

### getting people moving

WINTER/SPRING 2020

#### **Abbreviations**

ISSUE 8

The terms we use to keep things simple!

ADLs: Activities of Daily Living

**CSPO:** Cambodia School of Prosthetics and Orthotics

KCH: Kamuzu Central Hospital, Malawi

MCH: Mzuzu Central Hospital, Malawi

**MoH Malawi:** Ministry of Health of Malawi

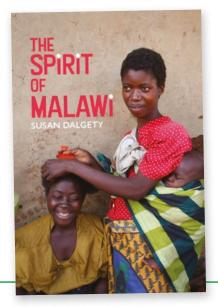
**MoH Zambia:** Ministry of Health of Zambia

P&O: Prosthetic(s) and Orthotic(s)
QIC: Quality Improvement Consultant
QMS: Quality Management System
SFH: St Francis Hospital, Zambia
UTH P&O: P&O dept. of University

Teaching Hospital, Lusaka, Zambia

### Out now

Look out for a new book called "The Spirit of Malawi" by Susan Dalgety, a trustee of 500 miles. It tells the story of Malawi through the voices of its people from all walks of life. It is due to be published this summer by Luath Press.





### Dear friends of 500 miles

Thank you for taking the time to open this newsletter. The main focus for this issue is some of our Malawian patients and their stories - but I would also like to keep you up to date with a few headlines about our work in Malawi and Zambia and to give you the chance to read Samuel's account of his time studying for his diploma in Cambodia – which I certainly think you'll enjoy.

I'd like to take this chance to say thank you to James Robb, who has left 500 miles' board of trustees after seven years of invaluable service. We're truly grateful for all the skill, time and advice he has brought to the charity, not to mention his expert perspective as a retired orthopaedic surgeon.



Finally, this issue is also a good opportunity to let you know about the next – and **last** – large-scale fundraiser for 500 miles as we move towards the handover of our two prosthetic and orthotic centres in Malawi over the next few years.

Thank you for your interest and for all of your wonderful support in all its many forms!

Ohina Giles

# Malawi

Olivia visited 500 miles' two P&O centres in Lilongwe and Mzuzu last September. The Principal Secretary of MoH Malawi did not keep his appointment with her (despite being in his room!) but she had very positive meetings with the directors of the two tertiary care government hospitals (KCH and MCH) where our centres are located and the plan now is to hand over our centres directly to these hospitals which are on the point of securing autonomy from MoH Malawi. Olivia hopes to be in Malawi in June this year to give one year's notice of the handover of our Mzuzu Centre on 1st July 2021 (as agreed with the director) with a clear plan to continue actively supporting it for a good few years thereafter.





### **Quality Control**

During 2019, our QIC, Sandra Sexton (pictured here with the team at KCH), carried out four visits to each of our centres to implement her quality improvement recommendations, the main one being to put in place a comprehensive QMS, which will be a lasting framework to sustain the quality of the products of the centres for the future. As such, it is a key part of our strategy for their handover. Sandy also carried out extensive clinical training of our staff (see the stories of Diquence, Silvester and Alinafe) as well as training in the theory and application of the QMS. It is essential that we embed the QMS thoroughly and continue to monitor quality, and identify and meet training needs, so we are working on how we can do that. Ian Walker of Johnson & Johnson, which funded 75% of this work in 2019 said, "J&J is delighted to be associated with 500 miles. The importance of QMS to delivering a sustainable model is crucial to the long term success of 500 miles' activities, and we are pleased to support this vital component of the work in Malawi".

#### **Continuing Professional Development days**

In October Samantha Burgio and Charlie Freeman, our joint managers at MCH, successfully organised our annual two-day CPD programme for the clinical and technical staff at both of our centres at which they consolidated their learning through our quality improvement programme.

The team enjoying the sunshine and (right) hard at work developing their skills.



### Malawi: Lilongwe

During 2019 we had 1,412 patient visits and 874 devices were issued. In September, our Lilongwe centre was given a thorough makeover by Glasgow City Building as you can see! It was nine years since the original team from Glasgow erected this building for us and it was tired. The electrics and plumbing were given an overhaul, the extensive damage caused by our termite eradication work was rectified and the whole building decorated inside and out. Thank you to Scott McEwan and his enthusiastic team for all of their hard work and to Brian Kelly and Gillian Walsh from the Lords Provost's department of Glasgow City Council for their facilitation.

Chief Joseph Kambuye, our senior technician, retired at the end of the year after working with 500 miles for almost 10 years. We will miss him and thank him for his excellent services.





The newly refurbished centre, above, and newly retired senior technician Chief Joseph Kambuye, left.

In December, three upper-limb amputees were treated at our Lilongwe centre, while at the same time, Sandy, our QIC, trained our Lilongwe staff in upper limb prosthetics. Here are the stories of Alinafe and Silvester, who are both Malawian. Later, you can read about how Diquence from Zambia also came to be treated in our Lilongwe centre.



### Alinafe

**November 2018:** It was rainy season and so pregnant, 18-year-old Alinafe Isaac, was cooking in the kitchen rather than outdoors. Her family told us that she was hit by lightning which forced her into the cooking fire. She sustained severe burns on her upper limbs, back and bottom so she was taken to Ntcheu District Hospital where both of her arms were

amputated above the elbow. A week later she was referred to the burns unit at Kamuzu Central Hospital for burns management.

**February 2019:** When Alinafe first visited 500 miles, her wounds were not fully healed. She had limited range of motion and her shoulders were stiff and turned in.

**May 2019:** When Alinafe returned, the amputation sites were fully healed and so our rehabilitation technician, Rabecca Mangani, gave Alinafe some counselling, range of motion exercises, positioned Alinafe's shoulders and taught her how to transfer from one surface to another and how to manage at home

September 2019: Our QIC, Sandy, was visiting when Alinafe next came to us to have casts for prosthetic arms. Sandy advised that, as Alinafe's stumps are short, it would be difficult to use prostheses. Also, the burns on her back were not completely healed and she had not yet gained full range of motion and muscle strength in her shoulders. Sandy told Alinafe they should first aim to get her using functional adaptive devices for ADLs which Alinafe could practice with at home in readiness for possible future prostheses, whilst also giving her time to heal completely and gain muscle strength.

At first Alinafe was reluctant, because she thought that what was being expected of her was too hard. But after Sandy comforted her and showed her videos of how other amputees all over the world are coping, she started to come round to the idea. To motivate her, we asked other patients at the centre to share their stories.

The first devices made for Alinafe were an adaptive feeding spoon and an adaptive feeding bottle. She was happy with the independence they gave her and was looking forward to the next stage.

**December 2019:** We invited Alinafe to visit again to coincide with Sandy's next QMS visit when Alinafe was also encouraged by Silvester and Diquence's stories. This time the focus was helping her to do all ADLs independently and to be able to take care of her baby. Rabecca and Sandy made her

adaptive devices for cleaning, grooming and dressing herself and her daughter. The next step will be to make Alinafe sockets with hooks to use for carrying things and for doing housework and farm work. The priority for Alinafe will be maximum functionality which means that she may or may not progress to using upper limb prostheses.

#### see videos at: 500miles.co.uk/patients

#### **Silvester**

Silvester Mwatisiya is 28 and lives with his wife. He worked as a minibus driver as well as doing a little farming to supplement food athome. But in October 2018, he was involved in a road traffic accident in which he lost his right arm at the elbow – and consequently his job. After a long stay in hospital, resourcefully, he opened a shop selling groceries, but even that was challenging for him as it involved



carrying goods and so he had to employ someone to assist with things like unloading delivery vehicles – an expense he couldn't afford. He could still watch football, but he had to give up his farming activities as he couldn't work alone and, naturally, he was finding daily life and ordinary domestic chores difficult. Silvester came to be referred to 500 miles because a South African woman for whom he used to work found 500 miles on the internet. Silvester's friend paid for his travel from Nkhotkota and for his accommodation in Lilongwe. When he arrived at 500 miles, Silvester was assessed and his elbow was cast so that Mwayi, his



prosthetist, could make him a perfectly fitting socket. 500 miles then provided him with a mechanical arm to which he can attach both a functional hook, which allows him to hold things, and a cosmetic hand.

After training in the use of the functional device, Silvester became competent and he left us feeling confident that he would be able to handle and carry goods at his shop more effectively and to hold and use some farming equipment. He said he was very happy with his device!



## Malawi: Mzuzu

During 2019, in Mzuzu, we had 628 patient appointments and we issued a total of 719 devices to patients like Malengo in July, Walison in September, Kingstone in November and Debra in December.

Malengo Phiri, 14, is the second eldest in a family of five children. She likes to socialise with people and to watch movies but she has never been to school because she has congenital lower limb deficiencies - both of her knees are badly contracted - and Malangazi Primary School is too far from her home for her to be carried every day. Malengo has to be carried to travel any distance and cannot assist with any household chores or join her peers in most of their activities. Malengo's parents have unsuccessfully sought help for her from various hospitals, but fortunately they heard about 500 miles' outreach to Malangazi Health Centre in June and brought Malengo to be assessed.



Malengo's prosthetist, Benadeta Singini, observed that although Malengo has knee contractures, she is able to walk if she bears her weight through her knees. She was given an appointment to come to 500 miles at MCH in July to get knee disarticulation prostheses. She was fitted in July, the whole process taking two weeks. She walked well with the prostheses without support although balance became harder as we increased her height to her natural height. Malengo needs crutches to use at home to gain confidence but we hope that when she returns for review she will be able to walk a reasonable distance without support.

**Kingstone Mhango** was born with Cerebral Palsy. Now four, he is not able to control his body and can't walk, stand or even sit without support He spends most of his time lying down and, even as an only child, he is a full-time occupation for his grandmother. As Kingstone's parents are farmers, his grandmother takes him to MAP (a Malawi government organisation which supports



people with disabilities) for physiotherapy once a month. The connection with MAP in Rumphi, with which 500 miles partners, meant that Kingstone attended a 500 miles outreach there in October. Kingstone was given an appointment to come to 500 miles at MCH in November when he was fitted with a neck collar, which is designed to keep his neck aligned whilst sitting and feeding. His grandmotherwas advised that the neck collar should be worn during the day when Kingstone is in a sitting position. She was very pleased to see Kingstone's neck held straight. Kingstone has started to develop Scoliosis so when he comes back, we might give him a spinal brace to help prevent this deformity.



**Debra Dziwa** was born with clubfeet. They could have been corrected when she was a child if she had been taken to hospital for serial casting, but she wasn't. Now 25, Debra has been walking bare-foot (as you can see from the video on our website) all her life as obviously she can't get footwear. Debra is one of six children but stays with her grandmother.

Fortunately, our clinical lead at 500 miles at MCH, Benadata Singini, met her at church and explained to her about our services. Debra was seen in December when she reported that her feet hurt when she walked in uneven areas, when it is hot and when she

see videos at: 500miles.co.uk/patients



walked long distances. The deformity can't be corrected without what, for an adult, would be major surgery, so Benadata made her a pair of orthopaedic sandals to accommodate the deformity and to support and protect her feet so that she can walk comfortably. Benadeta first cast Debra's feet and then made a positive model of them round which she fashioned the sandals. Debra bears more weight on the outside edge of her feet and so a wedge has been created on the outside edge of the sandals to provide support there and the sandals are lined with foam in order to distribute Debra's weight when walking. Debra can now walk comfortably - again, which you can see on our website. Debra is in form 4 at Ezondweni Secondary School in Mzimba District. Her sandals should help her complete her studies in more comfort.

When **Walison Soko**, now 29, was six years old he was severely burnt which resulted in his left leg being amputated above the knee. As a child, Walison had to be carried around and, even as an adult, he has had to be cared for by his parents. He has never been able to earn a living. As he is one of six children and his parents are subsistence farmers, there was no money to pay for someone to take Walison to school so he didn't attend. Latterly Walison has managed to get around on crutches but after he heard about 500 miles from a friend, he attended the orthopaedic clinic at MCH where he was referred to 500 miles.

Tiwonge Nyahoda made him a belt-suspended trans-femoral prosthesis. Using tips that our QIC, Sandy, had taught her, Tiwonge was able to give Walison a well-fitting socket and achieve good shaping. Walison was very grateful and said that he hopes his leg will give him his life back. He wants to start a small business so he doesn't need to depend on his parents. And, as watching football has always

been a hobby, he is looking forward to walking to matches.



Meeting Dr Lalick Banda

# Zambia

Since January 2017, 500 miles has been supporting a low-level P&O service at SFH in Katete in Eastern Province. Our plan is to gradually develop this service.

In November, Olivia attended a meeting in Melrose in the Scottish Borders arranged by <u>The Logie Legacy</u> for all European NGOs who support SFH. Lalick Banda, the director of SFH and Fred Ntongwe, his chief administrator were there! It was a perfect opportunity to understand the challenges facing a government hospital dependent on external funding even for its core operations and to network with other NGOs who know SFH well and who are much more extensively involved in Zambia than 500 miles. We have made a strong link with a Dutch NGO called <u>St Francis Hospital Medical</u> <u>Support Group</u> which is assisting us greatly with the logistics of increasing our support which is high on our agenda.



We are hopeful that the enthusiasm at SFH for a P&O service which is truly accessible by the poor will also spur on the P&O department at UTH, which has been our primary focus in Zambia, to work with us in a sustainable way so that people like Diquence Mwaka do not have to travel to Malawi to get assistance. (See below.)

### Diquence

Diquence is a 37-year-old Zambian who, in 2013, was hit by a car and dragged under it on his stomach for about 500 meters. Unconscious, he was rushed to intensive care. He sustained injuries to the right side of his head and he lost his right ear, his right arm at the shoulder and his left arm high through the humerus bone. His whole abdominal wall was burnt with friction and had to be skin grafted. He came round after 17 days but remained in

hospital for 10 months for his wounds to be dressed.

Since then Diquence has struggled with day-to-day life. He lost his job as a grading officer in the Mines Geological department and found that he couldn't travel long distances alone or participate in social gatherings. Diquence was able to eat directly from plate to mouth, to drink with straws and to write using his mouth. Amazingly he taught himself to do farm work using his feet but for a lot of ADLs, like washing, grooming and dressing, he needed help from his wife or father. In 2014 he managed to get a cosmetic prosthetic arm but he said it made him feel more disabled because it had no function.

Diquence contacted Olivia through our website in June 2019 asking for help as he had not been able to access any form of functional arm(s) through the Zambian services. Olivia told him that if he could get from his village in Ndola, Zambia to our centre in Lilongwe, Malawi we would help him there.

Just then, a donor with experience of working between Malawi and Zambia in his youth in service to the celebrated philanthropist and doctor, Donald Brownlie, got in touch with a large donation. Olivia asked him what he thought about spending some of the Gift Aid on that donation on accommodation in Malawi for another man who needed to travel between Malawi and Zambia and he agreed. We encouraged Diquence to attend during the week in December that



Sandy, our QIC, was teaching out staff about upper limb prosthetics. (See page 2)

And it all came together. Diquence was assessed as having a good range of motion and being very active for his condition. His left stump was cast , then fitted with a functional arm with a split hook to give him a grip. As well as the prosthesis, we made him an adaptive spoon on a functional angle with which he was able to eat his lunch, and an adaptive drinking bottle from which he could drink. Diquence had expressed his passion for writing and his difficulty in holding a pen in his mouth to write, so we made him an adaptive device to hold a pen. After a training session he was able write for a long time without getting tired. These devices were made from Velcro and elastic bands fitted round Diquence's stump and designed by Rabecca with advice from Sandy. We also gave him strengthening exercises for the left stump and trunk, dynamic balance training, training in donning and doffing and caring for the devices and for feeding, writing, drinking and using a computer and phone.

Diquence wrote to Olivia from Zambia days after he got home asking if we would like videos of him working in his garden to inspire others.

#### see videos at: 500miles.co.uk/patients

### **Our Best Student!**

In our last newsletter we reported that Samuel Mkomera from Malawi, a former technician at the 500 miles P&O Centre in Lilongwe, would soon graduate from CSPO with a 3-year international diploma and that we are looking forward to his return to work for us in March. Together with The Shoe Zone Trust, which funded a large part of Samuel's studies for us, we are extremely proud and happy to hear that he has won the school's "best student" award, voted for by his peers, just as he has passed his final exams. Samuel writes here about his experiences in Cambodia.

My whole journey started in March 2017 when I joined Cambodia School of Prosthetics and Orthotics (CSPO). I was so delighted in knowing that my dream will come true. The school time had been so amazing! However, I had to overcome many challenges.

CSPO's teaching programme is based on a system of nine modules, including prosthetics, orthotics, anatomy, pathology and other related subjects that help students to have an overall understanding of the service required and the ability to improve the quality of life for persons with disabilities. In addition, students are trained in leadership,



where we are trained on how to cooperate with their workmates and how to lead as managers.

In addition to the studies, we were given chances to explore

Samuel collecting his Student of the Year award

Cambodian cities, provinces, historical places and other recreation places. Visiting these places helped me to understand Cambodian culture, the people and their behavior.





Associating with different people helped me to meet many friends in Cambodia, in addition to my school friends. However, most of my friends are unable to speak English clearly, so I had to learn the local language (Khmer), which I succeeded to the extent that I am able to communicate well with the locals in the markets, transport services and leisure centres.

When I was in my second year, I was elected to be the President of the Student Association. That

### **Training: Samuel in Cambodia**

was a big assignment for me! Just imagine – I was supposed to lead students from more than 10 countries with different languages, cultures and behaviors. However, with my little leadership skills, plus being humbled and friendly to everyone, I succeeded until when I finished my term for one year.

It wasn't easy to adapt to the Cambodian environment at the beginning. I can't forget my first day going to the market where all the people around the market place were just staring at me.

Being the point of attention from the surrounding people was my big challenge. The other challenge was that I found Cambodia hotter than Malawi. It was also very hard to talk to my family due to time differences and high costs for international calls. Cambodians are friendly and hardworking hence I would like to follow their working habits. I have also learnt how to interact with different people plus learning a new language. In addition to that, clinical internship had equipped me with a lot of experience that am ready to apply them at my work in helping People with Disabilities when am back to Malawi.



Hard at work in the workshop



Making friends: left, with his fellow students on the football pitch and, above, showing off their latest work



### Fundraising



### **Edinburgh Revisited**

Last October, Gordon Hunter and Don Ledingham's photography and poetry exhibition at Stills Gallery in Edinburgh, called <u>Edinburgh</u> <u>Revisited</u>, was a great success. The exhibition was compiled into a beautiful book with an introductory message from Princess Anne and a forward by Alexander McCall Smith as well as contributions from some other well-known people. This extremely professional and impressive venture was undertaken by Gordon and Don for the joint benefit of <u>Leuchie House</u> and 500 miles. So far 500 miles has received £11,385 from sales of the book with possibly even more to come – which is quite incredible, especially when you think that is only half of what has been raised. <u>Please buy the book for £25!</u>



#### West Highland Way challenge

In May 2020 Douglas Gormley is aiming to walk the West Highland Way for 500 miles - in just five days. <u>Visit his sponsorship page</u> on gofundme.

### COMING SOON: The 500 miles Challenge

We will soon launch the **last ever** large-scale fundraising event for 500 miles. You will be able to raise money any way you like individually or as a group or club over a generous period of time but we will encourage you to devise your own challenge for 500 miles themed around the number "500".

The top fundraisers will earn free places at the 500 miles challenge ball. Look out for more details on who will be spurring you on!



### Another marathon effort

In 2010 Babs Ross, a teacher in Shetland, supported 500 miles by running the Amsterdam Marathon to celebrate her 40th birthday, raising a magnificent £754. 10 years on, we are so grateful that Babs is going to run the Stirling Marathon for 500 miles in October to celebrate her 50th! She is selflessly asking friends and family to donate to 500 miles instead of giving her presents - <u>see her fundraising page</u>. Babs told Olivia that she wanted to support 500 miles because, through her previous occupation as a podiatrist, she learned not to take her mobility for granted. We were delighted to discover that her daughter, Lois, is currently studying prosthetics and orthotics at Strathclyde University!



## 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.



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