Tumaini La Maisha
Tanzania

Annual Report
2018

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Message from the Board Chairman and CEO

Dear Partners,

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 for the year 2018. 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.

Thus it has been a busy and interesting year, as you read through the report remember all this has been made possible through the generous support of our entire friends who believe in our mission and what we do.

Thank you everyone for being part of this journey

Mr. Gerald Mongella

Dear Friends and Family of TLM,

It gives me great pleasure to share with you our latest report for 2018. We’ve had a busy and exciting year!

We’ve made new connections and friends in hospitals across the country and universities across the world.

We’ve launched new and transformative training programmes – especially for our children’s oncology nurse colleagues.

We’ve secured more funding to provide more quality services to our most vulnerable children.

But as always – there is so much more to be done. Thank you for helping us keep the faith on this long but vital journey. Dr. Trish

Mr. Gerald Mongella
Board Chair

Dr. Trish Scanlan
CEO
Over the last 8 years TLM has supported Medical and Non-Medical Services for children undergoing cancer treatment. Most recently TLM’s sights have been directed nationally to try to bring the quality services available in Muhimbili National Hospital located in Dar es Salaam, across the country. Currently TLM has established and support a network of 6 paediatric oncology sites across the country. All TLM supported services are provided at no costs to the kids or their families.

2018 HIGHLIGHTS

Over the last 12 years the reach of children’s cancer service provision has improved from approximately 100 children per year to more than 600 and from one hospital to six treatment sites. Long term survival has improved in that time from less than 10% to more than 50% of children seen. However the number of children seen represents less than 20% of the anticipated annual total.

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 similar to developed countries.

The plan involves strengthening and broadening all services currently available at Muhimbili National Hospital and supporting the development of a tiered network of paediatric oncology facilities in hospitals across Tanzania.

In 2018 TLMs efforts included many Clinical and Non-Clinical services including the provision of all chemotherapy for every single child receiving treatment right across the whole Country of Tanzania – entirely free of charge; the creation of the first Paediatric Intensive Care Unit (PICU) in Tanzania and a brand new Neonatal Intensive Care Unit (NICU), both at Muhimbili National Hospital; Haematology and Pathology Laboratory service strengthening and education in the areas of flow cytometry, immunohistochemistry and minimal residual disease analysis. We also conducted various training to medical personnel and the parents and care givers on health related topics.
OUR BRAND PROMISE
No child with Cancer should be left behind

VISION
“No child in Tanzania suffers or dies unnecessarily from cancer.”

MISSION
‘All children living in Tanzania who develop cancer, have appropriate access to quality services leading to cure rates seen in resource rich settings.’

APPROACH AND AIMS
All children living in Tanzania who develop cancer are diagnosed in a timely fashion to enable treatment with curative intent and have appropriate access to good quality paediatric oncology services.

OUR MOTTO
Curing kids cancer in Tanzania – together we can!
Our Impact in the year 2018

Monies raised moving towards a world where no child dies from cancer

Tshs 4,103,186,534

Number of New Children served

Children 670

Invested in purchasing of chemotherapy Safety Cabinet

1 machine

Construction & Equipping of Paediatric Intensive care Units

2 ICU units – Paediatric and neonatal

New patient and family who stayed at Ujasiri House

260 Children

Number of Grants received

13 Grants

New technology created for chemotherapy drugs administration

1 SAFE chemo automated prescribing sheet

New research grant awards

2 Research grants:

Awareness & Fundraising events conducted

3 Events Completed
CLINICAL WORK

Intensive Care Units (ICUs)

Our goal being to ensure that all Tanzanian children with cancer receive treatment to the highest quality medical care. Thus the improvement of health services particularly Children’s Intensive Care Unit at the hospital was one area we looked into in this year. The Hospital had two intensive care units (an adult medical and an adult surgical ICU), that catered for all serious adult patient referred from all over the Country. Children where occasionally admitted to these units as well however they were both generally over capacity and also not ideal for the care and treatment of sick children. There was a small high dependency unit in the paediatric department with no facilities for ventilation or other respiratory support. At the maternity wing there is a very basic ‘hot room’ with access to oxygen where all sick and preterm infants are cared for.

We were fortunate to receive grants for construction and equipping of PICU and NICU units at Muhimbili National Hospital, through the grant we received from Queen of Sharja.

The construction is underway and we have placed orders for various ICU medical equipment and by year 2019 we expect to have the 2 ICU’s in operation In addition with this grants, we have combined with grant from Bank of Ireland for construction of safe and clean drinking water for the paediatric building complex and the maternity ward building as well, thus once accomplished we will have two plants in place for clean and safe drinking water for the two building complex.
Chemotherapy
We continued purchasing chemotherapy drugs locally for the kids undergoing cancer treatment, all kids have been provided with chemo and other related treatment free of charge. We were also able to purchase protective equipment for the pharmacists and nurses administering the chemotherapy drugs.

SAFE Chemotherapy
An important initiative we would like to share is in the area of chemotherapy prescribing. We have created a wonderful excel based programme automating the prescription of chemotherapy. We believe this will remove 90% of common prescription errors. We hope to move this programme to a web-based app and merge this with our soon to be launched Paediatric Electronic Medical Record. This is a unique programme and once built and the beta testing phase is complete between the years 2019-21, we plan to offer these programmes to our partner centers and the resource limited colleagues across the continent.

IV Pumps & Cleaning Robot
Amongst the medical items that were acquired in this period, 20 infusion pumps were purchased and now are being used at the paediatric oncology wards. We also received a donation of Pulsed Xenon Ultraviolet-C Disinfection System for the purpose of reducing hospital acquired infection rates through disinfecting the wards.
A map showing the location of our partner sites across the Country

**National Framework of Collaborative Paediatric Oncology Centers**

A total of 3 new centres out of the planned 4 per year have been added to the network since January 2018 namely Benjamini Mkapa Hospital in Dodoma, Mbeya Zonal Hospital in Mbeya and Mnazi Mmoja Hospital in Zanzibar. Now giving us a total of 6 partner centers working in collaboration. Thus from January to December 2018 a total of 444 new cases were seen at MNH, whereas 149 were seen at these collaborating sites. Through this partnership, we were able to coordinate and offer advice and support to all hospitals in the network, through virtual platforms and weekly conference calls to discuss patients care at the collaborating partner sites.
EDUCATION & TRAINING

Nursing Training
Our first TLM Paediatric Oncology nurse training course took place in this year. 7 MNH nurses attended an intensive programme which involved 22 International and 6 local faculties. It was a very successful training. In addition the nursing diploma syllabus has been submitted at the Muhimbili National Hospital and it is under review.

Two advanced Paediatric Life Support (APLS) training courses were also conducted this year that benefited not only the Paediatric Oncology unit but staff across Muhimbili National Hospital. A team of 11 specialists in paediatric Emergency Life support skills visited and conducted a short course training of the trainers (ToTs) for one week at MNH.

TLM also provided training to our National partner centers who recently joined the TLM clinical treatment network. 2 Nurses and 1 Oncology Doctor from Mbeya Regional Hospital, were provided basic training in paediatric oncology for 2 weeks at MNH. It was on hand training, whereby they learnt through real cases.

Two paediatric nurses had an opportunity to attend a one month’s observership training at St John's Ward in Our Lady’s Children’s hospital, Dublin, where they got to have a first-hand experience on paediatric cancer treatment in Europe. They were able to share their Tanzania experiences and gained lots of Irish ones. On their return some of the new clinical ideas were shared and implemented at Muhimbili Hospital paediatric cancer ward.

We also conducted training in Mwanza Region (8 centers reached) in partnership with IMA World Health improving awareness on early warnings signs for childhood cancer and intensive teaching on Burkits Lymphoma.
**Laboratory Services Training**

This year Laboratory services continued with greater achievements, the pathology and hematology department; the aim being to strengthening local capacity on diagnostic testing to reduce number of samples sent abroad. We had one pathologist and one pathology scientist from MNH who attended and completed a 2-weeks training at Our Lady’s Children’s Hospital in Crumlin particularly on how to operate the immunohistochemistry Stainer machine (IHCS). This will enable the hospital to meet the demand by rapidly processing pathology samples and thus improve the capacity of the current local service. The IHCS machine, has been donated by a donor from the American Society for Clinical Pathology (ASCP) purchased it, now it is in the hospital.

This year we have started our plan to set up a new Flow Cytometry Machine called a FACS CANTO to provide more specialised (Minimal Residual Disease MRD) analysis system to assess treatment response in acute leukaemia. The first step we took was to train 2 hematology Scientists from MNH in Ireland for two weeks. In addition the first FACS CANTO machine has arrived at the hospital and it still awaiting installation.

The Mater Hospital and MNH have collaborated to consolidate and strengthen the diagnostic services at MNH for the identification of infectious pathogens. We supported one Microbiologist from MNH to attended one week training at Mater Misericordiae University Hospital.

We have been working with a number of teams to set up some combined clinical research projects, molecular Haematology Department at University College Dublin (UCD) have started the application process for a combined research project to analyze genetic mutations in samples from Tanzanian children with leukaemia.
INTERNATIONAL COLLABORATIONS

University Collaboration
To better improve our services to children with leukemia, we partnered with Molecular Haematology Department at University College Dublin (UCD) to implement a combined research project to analyze genetic mutations from samples from Tanzanian children with Leukaemia – the first stage of discussions have concluded and we are hoping to secure funding in the coming year.

We have partnered with a number of international universities for medical student exchange programmes. Our twinning program continued this year, one notable one from Boston University who had worked on our strategic plan as well as University of Arizona for students undertaking MSc. in Public Health.

“We just wrapped up one of the best courses I have ever taken - Program Design at BU SPH. My team worked with Tumaini la Maisha (TLM), a Tanzanian NGO that treats and cures childhood cancer. Tanzania experiences a fraction of the treatment & remission rates enjoyed in resource-rich countries, but TLM is tackling that issue head on; since its inception, TLM has seen the one-year disease-free survival rate of 12% in 2005 increase to 70% in 2016.” Kate Baker (Boston University.)

Visiting experts
We also had a wonderful opportunity to have a paediatric infectious disease consultant visit us at the Upendo Oncology ward and helped enormously to create an appropriate treatment strategy for oncology children who develop fevers. We also had a visit from a team of Irish Parliament

Twinning Programmes
TLM this year has facilitated and continues to manage a formal Esther approved partnership between MNH and OLCHC. This has unlocked a vast array of support and resources from Ireland including but not limited to: twice weekly sub-specialist review of pathology specimens; foundation of local service, resource support and remote authorization/supervision of specialist haematology investigations; expert visits; clinical engineering support and surgical specialist camps. Within the country we have continued with our weekly Tumor board meetings at the hospital as well as weekly partner sites meetings to discuss patients at our sister sites.
**Therapy Programmes**

Therapy programmes have been strengthened and more kids are now involved in the play therapy activities and in this year we placed a larger emphasis on the teenagers. We had videography training for the kids; it was a huge success, thanks to Steve Bent. We also had a wonderful artist from US goes by the name Shrine who had wonderful session with the kids who did therapeutic Art and also painted our Ujasiri house with amazing calming drawings and paintings.

**Nutritional Programme**

Nutrition Programme has now become a vital support to the children with cancer we serve due the children’s growth, development and weight gain/maintenance has significantly improved, which has led to higher tolerance of chemotherapy treatment and recovery, and the kid love the smoothies. The nutritious smoothies are given to the kids twice a day and in addition they get are given porridge as well every morning.

**Transport Programme**

Transport programme has been expanding throughout the country; we are now able to provide transport free of charge to all the patients from all over the country to and from the hospital particularly those who reside outside Dar es Salaam. This also included patients from our 7 partner sites who needed to come to Muhimbili Hospital. We were able to provide transport to more than 200 children with their care givers over this period.
FUNDRAISING IN TANZANIA

This year we had our first Tanzania TLM awareness and fundraising festival, which was a wonderful learning experience and also a very successful and enjoyable event. The Tumaini La Maisha Festival took place at Nafasi Art Space from 3 pm until late and aimed at raising funds and awareness about childhood cancers in Tanzania, the work of TLM and to create an uplifting and joyous event for children undergoing cancer at Muhimbili National Hospital in Dar es Salaam and all those who attended. With an estimated audience of 400-500 attendees, an online audience of approximately 5 million people and a total of 6,865,300 Tanzanian Shillings were raised; the event was an outstanding success!

New grants applied in this period were from: Wings of Support, Electric Aid, Irish Aid Fund, SONGAS, US embassy grant, Human Development Innovation Fund (HDIF), Esther Ireland, St. Georges Foundation. We also secured grant for the Retinoblastoma project which also included the funds to purchase eye clinic equipment for kids with Retinoblastoma and other eye related illnesses. This grant was donated by our friends at rotary Dar es Salaam and International. Friends of Cancer Patients, an NGO based in the UAE, donated funds to TLM for the construction of Paediatric Intensive Care Unit (PICU) & Neonatal Intensive Care Unit (NICU) based at MNH.
PROFESSIONAL DEVELOPMENT FOR STAFF

TLM organised training for the TLM team to gain the necessary skills for effective implementation of the project. Three main trainings were conducted namely, effective communication course for all TLM staff, leadership course was conducted for TLM and MNH management, this has bought a positive impact on the staff performance. TLM was privileged to attend various conferences on childhood cancer, namely SIOP conference in Kyoto, Healthcare Clowning International Meeting in Vienna it was a wonderful experience were we got to share our work and exchange ideas and learn from the best in this field of health care clowning.
FUNDRAISING & INCOME
TLM INCOME

Income Sources for the year
TLM Income came from a variety of sources as shown in the above diagram. Where categorized into 8 major categories as listed in the diagram. With over 90% of the funds coming from Non-profit organizations grant.

Our major grantor this year was for the construction and equipping of 2 Paediatric ICU, that’s why more than 60% of the income was spent capital purchase and projects. The capital purchase largely being medical items for the 2 ICUs.

Efficiency Indicators
This indicator highlight the portion of the total income received that is allocated to children with cancer with their families. For the year 2018 efficiency indicator was at 82%, indicating that only 17.6% was used on administration. Over the years efficiency has been improving. In the years 2016 and 2017 it was at 70% and 83% respectively.

Support Service Indicator
The costs involved in the treatment of childhood cancer vary a lot; depending on the child’s diagnosis and treatment cycle the child will take; TLM contribution to medical treatment costs and care per child is on average is approximately at Tshs. 1,104,131/- per year.
Statement of Financial Position 2017

This financial year has been a successful one with the organization now growing its financial base and experience. Mekconsult our Auditing firm audited our books and in addition advising us on how we can best continue to provide the best services to the children with cancer in Tanzania. In this section we will highlight our financial sustainability of the organization, efficiency and effectiveness. Taking into account the following: do we have the money needed to continue serving the kids tomorrow as well as today, do we serve as many kids possible with the existing resources at the lowest possible cost and are we managing our money responsibly. This year we were privileged to have an increase in the number of funds received from donors and partners. A total amount of grants and donations received was Tshs. 4,108,537,492/-.

During the year 2018 TLM received funds from various sources a large amount was for the construction and equipping of two ICU Paediatric and Neonatal. The project was funded by her Highness Sheikha Jawaher bint Mohammed Al Quasim (Wife of His Highness Sheikh Dr. Sultan Bin Mohammed Al Quasim Ruler of Sharjar) through The Big Heart Foundation. With grant value of USD 2.29 Million to include the construction, equipping and administration costs. And we received the first instalment amounting to tshs 3,019,843,816 and with these the corresponding expenditure on capital purchases and projects amounting to Tshs 2,513,809,997/-.
New cases seen by TLM has been increasing gradually over the years, but in the year 2017, the number had dropped slightly, and this year it has continued to drop by 27 patients this year 2018. Now more and more cases are being managed by the outreach centres, through our outreach program, thus reducing the number who would have otherwise had to come over to MNH to be treated.

Muhimbili National hospital saw and treated the most new cases followed by Bugando with 68 KCMC with 45 new cases, and Sengerema 13 new cases.

The number of new cases in terms of sex, the males have surpassed female by a small percentage, the number of males being at 52%, while for girls at 48%, which is similar to the previous year’s (2017), the percentage of girls was 49%, thus this year there has been a slight decreased of 1%, while for boys a slight drop of 1% as well. More and more girls are now being bought for treatment which is a positive move, while for boys the trend has gone down.
The year 2018, we have seen more children from different geographical location compare to previous years.

A large number still continues to come from Dar es Salaam, the capital city and where MNH is located, followed by Mwanza Dodoma, Morogoro and Tanga respectively.

Compared to last year (2017), Dar es Salaam, Dodom, Morogoro and Tanga’s number of new cases have increased while Kigoma and Pemba the number of new cases have reduced slightly.

The regions with the smallest number of new cases referrals are Katavi and Njombe and Kagera. These are the same regions as identified in the year 2017 with the smallest number of Referrals.
The most common new cases of childhood cancer we treated this year 2018 was Leukemia where 140 kids were diagnosed with this, followed by Retinoblastoma 115 children and thereafter, Wilm’s Tumor with 107 children. 37 comprised of the number of children with different types of childhood cancer. But we had a challenging year with lots of different and sometimes rare conditions presenting.

In comparison with the previous year, the 3 top cancer types are the same for both years, Wilm’s Tumor, Leukemia and retinoblastoma. But the numbers have almost doubled, Retinoblastoma in the year 2017 was 73 new cases seen, while in 2018 new cases increased to 115 new cases which is an increase of 58%, Leukemia increased by 98%, Lymphoma increased by 88% and Wilm’s Tumor by 45%.
PARTNERS & FRIENDS
Partners and Friends for 2018

[Logos of various organizations]
TLM Engine

*Our staff are so important*

Lilian Niyetabula
Chief Operations Officer

Alex Kajage
Chief Finance Officer & Donor Manager

Jane Kajage
Medical Director

Dr. Trish Scanlan
Chief Executive Officer

Alice Mutaganda
Outreach & Database Coordinator

Martha Kiula
Parent Liaison Counselor

Ezekiel Tunduje
Pharmacist

Monalisa Dennis
Finance Officer

Joyce Bulube
Procurement Officer

Leonard William
Social Manager & Play therapist

Sadrey Mbunda
Nurse

Magrete Msafiri
Nurse

Musa Simon
Nurse

David Makunja
Nursing Officer

Fora Mussa
Ward Clerk

Magramo John
Assistant Play therapist

Revinant Mura
Teacher

Doris Kabula
Teacher

Reuben Kasiga
Driver & Program Assistant

Hilda Mwagoni
House Supervisor

Alice Abogast
Down Doctor

Elisha Majeia
Down Doctor

Winfrida Mwigue
Family Liaison Officer

Blandina Mlguzi
Family Liaison Officer

Eunice
Assistant Nutritionist

Elizabeth Chabiko
Clown Doctor & Yoga Instructor

Hawa Mpona
Health Attendant

Joyce Kopwe
Health Attendant

Prasca Bello
Skills Teacher
Thank You