Children with Cancer in Malawi

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Summer 2023 Newsletter

2023 Visit to Malawi

It was wonderful to visit the unit in Blantyre again. As always, we were made to feel very welcome by everyone; it really is the friendliest country in the world. The unit is very appreciative of all the help and support from Children with Cancer in Malawi and from their friends at St Andrew's.

The trip was overshadowed by Cyclone Freddie, where sadly many people in Blantyre lost their lives and the hospital had many casualties. Professor Molyneux, with her extensive experience in emergency care, was invalauble and a rock to the Department. There was no water in the hospital for 36 hours and staff were having to wash their hands in buckets of rain water.

As with the rest of the world, inflation is high and costs increasing. Despite the increasing general hardship, the team continue to improve the care they give to the children. Sister Di Lullo resumed her on site nursing education which was very well received; there are now more nurses which has improved the care they are able to deliver. Sadly, Rachel the pharmacist is on a year's sabbatical which is a big miss. Dr Chagaluka is extremely busy, not only running the Unit but also the whole Paediatric Department. Professor Molyneux was also in Malawi at the same time and she continues to support Dr Chagaluka by visiting up to 4 times a year. We were also joined by Captain Adrian Jenkins, a British Airways captain who was as good at entertaining the children as he is at flying. Families and children at his wife, Nicola's, school donated suitcases full of clothes which were very useful especially for families who lost everything in the cyclone.

We manged to look at the strategic objectives of the team, and now have a 10 year plan for how the Unit can develop, and how CCM can support the Unit in the best way. It also gave us an opportunity to see how much has been achieved in the last 10 years. These achievements have included developing new treatment protocols for many cancers, ward improvements, introduction of technology to perform blood counts within minutes as well as to analyse electrolytes, more nurses and improved diagnostics. However there is still a long way to go.

Our visit also gave us a chance to reflect on all your amazing and sustained generosity and the difference it has made. Your help and kindness is much appreciated, by both ourselves and more importantly the children with cancer in Malawi.

Zikomo Kwambiri.

The CCM Trustees

Latest Updates from Blantyre

by Dr George Chagaluka

JOYS AND TRIBULATIONS: The first half of 2023 has been full of joy and tribulations. The joys emerged from the fact the Unit was able to see an increase in number of patients. In terms of tribulations, the country witnessed the worst cyclone ever to hit Malawi. Most families lost loved ones and crops. Deaths also resulted from a cholera epidemic that occurred following disruption of the water system from the cyclone. Patient follow-up was also affected. Most roads were rendered impassable to the extent that it was not only impossible for patients to come to the hospital but also difficult for hospital teams to reach patients in their homes.

NURSING: Some of the Unit nurses were able to attend training courses outside the country. Ellen Mpachika went to Tanzania in May to attend the 'Trainers of Trainers' workshop. Anizia Kamwendo and Elizabeth Mugawana went to Red Cross Hospital in Cape Town for a six-week oncology course. These two nurses also had online courses for four months prior to their departure to Red Cross. Bridget Nsusa received a scholarship from the Department of Paediatrics to study for a Master's degree in Paediatrics and Child Health. All of the above will help improve the delivery of care for children with cancer and will ultimately help improve treatment and survival.

CLINICAL: Dr Beatrice Phiri is towards the end of her training in Cape Town. She will be back in the Unit by next year and the team are looking forward to welcoming her back.

LABORATORY: The laboratory recruited a new laboratory technologist, Ndagha Mbisa Kalonga. Ndagha has a degree in Laboratory Technology and is passionate about her work She works very hard and enthusiastically and will be an asset to the team. Sadly, Richard Fudzulani, who worked in the laboratory over twenty years, retired. Although he has retired, we are still in touch with him. His dedication to duty and his beautiful slides will be missed.

The laboratory also received a blood gas analyser from the Malawi Government. The Government provided reagents and a service level agreement from the supplier, which is a welcome addition to the laboratory capability. Our old blood gas analyser currently serves as back-up machine.

DRUG AVAILABILITY: The country continues to experience erratic supplies of essential cancer medicines due to the lack of foreign exchange; this seems to be getting worse with the passage of time. We are very grateful for the continued support of CCM.

VISITORS: In the last six months we had several visitors to the Unit. We were privileged to be visited by Prof E. Molyneux, Prof S. Bailey and Sister Hannah Di Lullo. This visit is always important for us. Apart from the daily ward rounds that we conducted with the team, we also discussed and outlined the Unit's ten-year plan. We are grateful to our visitors and value their unwavering support to the ward.

Thank you on behalf of all the QECH team for your longstanding and unwavering support, we really appreciate it.

Touch-down in Blantyre

by Captain Adrian Jenkins

For many years Prof Simon Bailey, or "just Simon" as anyone who knows him knows that's what he likes to be called, has invited me to travel with him to see the work he does as a Trustee with Children With Cancer in Malawi, CCM.

Perhaps I should give a bit of background, as I'm sure he doesn't invite any stranger to Malawi with him.

Many moons ago, not even this Millennium, I trained and eventually qualified as a Staff Nurse. Amazing as this vocation was, I always dreamed of higher things (literally). Through an awful lot of luck, I found myself being taken on by British Airways as one of their sponsored cadet pilots. Fast forward several more years, whilst I was a Co-Pilot on the 747 I heard about another charity, Dreamflight. They take 192 deserving children on a holiday of a lifetime to Orlando every October. With my nursing background I applied to fly the trip one year, this is where I met the Medical Director and Trustee, the very same Simon Bailey.

We soon became friends and, knowing my love of the African continent and my medical background, he was very keen to tell me all about his other charity and love, CCM.

You cannot fail to be impressed with the work this charity does, and when I was invited to see it first hand, I knew I couldn't turn the invitation down. So it was in March this year, post pandemic, that I finally got to book my tickets to Blantyre Airport. Simon was very keen to see my opinion as an "outsider". So, here is what I found.

We landed into Chileka International Airport Blantyre on Saturday March the 11th, touching down just before the heavens opened. Little did we know this was just the start of things to come. For the next four days the area was hit by Cyclone Freddy, one of the worst tropical storms to strike this century. It wreaked havoc on the area with great cost to infrastructure and human life. Sadly the last count I heard was that over 50 children, despite the staff's best efforts, lost their lives. Many more were brought in injured and orphaned, it was like nothing I have experienced before. At times there was no running water, intermittent electricity and no Wi-Fi or data. I commented that if this had been the UK, the Hospital would have been closed to admissions, but no such chance here!

Despite the Children's Cancer Ward not being directly affected, it was still put under a huge amount of strain at the beginning of the week as resources were directed to where they were most needed. This made the welcome we received even more heart warming. Dr George Chagaluka and his team of nurses couldn't have been more accommodating.

I can't lie, when you come from a lifetime of NHS hospital wards, there is a real culture shock when you first step onto a ward in The Queen Elizabeth Central Hospital, and it did take a little getting used to, but more about that later.

During our week's stay, a typical day consisted of attending the morning paediatric hospital handover. We would then be invited to join the ward round on the children's cancer ward before sitting in on outpatients. There was time also for mini tours of other Departments in the Unit. It was on these tours where you could

see some of the initiatives started by CCM first hand, and see how they were helping to improve recovery rates for the children. Just one thing out of many is the camera, set up to a microscope, which then can be set up to a laptop computer. This means that almost instantaneously a slide can be reviewed by experts in Newcastle and a timely diagnosis can be made.

In the afternoons the team of visitors split to their own fields of expertise, Simon would go off with the Doctors to review some of the trickier cases and look into where further help could be given. Hannah Di Lullo, Oncology Nurse Specialist, would run training sessions with the nursing staff, who were all keen to learn and improve. Terry Asprey, as an adult physician, would go wherever he felt he could help and lend his knowledge and skills. Then of course there was Prof Liz Molyneux, I had heard all about this legend, she did not disappoint!

Feeling a bit of a spare part and quite considerably under qualified amongst all these experts, I did the only thing I felt I could do, deciding to entertain the children (and unbeknown to me maybe some of the parents).

Unfortunately my grasp of Chichewa, the local language, was non-existent and none of the children and few of the parents I met spoke English. This didn't seem to hamper us too much though, I grabbed my British Airways-issued iPad and downloaded a few simple games. I would then go round the ward introduce myself with a few pictures of my plane and some crazy places I have visited, then I would start showing them how to play the games. It wasn't long and I started to feel like the Pied Piper, I would always have my little posse following me round as I tried to share my time with all the children…….who would thought time could fly playing 4 to 5 straight hours of Candy Crush and Helix?

It was during these happy hours that the original "culture shock" fell away. Very quickly the ward started feeling like a second home. I loved the way the parents cooked food outside on open fires and did their washing in sinks outside the ward, all under a shelter provided by the charity. I will never forget the amazing sound of parents and visitors joining in with a communal song each morning. Despite the language barriers I started making friends and realised there was no difference on this ward than to anywhere else. The children wanted to feel safe and have fun, the parents just wanted their children to be well again. I was amazed at the stories of some parents travelling days to get their children to our ward, but then when you realised this was their only chance of survival, it made complete sense.

Here lies the great work undertaken on the ward by the staff, supported by the charity. From what I was told several years ago many of the children I met, entertained and made friends with, would have had a very poor prognosis. Now there is hope for many of them!

This is why I am so keen to stay involved with Children With Cancer in Malawi and have such a soft spot in my heart for the Cancer Ward in the Queen Elizabeth Central Hospital!

The work is not done yet though, what was apparent is that the Trustees of the charity are not prepared to sit on their laurels. Along with Dr George Chagaluka and his team, there is a 10 year plan to improve things further. Some of the plans are simple and hopefully easy to accomplish, others are very ambitious and will take a great deal to implement, but the rewards will be immense. I would like to thank all within the charity and everyone at the hospital for making me feel so welcome on my visit, I hope you can tell the impact it had on me.

For those reading this who are thinking of supporting the charity in any way, I urge you to do so in whatever way you can!

Fundraise or Get Sponsored

Anyone can use 'CAF' to raise money for CCM through online sponsorship, or to donate. It's free for charities (aside from credit card charges). So, if you're thinking of doing a fun run, climbing a mountain or any other sponsored challenge, head over to https://cafdonate.cafonline.org/12935#!/DonationDetails and raise money for CCM. Every penny will come directly to us.

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Use easyfundraising to shop online at stores including Argos, M&S, Ebay & Booking.com. The retailer will donate to CCM, free to you - just nominate us as your charity.

Donate

You can donate at: www.childrenscancermalawi.org/donate or by post at: Children with Cancer in Malawi, 39 Reid Park Road, Jesmond, Newcastle Upon Tyne, NE2 2ER, United Kingdom.