Children with Cancer in Malawi

UK Registered charity no. 1111112

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Winter 2016 Newsletter

CCM in 2016...

This year has been a year of change in the paediatric oncology unit in Blantyre which is continuing to flourish and despite the poor underlying economic climate in the worlds poorest country, (Malawi was officially the poorest country in the world in 2015) thanks to our supporters the children with cancer in Blantyre continue to have ever improving treatment.

Firstly our thanks to our many loyal supporters and especially to the wonderful people at St Andrews. The legacy of the incredible Father Michael continues as strong as ever. The generosity of all our supporters continues to amaze us and the team in Blantyre is incredibly grateful, they are heartened by the knowledge that people in the UK believe in them and are prepared to support them.

This year has seen some big changes in the Oncology unit. The incredible Professor Molyneux has relocated to the UK although she continues to travel to Malawi every 4 months or so for a few weeks. She continues to be an inspiration to us all and especially to Dr Chagaluka who has taken over the running of the unit. He is doing a great job maintaining the momentum that Professor Molyneux has generated over many years. We have continued to support the remote diagnostic service and are pleased to let you know that Dr Carey and Professor O' Brien are now also supported by Dr Dang and Dr McGregor. This makes looking and reporting the specimen slides much more sustainable, there are about 600 children a year whose blood counts, bone marrow samples, tumour samples and spinal fluid samples that are looked at. This is incredibly helpful to the team in Malawi as samples in Malawi can take up to 3 months to be looked at, too late to inform the childrens treatment.

More and more children with leukaemia are being treated with more intensive treatment to increase their chances of cure. The team feel that leukaemia is not only been thought of and diagnosed more often but also that teams from elsewhere realise that children with leukaemia in Malawi can be treated and are sending the children to Blantyre. This success means that more resources are required to purchase the drugs and space is becoming a bigger problem. It is only 5 years ago that the first child with leukaemia was treated in Malawi, incredible progress in a setting such as Malawi.

Ian Sharkey our chairman of many years standing has decided to step down, he has done an amazing job as chairman and has ensured the smooth running of the charity. Ian a huge thank you from all of us both in the UK and in Malawi. Happily he and his wife Joan are happy to continue choosing and packaging the toys that we send out at Christmas (we never understand how so many toys can be fitted in a box). The toys are on their way this year and will be as always received with much joy and excitement. We are also delighted that Hannah Di Lullo will take over the chair and the tireless Marian will continue as treasurer.

In this Christmas season we would like to thank you for your continued support over so many years, the team in Malawi have thanks to yourselves been able to continuously improve the treatment for the children with cancer in Malawi.

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

The Children with Cancer in Malawi Trustees.

Children with Cancer in Malawi; a step at a time over the last 40 years

Prof. Elizabeth Molyneaux

The beginnings

In 1974 Malcolm, my physician husband, and I first went to Malawi to work in a small mission hospital, but a year or so later the government asked us to come down to the big government referral hospital in Blantyre where there was no specialist in adult medicine: (the previous specialist had left the country). Malcolm is a physician and so we moved to work in the Queen Elizabeth Central Hospital and stayed there for 33 years.
I joined the only other paediatrician in the hospital and together we tried to manage all the various childhood illnesses, diseases and problems that presented to us. The mortality of children under five years of age was high (over 270/1000 live births) because of infectious diseases, and measles was a particular problem in the early days. Nothing was being done for the

children with cancer because of the overwhelming nature of everything else. It seemed to me to be particularly harsh that children who had survived the infections of early childhood would now develop a cancer and I wanted to do something about it. Burkitt's lymphoma was (and still is) the most common cancer in children and so we decided to start treating it. Our treatment was very simple – no lumbar punctures, only one IV drug – and yet about 25% of children did well and many more felt a lot better for it. We treated the children on the 'medical' ward where all the children over 6 months of age were admitted. It meant that the children with cancer were exposed to infections which was less than ideal. At one stage we put them in the surgical ward to try to separate them from infectious cases.
As we got more familiar with chemotherapy and the number of staff increased we were able to add a few more drugs to the regimen. Follow up of the children was difficult as they lived far away and did not have the money to travel into town for review. We did not have the funds to help them.

The oncology ward
In 1991 the College of Medicine opened and Prof Robin Broadhead was Head of the Paediatric Department. He persuaded Southern Bottlers, the local manufacturers and distributers of soda drinks (and beer) to build an extension to the paediatric department in which to house the oncology patients. It opened in 1997 with 2 nurses and about 12 beds.
Improving protocols for Burkitt's lymphoma (BL)
Not long after this Prof Peter Hesseling, with funding from the Society of International Paediatrics (SIOP), visited Malawi from Cape Town and help set up the first of a series of studies in which we tried to improve the outcome of children with Burkitt's lymphoma. We started with a modified version of one of the SIOP protocols but found it far to toxic for our malnourished children with advanced disease. Over the next 2 decades we fine tuned the treatment (often reducing doses) and tried to improve outcome without increasing toxicity. Prof Simon Bailey and the Newcastle team have been especially helpful with training the nurses, providing drugs, funding follow up and essential tests and being our mentors and friends. With their help we now have a regimen for BL with 73% one year survival; a huge improvement from the 25% success of the '70s and early '80s.

The old ward

Staff
There have been many other improvements. The ward was extended to 23 beds and the number of nurses increased to 5 and, this year, to six. A clinical officer (nurse practitioner) has been one of the team for many years and has been able to complete a bachelor's degree in palliative care and is just finishing a degree in health sciences. Another clinical officer has joined us in his absence. Dr Chagaluka has trained in Cape Town as a paediatric oncologist and is back in the QE leading the oncology programme.

Managing common cancers other than BL
Dr Trijn Israels came to Malawi from Amsterdam and did a PhD looking at Wilm's tumour. This helped us develop an appropriate protocol for Wilm's tumour and under her leadership a collaborative for WT management has been formed across several African countries.

Managing leukaemia is challenging. The treatment is long with periods of intensive chemotherapy which are hard to manage in our setting. But we are trying and have had some wonderful successes.
Retinoblastoma and Kaposi Sarcoma are other diseases for which protocols have been developed and from which children have benefitted greatly.

Palliative care
One very rewarding achievement has been the development of a pediatric palliative care team who help with pain control, counselling and follow up. This was the first palliative care programme in Africa that was specifically for children.
Challenges
There are still many challenges, for instance with; laboratory support, lack of radiotherapy, inability to feed intravenously, the many cancers that cannot be cured at present, and the many that present late. But the department is in good hands with Simon, Hannah and many others continuing to provide help and support. I retired last year. George kindly lets me visit a few times a year and it is encouraging to see how the ward continues to flourish and the children continue to improve. Long, long may it continue to do so.

Professor Molyneux and Dr Chagaluka

Introduction to The Nursing Staff

Dr George Chagaluka

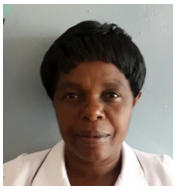
The number of admissions seems to be ever increasing mainly due to increase in the number of Medical officers in the District hospitals referring more children with suspected cancer. This is especially so for acute lymphoblastic leukaemia, and Burkitt's lymphoma. Support from Children with Cancer in Malawi is a lifeline to the Unit.

The nurses are extremely important in ensuring the children get the best treatment. The nursing staff has been pushed to the limit due to the increased number of cases but they have maintained their morale and strong work ethic. I thought you might like to know a little about each of them.

BRIDGET NSUNSA

Bridget is twenty-three years old and a holder of Bachelors of Science in nursing & Midwifery and started working in the unit on 18th July 2016. She is currently the head of nursing section. Her motto is "Cure for every little kid.'' Bridget is enthusiastic and a hard worker. She would like to pursue a career in Paediatric oncology and palliative care.

EMILY GONG'A

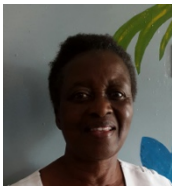


Emily is the St Andrews nurse. Emily talks very little, but does a lot of work. She has been in the Unit for 12 years. I am yet to see her show anger or frustration. She is a typical Malawian who will show you a smile even in difficult times.

ESNART NGWIRA

Esnart is a holder of Bachelors degree in Nursing & Midwifery. She started working as a volunteer in the ward on 18th January 2016. Her passion is to see critically ill patients get discharged from the ward alive and well. As with all the nurses she is very decicated.

EDITH MUMBA



She is fondly called 'Ankhazi' which means an aunt in her local language. Edith has worked in the unit for 16 years. She enjoys helping the young nurses gain oncological experience.

AGATHA THUNDU

Agatha has seen it all. She has worked in the Unit for 19 years and has seen the ward grow from a two-bed unit to the current twenty-five-bed ward. She has been crucial in the provision of orientation to new nurses who are joining the ward. She is a voice of experience and reason and is well liked and respected by all.

FELISTAS CHISALE

Felistas has been in the ward for seven years. She has an irresistible smile and the children love her. She is another hard worker.

WINIFRED LIKOLECHE

She claims to come from 'overseas'. Actually, her original home is Likoma Island (a beautiful island on Lake Malawi). She has worked in the unit for 14 years. Winifred is a hard worker and she will work 24/7. Her motto is to give the best of nursing care to patients and make them happy.

Paediatric oncology nursing at QECH remains stretched. However, the team is motivated and enthusiastic. Thank you for all the support for the nurses as well as the chemotherapy drugs, it is really appreciated.

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