



# Children with Cancer in Malawi

UK Registered charity no. 1111112

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## Winter 2015 Newsletter

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### CCM in 2015...

This has been a momentous year for Children with Cancer in Malawi, both for the charity and the children being treated. Much of the progress made is down to our very generous supporters, who have enabled advances by supplying much needed medication and equipment, as well as supporting the staff. Thanks to all of you, especially our friends at St. Andrews.



As Christmas draws near, the consignment of toys lovingly chosen by our Chairman, Ian, and his wife, Joan, are being packed and despatched. The ladies of Greenhead and Gilsland have sent out wonderful knitted clothes for the children; it does get cold at night especially in

the Winter and there is no heating. There have been many other shows of generosity and the team in Malawi are grateful for all that they receive.

This year saw the 10th anniversary of CCM, which we celebrated with an evening event, with some talks followed by an informal gathering, including a massive cake with the Malawian flag proudly displayed (kindly made and donated by Tracy Mitchell). There was an impressive turnout and it was wonderful to meet many of our supporters who have helped move cancer care in Malawi so much further on.



We would also like to take a moment to dwell on the imminent departure of Professor Molyneux from Malawi, who is retiring after nearly 40 years. She is the mother of paediatric oncology, not only in Malawi, but also in much of sub-Saharan Africa. Oncology is just one of the strings to her very impressive bow; in this time, she has led the development of the unit from scratch, and taken the level of care from a point where almost no child survived cancer, to one where many have a good chance of survival. Her inspirational leadership, outstanding vision, humbleness and gentleness has inspired a generation and made a real difference to so many children. Very few people in life can touch so many in such a positive way.

Happily she will still be involved and will be visiting the unit 3 times a year, to help collate data and offer wisdom and advice to those that remain. Thank you, Liz, on behalf of all the children and

families you have helped over many years. We have all learnt so much from you.

Dr. Chagaluka has taken over leading the Unit after his training in Cape Town; he is a wonderful and gentle man who is loved by the children and their families. He has already expressed his gratitude for all the help that CCM give to the unit in Malawi, and is very keen to work with us. The future is in good hands.

On the treatment front, the initial exciting results of the improved treatment suggested by the CCM team for children with Burkitt lymphoma have been confirmed and presented at a major international conference. This will be published in a medical journal soon. The overall survival for these children is over 70% using the new protocol, up by nearly 20% from the previous treatment. Children with leukaemia are also doing better than ever before, as are children with eye tumours.

Technology-wise, the microscope camera bought by CCM continues to be heavily used, with Dr. Peter Carey from Newcastle looking at nearly 1500 samples over the last 3 years. Prof. Steve O'Brien from Newcastle



has developed a web-based reporting system, which has been very useful to aid the microscope camera. The electrolyte machine supported by CCM has also helped many children receive optimal management.

Sister Hannah Di Lullo, one of our Trustees, has improved the level of nursing care exponentially with her visits and continued support (see her latest report later). The nurses, including the St. Andrews nurse, paid for by CCM have enabled nursing levels to be maintained and to continue to provide the care the children need.

A huge thank you to all of you for helping so many children over the last 10 years. We hope the next 10 years will be as fruitful.

Merry Christmas and a prosperous New Year to all of you.

**The Children with Cancer in Malawi Trustees.**

## A Letter from Malawi

By Prof. Elizabeth Molyneux

It is splendid to have George Chagaluka back in the Department to head up the Oncology Unit. He has settled in easily as he is so familiar with the ward, the setting and the staff.

Sister Kumwendo has a lovely baby girl who has rightly kept her occupied, and now Sister is off on a two year Master's course in Paediatrics. We wish her well and hope she will return to us on completing the course.

I too am on the move – as Malcolm my husband says – we are not leaving Malawi but simply relocating. We are moving our base to the UK to be nearer grandchildren who are growing up quickly and to be nearer our children who occasionally need us.

I move with an uncertain heart – glad and proud of George's return and pleased that the unit is in good hands. It will be good to see more of family – but Malawi has been home for nearly 40 years and it has been an enormous privilege to care for the children of Malawi.

Simon and I will be visiting regularly to help in any way we can. Thank you for all the help that you have given and continue to give. I know that the staff and children would want me to say how grateful they are to you for your sustained and generous support.

Zikomo ndithu.

## Return to Blantyre

By Sister Hannah Di Lullo



In July of this year, I was fortunate to be able to go out to Malawi for a fourth time to spend a week with Prof. Molyneux and the nursing staff. Having not been for a couple of years, I was keen to catch up with the team again and was welcomed so very warmly. As usual, I arrived with a box and suitcase full of medical supplies to help the nurses with their intravenous chemotherapy administration. The equipment that is provided by the hospital for this is often in short supply or equipment like syringes are inappropriate sizes. Therefore such supplies were very gratefully received!

This year, however, in addition to medical supplies, I took out a sample selection of children's jumpers and a blanket which a group of ladies from my village in Northumberland had kindly knitted for the patients on the ward. There were also some knitted puppets which went down very well! The blanket was given to a mother whose daughter has Burkitt's lymphoma and who had been on the ward for some weeks, far from home and separated from their close family. The knitting group continue to produce jumpers of varying sizes to fit all the children and beautiful large blankets all of which will be given to families who often arrive on the ward with very little and who have little means to clothe their children or keep warm on cool nights. Thank you to all the knitters!

During my visit, the ward was as busy as ever with all the beds full and more children arriving every day. I saw children with a variety of different types of cancer, some of whom were very sick but some who had made great progress, for example having arrived on the ward, unable to walk due to tumour burden, now walking with help. There were also two children who had lost their sight because of tumours who each day were able to seek comfort from playing with sensory toys that they could feel and hear, which had been provided by CCM. Betty, the play lady, continues to play a vital role in providing play opportunities for the children and useful distraction while the children stay on the ward, sometimes for weeks at a time. She makes sure every child has

toys to play with, either at their bed or in the play area which is always a busy, happy place.

Spending time with the nurses is always a privilege. It was good to catch up with them all and hear about how they have been getting on. Each morning I was able to deliver some educational sessions particularly surrounding the management of side effects of chemotherapy and with them, was also able to review some of their practices and look at different ways of dealing with some of the many difficulties they experience.



As ever, my visit was too short and there is always more to do but this year felt more poignant, being with Prof. Molyneux before her imminent retirement and in CCM's 10th anniversary year! Prof. Molyneux is a true inspiration who has done so much for children with cancer in Africa. I have learnt an incredible amount from her and wish her peace and happiness in her new life in England.

During CCM's 10th anniversary year, I have been able to reflect on all the tremendous progress made since Prof Molyneux set up the unit and then, more recently, in the last ten years since the charity CCM was born. In 2015, more children than ever before are surviving childhood cancer in Malawi, new treatment protocols are instrumental in this progress as are the team's developing knowledge and expertise. The experiences of the children and their families are also improving as the facilities, nursing care and improved supply of medication and equipment make a real difference. The future, therefore, is bright and I wish George Chagaluka and all the nurses a peaceful and successful 2016!

## Father Michael Corbett

It was with great sadness that we learned of the passing of Father Michael at the beginning of December. Father Michael helped many patients and their families as Chaplain at the Freeman and RVI Hospitals over the last ten years, as well as the parishioners of St. Andrew's and all the other parishes that he served in the Diocese of Hexham & Newcastle. He was a wonderful friend of CCM and will be greatly missed – our sincere sympathies go out to his family and friends.

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