

TUMAINI LA MAISHA TANZANIA
CARING FOR CHILDREN WITH CANCER IN TANZANIA



PROGRESS REPORT



Feb 2019

MESSAGE FROM TUMAINI LA MAISHA (TLM) BOARD

Warm Greetings from Tumaini la Maisha Tanzania.

We are delighted to provide you with this brief update outlining Tumaini La Maisha's (TLM's) achievements since we were founded in 2011. We are pleased to report that we have made great progress towards our mission of making sure that children with cancer in Tanzania get the best possible treatment and care, and that no child with cancer in Tanzania is left behind.

Cure rates at Upendo Children's Oncology Ward have increased 4-fold amongst the potentially curable conditions that arrives there, from 15% to 65%. But in real terms we have also reached many more children, thanks to TLM's awareness raising efforts and the creation of the National Children Cancer Treatment Network (spearheaded by TLM) – fewer than 100 new children presented in 2005; in 2017 this number has risen to over 600, such that TLM now supports one of the largest children's cancer services in the world. Importantly, everything is provided entirely free of charge.

We would also like to give you a quick update on TLM leadership. The Board of Tumaini la Maisha has been under the leadership of Dr. Blandina Lugendo since its establishment in 2011 until June 2018 when she resigned and took more responsibilities at the Management Level. Currently the Board is under the chairmanship of Mr. Gerald Mongella.

The Board consists of six members namely:

1. Mr. Gerald Mongella- Chairperson
2. Dr. Patricia (Trish) Scanlan – Member, and CEO of TLM
3. Dr. Blandina Lugendo – Member, and PRO of TLM
4. Mrs. Dixita Dewji – Member and Treasurer
5. Dr. Julius Mwaisalage – Member
6. Dr. Mwele Malecela – Member

We would like to acknowledge the efforts of our dedicated staff who work assiduously and make sure that TLM mission of providing best possible care to children with cancer in Tanzania is realised, and that **no child is left behind** because THEIR LIVES MATTER!

Gerald Mongella
Board Chairperson

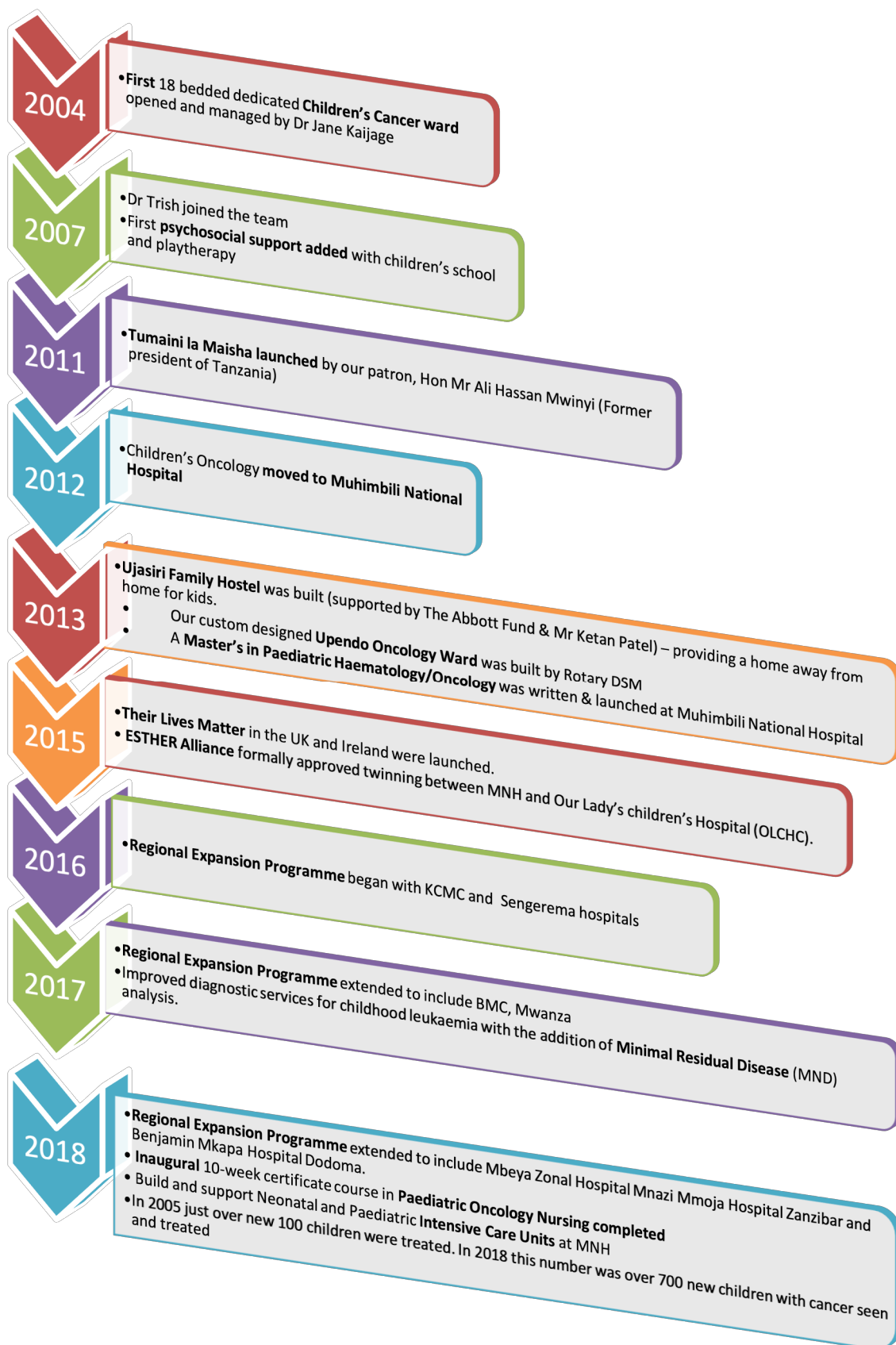
MISSION STATEMENT

“All children with cancer in Tanzania have easy access to locally based high quality curative and palliative treatment leading to survival outcomes similar to resource rich settings.”



HIGHLIGHTS OF MILESTONES REACHED

Key Achievements by Tumaini la Maisha to date include:



DETAILS OF TLM'S ACHIEVEMENT SO FAR

Over the last 10 years TLM and its founders have supported medical and non-medical services for kids undergoing treatment, originally at the Ocean Road Cancer Institute then at Muhimbili National Hospital. Most recently TLM's sights have been directed nationally to try to bring the quality available in Dar es Salaam across the country. All of this is supported by TLM at no costs to the kids or their families. The vision and goals achieved will be explained in the following section.

Component 1 - Clinical Services

1. Supporting paediatric cancer services at MNH

1. Supply all chemotherapy and high-tech supportive care medications to all children attending oncology services at MNH free of charge.
2. Build a custom designed paediatric oncology ward (**ACHIEVED**) including:
 - i. Piped wall oxygen
 - ii. Isolations rooms
 - iii. Secure and safe chemotherapy preparation facility
 - iv. Procedure and counselling rooms.
3. Build and support a Paediatric Intensive Care Unit (PICU) and a Neonatal Intensive Care Unit (NICU) at Muhimbili National Hospital (**CONSTRUCTION AND PROCUREMENT OF EQUIPMENT AND SUPPLIES FOR BOTH ICU FACILITIES UNDERWAY AND WILL BE COMPLETED BY MARCH 2019**).
4. Strengthening MNH laboratory services especially pathology, specialist haematology and microbiology services to improve diagnostics and supportive care for all. Improvements **ACHIEVED** so far include:
 - i. Establishment and funding of paediatric leukaemia diagnostic services at MNH – with Flow Cytometry
 - ii. Access to Minimal residual disease testing for leukaemia children
 - iii. Rapid accurate testing for Burkitt's Lymphoma at MNH using FNA flow assessment
 - iv. Special pathology service access for all challenging paediatric cases through our twinning partner in Crumlin hospital in Dublin, Ireland.
 - v. Automated immunohistochemistry to be launched by March 2019.

2. Creating the National Network of Collaborative Paediatric Oncology Centres

The current top priority is the creation of a network of collaborative Paediatric Oncology centres throughout the National University Hospital network in Tanzania. (**ACHIEVED so far...: 7 hospitals are currently collaborating in this network– Muhimbili National Hospital (MNH), Kilimanjaro Christian Medical Centre (KCMC), Bugando Medical Centre (BMC), Sengerema Hospital, Mbeya Zonal Hospital, Mnazi Mmoja**

Hospital Zanzibar and Benjamin Mkapa Dodoma Referral Hospital. All these participating centres have access to the following:

1. Centralised procurement and dispersal of sufficient quantities and quality of chemotherapy drugs to all participating Centers /Hospitals through TLM/MNH partnership. All provided free of charge to all participating sites by TLM.
2. Standardised national medical and nursing treatment guidelines for implementation on all paediatric oncology wards across the country thereby standardizing care. (CURRENTLY UNDER REVIEW AT A NATIONAL LEVEL)
3. **AUTOMATION OF CHEMOTHERAPY PRESCRIBING.**
4. Fast-tracked centralised specialist pathology services for suspected childhood malignancy diagnostics
5. **CREATION OF A SUPPORTIVE CARE HANDBOOK AND ASSOCIATED POCKET GUIDES GIVEN TO EVERY STAFF MEMBER WORKING ON UPENDO WARD.**
6. Centralized oncology advice and support to all our participating partners through virtual platforms and weekly conference calls so that each child undergoing treatment for cancer is discussed by a specialist no matter at which participating site the treatment is delivered – through the TLM/MNH partnership every single week.
7. Nutritional assessment and support designed locally for all children with cancer at participating centres.

Component 2 - Non-Clinical Support

1. Provide psycho-social support for children on treatment and their caregivers at Muhimbili National Hospital through play-therapy – 3 play staff, child-life programmes – 2 staff, education – 2 teachers and extra-curricular skills programmes – 1 skills teacher. (ACHIEVED)
2. Providing a home away from home hostel for children and their caregivers when home is simply too far away – (ACHIEVED) – a 22 bed hostel has been built and has 100% occupancy!
3. Develop curricula and teaching/support material that is locally appropriate and open source accessible to all participating sites. (ACHIEVED)
 1. A patient pathway story book
 2. A carer guide
 3. A play therapy manual
 4. Story books about chemotherapy, radiotherapy
 5. A video cartoon explaining cancer in simple terms.
 6. A video cartoon explaining the cancer journey for a child in MNH
 7. 2 Flipcharts with parental education regarding nutrition and malaria. More to be developed.

4. When required provide transportation to and from hospitals for the children on treatment. (ACHIEVED)
5. Support similar programmes at other collaborative centres / hospitals and provide a written blueprint for all centres to provide these services. This includes all generated teaching material required to run these programmes. (The material is available – need to strengthen the sister sites).

Component 3 - Education of Professionals and provision of specialist services

1. Facilitate formal and informal, local and international, training for all staff involved in the care of children with cancer including paediatric oncologists, surgeons, and other specialist doctors, nurses, laboratory staff, clinical engineers, administrators, teachers and play staff. (ACHIEVED): Formal course already developed/run include:
 1. A 2 years MSc in Paediatric Oncology – for paediatricians.
 2. A 10-week short course in paediatric oncology nursing.
 3. Advanced paediatric life support programmes
 4. Paediatric Early Warning Score programme
2. Set up and maintain twinning programmes between partnering health and education institutions, internationally and within the country (ACHIEVED = there is a formal ESTHER approved Twinning programme between MNH and Our Lady's Children's hospital in Crumlin, Dublin – facilitated and supported by TLM).

Component 4 – Data Management

1. Set up and maintain a National Paediatric Oncology Database at all participating centres/ hospitals. – Phase one of this database will be launched in March 2019 and it will be rolled out to all participating sites across the country over the following 12 months and beyond as more sites join.

Component 5– Outreach/ Follow-up/Awareness

1. Design the national network of paediatric oncology facilities which will be divided into 4 tiers:
 - ***Quaternary care: At MNH/ORCI***
 Where the central hub of this entire framework will provide: all central pathology services for children as required; all specialist procurement of chemotherapy, chemotherapy-protection, diagnostic and supportive care equipment and consumables for the treatment of children with cancer; centralised development of all treatment protocols; provision of a national database for all sites; sub-specialist care for all children. National awareness and sub-specialty training programmes; Fundraising efforts; coordination of the national transport and communications services.
 - ***Tertiary Care: All University Hospitals in Tanzania***

These care centres will provide cancer care treatment to all children with all forms of cancer unless quaternary level care is required. They will act as a hub to all regional Second and Primary level care facilities.

- ***Secondary Care:***

All regional centres with sufficient capacity and interest will be linked into this network to treat the pre-agreed easy to treat cancers and also work with other higher-level centres for follow up of children. They will also provide support to primary level facilities.

- ***Primary Care:***

These centres will be responsible to stabilize and safely and rapidly transfer, any child suspected of a childhood malignancy, to the appropriate centre where definitive treatment is available.

By implementing this model children in need will be fast-tracked to the most appropriate treatment site. The remote clinical facilities will be linked to regional centres and so have access to expert advice and diagnostic and treatment services not available locally. All components of outreach programme will incorporate this structure.

2. Increase the number of tertiary centres / hospitals to participate in this collaboration – **ongoing drive.**
3. Improve awareness of early warning signs of childhood cancer among health professionals and the general public through targeted initiatives:
 - information leaflets have been developed.
 - Hope to launch a national awareness campaign which is being planned currently.
4. Increase awareness of the network of centres treating children's cancer in Tanzania by working with the MoHCDGEC – **ongoing initiative.**

Component 6 – Strengthening and Growing the TLM NGO

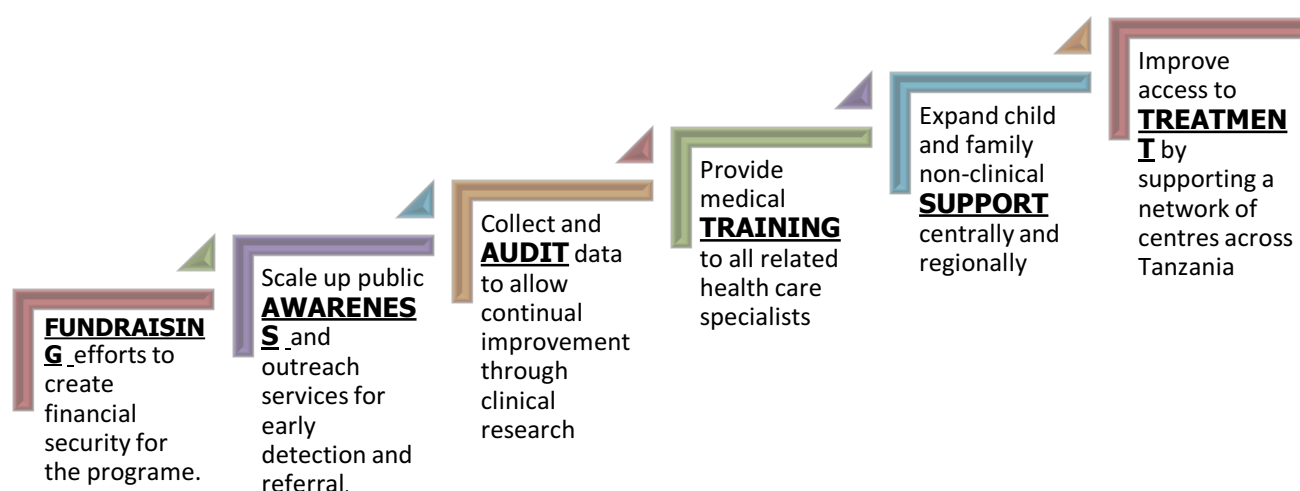
1. Continuing to support the professional development of all TLM staff and grow our team as required. – **ongoing.**
2. Strengthen the fundraising activities based in Tanzania– **ACHIEVED** the following:
 - In 2017 a fund raising manager was employed to lead this drive. This has led to a significant increase in successful grant applications.
3. Develop joint partnerships with charities interested in supporting our services. – Many such partnerships have been developed. **ACHIEVED** links with:

1. Operation Child Life – a surgical training and service NGO
2. IMA – a charity supporting our work and acting as our fundraising platform in the US
3. Molly’s Network – an NGO governance strengthening organisation
4. The Mo Dewji Foundation – a donor organisation
5. The Lions and Rotary Clubs of Dar es Salaam and many others listed below
4. Work closely with our sister charities in Ireland and the UK and expand our footprint to other countries. – **ACHIEVED AND ONGOING.**

EFFORTS TO OVERCOME CHALLENGES FACED

Children’s cancer is curable if children are treated in time and on the correct protocols. However many children still arrive too late – and these are the children we turn our attention to in the coming years. Over the coming years Tumaini la Maisha aims to reach **ALL CHILDREN WITH CANCER** in Tanzania **leaving no child behind**. That is estimated to include 3500 children annually.

To achieve this we will focus on strengthening six main programme components:



NEED FOR MORE SUPPORT

Treating cancer costs money. However central to our ethos is the belief that these costs should not be a burden to the families of children with cancer. As a result TLM provides all our services free of charge to all families. We encourage all our hospital partners to do the same. MNH, our quaternary hub is a shining example of what is possible – all hospital services are given to all children at no cost.

This does mean that TLM must raise significant funds each year.

The costs involved in the treatment of childhood cancer vary depending on the diagnosis – some are relatively cheap: Burkitt's lymphoma is the most common children's cancer in Tanzania. We cure 70% of children suffering from Burkitt's Lymphoma at a cost to TLM of 200,000 Tsh per child; while others are expensive - the average cost per child receiving Leukemia treatment at Muhimbili National Hospital is a minimum of USD 10,000 of which Tumaini La Maisha covers USD 4,500 (the remainder is supplied by the Government). The TLM contribution to each child with cancer receiving treatment across the Tanzania network is on average Tshs. 655,185 per year (almost 300USD per child).

Everything we achieve we do so collaboratively through an approach TLM helps coordinate but led by our partners in Government institutions, and with the help of many sponsors, donors and charities. As we improve and reach more children so our need for support increases.

We will not be satisfied until every child with cancer in Tanzania has access to care and treatment and a chance of cure equal to anything in the world today.



These children represent all of our futures – *their lives matter!*

Partners & Friends

