Workshop on Childhood Cancer in Ethiopia: Improving Access, Survival, and Quality of Care

WHO/ SIOP/CCI in partnership with Jimma University and The Aslan Project

May 11-12, 2016

Submitted by: Julia Challinor, RN, PhD (SIOP Advocacy Officer)
Date: June 7, 2016

Executive Summary

The WHO/SIOP/CCI Collaborative Workshop on Childhood Cancer was held in Jimma, Ethiopia on May 11 and 12, 2016 at the Jimma University.

Day 1, Session 1, We were welcomed by the President of Jimma University, Mr. Fikre Lemessa. The Honorable Patricia Haslach, US Ambassador, next spoke about historical US ties with Ethiopian healthcare and the importance of now addressing childhood cancer. Dr. Desalegn Tigabu, Director of Clinical Service Directorate, Ministry of Health, shared the Ministry of Health's work to date on cancer control with plans to have six centers across the country (Gondor, Mekele, Harar, Awassa, Jimma, Addis Ababa) to increase cancer therapy opportunities, and the newly released 2015 National Cancer Control Plan. Dr. André Ilbawi, WHO, shared WHO ADG's priority of childhood cancer in low- and middle-income countries (LMIC). He spoke about 2 key imperatives: access and equity. Finally, Dr. Aziza Shad, medical director of The Aslan Project, presented childhood cancer around the world and shared Aslan's history supporting childhood cancer in Ethiopia since 2012 (in Addis Ababa at Tikur Anbessa Specialized General Hospital [TASGH]) and plans for the new pediatric oncology unit and second The Aslan Project-funded fellowship program at Jimma University Specialized Hospital.

Day 1, Session 2, Dr. Julia Challinor introduced SIOP and spoke briefly about SIOP's work in LMIC. Next, Dr. Kunuz Abdella, Technical Adviser for Cancer Prevention and Control, Ministry of Health, presented the cancer burden in Ethiopia. He also mentioned cancer risk factors worldwide, but noted there was not much data on risk factors in Ethiopia. Dr. Kunuz, expanded on the components of the National Cancer Control Plan for Ethiopia (goal to decrease mortality by 15% by 2020 and increased engagement with IAEA) as well and mentioned the First Lady's commitment to cancer care. Dr. André Ilbawi followed with a presentation of the WHO Building Blocks for addressing childhood cancer: Service Delivery, Health Workforce, Information Systems, Medical Products and Technology, Financing/Governance, and Family Support & Community Engagement.

Day 1, Session 3. Dr. Aziza Shad presented the "Building Blocks of a Pediatric Cancer Infrastructure". Dr. Shad spoke about early and accurate diagnosis, effective service delivery, access to and affordability of essential medicines and technologies, community awareness, palliative care and parent/family support. She also described the need for government supply

of reagents and medical devices and cancer registries. Dr. Shad continued with a presentation of the minimal requirements for pediatric oncology units in LMIC, general guidelines for such, and a certification or needs assessment program.

Day 1, Session 4. Dr. Daniel Hailu Kefenie, a graduate of Aslan's fellowship training program at TASGH and the first pediatric oncologist in Ethiopia, presented a detailed overview of childhood cancer treatment at the only existing treatment center in Addis Ababa. He mentioned accomplishments to date and remaining challenges in the following areas: transfusions (committee established and increased availability of blood products), sedation for procedures (achieved), bone marrow aspirations (improving), morphologic diagnosis only (need for flow cytometry, cytochemical stains and cytogenetics), CT and MRI are costly for patients, intervention radiology (improving), PET and CT essential. Dr. Daniel also mentioned that they need apheresis capability, infection control improvements (consistent water supply, reduced overcrowding, but have hand sanitizer), microbiology has improved (e.g., cultures for blood, urine, stool and CSF available) but still need timely reporting and increased yield, resistance pattern reporting and direct involvement of microbiology e.g. rounding with physician. Dr. Daniel noted that most children are malnourished on admission, some severely, however, F75 and F100 as well as plumpy nut are available for supplementation. The psychosocial department has a playroom and a psychologist for addressing major depression in adolescents with bone tumors in particular. Parents need counseling and there is a family support group TAPCCO that provides biweekly coffee ceremonies for the families among other services.

Dr. Daniel's asked us all to "*Listen to the kids, listen to the parents and involve adolescents in disease management*".

Regarding drugs, Dr. Daniel mentioned that some government drugs had expired and private pharmacies are expensive. He said antimicrobials were limited and new drugs were needed. For antifungals, only fluconazole was available. Only acyclovir was available as an antiviral.

Dr. Daniel requested CMEs be available for those training on the job, an increase in cancer awareness activities, more centers to be opened and an expansion of existing centers. He stated that data registry was needed to determine disease prevalence, toxicities, outcomes, research, and the need for trained data clerks and biostatisticians.

Day 1, Session 4. Ruth Hoffman, Vice President CCI and Sara Ibrahim, President of TAPCCO (local parent group in Addis Ababa). Ruth presented the history of US and international parent advocacy efforts of engaging parent support groups, community and business leaders and advocates for childhood cancer, as well as the history of CCI. Sara shared TAPCCO's efforts to address essential medicines, support for a psychologist, ward security guard and providing milk and 1 egg daily to hospitalized children. TAPCCO's activities are supported by The Aslan Project. TAPCCO has also had a parent meeting with Dr. Kunuz and MoH representatives to listen to the parents' concerns.

Day 2, Sessions 1, 2, and 3 were devoted to group (2 groups each topic according to interest) work on importance of Early and Accurate Diagnosis, Strengthening Service Delivery, and Improving Access to Essential Medicines, Resources and Technologies.

Day 2, Session 4. Dr. Desalegn Tigabu presented the Plan of Action and Responsibilities including a summary of action items, identification of next steps, responsible parties, proposed timeline and the commitment to a detailed plan of action.

Day 2, Session 5. We were honored to have the First Lady of Ethiopia, HE Mrs. Roman Tesfaye present for the rest of the day. Dr. Aziza Shad presented the Building Blocks of Childhood Cancer Care and Treatment and showed the Child4Child video. This was followed by a presentation to the First Lady of participants' "My Dream for Childhood Cancer in Ethiopia" sentences (10 were chosen) by Ethiopian stakeholders led by Mr. Mamush a young adult survivor of childhood cancer and volunteer at TASGH.

The First Lady shared her comments on childhood cancer in Ethiopia and efforts to address this challenge in Amharic and then in English. She then presented certificates of recognition to the following individuals and organizations for their efforts: Dr. Daniel Hailu, Sr. Aster Kebert (head nurse pediatric oncology TASGH), SIOP, CCI, The Aslan Project and Jimma University.

Photo: First Lady of Ethiopia, HE Mrs. Roman Tesfaye and Dean, College of Health Sciences, Jimma University, Dr. Abraham Haileamlak

SIOP, CCI and The Aslan Project as well as members of the MoH and Jimma University were honored to be included in a dinner at the end of Day 2 given by Jimma University for the First Lady.

Photo L-R: ***Dr. Daniel Hailu Kefenie****, Chief, Div. of Pediatric Hematology/Oncology, Tikur Anbessa Specialized Hospital;* ***Dr. Abraham Haileamlak****, Dean, College of Health Sciences, Jimma University;* ***Ruth Hoffman****, Vice Chair CCI****, Julie Broas****, Executive Director The Aslan Project;* ***Dr. Desalegn Tigabu****, Director of Clinical Service Directorate, Ministry of Health;* ***Dr. Aziza Shad****, Medical Director The Aslan Project;* ***Dr. Kunuz Abdella****, Technical Adviser for Cancer Prevention and Control, Ministry of Health;* ***Dr. André Ilbawi****, Technical Officer, WHO;* ***Dr. Julia Challinor****, SIOP Advocacy Officer;* ***Dr. Miguel Bonilla****, Clinical Director Pediatric Oncology Program, Jimma University;* ***Linda Abramovitz****, The Aslan Project Volunteer Nurse Educator*

FINAL REPORT

☐ Attendance list

- First Lady of Ethiopia, HE Mrs. Roman Tesfaye
- Mr. Fikre Lemessa, President, Jimma University
- Mr. Kora Tushune Godana, Vice President, Business & Development, Jimma University
- Dr. Fikadu Assefa Jiru, CEO, Jimma University Specialized Hospital
- Mr. Ermyas Admasu, Director, International Relations, Jimma University
- Dr. Kunuz Abdella, Technical Adviser for Cancer Prevention and Control, Ministry of Health
- Dr. Desalegn Tigabu, Director of Clinical Service Directorate, Ministry of Health
- Dr. Abraham Haileamlak, Dean, College of Health Sciences, Jimma University
- Dr. Zeleke Mekonnen, Head of Laboratory Services
- Ms. Rahel, Head of Environmental Services
- Head of Human Resources, Jimma University
- Mr. Feyera Gebissa, Director Supply Chain, Jimma University Specialized Hospital
- Mr. Genale Wabe, Supply Chain Officer, Jimma University Specialized Hospital
- Dr. Daniel Hailu Kefenie, Chief, Div. of Pediatric Hematology/Oncology, Tikur Anbessa Specialized Hospital
- Sr. Aster Kebert, Head Nurse Pediatric Hematology/Oncology, Tikur Anbessa Specialized Hospital
- Ms. Sara Ibrahim, President of Ethiopian Parent's Group, TAPCCO
- Dr. Melkamu Berhane Arefayine (Assistant Professor of Pediatrics & Child Health Jimma University and Fellow in Childhood Cancer Program)
- Dr. Doreen Karimi (Kenyan pediatrician and Fellow in Jimma University Childhood Cancer Program)
- Nurse Dinsa, Head Nurse for Jimma University Childhood Cancer Program
- 12 nurses assigned to the new Jimma University Hospital Childhood Cancer Program
- Dr. André Ilbawi, Technical Officer, WHO
- Dr. Aziza Shad, Medical Director, The Aslan Project
- Ms. Julie Broas, Executive Director, The Aslan Project
- Dr. David Korones (pediatric oncologist and palliative care specialist, University of Rochester, NY, USA)
- Dr. Miguel Bonilla, Clinical Director of The Aslan Project Pediatric Oncology Program
- Dr. Julia Challinor, The Aslan Project/SIOP Advocacy Officer
- Linda Abramovitz, RN, MSN, CNS, (pediatric hematology/oncology and BMT nurse expert, University of California, San Francisco, visiting nursing faculty)

- Ms. Ruth Hoffman, Vice Chair, Childhood Cancer International
- Mr. Kenneth Dollman, Childhood Cancer International, African Region Representative

☐ Final Agenda – See Appendix A

☐ Summary of evaluations by participants -- not performed (First Lady's visit was only announced at end of Day 1 so schedule was rearranged to accommodate

☐ Evaluation form – not performed

☐ Handouts or description of handouts – See Appendix B

☐ Description of level of financial or in-kind support from each partner

Direct financial support

- Jimma University ~ USD 7500
- The Aslan Project ~ USD7500, funded through a grant from UICC
- SIOP USD 500

Indirect financial support

- Jimma University
    - Hotel rooms and food for The Federal Ministry of Health, The Aslan Project, SIOP, and CCI attendees
    - Lunches for the conference
    - Dinner day 1
    - Dinner for the First Lady day 2
- The Aslan Project
    - Flights for The Aslan Project attendees, a visiting nurse instructor (also taught for 3 days) and the three TASH attendees
    - Opening dinner before day 1
    - Conference bag and USB stick loaded with childhood cancer resources

☐ Brief description of follow-up activities or strategies planned during workshop and expected rough timeline for expected completion – See Appendix C (courtesy of Dr. André Ilbawi, WHO)

☐ Action Items by Building Block (notes from breakout sessions – See Appendix D

APPENDIX A

TIME	DAY 1 – MAY 11, 2016	Presenter/Moderator
0830-1015	Opening Session – Introductory Statements and Introductions • Jimma University President, Fikre Lemessa • US Ambassador to Ethiopia, the Honorable Patricia Haslach • Dr. Desalegn Tigabu, Director of Clinical Service Directorate, Ministry of Health • Dr. André Ilbawi, Cancer Control Officer, World Health Organization • Dr. Aziza Shad, Medical Director, The Aslan Project	Mr. Ermyas Admasu, Director, International Relations, Jimma University
1015-1045	*Coffee Break*	
1045-1145	Introduction of SIOP Cancer Burden in Ethiopia: Recent Progress & Vision for the Future • National Cancer Control Plan and Ethiopia's First Lady's commitment to cancer control WHO Building Blocks for Cancer Control	Dr. Julia Challinor SIOP Advocacy Officer Dr. Kunuz Abdella, Technical Adviser for Cancer Prevention and Control, Ministry of Health Dr. André Ilbawi, Technical Officer, WHO
1145-1245	*Lunch*	
1245-1315	Building Blocks of Childhood Cancer Care and Treatment	Dr. Aziza Shad, Medical Director, The Aslan Project
1315-1400	Case Study: The Tikur Anbessa Specialized General Hospital Experience	Dr. Daniel Hailu Kefenie, Chief, Div. of Pediatric Hematology/Oncology, Tikur Anbessa Specialized Hospital
1400-1530	*Coffee Break*	
1530-1630	Empowering the Community: Engaging Parent Support Groups, Community and Business Leaders, and Advocates	Ms. Ruth Hoffman, Vice Chair, Childhood Cancer International Ms. Sara Ibrahim, TAPCCO
1630-1700	Summary of Day 1 Activities and Preview of Day 2	Dr. Julia Challinor, The Aslan Project/SIOP Advocacy Officer
1700-1830	Visit to Jimma University Specialized Hospital and Pediatric Oncology Unit	Dr. Abraham Haileamlak, Dean, College of Health Sciences, Jimma University

TIME	DAY 2 – MAY 12, 2016	Presenters/Moderators

0830-1000	Importance of Early and Accurate Diagnosis
	• Presentation
	• Group work to identify the main areas of action
	  ○ Community awareness
	  ○ Timely referral
	  ○ Accurate diagnoses
		Sara Ibrahim, TAPCCO
		
		Dr. André Ilbawi, Technical Officer, WHO

1000-1030	*Coffee Break*	

1030-1200	Strengthening Service Delivery
	• Presentation
	• Group work to identify the main areas of action
	  ○ Human resource development
	  ○ Palliative care
	  ○ Parent and psychosocial support
		Dr. André Ilbawi, Technical Officer, WHO
		
		Dr. David Korones, The Aslan Project
		
		Ruth Hoffman, Vice President CCI

1200-1300	*Lunch*	

1300-1400	Improving Access to Essential Medicines, Resources and Technologies
	• Presentation
	• Group work to identify the main areas of action
	  ○ Essential resources, medicines & priority medical devices
	  ○ Health information systems & cancer registries
	  ○ Monitoring & evaluation
		Dr. Kunuz Abdella, Technical Adviser for Cancer Prevention and Control, Ministry of Health

1400-1430	Presentation of Plan of Action and Responsibilities • Summary of action items • Identification of next steps, including responsible parties and proposed timeline • Commitment to detailed plan of action	Dr. Desalegn Tigabu, Director of Clinical Service Directorate, Ministry of Health
1430-1435	Introduction of the First Lady of Ethiopia, HE Mrs. Roman Tesfaye	First Lady's Protocol Officer
1435-1500	Building Blocks of Childhood Cancer Care and Treatment • Showing of Child4Child video • Presentation to HE First Lady of "My Dream for Childhood Cancer in Ethiopia" 10 responses	Dr. Aziza Shad, The Aslan Project Ethiopian stakeholders led by Mamush (survivor of childhood cancer and volunteer at TASH)
1500-1530	Presentation of certificates for Jimma University, The Aslan Project, SIOP, CCI, Dr. Daniel Hailu Kefenie and Sr. Aster Kebert (head nurse of TASH D7)	HE First Lady, Roman Tesfaye

APPENDIX B

Material on USB handed out:

- SIOP Pocket Cancer Warning Signs
- AIEPI Early Diagnosis of Childhood Cancer
- Worldwide Palliative Care Alliance – Global Atlas of Palliative Care at End of Life
- WHO Guidelines for Pain in Children
- St. Jude booklet – What is a Cell?
- St. Jude booklet – What is Cancer?
- PAHO Safe Handling of Hazardous Chemotherapy Drugs in Limited-Resource Settings
- CCLG Caring for a Child with Cancer

Workshop on Children with Cancer in Ethiopia: Improving Access, Survival, and Quality of Care

Childhood cancer control in Ethiopia

Draft Action Plan for 2016-2018

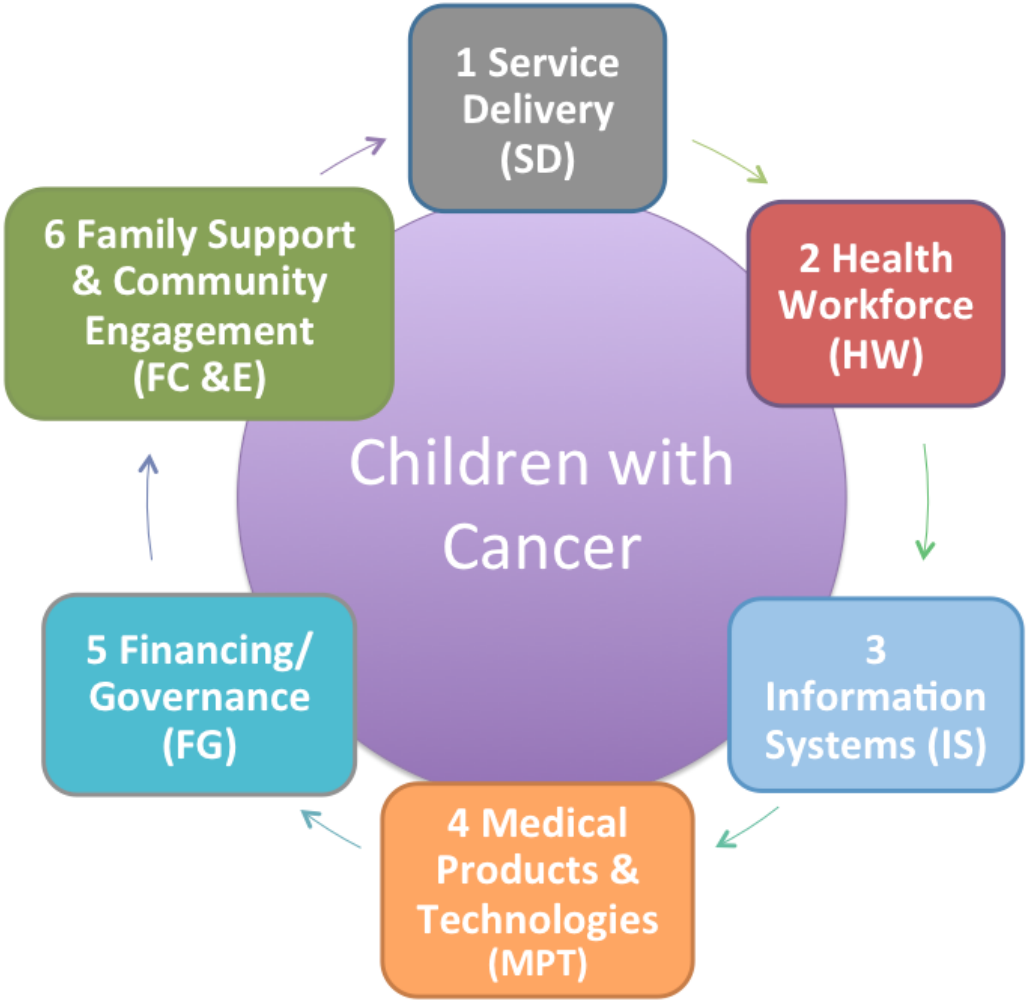
GOALS'

To improve childhood cancer care in Ethiopia by 2018

Improve timely diagnosis & treatment services	Strengthen access to essential medicines	Increase resources for health workforce	Engage multi-sectoral partners

Increase the number of children with cancer diagnosed, treated, and completing therapy

Health System Building Blocks Adapted for Childhood Cancer Control Planning



SERVICE DELIVERY

Goal 1: Improve awareness about childhood cancer care (symptoms, availability & success of treatment)

Priority activity: Use Jimma & national radio stations to communicate key message

Responsible party & contact point

- Jimma University
  - TAPCCO, CCI, SIOP, WHO offer tools for messaging
- FMoH to assist with finalizing message

Resources needed

- Human resources from partners
- Media and communication strategy

Benchmark at 1 year: Radio message every 1month for 1yr (to start asap)

Goal 2: Improve (timely diagnosis through high quality pathology

Priority activity: Strengthen national supply chain for pathology

Responsible party & contact point

- PFSA/FMHACA (FMoH), international organizations, & university hospitals

Resources needed

- Budget allotment, international partners

Benchmark at 1 year: All essential equipment purchased & procured

HEALTH WORKFORCE

Goal 3: Increase human resource capacity in childhood cancer care

Priority activity: Training, retention & recognition of specialty providers in childhood cancer care

Responsible party & contact point

- FMoH, FMoE, Human Resource Directorate, Jimma Univ

Resources needed

- Local university hospital, Ministry of Education, twinning partners

Benchmark at 1 year: Training of pediatric hematologist-oncologists, oncology nurses, pediatric surgeons, pathologists, radiation

oncologist, onco-pharmacists, social workers, technicians, nutritionists, etc.

INFORMATION SYSTEMS

Goal 4 Improve data gathering

Priority activity: Establish electronic medical record for childhood cancers and link to registry

Responsible party & contact point

- National Pediartric Cancer Task Force for M&E
- Jimma Univ, FMoH, IARC

Resources needed

- Technical support for registry
- Funding for record system

Benchmark at 1 year: Development of cancer registry, Implementation of electronic medical records

MEDICAL PRODUCTS & TECHNOLOGIES

Goal 5 Improve access to essential medicines

Priority activity: Ensure WHO EML medicines on national medicines list

Responsible party & contact point

- FMoH, PFSA, local hospital

Resources needed

- Expert panel to identify essential medicine
- Budgetary allocation for childhood cancer medications
- Surveillance of quality of medicines

Benchmark at 1 year: Chemotherapy, antibiotics, morphine provided to pediatric cancer units

CHILD & FAMILY SUPPORT

Goal 6 Pain relief & social support

Priority activity: Provide oral morphine for every child with cancer who is in pain

Responsible party & contact point

- FMOH, facilities
- Pharmacists at local hospitals

Resources needed

- Morphine
- Pain specialists, local oncology teams
- Pain management guidelines

Benchmark at 1 year: Children with cancer at Jimma have morphine available from time child first arrives (<3 mo.), Palliative training stated, at least one physician

APPENDIX D

ACTION ITEMS BY BUILDING BLOCK

SERVICE DELIVERY

Session 1, group 1: Community awareness, timely referral

Community Awareness and Referral

Message

- Craft short, meaningful, precise messages
- Initiative to remove misconceptions about childhood cancer. Make them *believe* that there is hope for cancer patients!
- Treatment is available locally
- Technical information on early symptoms

Medium

- Radio (preferred, live interviews, prepared messsages)
- Printed material (use graphics of key symptoms rather than text)
- Invite community leaders to visit JU trainings to show them that treatment works

Target

- Local leaders (religious leaders/community events)
- Health workers (HEW)
- Primary care providers / health centre

Action Items

- Clearly identify our audience!
- Tailor the message to each for maximum impact
- Engage local leaders
- Use existing workstreams – chronic illness project, health extension program, Jimma University teaching programme (students)
- Focus activities during times of international visibility (eg, International Childhood Cancer Day)
- Consider training program hosted at Jimma University for local leaders and advocates
- Message should offer guidance on how to proceed with care
    - Come up with a clear, focused message on childhood cancer

- Develop training materials on early warning signs of childhood cancer that are culturally adapted and translated into local languages
- Community activities to target for outreach are: churches, mosques, coffee ceremonies
- Engage Jimma (+national) radio stations
    - Radio (30 second spots)
    - There is community radio and University radio that serves Jimma
    - Jimma University will be the focal point on the message itself and the strategy to spread the message
    - Radio is expensive, but Jimma University will be able to cover those expenses

One-year benchmark for community radio to be fully on board

- Utilized health extension program to spread awareness
    - Health extension workers probably the best channel
    - We can't create new additions to them, but we can make sure that childhood cancer is part of what they are already doing
    - Develop and test cancer awareness messages and channel them through Health Extension Worker and Health Development Army programs
    - 20% of health workers receive training every year (100% in five years) in community / Health professionals as well as health centers
    - The materials we are using in Jimma are graphic, visual in nature
    - Using community extension workers to transmit the message during special days/holiday activities & festivals, anywhere people come together
- There are a lot of special days in Jimma, but maybe none exclusive to Jimma
- Provide training material for primary care workers on early signs/symptoms of childhood cancers
- Multi-sectoral engagement with industry to increase visibility & raise funds (e.g., coffee)
    - Coffee plantations & business can brand products as one that supports childhood cancer (Difficult!)

Priority activity: use Jimma & national radio stations to communicate key message

Responsible party & Focal point

- Jimma University (focal point to be assigned by Prof Abraham)
- CCI, SIOP, WHO to offer tools for messaging
- MoH to assist with finalizing message

Resources needed

- Human resources: Jimma University, CCI, SIOP, WHO
- Financial resources: TBD

Benchmark at 1-year: Radio message every 1month for 1yr (to start asap)

Session 2, group 1:

Human resource and infrastructure development

- Infection Control
    - Establish separate unit dedicated to the treatment of pediatric cancer
    - Establish standard training program for infection control
        - Healthcare professionals
        - Parents
        - Cleaners
    - Establish standard hospital-based protocol re infection control to serve as national benchmark
        - Hand sanitizers in and outside of every unit
        - Personal protective equipment (protective gowns, gloves)
        - Guards to control visitors to POU
        - Clothes washing and personal hygiene for healthcare professionals and families

Palliative care, parent and psychosocial support

Pain

- Provide oral morphine for every child with cancer who is in pain
- Training in morphine for every child in pain from time of diagnosis

Responsible party & Focal point

- Ministry of Health responsible for supplying local hospitals
- Pharmacists at local hospitals

Resources needed

- Morphine

Financial resources: TBD

Benchmarks at one year –

- Children with cancer at Jimma will have morphine available from the time the first child with cancer arrives (less than 3 months).
- Palliative training must be underway, at least one physician at various hospitals
- Education, training, and pain management guidelines for all health care professionals regarding assessment and treatment of pain

Responsible party & Focal point

- Ministry of Health
- Local oncology programs

Resources needed

- Pain specialists, local oncology teams
- Pain management guidelines and protocols

Financial resources: TBD

Benchmarks at one year

- Children with cancer and pain at Jimma will be treated according to standard pain management guidelines
- Physicians, nurses, and pharmacists will have understanding of indications, doses, and side effects of morphine
- Psychosocial support
- Free housing, nutrition, and transportation for out-of-area families

Responsible party & Focal point

- Local hospitals and NGOs
- Parent support groups

Resources needed

- Free housing, nutrition supplements, transportation

Financial resources: TBD

Benchmarks at one year

- Immediate: Children with cancer and families who live far away will have access to nearby housing and nutrition as soon as the program begins
- A dedicated pediatric hematology/oncology social worker

Responsible party & Focal point

- Local hospital

Resources needed

- Social workers

Financial resources: TBD

Benchmarks at one year

- Every child with cancer will be evaluated by a social worker and assistance to be offered
- Establish a parent support group

Responsible party & Focal point

- TAPPCO, local parents, oncology team, social workers

Resources needed

- Parents!

Financial resources: TBD

Benchmarks at one year

- A parent support group will have been formed

Session 3, all participants: Essential Resources

Separate unit for children with cancer

- Decreases infection rates
- Ensures adequate attention to the child with cancer
- Pediatric sedation room
- Existing use of propofol and ketamine, with monitoring before and after procedure.
- Used for bone marrow aspirates, bone marrow biopsies, and lymph node biopsies
- Pain control is essential for children

HEALTH WORKFORCE

Session 1, group 2: Accurate Diagnosis

Provide and retain pathologists and technicians with specialty training in histo- and hemato-pathology, immuno-hematology, and procedures for preparing slides and taking biopsies

Description:

- Pathologists (local university hospitals/twinning partners) (CEO) (1 year) (3 trained per hospital)
- Number of technicians (local university hospitals/twinning partners) (CEO) (6 months) (10 trained per hospital)

Action: CMEs and incentives for retention, in-country training, E-Learning and books/resources, observerships

Session 2 group 2: Human resource and infrastructure development

- Develop radiotherapy capability
- Develop human resource capacity
    - Physicians and designated radiotherapy nurses
    - Mid-level health workers – technologists, radiographers , medical physicists
    - Link MoH and local university hospital to IAEA and other training programs (eg, IPOS)

- Improve human resource capacity & credentialing
- Train and retrain qualified pediatric oncology nursing workforce
    - Master's level training for selected oncology nurses
    - Certificate training (8-10 weeks) for clinical pediatric oncology nursing team
    - Provide longer-term training with recognition/incentives
- Train and retrain qualified oncology pharmacy workforce
    - Training for oncology pharmacists
    - Mixing of chemotherapy by pharmacists
    - Recognition of oncology pharmacists
- Provide similar training programs for social workers, other supportive specialties
    - Psychosocial support services
- Family navigators - Appoint patient/family navigator to act as the liaison between parents, children, and healthcare professionals and unit staff

Align pediatric oncology nursing, pharmacy, and other training programs with national human resource plan so that training and particular qualification are recognized (MOH Human Resource Directorate/MOE)

HEALTH INFORMATION SYSTEMS

Session 3, all participants:

Electronic medical records for childhood cancer

Comprehensive medical record in place is goal

- Medicines that MoH is supporting are recorded manually so trying to monitor is very difficult
- opens possibility of leakage into private pharmacy
- Electronic records make research easier
- parent access to an electronic record, so children can take them along with them as they become survivors
- Current recording systems needs improvement
- should synchronize medical record with laboratory, etc.
- should be well funded and comprehensive

Action: find model to do this synchronization

- Information Tech staff (number 11). They have already started to implement the electronic medical record for JUSH

Budget – they had additional budget and they are committed to it

Cancer Registries

- 2-year experience in TASGH with cancer registry for adults mostly
- seen great benefit
- IARC is main organization overseeing cancer registries
- Ethiopia has hospital-based registry and was on the forefront on this
- Gold standard is population-based
- Focal point at IARC is ready to support cancer registries in Ethiopia for pediatric oncology
- Before, electronic medical records, we need a hospital-based cancer registry because it is the foundation of our practice.
- At the end of the day, we have to show that we have made an impact and we can't do this without the data and documentation
- This is what they did with HIV and this is the core
- The MOH had to take this seriously and force institutions around the country to establish their data registry.
- Registries have been captured in the MoH NCCP 5-year plan.

MOH has indicated that they will set up cancer registry in TASGH and other sites.

Monitoring and Evaluation (M&E)

- Twice yearly workshops are difficult.
- Doing them in target areas might be helpful

Action: Perhaps the group doing Essential Medicine meets twice a year and monitors movement towards achieving targets.

- All three areas are relevant, registry, electronic records and M&E

Question: when you say M&E, that is at national level. Should it not start from institutional level to sort challenges? Should it not start from bottom up?

ESSENTIAL MEDICINES & TECHNOLOGIES

Session 1, group 2:

- Strengthen national supply chain for pathology
- Request for placement of necessary reagents and cytochemicals on essential medicine list (local university hospital)(immediately)(request made)
- Placement on and procurement of necessary reagents and cytochemicals (PFSA/FMHACA) (immediate) (placement on list and procurement as requested/needed)
- Establish stable, effective, and adequate inventories of necessary reagents and cytochemicals (local university hospitals) (immediate) (reagents and cytochemicals purchased)
- Availability of necessary diagnostic equipment (e.g, multi-headed microscopes, flow cytometers, microtome blades) (local university hospitals) (CEO) (6 months)(2 microscopes and flow cytometer purchased)
- Maintain and/or replace diagnostic equipment (local university hospital) (CEO) (6 months)
- Strategic allotment of equipment and other resources (MOH) (1 year)(national resource plan)
- Procurement of necessary microscopes, reagents and cytochemicals
    - Responsible parties: PFSA/FMHACA, international organizations (e.g., CDC) and local national university hospitals
    - Resources: Budget allotment, international partners
    - Timing: 9 months
    - Benchmarks: Necessary items are purchased for each operating POU
- Specialty training of pathologists, ground-level technicians and other clinical medicine laboratory specialists for each national cancer center
- Responsible parties: Local university hospitals/twinning partners
    - Resources: Budget allotment, appropriate candidates, twinning partners

    - Timing: 1 year/6 months/1 year
    - Benchmarks: 3 pathologists, 3 ground-level technicians and 3 laboratory specialists trained in specialty areas for each national cancer hospital with a pediatric oncology unit
- Provide personal protective equipment for protection of nurses and pharmacists

Session 3, all participants:

- Prostheses are needed
    - for children with bone tumors, osteosarcoma and Ewings sarcoma, but also in retinoblastoma
    - for retinoblastoma, cosmetics is a big issue
- Place essential cancer and supportive care drugs on nationally approved Essential Medicines list of Ethiopia MoH
    - If drugs are not registered on the MoH list they are difficult to obtain
    - Procurement process is lengthy; 6-12 months
    - MoH has sequestered the funds for cancer drugs, but it is left to one agency to operationalize and they are not always ready to act
    - Hazardous waste disposal is an issue that needs to be addressed from the unit level (hazardous waste bags) to incineration procedures
    - MoH is working with TASH and Dr. Daniel with list of needed drugs and amounts based on patient load
    - MoH needs scientific quantification for ordering drugs so there are not over buys and stockouts
    - MoH needs to monitor expiration dates on drugs so they are not expiring before use
    - WHO can help with quantification of need and ordering
    - WHO Essential Medicine List for children is a good resource
- What to do during international shortages of essential medicines?
- Oncology pharmacy is needed that is open 24/7
- Biosafety cabinet is essential technology equipment
    - Training for use of biosafety cabinet is needed
    - Oncology pharmacist training is already in place in Jimma
    - has occurred in Addis Ababa at TASH and administration has agreed to train more oncology pharmacists
- Critical supplies needed
- Bone marrow needles (various gauges for pediatrics) and lumbar puncture needles, IV infusion pumps, pulse oximeters, prosthetics, PICC lines

Action: Large project going on in Ethiopia to set up radiotherapy programs outside TASGH that has been fully funded by MoH, equipment is ordered

- Radiation therapy should be child-friendly.

FINANCING

LEADERSHIP/GOVERNANCE PARENT & COMMUNITY ADVOCACY (CHILD & FAMILY SUPPORT)
Session 3, all participants:

Leadership

- We should also consider our future relationships with adult oncology and adult pharmacology and ophthalmology so patients can be referred earlier
- We need Ethiopian Pediatrics Association and MoH to address what is pediatric
    - In US is up to 25 because they have pediatric tumors
- Adolescence has not been addressed yet in Ethiopia
    - one solution is for adult and pediatric oncologists work together
    - we are establishing relationships with adult hem for hemophilia and AML, but it is harder with medical oncology.
- Having a National Pediatric Cancer Task Force would be helpful.
    - Could be at MOH level

Everyone Has a Role

Stakeholder	Sample Contributions
Univ of Jimma	Increase training & accreditation of specialist providers Promote safety through infection control, PPE Identify priority medical devices (to communicate to MoH) Generate advocacy messages (e.g., radio station, link with local leaders)
Ministry of Health	Strengthen supply chain for pathology (PFSA/FMHACA) Support training & accreditation of specialist providers Ensure availability of essential medicines (in particular chemotherapy & morphine)
Ministry of Education	Support training & accreditation of specialist providers
Ministry of Finance	Increase funding & support for childhood cancers
WHO, IARC, IAEA	Engage multi-sectoral action. Support cancer control planning including essential medicines & devices. Assist with cancer registries (IARC) Support radiotherapy capacity (IAEA)
The Aslan Project	Support human resource development Provide childhood cancer global advocacy Provide financial support for capacity building.
TAPCCO, CCI	Develop & strengthen parent support group in Jimma Support free housing, nutrition, and transportation for out-of-area families.
SIOP	Provide childhood cancer global advocacy. Offer technical training.