Curing Children's cancer in Tanzania: 2015-2020.

We are TLM

CARING FOR CHILDREN WITH CANCER IN TANZANIA

Tumiani la Maisha

Their Lives Matter

With sincere thanks to the students at Boston University School of Public Health who worked so hard creating the framework for this document: Sandra Kneer, Mikaela Ringquist, Salome Kuchukhidze , Toyin Shonukan

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List of Acronyms

CCBRT	Comprehensive Community Based Rehabilitation in Tanzania
CiC	Children in Crossfire
KCMC	Kilimanjaro Chrisian Medical Centre
MNH	Muhimbili National Hospital
MUHAS	Muhimbili University of Health and Allied Sciences
NPC	New Paediatric Complex
PCH	Paediatrics and Child Health
TLM	Tumaini la Maisha/ Their Lives Matter
TMoHSW	Tanzanian Ministry of Health and Social Welfare
UM	University of Minnesota

EXECUTIVE SUMMARY

More than 85% of childhood cancers occur in developing countries, including countries in sub-Saharan Africa. Late presentations at treatment centers, delayed diagnosis and poor access to healthcare contribute greatly to the poor survival outcomes in these countries.

The government of Tanzania, as part of it's pledge to provide cancer care free to all citizens, recently established a modern paediatric cancer unit within Muhimbili National Hospital (MNH) in Dar es Salaam. The Upendo Children's cancer ward at MNH is currently the only children's cancer ward in the country. All services provided on Upendo ward are offered free to all children.

TLM is an international NGO group that actively participates in clinical and non-clinical service provision and fundraising. TLM also coordinates the efforts of all interested donors and supporters of children with cancer in Tanzania. All efforts are undertaken within Muhimbili National Hospital (the largest public University Hospital in Tanzania) and in close dialogue with the MoHSW.

Over the last 9 years this team has helped: implement international treatment protocols and reproducible standards of care; improve inpatient capacity from 17 to 70 beds; improve access to drugs and specialty trained staff; increase access to hi-tech investigations for diagnosis and staging; create and maintain a locally based masters programme to train Tanzanian sub-specialty doctors; provide broad-based psychosocial support including a hostel, a school, play therapy, nutrition, transportation and counseling. None of the achievements were possible without partnering closely with the Tanzanian Government who provides all other vital services free of charge – including admission, radiology and blood tests, transfusions, radiotherapy and surgical services.

In addition outreach programmes to spread cancer awareness messages, to reduce numbers of children presenting in late stage disease have been piloted in chosen regions with the plan to grow this initiative nationwide over the medium term.

The results have been dramatic; from 2007 to date, one year survival rates increased from around 12% to 60%. The high quality paediatric cancer care and associated improved survival rates has resulted in increased demands for this service. Referrals from district hospitals has increased 5-fold, from less than 100 in 2005 to over 500 expected in 2015.

Despite all these improvements currently less than 20% of the 3,500 predicted annual cases are admitted to Upendo ward and of these only 50% are surviving. We can and must do better.

Our goal is to ensure that all Tanzanian children with cancer to receive treatment to the highest quality medical care and ultimately achieve survival rates of 85% - equal to developed countries. With this in mind we have devised a comprehensive 3-5 year plan with a 10-year vision. The plan involves strengthening and broadening all services currently available in Dar es Salaam and supporting the development of a network of multi-disciplinary holistic paediatric oncology facilities in University hospitals around Tanzania.

Our proposal consists of six main components: 1) to support improved access to all hi-tech equipment, clinical services and quality consumables on Upendo ward, (MNH) and to assist with the founding of additional treatment centres throughout the country; 2) to expand the psycho-social

support of patients and their families; 3) to provide training of sub-specialty multi-disciplinary healthcare workers; 4) to create reliable data to allow continual audit and improvement through clinical research; 5) to scale up outreach services to support both follow up care and the preventative approaches, creating increased public awareness of common childhood cancers with more robust standards for early detection and referral; 6) to focus on fundraising and efforts to create financial security for the programme by expanding the TLM charity family to Ireland, the UK (and in time the US).

SITUATION ANALYSIS

Tanzania is one of the first Sub-Saharan African countries to prioritize the cancer care. The government of Tanzania has pledged to offer free care and clinical treatment for all patients with cancer – children and adults. Cancer care for children is coordinated through the Ministry of Health and Social Welfare. The initial public children's ward was based at the Ocean Road Cancer Institute (ORCI) from 2004. Since April 2011, all children are cared for within the paediatric department at Muhimbili National Hospital (MNH) in Dar es Salaam. In August 2013, a new custom designed paediatric oncology ward was opened with a capacity of more than 50 beds at MNH. The Upendo/Tumaini children's cancer ward complex is the only specialized children's cancer ward in Tanzania, providing cancer care and treatment free of charge. The majority of children admitted is from poor families and have travelled long distances from all over their large country.

In November 2011 Tumiani la Maisha was formed in Tanzania to support the care of children with cancer who present for treatment in Dar es Salaam. This year sister charities have been registered in Ireland and the UK called 'Their lives Matter'. Combined this group is known as 'TLM', a small NGO family with a large mission: to help cure children with cancer in Tanzania. It is dedicated to support the Tanzanian Ministry of Health and Social Welfare (MoHSW) in the delivery of high quality holistic care to all children with cancer across Tanzania.

TLM coordinates the efforts of all interested donors and supporters including local and International NGO's and donor organisations, individual philanthropists, the Tanzanian business sector, Rotary, and the diplomatic community. All efforts are undertaken within the framework of the Tanzanian health service and in close dialogue with the MoHSW. We currently work with Muhimbili National Hospital (MNH), the largest Government run University hospital in the country, to provide both clinical and non-clinical services to patients and their families.

Over the last 9 years this team has helped: implement international treatment protocols and reproducible standards of care; improve inpatient capacity from 17 to 70 beds; improve access to drugs and specialty trained staff; access hi-tech investigations for diagnosis and staging; create and maintain a locally based masters programme to train Tanzanian sub-speciality doctors; provide broad-based psychosocial support including a hostel, a school, play therapy, nutrition, transportation and counseling. All has been successfully conducted at the Muhimbili University for Health and Allied Sciences. None of the achievements were possible without partnering closely with the Tanzanian Government who provides all other vital services free of charge – including admission, radiology and blood tests, transfusions, radiotherapy and surgical services.

In addition TLM has recently begun outreach programmes to spread awareness and reduce numbers of children presenting in late stage disease.

With the improved availability of drug and nursing care, and all other services the unit has over the last 9 years achieved much - an increased survival – the one year disease-free survival rate of 12% in 2007 to 60% in 2011 and an increased demand from less than 100 new children in 2005 to over 500 expected in 2015. But there is more to do!

The current level of access to quality of care and the associated improved outcomes for Tanzanian children with cancer attained at MNH in the last 8 years has been achieved through complex partnerships between several public, private and NGO organizations – the MOHSW, the Ocean road cancer Institute, MNH, Tumaini la Maisha (TLM, the first NGO dedicated to improving the wellbeing of children with cancer in Tanzania) CIC, Rotary, IMA World Health, Our Lady's Children's Hospital Crumlin (OLCHC) and many private companies and individuals - These organizations have together established the groundwork for the creation of a comprehensive approach and includes efforts to improve: medical skills and technical education of physicians and nurses; speed and accuracy of diagnostic testing; quality of supply chain for medications and other disposables; supportive care through improved nutrition and provision of housing; social support including transportation and school and play based activities for the children; outreach to educate community physicians and parents.

To address the need of physicians with specialized skills in paediatric haematology/oncology, Muhimbili University of Health and Allied Sciences (MUHAS) established the first ever Masters programme in Paediatric Oncology in Tanzania. The programme has successfully executed the first year of teaching, with two paediatricians progressing through the programme. The first course will end in June 2015 with two internationally qualified Tanzanian paediatric oncology specialists who will be able to provide much needed sustainable capacity within the national health system. It's second intake of students will begin in September 2015.

TLM has in addition, organized a range of other activities to directly support children with cancer and their families including creating awareness of children's cancer across Tanzania. Some of the activities are the educational programme (a daily school) for the children in the hospital, income generation activities and life skills education, therapeutically play programme, family support programmes, as well as, palliative care and counseling services.

With a population of 49 million, more than 50% of whom are under the age of 18, Tanzania can expect to see up to 3500 new paediatric cancer cases each year. There is therefore a need to improve and expand the service currently rendered at MNH - both in terms of services offered at MNH and beyond, reaching children in all other university cities, in order to achieve our goal of ensuring that all Tanzanian children with cancer attain survival rates that equal those in developed countries.

To this end, in 2015 we are hoping, not only to continue our push for excellence at MNH but also to establish collaborations between MNH and two other University hospitals – Kilimanjaro Christian Medical Center (KCMC) in Moshi and Bugando Medical Center (BMC) in Mwanza. Our proposal is to create a national strategy for paediatric oncology stretching across these three centers and thereby providing access to many hundreds more children. Currently, the journey for many families with sick children to MNH in Dar es Salaam takes several days/weeks. The establishment of these two new paediatric oncology centres which will be located at the northeast and northwest corners of the country respectively, would ensure that two

thirds of Tanzanian children access to high quality cancer care within a day's journey from their homes. We envision that we could improve this further by establishing the same level of care at medical centers in Mbeya, Dodoma and Kigoma – thereby providing a paediatric Oncology site within a few hours journey for all Tanzanians within 5 years.

The focus of this proposal is the role TLM will play in this comprehensive national programme. Such an undertaking requires a coordination of efforts of multiple institutions and organisations. TLM and MNH will coordinate and guide this expansion and MNH will act as the tertiary/quaternary referral centre for more complex and challenging conditions. A focus on supporting clinical services at all hospitals with a more reliable, pooled drug and supplies procurement system and integrated sub-specialty training of medical professionals in paediatric oncology is an imperative. Secondly, there is need for expansion of psycho-social support of patients and their families mainly through provision of nutrition and counseling programmes in conjunction with providing increased transportation and housing services for the children and their caretakers who travel long-distances to receive care. Thirdly, there is a need for scaling up of the preventative approaches and community outreach, and specifically, an increased public and specialist awareness of the early warning signs of common childhood cancers and more robust standards for early detection and referral.

TECHNICAL PLAN

Our project will have an overarching impact of increasing the cancer survival rates for children in Tanzania though improving the quality of life of patients and families, increased quality of clinical care and the increased likelihood of early cancer diagnosis. As outlined in our Logic Model in Figure 1 we will achieve these goals through the five following programme components:

- **Increasing access to and affordability of quality paediatric cancer clinical services, (including consumables, and equipment)** through pooled procurement; establishment of a Paediatric Intensive Care Facility and Emergency paediatric Laboratory at MNH; creating a specialist centralised paediatric oncology pathology service at MNH for all of Tanzania; and assisting the establishment of additional centres for paediatric oncology outside of Dar es Salaam

- **Improving adherence to treatment and reducing lost to follow** by increasing general parental support; improving family understanding of goals and treatment plans and minimising external stressors affecting the cancer patients and their families during treatment.

- **Expansion of locally based specialists for paediatric cancer** in Tanzania − to do so we will expand our MSc in Paediatric Haematology and Oncology for local and regional paediatricians; offer training for medical laboratory scientists, specialist oncology nursing, paediatric oncology pathologists, palliative care specialists and medical engineers.

- **Improve understanding of the impact of our efforts and identify areas of urgent need** by creating a hospital and national database for paediatric oncology patients. All children attending a paediatric oncology service in Tanzania will be included and reports generated will be studied and audited and all future plans and changes to be based on facts generated from this system.

- **Supporting follow up services and awareness of paediatric cancer in Tanzania,** through our outreach programme − to do so, we will engage with local and regional hospitals, community leaders, NGOs and family caregivers to increase understanding and awareness of the childhood cancers. This will reduce lost to follow-up and increased early recognition and prompt referral of childhood cancer increasing physician awareness of in-country cancer resources.

- **Supporting all these initiatives with a robust development plan for TLM as an NGO structure.** This will involve local and international fundraising; partnering with new and old supporters and donors; supporting the development, expansion and capacity of existing staff, structure and mandate of the Tanzanian organisation; and developing an international network of charities with a common umbrella – 'we are TLM'.

We also acknowledge that the external factors will influence the timeline and the efficiency of the programme implementation.

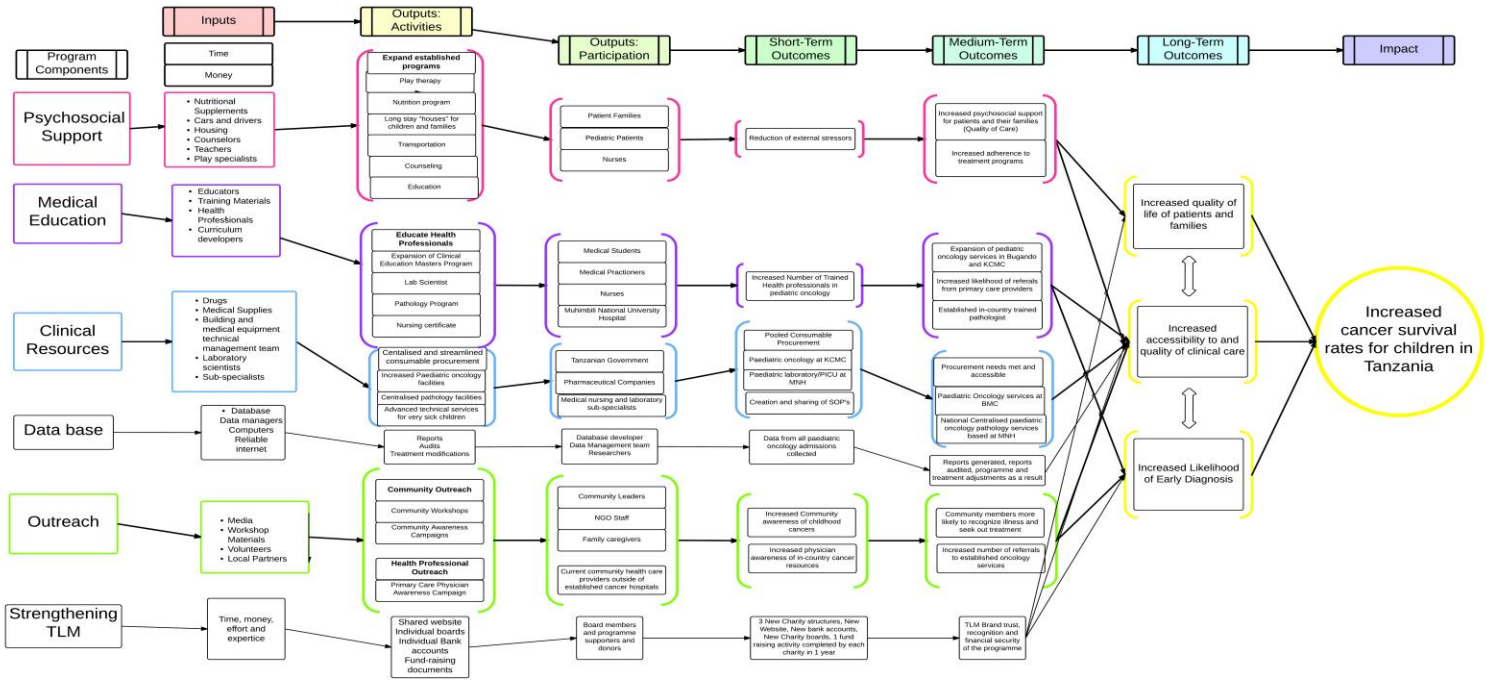

Figure 1: Logic Model

GOALS AND OBJECTIVES

Though a multi-component and comprehensive approach we aim to increase accessibility to clinical care and early diagnosis as well as improving the quality 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.

Component 1 - Clinical Services

- Create a centralized drug and equipment procurement system sanctioned by the government, for all three hospitals to access, thus allowing all centres best quality oncology products at the best prices available in Tanzania within three years.
- Develop relationships with pharmaceutical companies for in kind donations of oncology products over the next 3-5 years.
- Develop and institute clinical medical and nursing SOP's based on international quality recommendations modified for implementation on Upendo and Tumaini wards within 2 years but reviewed annually.
- Build and support a Paediatric Intensive care Unit at the NPC at MNH within 3 years.
- Strengthening laboratory services over 5 years including: continued support for existing services; creating an emergency paediatric laboratory and a National Centralised Pathology laboratory for paediatric oncology; the development of a microbiology service in each hospital capable of delivering reliable and accurate results in both culture and sensitivity of samples tested.
- Supporting the creation of a framework of collaborative paediatric oncology clinical care centres throughout the national University hospital network in Tanzania over the next 10 years starting with KCMC and BMC, in time including centres in Dodoma, Mbeya and Kigoma and possibly others.

Component 2 - Non-Clinical Support

- Improve psycho-social and nutritional support for children undergoing treatment at MNH through expanded nutritional, play and school/education programmes; and hostel facilities; and skills lessons for parents; and transportation to and from hospitals.
- Improve similar programmes at other collaborative centres by providing leadership and experienced guidance on requirements for psychosocial support for children and families of children with cancer.

Component 3 - Education of Health Professionals and provision of specialist services

- Complete training of two additional paediatric oncologists through MUHAS MSc programme within two years.

- Establish a lab scientist training programme for pathology in collaboration with MUHAS and Dublin Institute of Technology with a minimum of two students enrolled within three years.

- Establish a direct entry certificate course for nurses on hematology and oncology in collaboration with Our Lady's Children's Hospital Crumlin OLCHC, the Dana Farber

Cancer Institute, University College Dublin and Oxford University with a minimum of fifteen nurses enrolled within three years to be delivered through blended learning flexible modular course.

- Establish a dual Irish-Tanzanian MD programme for pathology, sub-specialising in paediatric oncology in collaboration with Tanzanian MoHSW, MUHAS, UCD and OLCHC, with a minimum of two students enrolled within two years.

- Maintain ongoing training of haematology laboratory staff in the art of Flow cytometry, with a minimum of 3 additional staff trained and the current 3 staff fully supported with remote expert advice within 3 years.

- Provide training for medical clinical engineers to maintain the paediatric intensive care unit once established through an educational visit of one Tanzanian medical clinical engineer to train at OLCHC clinical engineering department within 2 years.

- Officially twin OLCHC and MNH; Oxford University hospitals and MNH; (Duke University paediatric oncology department with BMC oncology; University of Minnesota oncology with KCMC oncology – TLM not directly involved in these partnerships); formal relationships between these organisations/institutions and TLM including an agreement to share documents, protocols, procurement processes, pathology services etc etc.

- Expand tumour board meetings to include additional specialists e.g. pathologists, radiologists and sub-specialist surgeons.

- Train 2 new pathologists to meet this increasing need in the next 5 years.

- Training 2 palliative care specialists and 2 palliative care nurses over the next 5 years.

Component 4 – Data Management: Guiding progress

- Complete paediatric clinical oncology database tool and share with 2 other centres within two years. An alternative option may - to move to the CanReg system of recording and analyzing data.
- Register all relevant clinical data for children attending any of the three hospitals on the agreed database within 5 years
- Regular audit of data to identify areas of need and success guiding treatment and planning interventions with locally generated knowledge

Component 5– Outreach: follow-up and awareness

- Identify children 'lost to follow up' and make efforts to locate each child with registered details available within 3 years
- Train a minimum of 5 medical staff in all regions to identify early warning signs of childhood cancer and correctly refer children through existing channels within five years.

- Increase community awareness of childhood cancers by 50% within 5 years using all forms of appropriate media to conduct regular Early Warning Signs (EWS) campaigns.

Component 5 – Strengthening and Growing the TLM NGO Structure and finance base:

- Strengthen the fundraising activities based in Tanzania over 3 years by creating a fundraising advisory committee and hold fundraising activities annually.
- Create 3 new charities – TLM Ireland, UK within 1 year (and USA within 3 years).
- Online fundraising through a new website for all 4 charities – weareTLM.org – within one year
- Double the number of grant applications sought and made in next 2 years
- Improving financial oversight by engaging with an accountant and generating annually audited accounts
- Providing ongoing professional development to staff – particularly in the area of child play therapy, palliative care and any other area that is identified as requiring support.

PROGRAMME ACTIVITIES

The following are the descriptions for each planned activity within the four components of our programme that will aid in reaching our goals and objectives. Figure 2 provides the predicted timeline for the implementation through comprehensive work plan.

Component 1 - Clinical Resources

Procurement

Currently, consumables are procured at MNH using several different processes and sources. Most standard clinical supplies are supplied by MNH through the hospital pharmacy. However, most oncology specific supplies such as bone marrow aspirate and biopsy needles, tru-cut needles, intra-thecal filters and intra-thecal chemotherapy etc., are currently not available in country and are imported from sources overseas. In addition all other supplies (including all chemotherapy) are purchased locally from small-scale retail pharmacies where significant markups are applied to the costs of the items. Almost every item used on the ward is a generic product and there is the additional concern regarding the quality of these products.

Recognizing that a reliable supply of drugs is essential to the delivery of care to our patients, we plan a single procurement process involving MNH/TMoHSW. This will enable us to negotiating more competitive prices and establishing reliable sources. We are in the process of working out the details of the procurement system but it will involve creating a tender document agreed by all involved (clinicians, pharmacists, nurses, donors, MoHSW). This will also facilitate the importation of medications not currently available in Tanzania.

Once the process has been agreed each hospital would then simply order their supplies and drugs from this procurement structure. The costs and quantities will be estimated for an annual supply for each centre.

Medications procured include chemotherapy, anti-microbials, anti-emetics and bone marrow stimulators. A list of the drugs is in the Appendix C of this proposal.

SOP's

Using available literature standard operating procedures and clinical manuals will be developed that are locally appropriate and relevant to guide all clinical procedures and programme activities. These will cover nursing, medical and psychosocial services and will be shared in an open source manner to any new and Nationally approved paediatric oncology centre seeking to join the network.

Paediatric Intensive care Unit

Many of the paediatric oncology children are extremely unwell and unstable on first presentation or secondary to treatment related toxicities. These illnesses are often profound but usually of short duration. Currently the majority of these children die due to lack of high tech support services. HRH the Queen of Sharjah, who visited the oncology programme in 2014, has agreed to fund a

paediatric intensive care unit which will service all critically ill children who require short term high intensity support including paediatric oncology patients.

Laboratory services:

1) Flow Cytometry
Flow cytometry is a specialised haematology service, which allows rapid and accurate diagnosis of leukaemia and lymphoma. Through the collaboration with OLCHC this service has been running at MNH for 2 years to a very high standard. We plan to continue this collaboration.

2) Emergency Paediatric Laboratory
Rapid access to quality laboratory services is one of the key elements to a successful paediatric oncology programme. HRH the Queen of Sharjah has agreed to fund the development of an emergency paediatric laboratory based at the NPC, in MNH. This will provide emergency and rapid access services for all sick children attending the NPC, in MNH.

3) Centralised Paediatric Oncology Pathology Services
As part of the new laboratory services developing (thanks to collaboration with HRH the Queen of Sharjah), a paediatric oncology pathology unit will be developed. The location has yet to be agreed. It may be housed in the new emergency laboratory at the NPC or in the main pathology laboratory at MNH. It is proposed that this unit will become the National centre for paediatric oncology pathology. As there is a critical shortage of pathologists in Tanzania it is proposed that only one centre of excellence in pathology for paediatric oncology be developed in the next 5 years in Tanzania. If agreed by all parties all specimens from all centres treating children with cancer in Tanzania will be sent to MNH for assessment and reporting as soon as the paediatric oncology pathology unit is estabilished at MNH.

4) Microbiology
Microbiology services are an essential element to the care and treatment of children with cancer. Chemotherapy and disease lead to severe compromise of the children's immune systems. At present the culture and sensitivity services at MNH need considerable support. It is hoped that in the next 5 years this service can be strengthen and improved.

National Framework of Paediatric oncology Centres:

Currently Upendo ward at MNH is the only dedicated childrens cancer ward in Tanzania. Over the next 5-10 years additional paediatric oncology treatment sites will be developed within the National University network of teaching hospitals. This growth and expansion will be conducted in a planned and collaborative fashion under the guidance of the Tanzanian Ministry of Health and Social Welfare. All centres will share many services including procurement process, protocols, SOP guidelines, centralised pathology services and access to paediatric oncology higher education.
KCMC has an established relationship with FCCT which is affiliated with the University of Minnesota This organisation is very interested in supporting paediatric (and Adult) oncology services at KCMC and TLM plans to work with both the department of paediatrics at KCMC and the FCCT team to establish the second national paediatric oncology centre at KCMC within the next 12 months.

Bugando Medical Centre has an established relationship with Duke University and a paediatric oncologist is already situated at Bugando. TLM plans to work with BMC and Duke Univereisty to support the development of a third paediatric oncology facility at BMC within the next 2 years.
For a country as vast as Tanzania it would make sense to have additional centres spread geographically for ease of access to all patients. These will be identified and developed over time and will include Dodmoa, Mbeya, Kigoma. This planned expansion will be complete when all children with cancer can travel to a centre within 4-5 hours.

Component 2 - Non-Clinical Support Programmes

School and Play Therapy Programme

We have already established a play therapy programme at MNH, which is vital to the children's well-being and everyone's happiness. It was created by two internationally certified play therapists. The therapeutic play programme includes activities in the junior classes at the daily school and the establishment of a 'one-to-one bed programme' where a specially trained teacher plays with those children who are bed-bound. We are also hoping to increase our Child Life activities – a programme to gently introduce children to hospital procedures.

We have also established a school programme in MNH which is led by two Tanzanian teachers and 2 assistants. The children are split into two groups, the older ones are known as the Tembo class (Elephants) aged 6-15 and they cover subjects such math, literacy and arts and crafts projects. The younger group is called the Sungura's (Rabbits) aged 2-5 and this group focuses on playing and entertaining the children to stimulate them, make them smile and laugh and generally be children and forget about being patients for a while. It also helps by giving their parents a well needed break. The older group, the Tembo's, have more academic classes but due to the ever changing attendance and the temporary nature of the school they need a lot of individual attention when studying. The purpose is to allow the children a level of normality and fun in their lives, a way of escaping their medical realities for a few hours each day.

Having established the value of play and school therapy as part of the approach in all non-clinical services, our proposal will establish play and school therapy programmes currently implemented in MNH to KCMC and BMC. BMC have a very new programme. This will be expanded over time.

Counseling and Palliative care Services

Individual and group counseling sessions is an important part of our support care services offered to all children and families admitted to Upendo ward. Families and children learn about their different cancer conditions and also have opportunities to ask questions or express fears and share emotions. The group therapy sessions are extremely interesting and valuable as individuals become part of the cancer care community.
End of life issues are extremely important to address prior to discharge in our setting. We can rarely visit a child at home given the distances and also the number of children attending the service. But parents take some comfort by being well counseled and prepared prior to discharge and having Dr Jane Kaijage's support at the end of a telephone at all times. We plan to expand our palliative care team and train other staff in this vital field over time.

Nutrition Programme

Many children present to our service extremely unwell and malnourished. In addition, for various illness and treatment related reasons, normal food (which is supplied by MNH daily) may not be tolerated or adequate to sustain these vulnerable children. Alternative food supplements are critical to speed recovery and assist chemotherapy tolerance. Fresh whole food plant based blended drinks and smoothies are a simple cheap nutritious and easily ingested and digested option.
It is Internationally recommended to provide supplemental nutrition as part of the best paediatric oncology practice. Thanks to the support of organizations around Tanzania, we have been able to outfit a kitchen in the family hostel on the MNH campus and have now procured a refrigerator and a small blender. Each child admitted to the ward at MNH currently receives 1 cup of nut milk/fruit/veg/spice smoothie blend each day.

As the children improve and progress on their treatment, it is essential that we continue supplementing their daily diet with healthy vegetables, fruits and vitamins. The nutrition programme's aim is to improve digestive and immune health, prevent malnutrition and provide dietary supplements during treatment in order to help the children stay strong and nourished, so they can continue with their cancer treatment.

The continuation of the programme and the proposed expansion in KCMC and Bugando will require a setting up of a kitchen, a weekly supply of fruits, nuts, vegetables and spices to be delivered to the hospital, a deep freeze and refrigerator to keep the items cold and safe from bacteria. We would also require a full time employee who will be responsible for the purchasing, preparation, distribution and education of the parents about the importance of the smoothies.

Transportation Programme

Currently MNH in Dar es Salaam is the only children's cancer facility treating all children with cancer. Many villages and towns of Tanzania are many days overland travel away. Most families live on the ward for many months and have no income during their stay. To assist these families once they have completed treatment, bus or train tickets are purchased on their behalf.
We also have the assistance of a local airline who transfer palliative care children home in some comfort and speed.
We also offer a transport service for children who are identified as probable oncology patients in hospitals around the country. Money is sent from our team to a designated local staff member, who then purchases the bus tickets. Children and carers are thus transported to Dar es Salaam. This service will be expanded when KCMC and Bugando are functioning paediatric oncology centres. Their services will significantly reduce travel times for a large proportion of patients.

A bus was donated to children in MNH in order to give them the opportunity to escape the confines of the hospital and explore the world. It is also used for some administrative tasks for the smooth flowing of the day to day service.

Outpatient and Family Housing programme

To alleviate the overcrowding on the ward and give families/guardians a home away from home while waiting for the next treatment cycle a family house is located on the grounds of MNH.

Currently each family is provided with 3 meals a day, education and play activities, security services for 24 hours a day, bed linen and cleaning, furnishing and house attendants to look after the buildings and grounds. In order to expand our services to KCMC and Bugando, we will need the following resources:

1. 3 meals per day for in-patients and carers
2. Utility bills such as electricity, water, etc
3. Bed linens and cleaning
4. Furnishings including beds, tables, chairs, window blinds, mosquito nets, etc.
5. 2 house attendants to clean and look after the buildings and grounds.
6. Collection and delivery of food from the kitchen to the housing unit
7. A housing manager to oversee the facility grounds

Component 3 - Medical Education and development of Expert Services

Staff shortages for paediatric oncology remain an urgent priority. Even with the required cancer facilities in place, patients will not receive the necessary treatment without doctors, nurses and other health professionals trained in the specifics of paediatric oncology and hematology. Therefore, the need for rigorous educational programmes in paediatric oncology and hematology to train the next generation of Tanzanian paediatric oncologic specialists is imperative.

MSc in Paediatric Oncology/Hematology

There are currently no qualified Paediatric Oncologists in Tanzania. It is an essential part of the strategic plan for Paediatric Oncology to ensure that there are local skilled human resources available over the next 15-20 years to meet the demands of the expanding capacity of Paediatric Oncology services in Tanzania. MUHAS, Muhimbili National Hospital (MNH) and other Tanzanian Medical University centres, including Bugando Medical Centre (BMC), KCMC and Mbeya Hospital have a cadre of specialists with postgraduate training in Paediatrics and Child Health (PCH) who have an interest in paediatric haematology/oncology, and who are currently managing patients with haematology/oncology disorders but do not have training in this specialized field.

The locally based MSc in Paediatric Haematology/Oncology was designed, funded and commenced enrollment in September 2013. Enrolled students are in their second and final year. A second enrollment will begin again in September 2015. This masters programme currently relies heavily on international experts with more than 20 lecturers from all over the US, Europe and Africa, supervising and training students. Over time locally trained experts will take on this educational role. This Programme is hoped to train sufficient paediatric haematologist/oncologists for Tanzania and the region of East Africa. .

Nursing Certificate

Currently, there is no recognised training for nurses in Paediatric Haematology/Oncology. TLM in collaboration with MUHAS and the Tanzanian government will development a Certificate Programme for Nursing in Paediatric Oncology and Haematology. The Certificate Programme will be direct entry for practicing nurses. The programme will consist of 10 modules that each

student must complete in order to gain the certificate. Modules can be completely on an individual basis to allow nurses to continue working while studying in the certificate programme.

Lab Scientists Training Programme

TLM in collaboration with the Dublin Institute of Technology, Ireland will develop a training programme for lab scientists with a focus on hematology and pathology. Once trained, the lab scientists will conduct all in-country biopsy analyses for oncology/hematology specimens, including Immunohistochemistry, in Tanzania.

MD in Paediatric Pathology

University College Dublin have offered (through TLM) to create an MD programme for Tanzanian and Irish pathologist interested in training in Paediatric oncology pathology. This course will be based at UCD but all research topics will be related to the clinical oncology service at MNH and the students will be expected to run all samples through the newly designed paediatric pathology unit. The programme will train an in-country pathologist with a dual Irish MD and Tanzanian MD degree.

Pathology training at MUHAS

The number of trained pathologists in Tanzania are hugely inadequate for the current need. We expect this need to rise significantly as access to quality services improve. MUHAS offers a quality pathology training programme. We would like to support the training of at least 2 further pathologists over the next 5 years to begin to meet this need.

Twinning Programmes

International hospitals, Universities and NGO's have been identified to assist with the development and maintenance of these services not only in MHH but at two additional Universities – KCMC and BMC. OLCHC has a long relationship with MNH and is officially twining in 2015 thanks to an initiative supported by the European Ester Alliance. The Oxford University hospital group (supported by THET) is also exploring the option of officially twinning with MNH. KCMC is partnering closely with the University of Minnesota and a group called Foundation for Cancer Care Tanzania. Bugando has a long relationship with an Italian group called AFRICOG and more recently with Duke University. Although TLM will not be twinning directly with any of these additional international partners, board agreements are being negociated such that Tanzania will have a single National Paediatric strategy – sharing drug procurement, protocols, documents, and some services – including pathology.

Palliative care training

Both doctors and nurses will be formally trained to provide end of life care to children with cancer and join the existing palliative care team at MNH. Over time others will be identified to provide a similar service to the children's oncology services in sister institutions.

Clinical Engineering support

In order to maintain all the equipment both for the planned PICU and the existing paediatric oncology ward it is planned to provide ongoing professional education to an existing clinical engineer at MNH through the twinning programme between MNH and OLCHC. The funds for the initial training will come from the funds for the PICU build. A small clinical engineering work shop will be created next to the PICU.

Tumour board Meetings

In order to improve communication between all sub-specialists involved in the care of children with cancer a weekly tumour board is vital. This has been established at upendo ward but will be strengthened and developed over time. Once sister sites have been established these sites will be encouraged to develop separate TBM and in addition will be invited to join (via virtual technology) the MNH meetings and present any especially challenging cases.

Component 4 – Data Management

In order to report accurately on the success of this programme follow-up data is required for many years from completion of each child's treatment. Most children are not deemed successfully cured until they have reached 3-5 years post treatment. (Burkitt's Lymphoma is one of the only exceptions. These children are considered cured if they remain disease free 12 months from completing chemotherapy).

Database

A database programme will be designed/completed to capture all relevant and locally appropriate data. Data from all children attending paediatric oncology services in Tanzania will be included in this database. This will be kept up to date daily with a data management team and an effort to input the data of historical cases from the last 2-5 years will be made (understanding that charts may be incomplete or missing). It will help enormously to identify all areas of care that need to be strengthened including those children lost to follow-up.

Research and Audit

Reviewing the reports obtained from the database will be used to target clinical areas needing support or research in order to continue to improve all services offered to the children of Tanzania needing oncology care and treatment.

Component 5: Outreach – Follow-up and awareness.

The project will develop cancer awareness campaigns to be implemented by TLM to improve early detection through medical and general awareness.

Health professional Outreach Programme

Our outreach team who are tasked with educating and partnering with other organisations and hospitals will also assist with the follow up of children who have been deemed 'lost to follow up'.

This programme will focus on the education of first-line medical staff in catchment areas, enabling them to identify early warning signs of childhood cancer and correctly refer children through existing channels. This will be done in in cooperation with already established partnership with Comprehensive Community Based Rehabilitation in Tanzania (CCBRT) and build on the successes and lessons learned from the 'Early Intervention for Childhood Disability' project. Through this outreach we will be able to ensure that first line healthcare workers are aware of the referral process and the resources available to their patients that demonstrate the early signs of childhood cancers. This outreach will thus increase earlier diagnosis along with the chances of recovery.

General awareness Programme

Our general awareness programme will use local and national media platforms to deliver easy to understand message to the general public regarding children's cancer. This will include early warning signs and what to do to access care. Since many of the common childhood cancers are characterized by visual observed symptoms, education through television, radio newspapers and billboards have the potential to drastically reduce the time it takes from the family notice that 'something is wrong' and increases the chance to seek out necessary treatment. This would lead to increased survival rates and a reduction in serious side effects for survivors such as the loss of an eye to retinal cancer. At the same time, earlier diagnosis reduces the cost of treatment substantially as children stay in hospital for a shorter period of time and fewer drugs are used in treatment. This, in turn, would improve long-term sustainability of childhood cancer treatment in Tanzania.

Component 6 – NGO core strengthening

The more successful this programme becomes the more expensive it is to run. This is a result of more and more children successfully accessing a more and more complex and effective service. As a result fundraising is a key issue needing attention in the coming years. To ensure adequate funds are raised both local and international efforts will be intensified.

Fundraising in Dar es Salaam

We plan to continue to work with existing donors many of whom have been with us since the beginning of the programme. In addition we hope to attract the support of new donors. We plan to have annual fundraising events – fundraising dinners, charity sports activities etc.

3 New Charity entities

We are launching three new charities: TLM Ireland, UK and USA. As Tumaini la Maisha is not a recognizable name outside of Swahili speaking regions the decision has been made to call these charities 'Their Lives Matter' – with the same initials for all 4 entities – TLM. These new entities will largely be involved in fundraising and volunteer initiatives for all the programmes based in Tanzania and run by Tumaini la Maisha.

Online Fundraising

A new website has been designed for all 4 charities – weareTLM.org; This will allow online fundraising including – sponsoring a child, online cash donations (in various currencies), fundraising pages and online shopping.

Grant Applications

Efforts will be made to apply for additional grants to support various aspects of the programme. This document will help explain the nature of each programme.

APPENDIX C: DRUG PROCUREMENT LIST

Below is a list of some more common medications we will procure for MNH very 6 months. The quantities for Bugando and KCMC will be determined based on patient load and availability of storage (including refrigeration for some drugs).

1. Amikacin 500mg – 1000vials every 6 months
2. Acyclovir Tabs 2000 tabs every 6 months
3. Actinomycin D 120 every 6 months
4. Amphoteracin B 90 every 6 months
5. Bleomycin 15iu 20 every 6 months
6. Carboplatin 450mg 90 every 6 months
7. Cytarabin 1gm 30 every 6 months, cytarabine 50mg IT injection, 200 vials per month
8. Cyclophasphamide 90 every 6 months
9. Calcium Gluconate 120 every 6 months
10. Doxorubicin 50mg 60 every 6 months
11. Daunorubicin 20mg 90 every 6 months
12. Etoposide 5ml 180 every 6 months
13. Emeset 4mg 1500 every 6 months
14. Flurouracil 5FU 250mg inj: 30 every 6 months
15. Flurouracil cream 60 every 6 months
16. Folinic Acid tablets 200 tablets every 6 months.
17. G-CSF – we don't use this often as we only have a limited supply but would use significant amounts if it could be supplied regularly
18. Isotrentinoin 30 X 20 every 6 months
19. Ifosphamide with mesna 210 every 6 months
20. Mecaptopurin 50 X 100 every 6 months
21. Methotrexate tabs 2.5 mg 100 X 60 every 6 months
22. Methotrexate 15mg/ml (preservative free) 60 every 6 months
23. Methotrexate 50mg/ml X 30 every 6 months
24. Potassium 10 ml vials 400 every 6 months
25. Rituximab – We do not have quantity as these have never been used to date.
26. Sodium Bicarb 100 per every 6 months
27. Trexamin acid 500mg vials -10vials per box: 8 boxes every 6 months
28. Vancomycin 500mg 200 every 6 months
29. Vinblastine 10mgX10 in each box:30 boxes every 6 months
30. Vincristine 1000vials every 6 months
31. Tazocin – 400-500 vials a month

Special drugs and supply items:

1. Biopsy needles: Purchased in Ireland at an extreme discount or continued donation by ProjectCure in the United States and carried in country due to supply and issues in country
2. Asparaginase – 10,000IU/vial - 500 vials every 6 months, enough for 5-10 cases of acute lymphoblastic leukemia (ALL), a cancer of the blood, are diagnosed every month at MNH. The use of this drug will improve survival in children with ALL
3. Merapenum. Another expensive drug ($400 per a 10 day course).Merapenum will be used in up to 10 children per year, because of deteriorating clinical conditions despite standard antibiotic treatment. It is used in extreme life-threatening infections.

Palliative care drugs:

Morphine – in liquid form will be supplied by the government. To expand the range of administration of the drugs, we plan to procure drugs that are administered through alternative routes of administration e.g. fentanyl patches or tablet/capsule/IV opiates.