



# Children with Cancer in Malawi

UK Registered charity no. 1111112



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## Winter 2018 Newsletter

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### There goes 2018...

Merry Christmas to all the supporters of Children with Cancer in Malawi. Another year has flown by and your amazing support has remained undimmed. It is clear to us that significant progress continues to be made in many areas thanks to your generosity. As always, on behalf of the children in Malawi, prolonged and heartfelt thanks to you all and especially to the parishioners at St. Andrews.



We have recently supported the introduction of first treatments for leukaemia in Malawi, and initial assessments of the results of these treatments are coming through. Five years ago, these children were not treated at all, and now a third are surviving. We have way to go but this is a very encouraging start. The treatments are prolonged and involve a lot of drugs which you all so generously supply.

There are also many other improvements which the following articles in this

Newsletter will focus on. Dr. Chagaluka continues to lead the enthusiastic team and has more plans to continue the improvement in outcome for the children with cancer in Blantyre.

May you all enjoy the festive season and thank you once again for your generosity, it is very much appreciated – our work simply wouldn't be possible without you.

**The CCM Trustees**

### The View from the Chair...

**An update from Hannah Di Lullo, CCM Chairperson**

CCM is now in its thirteenth year and continues to go from strength to strength. Thanks to all your wonderful support and generous donations, our work can continue to help facilitate the care and treatment of children and adolescents with cancer in Malawi.

This year, we have continued to fund three nurses' salaries and have sent out supplies of essential drugs and medical equipment which are currently unavailable in Malawi, including chemotherapy drugs, antibiotics and other medication which can alleviate distressing symptoms. As a nurse myself, I understand the frustration that is caused by not having enough, or being

unable to get the right drugs and equipment needed to care for your patients. Therefore, by simply ensuring this supply continues, we can help the team in Malawi to deliver optimal care within the resource-stretched environment they are in.



We are also moving with the times! 2018 has seen the launch of CCM onto two social media platforms, courtesy of Steve O'Brien's daughter, Lucy. We therefore now have a presence on Facebook and Twitter and are hoping to further develop the use of these in the near future – watch this space!

In February this year, the work of some of our trustees and colleagues in Newcastle was presented on the BBC Look North's Inside Out programme (see our website). This short piece showcased the achievements that have been made following the collaboration between medics in Newcastle and Malawi to aid the diagnosis of patients with Burkitt's Lymphoma and leukaemia by using the microscope camera.

In March, three of us were able to make a joint visit to the unit at Queen Elizabeth Central Hospital, Blantyre. Simon Bailey, Steve O'Brien and I flew out to Malawi to join Professor Liz Molyneux who was visiting the unit at the same time.

It felt weird to be leaving a snow-covered Britain to land in a hot, sunny African land! Liz Molyneux met us in her Green Machine which was to be our transportation for the week. Between us we had 5 large bags/suitcases and a bicycle but there is always plenty of room in the Green Machine!



Next stop was Kabula Lodge, which provided us with a peaceful place to stay not far from the hospital and where we met up with Vikki Rand (see below) who had arrived a few days earlier.

This was my fourth visit to the unit in Blantyre and I couldn't wait to see all the nurses again – together with some new faces. George Chagaluka and the team (see photo) gave us a very warm welcome and we were able to handover all the equipment we had carried out with us, together with a very large suitcase full of knitted blankets, hats, vests and toys courtesy of the Greenhead and Gilsland knitting group in Northumberland! It was good to meet Sister Anizia Kamwendo again, who has returned after maternity leave and with a Masters Degree! And to meet Sister Bridget Nsusa who has joined the team since I last visited.



Then it was time for the daily morning ward round which is still such a vital part of the ward's day, being used for clinical examination and assessment of all the inpatients as well as some outpatients who arrive during the morning for treatment and/or follow up. It is used for diagnosis and treatment planning, discharge planning, referral to other members of the multidisciplinary team such as the palliative care team, surgeons, physiotherapy but is also a very useful educational opportunity for junior medics, medical students and nursing staff.



After the ward round, the nurses are busy with all the children needing chemotherapy that day and for each child this can take some time from siting the intravenous cannula and taking any blood samples required to then making up the chemotherapy and giving it either as an injection or as an infusion over a period of time. There are also some children undergoing a bone marrow aspirate and/or lumbar puncture as part of their treatment or to make a diagnosis and these

procedures are being done in the treatment room at the end of the ward round, too.

After a short lunch break, the nurses are back monitoring the patients and giving out medication as well as looking after the intravenous infusions and possibly some blood transfusions.

Despite all this activity, however, I was able to spend a lot of time with the nursing team, running short education sessions at the beginning of their shifts and then working alongside them during the day, offering help, advice and troubleshooting any issues they were needing help with. And together with Simon, Steve, Liz and George we were able to tackle various problems from different angles and work on solutions whilst also being able to feedback in real time to each other.

For example, delivering intravenous fluids can be challenging when there are no suitable intravenous pumps available, something that would be unheard of on paediatric wards in the

West where high tech equipment is the norm. In Malawi, regardless of funding, the use of intravenous pumps is fraught with difficulty due to regular power cuts and surges, lack of appropriate giving sets, training and regular servicing. We therefore spent some time exploring various options and work is ongoing to help improve how intravenous fluids can be safely delivered.

The week flew by and as always there is SO much more to do but we are already planning our next visit for 2019. It was time then to leave the warmth of Malawi and head back to yet more snow!

## Return to Blantyre

By Prof. Elizabeth Molyneux

It is always such a pleasure to step out of an aeroplane in the tropics and take a deep breath. The air is hot and dry and smells of dust and frangipani; it feels like home. Perhaps the atmosphere takes me back, not only to Blantyre where we lived for 33 years, but also to my childhood in India.



I was in Blantyre in October and it was lovely to meet old friends in the hospital, catch up with Dr. George and do some ward rounds with the team. The ward has about 25 beds and was constantly full. Indeed, the children's cancer ward is now one of the busiest wards in the unit – in terms of bed

occupancy. Staffing remains the same with the number of nurses unchanged and Sister Kamwendo in charge. They really are busy as they give all the inpatient and outpatient treatments. Dalida our data manager has been in the ward for 9 years and is a pillar of strength. She not only records all the data but follows up patients in the village if they have failed to return to outpatient's clinic; she sorts out welcome packs for new comers on the ward and deals with surgical specimens that have to be taken to specific laboratories. Dalida's husband has been transferred for his work to Lilongwe and so she will be leaving us to follow him. She will be missed greatly. Someone has been appointed to take her place and we feel sure she will be excellent – but Dalida is a hard act to follow.



Prices have gone up – especially of fuel which means it is hard for parents to return for a clinic appointment. We provide travel monies (from gifts of donors) but there are always extra hidden

expenses that are covered by the family. Food for the journey, sometimes an overnight stay on route or in Blantyre.

Like the rest of the world there is increasing bacterial resistance to antibiotics. The problem in Blantyre is that there are not many alternatives to use; and those that can be obtained are very costly. Children with Cancer in Malawi has done a great job of not only making sure that the necessary chemotherapy is available, but also that some of the vital 'second and third line' antibiotics and antifungals are available too.

I am trying to adapt to Christmas in the UK. It seems to start awfully early. The children on the ward in the Queen Elizabeth Hospital will doubtless get a couple of visits from church groups and Muslim or Hindu ladies. Each child will receive, maybe, a small bag of sweets, a fizzy drink, a bag of crisps and a lollipop. The mothers will probably receive some hand soap, a small bag of maize flour, another of sugar and maybe even a plastic bucket. All of them will be delighted and will thank the donors with songs and dances. Perhaps later this month there will be enormous excitement when a parcel from Children with Cancer in Malawi will arrive full of carefully chosen books, puzzles, games and toys for of all the children to play with on the ward.

It is humbling to see how much joy is shared and how delighted the children are when receiving so little. It makes me wince a bit at our celebrations.

Many of the children on Sobo ward are undernourished, anaemic and ill, but they have a wonderful way of remaining positive, happy and hopeful whatever life throws at them.

They have a lot to teach us: we have a lot to learn.

## The Team's New Boffin!

We're pleased to introduce Dr. Vikki Rand from Newcastle University

This was my first visit to Malawi, and my first visit to Africa. It definitely won't be my last! From the minute I arrived and Prof Molyneux picked me up in the "Green Machine", to the moment I left Blantyre I had the most incredible experience and met the most amazing people.



As a scientist, I was not sure what my week would involve. I had plans to go through patient notes and to discuss research opportunities with the QECH and College of Medicine. I can't thank Liz, George and all of the staff enough, for welcoming me to the department, and providing me with so many opportunities to become part of their fantastic team. On the first day I joined the clinical hand-over meeting where I was

introduced to the team and got to hear about several patients. I was then swiftly whisked off to my first ever ward round, where George and Liz described each case to me and patiently answered my many questions. This was a very special and humbling experience as I saw first-hand how children with different cancers responded to their treatment.

It was also a very emotional experience.



I have been working with Liz, George, Simon and the team in Malawi for several years, researching Burkitt lymphoma in order to understand the biology of this disease and identify biomarkers to determine which patients will or won't respond to current treatment. We have collected tumour samples from 100+ patients and the associated clinical follow up data, such as whether their tumour came back or whether they survived their treatment.

However, to see the children in the hospital first hand, and their courage and bravery, was very moving and inspiring. During my visit, there were some children who were discharged including a very happy little boy who was successfully treated for Burkitt lymphoma. We enjoyed playing together with the stickers and

colouring books I brought with me as a present from my lab. However, this wasn't the case for some. There were children who had originally responded to treatment but had returned with relapsed disease, including one teenager who had returned with a second relapse. To see the discomfort because of the size of the tumours and hear about the limited treatment options available for them was upsetting but very motivating to achieve our research goals and strive further.

Now back in Newcastle and reflecting on my visit, I find myself wondering why I hadn't been to visit sooner. I look forward to my next visit, putting our research plans into action, working with talented Malawian scientists and clinicians, and helping improve treatment of Burkitt lymphoma and other childhood cancers.

Follow me on Twitter @vikkirand

## Donate

You can donate at: [www.childrenscancermalawi.org/donate](http://www.childrenscancermalawi.org/donate) or by post at: Children with Cancer in Malawi, Ward 14 Day Unit, Royal Victoria Infirmary, Queen Victoria Road, Newcastle-upon-Tyne, NE1 4LP, United Kingdom.

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