

TLM UK: 106 Abbots Road, Abbots Langley, Herts, WD5 0BH Website: www.wearetlm.org Email: drtrish@WeAreTLM.org

TLM UK Newsletter

Message from Dr Trish

I want to start this newsletter with a thank you – if you're receiving this it's because of the support that you have shown to TLM, enabling us to care for Tanzanian children with cancer and their families. It is estimated that 3,500-4,000 children in Tanzania develop cancer on an annual basis. When I started working in Tanzania about 100 children a year were being treated with an approximate 5% survival. Over 600 children received treatment last year and survival rates are now approaching 50%.

It is the children themselves who are the most powerful advocates for our work. So please meet a very happy young chap called Felix. The photo on the left was taken ten days after two surgical teams operated simultaneously on his kidney and heart. Felix, now fully recovered, and his mum returned to visit us in 2016 (middle photo). Gervas (photo on right) is one of the first patients to be treated at the newly established paediatric oncology centre at Sengerema Hospital in Mwanza. The opening of the new centre means that Gervas was able to finish his treatment close to home rather than travelling thousands of miles and staying for months in Dar es Salaam.



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Tumaini la Maisha ("Hope for Life") was launched in Dar es Salaam back in November 2011. To assist Tumaini La Maisha in expanding children's oncology in Tanzania two new charities were established in late 2015 - Their Lives Matter UK and Their Lives Matter Ireland. Although governed by separate laws and guided by different boards these two NGOs both support the activities conducted by Tumiani la Maisha. It was felt that a recognizable English name should be chosen with the same acronym (TLM) and "Their Lives Matter" succinctly sums up our ethos — children in Tanzania have as much right to a healthy life as children in developed countries. Together with the Tanzanian Ministry of Health and other partners the three organisations aim to cure children's cancer in Tanzania. Almost every patient and family we care for are poor and so all services offered in this programme are done so entirely free of charge to the families.

At the end of this newsletter we have included more information on the development of Tumaini La Maisha and the key milestones we have achieved since 2004 when the first 18 bed dedicated Children's Cancer Ward was opened at the Ocean Road Cancer Institute in Dar es Salaam. We have come a long way since then and Tumaini la Maisha is now working with the Tanzanian Ministry of Health to create a fully integrated network of paediatric oncology services throughout the country. We now have a shared care partnerships with Sengerema Hospital in Mwanza region and with KCMC hospital in Moshi which mean that children in those regions no longer have to travel to Dar es Salaam for treatment.

During this expansion it is essential that we also continue to improve the standard of care that has been established at Upendo Children's Cancer Ward in Muhimbili National Hospital. We are delighted to be able to show you our new chemotherapy preparation room.



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In addition to developing our facilities we recognise the importance of continued education and development for the wonderful nurses working with us at Muhimibili Hospital. We therefore started paediatric early warning score training in 2016 which is a scoring system based on the vital signs of the children. It will prompt nursing staff to immediately call for help should a child on the ward trigger a higher score so preventing the child becoming sicker.



TLM also recognises the importance of play therapy and creative activities to keep our little patients entertained and positive. Play therapist, Leonard (pictured below left), has been with the programme from the very beginning when his first classroom was under a tree. 'Clown Doctors' (pictured below centre) are also a regular feature on the ward to help make everything, from extra nutrition, to scans and even radiotherapy treatment less scary.



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Focus on TLM UK 2016-2017

The funds that were raised by TLM UK during 2016 have been dedicated towards the costs of shipping donated drugs from Europe to Tanzania. TLM is committed to ensuring that Tanzanian patients benefit from the latest and best diagnostic technologies. TLM UK has therefore set itself the ambitious target of fundraising for an automated immunohistochemistry stainer in 2017. This machine will be able to scan the histology slides which are currently being sent to Our Lady's Children's Hospital Crumlin (OLCHC) in Ireland for diagnosis. The number of children being treated has risen from 100 patients a year in 2005 to 600 currently and the goal is to reach 3,500 children per year. Since 2016 specimens are also being received from the new paediatric oncology centre at the Kilimanjaro Christian Medical Centre in Moshi with plans to expand this service to three other centres in 2017. Therefore the ability to promptly and accurately analyse specimens in Tanzania is a key opportunity to reduce costs and increase sustainability.

Negotiations with two potential suppliers to ensure highly discounted pricing are proving positive and the estimated cost of the machine is £50,000. This cost includes installation and specialised training for the technicians who will be operating the stainer at Muhimbili Hospital plus reagents, antibodies and consumables for the first year. To ensure quality assurance, for twelve months after installation of the machine, samples will be tested at both Muhimbili Hospital and OLCHC. The plan is that the stainer will be located in the hospital's main pathology laboratory which will mean that thousands of adult cancer patients will also benefit. The hospital has committed to running the service and TLM will only need to fund the reagents and antibodies for the children.

For More Information

We are in the process of updating our website www.wearetlm.org.

In 2014 Dr Trish was awarded the inaugural alumni award for medicine by University College Dublin and this two minute video explains why:

https://www.youtube.com/watch?v=Ls1 PEov05M

In 2016 Dr Trish was interviewed for 20 minutes on Tanzanian TV about her work: https://www.youtube.com/watch?v=ZumempTizcQ

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Opportunities for Involvement

- Donations can be made online at www.wearetlm.org
- Please contact us by email if you would like to organise a fundraising event and require further information (drtrish@WeAreTLM.org)
- Volunteers are welcome at the Upendo/Tumaini Oncology Ward and Ujasiri family hostel in Dar es Salaam, again please email for details (drtrish@WeAreTLM.org)

Background Information

Tumaini la Maisha (TLM Tanzania) is an NGO registered in Tanzania, whose foundation and mission is entirely focused and committed to supporting paediatric cancer services in Tanzania until every child has been reached each year. Though a multi-component and comprehensive approach we aim to increase accessibility to clinical care and early diagnosis as well as improving the quality of this care and the general life of cancer patients and families. These will help us achieve our overarching goal of providing free access to timely diagnosis and high quality paediatric oncology care for all children diagnosed with cancer in Tanzania.

Through close partnership with the Tanzanian Government, TLM supervises all paediatric cancer clinical and non-clinical service provision and all awareness and access activities throughout the country. TLM also coordinates the fundraising efforts and in-kind support of all interested donors and benefactors of children with cancer in Tanzania. All efforts are centralised within Muhimbili National Hospital, the largest Government Hospital in Tanzania, and in close dialogue with the Ministry of Health.

From 2007 to date, long term survival rates in those children who arrive to the ward with curable stage disease have increased from approximately 20% to 70%. The high quality paediatric cancer care and associated improved survival rates have resulted in increased demands for this service. Our goal is to ensure that all Tanzanian children with cancer receive treatment of the highest quality medical care and so achieve survival rates of 85% for all children which is equal to developed countries. Targeted interventions improve awareness of the curability and early warning signs of childhood cancer so leading to prompt referrals and presentation of early stage disease. The design and provision of world-class certified training programmes is vital for the long-term sustainability of paediatric oncology in Tanzania.

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Since 2007, TLM has worked and developed partnerships, relationships and alliances with local and international experts, supporters and donors spearheading efforts to improve access to and quality of cancer services for children in Tanzania. TLM was first providing its services at the Ocean Road Cancer Institute, thereafter at Upendo Ward at the Muhimbili National Hospital and now spreading to University Hospitals across Tanzania. Local stakeholders include the Ministry of Health, Muhimbili National Hospital, Muhimbili University for Health and Allied Sciences, Ocean Road Cancer Institute and two newly established paediatric oncology centres at the Kilimanjaro Christian Medical Centre (KCMC) in Moshi and at Sengerema Hospital in Mwanza.

Key Milestones:

2004:

- First 18 bed dedicated Children's Cancer Ward opened at Ocean Road Cancer Institute
- First research clinical trial began improving Burkitt's Lymphoma survival from 5-10% to 70% within 3 years

2008:

- First psychosocial support added with a children's school and play therapy programme
- Accurate pathology services accessed through a partnership with DHL and Our Lady's Children's Hospital in Dublin

2011:

• Tumaini la Maisha (TLM Tanzania) children's cancer charity launched by its patron Honourable Mr Ali Hassan Mwenyi (former president of Tanzania)

2012:

- Children's oncology services moved to Muhimbili National Hospital
- Radiotherapy remained at Ocean Road Cancer Institute

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2013

- 22 bed "Ujasiri" (Strength) Family Hostel built providing a home-away-from-home for the children in between cycles of treatment
- Therapeutic play, life skills coaching, counselling and palliative care introduced
- Custom-designed 60 bedded "Upendo/Tumaini" (Love/Hope) Oncology Ward complex built by Rotary Dar es Salaam
- A Master's in Paediatric Haematology/Oncology established at Muhimbili University of Health and Allied Sciences

2015

- Their Lives Matter in the UK and Ireland launched
- ESTHER Alliance formally approved twinning between Muhimbili National Hospital and Our Lady's Children's Hospital in Dublin
- Paediatric Oncology Nutrition programme established to treat all children but target the malnourished in particular

2016

- National Retinoblastoma Task Force established in Tanzania
- Two new Satellite Paediatric Oncology treatment centres established in Moshi and Mwanza.

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