REPORT ON WHO/SIOP/CCI CHILDHOOD CANCER STAKEHOLDERS' MEETING, ACCRA, 27TH JANUARY 2016

Venue: Ghana College of Physicians and Surgeons, Accra

The meeting started at 9.45am. Prof. Lorna Awo Renner welcomed all the participants (27 in total) and informed them of the purpose for the meeting. This was followed by general introductions, a message on behalf of Childhood Cancer International delivered by Dr Kwame Aveh, chairman of Ghana Parents' Association for Childhood Cancer (GHAPACC) and then a short message by the CEO of World Child Cancer (WCC), Jon Rosser.

In a presentation on the Current state of Paediatric Oncology in Ghana, Prof Lorna Renner enlightened participants on some alarming facts. Only about 30% of estimated annual number of expected cases is seen at the two major comprehensive treatment centres. Achievements as a result of the World Child Cancer Twinning programme were mentioned including development and dissemination of awareness creation posters together with the Ghana Health Service, training workshops for multidisciplinary teams from selected hospitals, nurses' online training and initiating the development of satellite centres. Challenges include: late presentation with the only option being palliative care; delays in referral; up to 40% abandonment of treatment with families having to bear the cost of treatment as childhood cancer is not included under NHIS cover; drug access issues; accommodation difficulties. She illustrated this with the typical example of a young child with retinoblastoma and how early diagnosis could have led to a 95% chance of cure. This put participants into a very sombre, pensive mood.

The representative of the WHO Country representative, Dr Rosaline Doe then presented the WHO position on Access to Essential Medicines for children with Cancer. Quoting the Director-General of WHO, Margaret Chan, she said, 'When new effective medicines emerge to safely treat serious and widespread diseases, it is vital to ensure that **everyone** who needs them **can** obtain them'. She stated that access implied availability, affordability, accessibility and acceptability. Although childhood cancers are relatively rare, the high cure rate is compelling evidence for including drugs for their treatment on the essential medicines list. Challenges include limited diagnostic and treatment infrastructure, financing, perception of disease fatality and stigma. She called for sustained commitment and partnership by all stakeholders to tackle the issues.

This was followed by discussions.

First session: Chaired by Dr Gloria Quansah-Asare, Ag, Director-General, Ghana Health Service (GHS).

Discussion points:

1) Improving awareness
2) Early diagnosis in community, at health facilities
3) Improving specific diagnostic capacity
4) Access to essential medicines

Second session: Chaired by Mr Owusu-Ansah, Director, Policy, Planning, Monitoring and Evaluation, Ministry of Health (MOH)

Discussion points:

5) Reducing treatment abandonment
6) Effective supportive care
7) Capacity building including satellite centres
8) Role of stakeholders, working together

Summary of Discussions:

Access to essential medicines

NHIS is guided by an act of law. It's by this law that is why cervical, breast cancers are paid by health insurance and prostate cancer is being reviewed for inclusion. There is a need to do advocacy for a change to the law so childhood cancers can be added to the NHIS list. Currently, an NHIS review process is ongoing and a letter should be sent to the Minister for a change to be considered.

Dosage forms of drugs should also be considered as some of the doses and formulations are not readily available. Drugs used for cancer in children should be manufactured in smaller dosages to reduce waste and cost.

Oncology medications have been exempted from VAT during importation since October, 2015. All Paediatric medicines undergo fast track review. Unlike adverse events, drug efficacy issues are not reported to FDA so service providers should be advised to do so.

We should explore the possibility of having paediatric clinical trials for cancer drugs

Awareness

For awareness creation, a health system approach should be utilized. Ghana Health Service (GHS) staff and Community health officers who go on outreaches can be educated and used for that purpose. They don't have the requisite knowledge and skills to talk about childhood cancer during outreaches and so if they are empowered through education, then it will enhance an effective outreach.

We should promote community empowerment by creating awareness about cancers. There should be involvement of chiefs, opinion leaders and assembly members. The impact is always better that way.

We need to work with the traditional and spiritual leaders to also help healthcare professionals and refer appropriately.

The important role of media including TV was emphasized. Media should be invited to attend programmes such as this.

Diagnostic Capacity

In the Child welfare clinics, the health care personnel can use the opportunity to examine the patients especially for retinoblastoma.

We should emphasize the need for training of a paediatric oncologist for Tamale Teaching Hospital.

Health facilities - this goes beyond the teaching hospital to the district hospitals and lower. We need to improve the diagnostic capacities of these peripheral hospitals.

Issue of payment out of pocket for some important diagnostic investigations for example scans was brought up. NHIA stated these are covered by NHIS. KBTH responded that the tariffs were low and did not cover the actual cost. NHIA advised that these should be reviewed by an independent body with input from service providers.

Abandonment

Abandonment is linked to hopelessness.

A little empathy by doctors and healthcare workers can help encourage parents to continue their child's treatment.

A complaint from parents is about the long waiting time for treatment. No place to sleep for parents also leads to abandonment. GHAPACC is trying to raise funds to build a hostel at Korle Bu Teaching Hospital (KBTH). High cost of chemotherapy can lead to abandonment. Psychosocial support is needed to reduce abandonment.

Hostel facilities when available could free hospital beds for further use by sick children.

Play areas and access to education should be available for children whilst on admission.

Other issues eg cost of transportation and loss of livelihood affect the families. They should be given something to do during their free time.

A fund should be created to receive donations to support patients.

We should get a unit in the hospital to undertake fundraising and Korle Bu Teaching Hospital responded that they are planning to start a fundraising drive.

Supportive care

There have been intermittent shortages of blood and blood products at the national level and these impact negatively on the supportive care of patients.

Capacity building

Advocacy is required for palliative care and childhood cancers to be included in the nursing curriculum. We also need to work with the Nurses and Midwives council.

We need to educate medical educators so that they can include childhood cancer in their curricula.

Doctors in the regional and district hospitals, medical and physician assistants should have professional development about childhood cancers.

We need to have a strong partnership with GHS and especially the medical herbalist in GHS facilities for early referral of childhood cancer cases.

There is the need for better collaborative research in institutions and we need to collaborate to get a good population based registry. Kumasi has a population based registry for its environs.

Role of Stakeholders

We should extend the partnership for cancer care to other development agencies in addition to those currently supporting us.

Childhood cancer should be put on the agenda for relevant ministerial meetings.

Next Steps:

i. Report of this meeting – communique to be issued to media by Prof. Lorna Renner by first week of February
ii. Childhood cancer to be put on the agenda for the next Health Sector Working Group meeting on March 11th 2016 - responsibility for this is Ministry of Health. The Director, PPME assured this would be done.
iii. Advocacy with developmental partners – WHO will be involved with this
iv. Early detection with particular emphasis on retinoblastoma – responsibility for this is Ghana Health Service. The Ag, Director-General affirmed positive steps would be taken by the end of March 2016.
v. Engaging NGOs in Health and Civil Society Organisations for advocacy and awareness creation starting at the community level – World Child cancer has started this and will be responsible for this from January 2016 onwards.
vi. An adult survivor of childhood cancer who came with her baby and husband volunteered to help with the outreaches. She is committed to helping the GHS & MOH for advocacy
vii. National Health Insurance Scheme – NHIA advised that there should be more advocacy at the policy level including parliamentarians as it requires changes in the law. Need an independent body to do costing of services so that the tariffs are realistic.
viii. Access to quality medicines – Food and Drug Authority fast tracks Paediatric medicines, will process permits for individual drugs, all oncology drugs exempt from VAT as of October 2015. Service providers should engage institutional pharmacovigilance officers for issues of efficacy
ix. Data collection at all levels – Ghana Health Service suggested the use of the Ghana Health Service Research centres, no time limit given
x. Fundraising at the two comprehensive treatment centres – Teaching hospitals to take this up as part of their planned strategies – already in the planning process
xi. WHO and GHS should collaborate to organize training workshops for health personnel.
xii. Implementation of strategies in Cancer Control Plan – advocate for childhood cancer sub-committee under the MOH National Non-Communicable Diseases Steering Committee. NCD programme manager to take this up. Meeting of the steering committee of which Prof. Lorna Renner is a member, is scheduled for February 2016.

Closing remarks made by Dr Gloria Quansah-Asare (Ag. D-G, GHS) during which she thanked all the stakeholders for their active participation and WCC/DFID for funding for this important meeting. Meeting ended at 2.00pm