at LION. You can read about that and our future plans in Lilongwe below.

I also saw the significant repercussions of the cost of living crisis in Malawi. If things are challenging here, with lack of FOREX and rampant inflation, they are very much worse in Malawi which is also still recovering from Cyclone Freddie in March and a Cholera epidemic which was only declared under control in June - and that is especially so for poor people with disabilities. The vast majority of people who need a prosthetic or orthotic device for themselves or their children cannot afford to make even a contribution to the price – and that is why we depend on you.



Ohira Giles

But in this newsletter, you can enjoy some uplifting patient stories, Samuel Mkomera's update on his studies in Thailand and some very positive fundraising news including reaching our target on our final appeal and a rebranding of One Smile which is going to become the main focus of 500 miles.

### And you might want to visit our recently updated website

#### **Abbreviations**

The terms we use to keep things simple!

KCH: Kamuzu Central Hospital, Malawi

**LION**: Lilongwe Institute of Orthopaedics and Neurosurgery at KCH

MACOHA and MAP: Malawian NGOs which support people in Malawi with disabilities

MCH: Mzuzu Central Hospital, Malawi

MoH Malawi: Ministry of Health

of Malawi

MoH Zambia: Ministry of Health

of 7ambia

**P&O:** Prosthetic(s) and Orthotic(s) SFH: St Francis Hospital, Zambia

#### Thank you Sandra!

Sandra Sexton has been our invaluable quality consultant in Malawi since 2018, having previously worked at our Lilongwe centre for 10 months in 2014. Sandra was compelled to retire early at the end of October this year due to a multitude of painful fractures leading to a diagnosis of secondary breast cancer in her bones. You can read the article that our trustee, Susan Dalgety, wrote about Sandra and secondary breast cancer here. In the article, Sandra said that whatever happened, she was going to dance at her daughter's wedding in July - and she did!

500 miles would like to thank Sandra for designing our bespoke quality management system (QMS) for the P&O centres in both Lilongwe and Mzuzu. Sandra, who won ISPO's Sepp Heim award this year for making "a major contribution to mobility device education and/ or improving mobility device services in less resourced settings", is in fact irreplaceable! but we will continue to do our best to complete the installation of her QMS in our Lilongwe service and to embed it so that it becomes automatic routine before we handover the service to MoH Malawi/LION as we believe that is crucial to the longevity of the service.



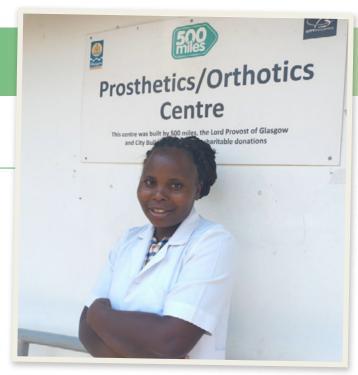
### **Project updates**

### **Malawi: Lilongwe**

In the 12 months since our last newsletter, the Lilongwe centre has delivered 1,322 devices - 253 prostheses and 1,069 orthoses, and an average of 110 devices per month.

Over half of those numbers are returning patients but we still have a steady flow of new patients.

At the beginning of July, we were delighted to welcome Benadeta Singini as the new Malawian manager of our Lilongwe centre. If Benadeta's name is familiar to you, it is because up until then she has been the senior clinician and, for the last two years, also the manager, of the P&O centre that 500 miles created at MCH. Evelyne Huizinga, a former manager of our Lilongwe



Benadeta Singini outside the centre at Lilongwe.

centre very kindly came back to Lilongwe from Budapest, where she lives now, to give Benadeta a 3-month induction because Beth Sheehan had to leave on short notice as she was pregnant and decided to return to her native Australia to have baby Xavier. Congratulations Beth! Benadeta has settled in impressively quickly! You can read Benadeta's profile **on our website**.



We seem to have been anticipating our move to LION for several years now! LION is the Lilongwe Institute of Orthopaedics and Neurosurgery (LION) at KCH which is being created by a Norwegian consortium called The LION Trust at KCH. But when I visited in February, phase 1, which contains all of the surgical theatres and wards, was very nearly complete and I could see substantial progress on the rehabilitation building which forms phase 2. Phase 1 was officially opened at the end of April and from these recent photos, we can now really envisage being installed in the whole of the ground floor of phase 2 before the end of this year and operating at LION from January 2024.

Family, friends and supporters have frequently asked me what the difference is between 500 miles' move to LION and the handover of 500 miles' P&O service in Lilongwe to MoH Malawi/LION. Our move to LION is just a physical move which, as above, we expect to take place immanently, but 500 miles will continue to run the service at LION. That will be the position until we hand over the service around the end of 2024, at which point 500 miles will pass over fiscal and administrative control of the service to MoH Malawi/the LION Trust - although we intend to continue to provide financial support for a period of four years after handover.

### **Project updates**

### Malawi: Mzuzu

In July 2021, 500 miles handed over a fully equipped, fully operational, purpose built, 250 square metre prosthetic and orthotic centre with a fully trained Malawian staff to MCH and MoH Malawi. We were concerned that our offer to buy the next annual supply of imported materials so that there would be no hiatus in service in Mzuzu was declined, but after a hiatus of a couple of years, the centre has been stocked by MoH Malawi and MCH and a full P&O service at MCH is running!



Timothy works with a patient, fitting his new prosthetic legs and guiding him through the first few steps.

### Zambia: Lusaka

Timothy Miti qualified with a three-year diploma in P&O from Mobility India in July 2022. Since his return to Zambia, we have been trying to help him to find employment as a prosthetist/orthotist in Zambia - but he first needs to pass his professional exams in Zambia. Unfortunately, he missed two diets of those exams because he didn't have a school level pass in biology, an exam which he was only able to sit (and pass!) in August. Timothy will now sit his professional exams in February/March 2024. In the meantime, in order to keep is skills high, 500 miles has been giving Timothy a monthly living allowance so that he can volunteer at the P&O department of the University Teaching Hospital in Lusaka where we hope and expect that he will eventually be employed.

### **Zambia: Katete**

We are going to continue our small, lowlevel, P&O service at SFH in Katete in Eastern Province until the end of 2024. Our representative at SFH does not have the training, machines or materials to make prostheses or complex orthoses, but she is kept busy making simple orthoses and carrying out repairs to more complex prostheses and orthoses. We have a list of 202 people who currently need such complex devices and if MoH Zambia will fulfil its promise to UTH to supply it with low-cost stock, 500 miles will help those who can travel to Lusaka by paying for the devices they need - but at the time of writing UTH does not have low-cost stock.

Right: two patients from our waiting list in Katete





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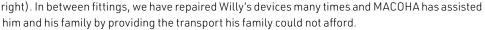
### **Our patients**

As poverty tends to go with disability, the majority of our patients can't afford even to make a contribution to the price of their devices, especially if they have paid to travel to our centre, and almost all of our devices are subsidised to some extent. Our One Smile fund covers the deficit. These are the stories of six patients assisted through One Smile. You can read more about One Smile on page 7.



#### Willy

Willy Banda is a regular patient at our Lilongwe centre. Now 16 years old, Willy was born with congenital malformation of his right leg. The femur (thigh bone) is short. In 2013, when he was 6, Willy was first referred to the 500 miles centre by MACOHA for an ortho-prosthesis (a combination of an orthosis to support the existing leg and a prosthesis to replace the missing length). Since then, we have fitted Willy with four more devices, including the last in May 2020 (pictured



Willy was recently referred again to 500 miles by MACOHA for his sixth ortho-prosthesis because the last device was broken, too tight and basically worn out – a happy sign of heavy use! – but it's not so good that Willy came to our centre with the device in his hand. He had been walking for a while without the device, causing him pain in the hip and preventing him from walking long distances. Casting for a new device was carried out on the same day followed by fitting of the device. Willy immediately walked very well with the new device, as you can see in our **short video on YouTube** showing him walking with and without his new device. We also provided him with a new pair of shoes from our

store because his family is very poor. Willy and his mum were both very happy with the new device and grateful to One Smile for paying for it. Willy said that he could now walk without pain in his hip and that he was looking forward to being fully mobile again and to walking long distances.



**Priscilla Weckster** was born at Ntcheu District Hospital with left hip disarticulation – her left leg was absent from the hip joint. When she was 1 year old, she was referred by MACOHA to the 500 miles centre for a prosthetic leg. It was a simple device with no joints, but which helped her learn to stand. Unfortunately, when she outgrew that first one, she was left to manage with an auxiliary crutch.

When she was 9, Priscilla was referred to 500 miles again, this time by Beit CURE, an American hospital. We immediately prescribed a new hip disarticulation prosthesis, took a cast on the same day and then fabricated a new leg with both a hip joint and a knee joint. We fitted the new prosthesis the very next day, so Priscilla and her mum did not have to stay long in Lilongwe, because it is expensive.

It is hard to control a hip joint and a knee joint without a lot of practice but Priscila really impressed us with her first efforts. Priscila and her mum were very happy because she was able to walk with her new leg straight away – without the crutch! Have a look at our **short video on YouTube** to see the difference the device makes!

Remember this was the first time Priscilla has tried to walk with a "jointed" prosthesis. We hope to see the child walking more smoothly and confidently once she's used to the device. Beit CURE paid 40% of the cost of Priscilla's device with One Smile covering the remaining 60%.



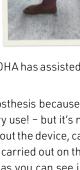


#### **Boniface**

When **Boniface Gladwel** was two, he contracted Malaria and developed a severe fever. He was taken to a local clinic where, extremely unfortunately, he was given an injection which damaged the peroneal nerve (which supplies movement and sensation to the lower leg, foot and toes), causing foot drop. A few months later he was referred to 500 miles by MAP and fitted with an ankle foot orthosis (AFO) to support his right foot. Of course, he quickly grew out of the AFO but his parents couldn't afford to bring him back for a new one until quite recently.

Without the AFO, Boniface finds it difficult to lift his right foot, which makes it tiring for him to walk even a short distance because he has to strain his hip flexor muscles to lift his leg high enough to prevent his foot dragging on the floor. The AFO significantly reduces his energy consumption by keeping the foot in a neutral position when swinging the leg forward, as you

can see in our **short YouTube video**. Hopefully Boniface will also be more comfortable playing football with his friends at home and at school. Although his AFO cost only **£50**, Boniface's parents had to rely on One Smile to pay for it and supply him with a pair of shoes.





### **Our patients**



#### Ivon

Ivon Khondowe has idiopathic scoliosis. Scoliois is an abnormal sideways curving of the spine. Idiopathic means there is no definite cause. Idiopathic scoliosis tends to run in families and it affects girls 8 times as often as it affects boys.

Ivon first realised her back was twisting when she was about 7, but because it was mild, it was easy to ignore. However, by the time Ivon was 16, the deformity was much more severe and noticeable and it was causing her significant pain when she sat or stood for long. That was when Ivon's parents decided to bring her to KCH and the orthopaedic surgeon diagnosed her condition. The surgeons also realised that Ivon was holding her body in an unnatural (and uncomfortable) way to try to imitate a normal posture and advised immediately that 500 miles fabricate a thoracic lumbar corset to halt the progression of the deformity.

After we fitted Ivon with her corset, we realised that she was still trying to compensate for the curvature, even when wearing the brace so we taught her some exercises to improve her posture and advised regular physiotherapy. The results were very positive and her posture has improved. At 16 and doing well in Form 3, Ivon is healthy, but she needs to be able to sit in class all day to secure her future. Ivon's treatment at 500 miles was paid for through One Smile.



#### **Dziwitsani**

**Dziwitsani Elisa** is a 14 year old boy who lives with his parents and two siblings in Mponela which is quite close to Lilongwe. Both his father and mother are farmers who sell crops to earn a living. Dziwitsani wants to be a farmer like his dad when he grows up.

In 2020 Dziwitsani noticed a small wound on his right toe. Unfortunately, it was getting bigger rather than healing. When he then started to have frequent fevers, his father brought him to KCH where he was diagnosed with cancer and admitted to the cancer centre there. The cancer was spreading and so, as well as treating Dziwitsani with chemotherapy, the doctors amputated his right leg through the femur. From the cancer centre, Dzitwitsani was referred to 500 miles for a trans-femoral prosthesis. We taught him some exercises in preparation for the prosthesis and he was then given an appointment for a cast of his stump to be taken. A week later, Dzitwsani received his above-knee prosthesis.

Dziwitsani was very happy to see that he was able to stand on both of his feet – and walk! You can see Dziwitsani's progress from walking between bars, to walking with two crutches and then just one crutch in **our short video on YouTube**. Dziwtsani said now he looks like all his friends again. His father celebrated because he had hope for his son's future again.

In accordance with our charging policy, we asked Dwiwitsni's father if the family could make a contribution to the cost of the leg, but when he explained that they had spent their savings on traveling between their home and KCH for all of Dziwitsani's treatment, we agreed that Dziwitsani could be assisted by One Smile.











#### **Kinros**

**Kinros Maliseni** was still at nursery school when he was playing at the maize meal shop with his 4-year-old friends. Not understanding the danger of the grinding machine, he was sitting with his right leg in the idle machine when it was suddenly turned on. He suffered a very traumatic amputation and is lucky that he only lost his right leg below the knee.

KCH referred Kinros to 500 miles for a prosthesis.

Kinros is very young and his coordination is poor so he struggled to weight bear and walk with the device but he eventually managed as you can see in **our short video on YouTube** – and with physiotherapy and gait training he will improve as he also gains confidence.

The price of Kinros's leg was £175. His family contributed about 45% with One Smile making up the difference.

See more of our patients at: 500miles.co.uk/patient-stories

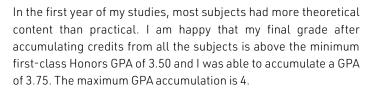
### Training update

### Samuel

As we reported in our last newsletter, in July 2022, Samuel Mkomera left his position as assistant manager of the 500 miles P&O centre in Lilongwe for the Sirindhorn School of Prosthetics and Orthotics, which is part of Mahidol University in Thailand, to

upgrade his three-year diploma (from the Cambodia School of Prosthetics and Orthotics) to a degree over two years.

Samuel is the third Malawian to be sponsored by 500 miles for a degree in P&O. You can read **Samuel's profile on our website** but this is his update on his studies in Thailand after completing his first year with great success and looking forward to a different kind of experience in second year.



The first semester of the second year is the busiest with many practical and less theoretical studies. We have five subjects to complete plus the pre-clinical experience scheduled for the final month of the semester. The five subjects are Wheelchair and Seating Orthoses, Cranial Remolding Orthosis (as you can see from the photo below), Upper Limb Prostheses, Hip Disarticulation and Partial Foot Prostheses, and Orthotics for Charcot Foot. We also have two comprehensive exams on medical science subjects and orthotics science subjects to be taken on 19th October and 20th



December. We have already completed four of these subjects for which we are expecting the final examination results at the beginning of the second semester in January 2024.

The most interesting part of the second year is that we are given more individual practical sessions which makes classes

more interesting. In addition, at the end of each subject, we are given an assignment on which we have to give a slide presentation in class, hence improving oral presentation skills.

The second semester will start on 8th January 2024 and is expected to terminate at the end of May 2024. It may be less busy because we have only two subjects - Transfemoral Prostheses





and Knee Disarticulation Prostheses - to complete in the months of January and February, followed by the comprehensive exam in prosthetic sciences, the ISPO practical exam, and a research project presentation in the month of March. We will have a second clinical experience from April to May.

In addition to studies, the school organizes social events to allow students to have fun and social interaction. At the beginning of this semester, we had a welcome party, and we are expected to have a school trip to Pattaya, a seaside city in Southern Thailand, in November this year.



Read more about our students at 500miles.co.uk/projects/training

#### **One Smile**



### 500 miles: One Smile

Obviously, our P&O service in Lilongwe is "not for profit", but in order to secure the financial viability – and therefore the longevity – of the P&O service, it needs to bring in as much in-country income as possible. Therefore, we ask patients or their families to pay as much as they can afford to contribute towards the price of the device. For the majority, that is a token amount or nothing at all – and that is where One Smile comes in.

One Smile is a fund within 500 miles which is used only to pay for P&O devices for those who really cannot afford to pay for what they or their children need just to stand up and walk or enjoy maximum body function – so they can to go to school or work and participate in community life – people like Willy, Dziwitsani, Priscilla, Boniface, Ivon and Kinros, whose stories are on pages 4&5.









As part of the ongoing integration of our P&O service in Lilongwe with the Malawi National Health Service in preparation for handing it over at the end of 2024, we have passed over responsibility for paying for an increasing amount of locally available materials and for more local salaries to MoH Malawi and KCH, and so already over half of our overall expenditure is on such device costs. After we hand over the service, almost all of our ongoing expenditure will be on direct payment for such devices, and so One Smile will in fact become the focus and main purpose of 500 miles. All donations to 500 miles which are not made

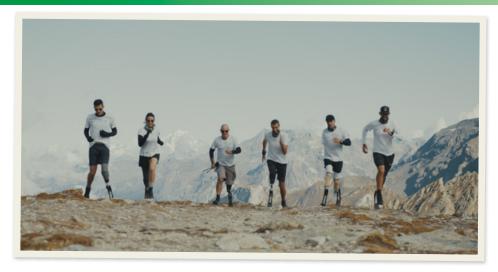
for a specific purpose, such as training, will be applied to One Smile and used to pay for such devices, thereby also creating income to sustain the service for the long term. We hope you like our new logo for One Smile within 500 miles!



One-off donations to One Smile are of course extremely welcome and gratefully received but regular donations to One Smile are really the life blood of the charity – and will become even more important. You can read about the prices of our devices here.

A regular donation of £12 a month with Gift Aid (£15 without Gift Aid) would pay for an average prosthesis or orthosis, such as a below knee prosthesis, for someone each year. If you would like to help in this way, please follow this link.

### **Fundraising**



#### On My Own Two Feet

**Olivier Lambert** won first prize of £100 at the Fort William Mountain Festival with his film called "On My Own Two Feet" and very kindly donated the prize money to 500 miles. The extremely inspiring film is the story of six amputees, ranging in age from 19 to 64, who set out to climb a 3,000m peak in the French Alps. You can watch it here.



## Soroptimist International flies the flag for 500 miles at Coronation Lunch

In May, **Pamela Turner of Soroptimist International** of Northern England held a precoronation lunch in Stannington, near Morpeth. The village hall was beautifully decked out in red, white and blue with gorgeous floral table centres. The guests were treated to quiche with lovely summer salads and a large array of delicious deserts. Through ticket sales and the raffle, the Soroptimists and their friends raised the wonderful sum of £1,375 for 500 miles!

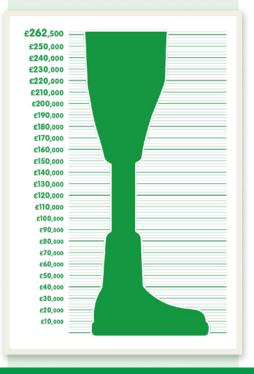
**Just Giving:** We've noticed that Just Giving have begun to invite donors to "add a small tip on top of your donation so that they can continue to help more people". Just Giving says this is to avoid charging charities a platform fee - but 500 miles does already pay Just Giving a monthly fee and in addition, Just Giving makes a charge on each donation, so there is absolutely no need to do this! You can select the "Enter custom amount" option and specify "0".



# Big news for the BIG dinner 2

We are thrilled and very grateful to report that we have reached our target of £262,500 which is the equivalent of 1,500 average prosthetic and orthotic devices at £175 each. The BIG dinner 2 was our final community appeal to raise sufficient funds to achieve the handover of our Lilongwe centre to MoH Malawi /LION.

Although we have taken down the appeal page on our website, we know that the Recipes & Tips section was popular and so we have saved it and you can still **reach the content here**, or through a link on the BIG dinner 2 item on the Fundraising - Activities page.



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Registered Charity Number: SC038205