Children with Cancer in Malawi

UK Registered charity no. 1111112

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2013-2014 Newsletter

2013 in Malawi....

Happy Christmas to you all and a huge thank you once again for all the wonderful support that you have given to the children in Malawi in 2013. Professor Molyneux and her team remain very grateful for your support; it means they are able to continue to provide a good service for the children and their families as well as making strides forward. Once again a huge thank you to the parishioners at St. Andrews for your unstinting generosity.

This year, a number of exciting developments have taken place. As you may know from our previous newsletters, a new protocol to treat children with acute leukemia was developed two and a half years ago, using drugs provided by our charity. A new, more intensive, leukaemia protocol has now opened which will hopefully provide even greater chances of cure. This has required different chemotherapy drugs, which we have again provided.

The microscope camera that you bought last year has enabled 300 children's samples to be assessed in Newcastle within hours of being taken in Blantyre. It continues to enable Professor Molyneux and her team to treat the children more effectively. The country's first neurosurgeon has started operating on children using a microscope donated by the Royal Victoria Infirmary in Newcastle, and sent out by us (below). This will help enormously and is the start of being able to treat some children with brain tumours.

We have continued to supply an increasing range of chemotherapy drugs as well as some more effective drugs to help with nausea and vomiting. We continue to pay for the cartridges which allow vital blood tests to be done 24 hours a day.

Dr. George Chagaluka is now undergoing the final part of his training in Cape Town and he recently met Simon Bailey (CCM Trustee) during a visit there. He is very grateful for all the support the Malawi unit receives from CCM.

A package of toys, expertly chosen by CCM chairman Ian Sharkey (left) and his wife Joan, have once again been sent out to Blantyre for this Christmas. The childrens' faces when opening the box are wonderful to behold.

Once again, a very big thank you for all your generosity in ensuring that children with cancer in Malawi are able to be treated in an effective manner.

A Blessed Christmas to you all. Zikomo Nduthi.

The Children with Cancer in Malawi Trustees

A message from Malawi

From Prof. Elizabeth Molyneux, Queen Elizabeth Central Hospital, Blantyre.

The weather is hot and humid we are waiting for the rains; the children and their families from the ward are glad of the shelter, where they sit and talk and play. The ward is full – 30 children in the 25 beds, but Betty the play lady keeps them occupied and many of the older ones spend a little time every day in the school.

The nurses have taken on extra duties this year; we have increased the treatments of the children with leukaemia which has meant getting familiar with 'new' drugs, we have treated more retinoblastomas, and now we are being sent several albino children with difficult skin tumours. Lilongwe, 330 km north of us, are sending us all their Wilm's tumour children for surgery.

So it has been enormously helpful to get regular provision of drugs from Children with Cancer in Malawi.

Simon Bailey and Hannah DiLullo both came, taught and advised on patient management and ward protocols this year. It was splendid to have them, they not only teach us, but they boost our morale.

Kondwani Banda, our clinical officer, gained a Bachelor's degree in Palliative care and for the first time we have a government nurse join the team. She got married last month. She writes later in this newsletter. George Chagaluka is in Red Cross Hospital in Cape Town specialising in paediatric oncology.

At Christmas you send the children toys - wonderful, robust, interesting toys - that all the children enjoy (I think Betty and the mums do too). The toys last all year and keep many little children happy and distracted from all the discomfort of treatments and being in hospital for long periods of time.

Today as I walked down our hospital corridor I met one little girl on her way home after chemo; she is not completely well yet, but was happy to be going home for a couple of weeks. Further down the corridor a little boy greeted me, smiling from ear to ear. He had not been able to walk when he came into the hospital with Burkitt's lymphoma a couple of months ago, and here he was walking down the corridor towards me.

Despite the challenges and difficulties there are days when everything seems utterly worthwhile. Thank you for helping make it so.

Happy Christmas.

Some thoughts from the Ward

By Sister Anizia Kumwendo, Queen Elizabeth Central Hospital, Blantyre.

The Paediatric oncology ward is one of the wards at Queen Elizabeth Central Hospital which takes patients from 0 to 15 years old with cancer. It has 24 beds of which two are in an isolation room for leukaemia cases. The award admits up to 35 patients, the extra patients use matrasses on the floor. There are six nurses in the ward, only one (myself) is employed by the government and the rest of the other five are paid for by charity, 3 from your Children with Cancer in Malawi charity. The patients come from all over the country because the Queen Elizabeth Central Hospital is the only hospital in Malawi with a separate paediatric oncology ward.

Sister Anizia and Dr. George Chagaluka

On admission every patient gets a welcome pack up which contains sugar, tea leaves, cooking oil, salt, washing soap, matches, toothpaste, tissues and a toothbrush. Some families do not have enough money to return for checkups or further treatment and are given some money to make sure they have enough to return. With the number of nurses working in the ward, it's also a challenge, as often there are only two on duty with 30 or more patients which makes it difficult to deliver quality care to all patients.

Thank you for the help you give to the children in our ward and to the staff, we appreciate it very much.

Sister Anizia

Hannah makes another flying visit!

By Hannah DiLullo, CCM Trustee.

It is with great pleasure that I am able to report back on my third visit to the Children's Oncology Unit at Queen Elizabeth Hospital, Blantyre. Following my previous visits, I was keen to meet up with the team again and to continue my educational work with the nursing staff.

My arrival, however, did not go according to plan when I discovered that my suitcase (which not only held all my personal attire but was also full of medical and nursing supplies) had not arrived with me!! Though not an uncommon occurrence for travellers to Malawi, my concern was that the suitcase and all the supplies would not arrive before I had to leave and return to the UK. It was with relief, therefore when I found that my case had made it to Chileka airport mid-way through my week in Blantyre and I could put on some clean clothes!!

The team on the ward in Blantyre

Despite that unfortunate beginning, I was given an extremely warm welcome by everyone on the unit. It was great to see Prof. Molyneux and her wonderful team again and to see that yet more progress and improvements have been made over the past year to improve the care that the children and their families receive.

The ward looked as bright and cheerful as ever with some new colourful curtains to compliment the art work on the walls. As usual the ward was very busy and full of children with their parents but despite their adversity there were still smiles and some giggles from the children who were well enough to run around and play. Betty, the play lady continues to do a great job of distracting the children with the wonderful toys sent each year by CCM – the play area was often crowded with children busy playing. Thanks also to all your amazing support, there was a well-stocked drugs fridge full of chemotherapy drugs and plenty of other drugs on the ward to aid supportive care, including painkillers and anti-sickness medicines. Chemotherapy remains central to the treatment of childhood cancer in Malawi and makes up the bulk of the workload for the nurses on the ward, hence the need for your continuing support to help this process.

A major development for the unit, this year, has been the appointment of a government-funded nurse, Sister Anizia Kamwendo. This is the first time that a nurse has been funded directly by Queen Elizabeth Hospital rather than by charitable funds, an important step forward indicating some recognition by the government of the need to fund a children's cancer unit in Malawi despite the years and hard work it has taken Prof. Molyneux and her team to build up the unit from scratch. Sister Kamwendo's addition to the team has been welcomed and it is hoped that there will be more government-led funding in the future.

George Chageluka will also rejoin the team next year following his last few months' training in south Africa to become Malawi's first home grown Paediatric Oncologist. Everyone looks forward to his return to Blantyre next year to start work as a Consultant!
Another development this year has been the introduction of a more intensive treatment protocol for leukaemia. In the West, most children who are diagnosed with leukaemia are cured compared with a small minority in Malawi. It is hoped, therefore that this new protocol, which has been carefully adapted from protocols used in the West, will improve long term survival rates. During the week I was there, I was able to introduce this protocol to the nurses by holding several teaching sessions about the new chemotherapy drugs they would be using and the nursing care issues involved. I helped them set up an emergency drug box for use in case of allergic reactions to specific drugs and discussed ways of helping a family's compliance for a child to take oral medication for up to two years of treatment.

This year, I was also able to run a teaching session each morning at 8am which meant that those nurses on both day and night duty could attend and in fact the nurses that were not on duty that day also came in for the sessions on their days off, showing the high level of commitment and dedication to the work they do and their wish to improve their knowledge and skills!

The week I was there also coincided with a visit by a nurse, from Lilongwe, who works in a small unit which is beginning to treat children with cancer from the north of the country. She had come to observe the nurses' work on the unit in Blantyre and was therefore, also able to attend my teaching sessions. It is hoped that further links will be made with the unit in Lilongwe to help treat children more locally instead of families having to travel long distances south to Blantyre.

As on previous visits, my week flew by and before I knew it, I sadly had to say goodbye to all my friends in Malawi. Thanks, once more, to the team for having me but especially to Prof. Molyneux and the Sisters Kamwendo, Thundu, Chisale, Likoleche, Mumba and Gong'a - you are inspirational!!

Thank you, Jamie

Jamie Shield is a very special young man. Jamie has had a number of health issues to deal with which he has done so in a courageous and determined manner. He has been left needing to use a wheelchair for mobility but this has not slowed him down. So determined is he to help others that he completed the Great North Run (half marathon distance) in his chair (it is seriously hard work) in order to raise money for Children with Cancer in Malawi. He has raised an amazing total of over £650 which will provide enormous benefit to the children in Malawi.

We salute you Jamie for your unselfish courage and determination. The children and team in Malawi thank you for your superb effort.

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