Twinning programs, building capacity in Paediatric Oncology in Low resource setting:
The Uganda experience

Kenya Paediatric Association Annual Scientific Conference - Mombasa
Dr. Robert Kimutai – Paediatric Hematology and Oncology Fellowship Program PHO II
Friday 12th April 2019
Outline

• The morally intolerable situation

• The formula for success – lessons from Uganda
  • Partnership: Government, community, private sector, and Devpt partners
  • The foundation: Platform of HIV/Infectious Diseases
  • Capacity building: Skilled health workforce
  • The Rising Tide that Floats all Boats

• Conclusion
NCDs are a Major Cause of Under-5 Mortality and Morbidity in Africa

- 30,000 new cases of Paediatric cancer per year in East Africa; <10% survive

- 100,000 babies born with sickle cell disease per year in East Africa; ~80% die as infants

- Difficult to measure burden due to conditions requiring surgery/anesthesiology, critical care
The Access Challenge:
A Morally Intolerable Situation

In the United States, 15,000 children develop cancer annually. 80% survive!

IN Sub-Sahara Africa, 100,000+ children develop cancer annually. 90% die!
Twinning Programs

• Twinning is the concept of two organizations working together
  • A centre in a high-income country partners with centres in a low-income country
  • Educate each other to improve patient treatment and care through support of infrastructure, human resource and capacity building

• Considered one of the most effective models for sustained improvement in childhood cancer in Lower and Middle Income Countries (LMICs)
Global Twinning Projects Map

Uganda Cancer Institute (UCI) / Makerere University College of Health Sciences (MakCHS) / Mulago National Referral Hospital (MNRH) Uganda-Baylor College of Medicine-Bristol-Myers Squibb-Texas Children’s Hospital-Children’s Clinical Centre of Excellence

Twinning Partners: Baylor College of Medicine, Texas Children’s Hospital, Uganda Ministry of Health, UCI, Makerere University College of Health Sciences, Mulago National Referral Hospital, Baylor College of Medicine Children’s Foundation Uganda.

Project Leads: Parth Mehta, Director of Global Oncology Programs at Texas Children’s Cancer and Hematology Centers (pmehta@txch.org) or (globalhope@txch.org)
Joseph Lubega (jlubega@txch.org)

Name: Uganda
City: Kampala
Global HOPE
HEMATOLOGY-ONCOLOGY PAEDIATRIC EXCELLENCE
A Formula for Universal Health Care for Children with NCDs in Africa

- **Partnership**: Government, community, private sector

- **The foundation**: Platform of HIV/Infectious Diseases

- **Capacity building**: Skilled health workforce

- **The Rising Tide that Floats all Boats**: Paediatric Hematology/Oncology
## Unprecedented Improvements in Outcomes of Children with Cancer

<table>
<thead>
<tr>
<th>Before in Uganda or Typical in Sub-Saharan Africa</th>
<th>Since Texas Children’s Global HOPE Program in 2016</th>
</tr>
</thead>
<tbody>
<tr>
<td>30% of children with cancer alive and on treatment at 1 month; Uganda Cancer Institute</td>
<td>85% of children with cancer alive and on treatment at 1 month; Uganda Cancer Institute</td>
</tr>
<tr>
<td>No prior data in Uganda; Many centers in SSA don’t treat childhood leukemia</td>
<td>91% of children with childhood Leukemia in remission at 1 month</td>
</tr>
<tr>
<td>No data</td>
<td>90% overall survival at 2 years of children with Hodgkin lymphoma</td>
</tr>
<tr>
<td>50 – 70% of children lost to follow-up or abandoned therapy at 1 year</td>
<td>24% of children lost to follow-up or abandoned therapy at 1 year</td>
</tr>
<tr>
<td>1 – 4 weeks to confirm a diagnosis of leukemia; no specific subtype</td>
<td>≤ 24 hours to make a diagnosis of leukemia; specific subtype</td>
</tr>
</tbody>
</table>
Improved Quality of Life of Children with Cancer

- No child sleeps on hospital verandah or under a tree, while receiving cancer treatment
- Annual Children’s Cancer Survivors’ camp
Engaging, mobilizing, and energizing local communities
Engaging, mobilizing, and energizing local communities
### Impact on Capacity to Provide Care to Children with Cancer and Blood Diseases

<table>
<thead>
<tr>
<th>Before in Uganda or Other East Africa Countries</th>
<th>Since Texas Children’s Global HOPE Program, 2016 – 18</th>
</tr>
</thead>
<tbody>
<tr>
<td>ZERO Paediatric Haematologist in Uganda and Tanzania; 1 in Kenya</td>
<td>6 Paediatric Haematologists in Uganda in 2018; Anticipate 2 in Tanzania by 2020; 4 in Kenya by 2020</td>
</tr>
<tr>
<td>ZERO Paediatric Oncologist in Uganda; 1 in Tanzania; 1 in Kenya</td>
<td>7 Paediatric Oncologists in Uganda in 2018; Anticipate 2 in Tanzania by 2020; 4 in Kenya by 2020</td>
</tr>
</tbody>
</table>

Total number of Paediatric Hematology Oncologists at Texas Children’s Hospital = 60
Acknowledgement to AAFP and partner institutions building capacity in Africa
The First Graduates of Global HOPE’s Paediatric Hematology-Oncology Fellowship Training program in East Africa
Global HOPE has Shifted the Paradigm of Sub-Specialty Medical Education in Uganda

- Neonatology Fellowship
- Paediatric Critical Care Fellowship
- Medical Oncology Fellowship
- Gynaecological Oncology Fellowship

‘We weren’t thinking about fellowship programs before – Prof at MUK’
# Global HOPE Trains the Paediatric Multi-Disciplinary Workforce

<table>
<thead>
<tr>
<th>Cadre, No. trained</th>
<th>Nature of Training</th>
</tr>
</thead>
<tbody>
<tr>
<td>Nurses, 24</td>
<td>Annual 2-day seminar, weekly CNEs</td>
</tr>
<tr>
<td>Medical Officers, 6</td>
<td>Bedside (ward rounds &amp; clinics), clinical conferences</td>
</tr>
<tr>
<td>Medical Students, 16</td>
<td></td>
</tr>
<tr>
<td>USA Global Health Residents, 3</td>
<td></td>
</tr>
<tr>
<td>Residents, 43 (from 3 medical schools)</td>
<td>Lectures, tutorials, bedside (ward rounds &amp; clinics)</td>
</tr>
<tr>
<td>PHO Fellows, 14</td>
<td>East Africa PHO Fellowship</td>
</tr>
<tr>
<td>Laboratory Scientists, 2</td>
<td>Leukemia/lymphoma diagnostic flow cytometry, cell processing</td>
</tr>
<tr>
<td>Administrative, 4</td>
<td>IT, Monitoring &amp; Evaluation</td>
</tr>
<tr>
<td>Continuing Medical Education, 20</td>
<td>Tumor Boards, Morning rounds, grand rounds</td>
</tr>
</tbody>
</table>

Total People Trained: 125

Trainee-hours (Excluding fellows): 4,800
Empowering nursing team

N2
HUMANIZATION OF NURSING PROFESSIONALS IN PEDIATRIC HEMATOLOGY AND ONCOLOGY DEPARTMENT: NEED OF NATIONAL PROGRAM

FZ. Eldrissy, K. Lambach, F. Elkazir, M. Elbaz, J. Elhoudi
Pediatric Hematology & Oncology Department University Hospital Mohammed Vth- Marrakesh Faculty of Medicine- Cady Aïad University- Marrakesh- Morocco

N3
CONTINUING NURSES EDUCATION AT THE UGANDA CANCER INSTITUTE: A BASELINE ASSESSMENT

Joan Nakabir(1,2), Robert Kmuta(1,3), Aisha Ndege(1,2), Mulyowa Isaac(1), Nankinga Rose(1), Joyce Kambugu(1)
1. Uganda Cancer Institute Paediatric Department, Kampala, Uganda; 2. Bayer College of Medicine- Uganda, Kampala, Uganda; 3. Kenya Medical Research Institute, Nairobi, Kenya
Global HOPE Trains the Paediatric Multi-disciplinary, Multi-specialty Workforce

- Blackboard
- Online library
- Leadership reflective seminars
- Visiting professors
- Journal club
- Morbidity & Mortality review
- Mentorship and travel
Texas Children’s Hospital

Global HOPE

A Formula for Universal Health Care for Children with NCDs in Africa
The Global HOPE formula for Universal Access to Health Care for Children in Africa

- **Partnership**: Government, community, private sector

- **The foundation**: Platform of HIV/Infectious Diseases

- **Capacity building**: Skilled health workforce

- *The Rising Tide that Floats all Boats*: Paediatric Hematology/Oncology
Partnership: Understand, Engage, Integrate

- Systematically assess and understand the local context: priorities, resources, systemic weaknesses

- Government is the majority provider of health care in Africa, and is necessary for broad systems interventions

- Local communities are an enormous resource

- Integration of programs achieves more, sooner, and ensures cost-effectiveness and sustainability
Delay in diagnosis
Mostly in the medical referral system, not at home

Poverty and socio-cultural barriers
Financial strain on marriage is a major problem

Inadequate facilities and technology
Highly skilled surgeons hampered by operating room space, equipment, and lack of paediatric anaesthesiology and critical care

Poor access to drugs
Cancer drugs “including” hydroxyurea and supportive care; children’s formulations

Lack of trained doctors and nurses
Extremely high motivation to train in this field, by nurses, paediatricians, surgeons, etc.

Need to adapt protocols
Locally adapted protocols based on local research and available capacities

Lessons learned by Global HOPE:
Why death and morbidity from cancer, sickle cell disease, and blood diseases are so high in Africa
The Global HOPE formula for Universal Access to Health Care for Children in Africa

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• *The Rising Tide that Floats all Boats*: Paediatric Hematology/Oncology
Use, Strengthen, and Sustain the Foundation of HIV/Infectious Diseases

Flow cytometry and diagnosis of leukemia/lymphoma in children in Uganda

• For the first time, we are able to subtype acute leukemia and lymphoma in children in Uganda.

• Leukemia/lymphoma diagnosis made within 24 hours

Multi-parametric flow cytometry of tumor tissue

Conclusion: Lymphoblastic lymphoma, NOT Burkitt lymphoma
The Most Profound Lesson from the HIV/AIDS Response in Africa

It can be done!
The Global HOPE Program is Built on the Foundation of Baylor International Paediatric AIDS Initiative (BIPAI)

• BIPAI NGOs in 7 countries in Africa
• BIPAI is the single largest provider of Paediatric HIV care in the world;
  • Treated 1,000,000+ children with HIV/AIDS;
  • Mortality rate of only 1%;
  • Trained 52,000 African healthcare professionals
• Saved a generation of African children!
The Global HOPE formula for Universal Access to Health Care for Children in Africa

- **Partnership:** Government, community, private sector

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- **Capacity building:** Focus on the health workforce

- *The Rising Tide that Floats all Boats:* Paediatric Hematology/Oncology
Global HOPE initiated and conducts
The East Africa Paediatric Hematology-Oncology Fellowship Program

- Two-year, structured, rigorous curriculum and assessment
- First of a kind in Sub-Saharan Africa
- Applicants increased from 4 in 2016 to 35 in 2018
Unique Features and Lessons from Global HOPE’s East Africa Paediatric Hematology-Oncology Fellowship Program

- **Training locally** has numerous advantageous vs. moving to developed countries or sandwich programs.
  - Prevents brain drain
  - More cost-effective
  - Trains the entire team rather than an individual
  - Training is appropriately tailored to local context and realities
  - Does not or minimally disrupts family life of trainees

- Trainees value **structured**, rigorous training with formal assessments and a certificate over informal “clinical attachments”.

- Trainees and graduates in Africa have **unique mentorship** and needs focused on both technical and leadership skills.

- Generates a local **ripple-effect** – exponentially increasing access to specialist, high-quality care
Global HOPE’s Ambitious Program:
Build critical capacity that will create a ripple to save the lives of millions of children, infinitely

- 5,000+ children to be treated in Botswana, Uganda, and Malawi
- 25,000+ treated by Global HOPE-trained professionals throughout Africa
- 500,000 benefit from Global HOPE’s pan-Africa network
- 1,000,000 receive lifesaving care
The Global HOPE formula for Universal Access to Health Care for Children in Africa

• **Partnership:** Government, community, private sector

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• *The Rising Tide that Floats all Boats*”: Paediatric Hematology/Oncology
Paediatric Haematology and Oncology is *the Rising Tide That Floats All Boats*

*What does it take to cure a child with cancer or blood diseases?*
*A village of child health professionals, each with a special tool box*

- Paediatric surgical and anaesthesia services
- Paediatric critical care
- Infection prevention and treatment
- Radiology
- Newborn screening for sickle cell disease
- Blood transfusion services
- Child psychosocial support and rehabilitation
- Palliative care and pain control
- Social services
Accurate Pathology and Supportive Care Critical to Improved Outcomes Children with Cancer

Survival of Children with Burkitt lymphoma at Uganda Cancer Institute, 2016 – 2018
A Tale of Two Girls Whose Cancer Outcomes were Different Because of Access to Paediatric Surgical Services and Critical Care

Fortunate

Farida
The Global HOPE formula for Universal Access to Health Care for Children in Africa

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- **Capacity building**: Focus on the health workforce
- **The Rising Tide that Floats all Boats**: Paediatric Hematology/Oncology
Global Hope
HEMATOLOGY-ONCOLOGY PAEDIATRIC EXCELLENCE

“A Rising Tide Floats all Boats”
## State of Paediatric Oncology in East African region, November 2016*

<table>
<thead>
<tr>
<th>Center</th>
<th>No. of PHO Specialists</th>
<th>Cases/Yr</th>
<th>Dedicated PHO ward?</th>
<th>Dedicated PHO clinic?</th>
<th>Estimated BL survival</th>
</tr>
</thead>
<tbody>
<tr>
<td>Uganda Cancer Institute, UG</td>
<td>1 (7)</td>
<td>500</td>
<td>YES</td>
<td>YES</td>
<td>25 – 50%</td>
</tr>
<tr>
<td>Muhimbili National Hospital, TZ</td>
<td>1</td>
<td>500</td>
<td>YES</td>
<td>YES</td>
<td>60%</td>
</tr>
<tr>
<td>Agha Khan University Hospital, Kenya</td>
<td>1</td>
<td>&lt;100</td>
<td>NO</td>
<td>NO</td>
<td>80%</td>
</tr>
<tr>
<td>University of Nairobi, Kenya</td>
<td>0 (2)</td>
<td>300</td>
<td>YES</td>
<td>NO</td>
<td>75%</td>
</tr>
<tr>
<td>Moi University, Eldoret, Kenya</td>
<td>00</td>
<td>200</td>
<td>YES</td>
<td>NO</td>
<td>30%</td>
</tr>
<tr>
<td>Bugando Medical Center, Mwanza – Tanzania</td>
<td>00</td>
<td>200</td>
<td>NO</td>
<td>NO</td>
<td>&lt;25%</td>
</tr>
<tr>
<td>Mbarara Regional Referral Hospital, Uganda</td>
<td>0 (1)</td>
<td>200</td>
<td>YES</td>
<td>NO</td>
<td>40%</td>
</tr>
<tr>
<td>St. Mary’s Lacor, Gulu, Uganda</td>
<td>00</td>
<td>200</td>
<td>NO</td>
<td>NO</td>
<td>&lt;48%</td>
</tr>
</tbody>
</table>
Future and Strategic Dream

• Share program lesson that has led to success Paediatric Oncology patient care

• Improve outcomes to bridge the gap high income countries & LMICs

• Collaborate to standardized approaches
  • Diagnosis and diagnostic (s)
  • Treatment protocols that are effective with minimal toxicity
  • Cancer registries

• Learn from others and build oncology research groups to write protocols that continuously improve outcomes
Conclusion

- Twinning programs build interaction between established cancer centres and cancer treating hospitals in LMICs

- Successful programs require
  - Partnership: Government, community, private sector, and Devpt partners
  - The foundation: Platform of HIV/Infectious Diseases
  - Capacity building: Skilled health workforce
  - The Rising Tide that Floats all Boats

- Achieves the mission to significantly improve patient outcomes
Thanks and Acknowledgments

• Patients and the consent for photos

• Colleagues: Attendings, Paediatric Surgeons, Radio-oncologists, Radiologists, PHO Fellows, Medical Officers, Pharmacists, Nurses, Laboratory Staff, Social Workers, Support Staff

• Institutions: Uganda Cancer Institute, Makerere University, Mulago National Referral Hospital, Nakasero Blood Bank, Palliative Care, BIPAI, Texas Childrens Hospital, Baylor College of Medicine, Bristol Myers Squibb, Global Hope Program, Republic of Uganda Ministry of Health and Government of Uganda