Report on the Commemoration of International Childhood Cancer Day

15th February, 2016

“Better access to care for children and adolescents with cancer everywhere”

Vaccinated Against HPV

Uganda Cancer Institute

Uganda Cancer Society
Acknowledgments

We do acknowledge that the success of the commemoration of International Childhood Cancer Day (ICCD) - 15th February, 2016 was as a result of joint effort from all cancer control actors in Uganda who actively took part in marking this day.

The leadership; first, of the Government of Uganda through Ministry of Health (MoH) and Uganda Cancer Institute (UCI) and secondly, of the Civil Society through Uganda Cancer Society (UCS) in the preparations and marking of ICCD is recognized and well appreciated.

Special appreciation again goes to the Government of Uganda through UCI for accepting to host activities in commemoration of ICCD at UCI premises. Your efforts and leadership in cancer control in this country are well acknowledged and valued.

In the same spirit, we would like to recognize and thank Mulago Adolescent Clinic and Nakasero Blood Bank for adjusting their schedules in order to join the rest of the Uganda Cancer Control community in commemorating ICCD. The two respectively conducted vaccination for Human Papillomavirus (HPV) for eligible adolescent girls and blood donation as a way of making their contribution in marking ICCD together with the rest of cancer control community.

In a similar manner, we recognize and appreciate the great insights, information and guidance on childhood cancer from panelists of the Breakfast dialogue meeting. The panelists included: (Managing Director UCI, Dr. Jackson Orem; Senior Pediatrician, Head of the Adolescent Clinic at Mulago and member of the National HPV vaccination steering Committee, Dr. Sabrina Kitaka; Head Pediatric Oncology UCI, Dr. Joyce Balagadde; Head Comprehensive Community Cancer Awareness Program UCI, Dr. Noleb Mugisha and the Team Leader Uganda Child Cancer Foundation (UCCF), Mr. Ben Ikara). Similarly, we would like to recognize and appreciate the session moderator Mr. Paul Ebusu the Program Director UCS for steering the Breakfast dialogue meeting.

The wider civil society under the umbrella of UCS are highly recognized and appreciated in the preparations and commemoration of ICCD 2016. Your cooperation and positive response played a vital role in seeing this day become a true success and is not only humbling, but gives hope to cancer control efforts in Uganda. We thank each and every organization for their contribution towards the successful commemoration of the ICCD.

The media is greatly thanked and well appreciated including among others; UBC TV and radio, Bukedde fm, BBS TV, NTV, Radio One/Akaboozi, KFM, Star fm, Gulu fm, CBS fm, Urban TV, Monitor publications, the Independent Newspaper, the Observer, and New vision Uganda, among others. Your role and contribution in cancer control and childhood cancer in particular, cannot be overstated.

Last but not least, we extend our gratitude to parents who brought their adolescent girls for HPV vaccination and all members of the community who responded to donate their blood with the blood bank.

Finally and once again, great appreciation goes to the UCI and UCS secretariat for actively mobilizing and coordinating the preparations and commemoration of ICCD - 15th Feb, 2016.
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## Acronyms

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<tr>
<td>3C</td>
<td>Children Caring about Cancer</td>
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<tr>
<td>AIDS</td>
<td>Acquired Immune Deficiency Syndrome</td>
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<td>BL</td>
<td>Burkitt's Lymphoma</td>
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<td>CSOs</td>
<td>Civil Society Organizations</td>
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<td>ICCD</td>
<td>International Childhood Cancer Day</td>
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<td>IEC</td>
<td>Information, Education and Communication</td>
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<td>KCR</td>
<td>Kampala Cancer Registry</td>
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<td>LMIC</td>
<td>Low and Middle Income Countries</td>
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<td>MoH</td>
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<td>Uganda Child Cancer Foundation</td>
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1. Executive summary

This report comes to highlight activities conducted by the Uganda Cancer Control community in commemoration of ICCD 2016. The day was commemorated under the global unified message: “Better access to care for children and adolescents with cancer everywhere”.

For the Uganda Cancer Control community, the objective of commemorating ICCD 2016 was to bring together Uganda’s stakeholders to share information and raise awareness on the burden of childhood cancer while appreciating efforts made and recognizing challenges faced in the fight against this burden.

A number of activities were conducted in commemoration of ICCD by the Ugandan cancer control community including; a breakfast dialogue meeting which was held from 9:00am to 11:00am at the UCI premises, followed by T-shirt branding for the adolescent girls between 11:00am to 11:30am in preparation for the HPV vaccination for the adolescent girls which was carried out between 11:30am to 12:00pm and finally the blood donation drive.

The breakfast dialogue meeting was attended by a total of 54 participants representing 16 organizations and 12 media houses and members of the general public including adolescents and parents. The submissions from the panelists during the breakfast dialogue meeting were very informative with a number of issues relating to childhood cancer being discussed. Among others was the appreciation that childhood cancer is real and poses a burden to Uganda’s society. Similarly was the recognition of both the efforts made towards childhood cancer control and the challenges faced in the fight against the burden.

In branding the T-shirts for adolescent girls who came with their parents for HPV vaccination, the girls were given a moment together with the parents to appreciate facts around childhood cancer and to know that prevention is better than cure. They and their parents wrote messages on the T-shirts about what they feel and or understand about childhood cancer.

The actual HPV vaccination conducted in liaison with Mulago adolescent clinic for eligible girls who came through was meant to demonstrate need for all children /adolescents both boys and girls to get vaccinated against HPV in order to prevent acquiring related cancers in the future i.e. cancer of the cervix and penile cancer in women and men respectively.

The blood donation exercise conducted by Nakareso blood bank was a demonstration of the link between cancer treatment and the need for continuous blood transfusion for the patients. Indeed, the cancer institute is on top of the blood bank’s list for blood supply.

In summary, the efforts of all actors who positively responded towards the commemoration of ICCD made it a success regardless of the short period in preparations. It’s recommended that ICCD commemoration going forwards be put to special consideration and arrangements made early enough to prevent the events leading to the commemoration of WCD from overshadowing it.
2. Introduction

International Childhood Cancer Day (ICCD) is globally recognized and celebrated on the 15th February each year. The day provides a platform for raising awareness about childhood cancer and offers an opportunity for each and every one to express support for children and adolescents with cancer, the survivors and their families. During this day, we get to again appreciate and deeper understanding of issues and challenges relevant to childhood cancer which impact on children/adolescents with cancer, the survivors, their families and the society at large. It also highlights the need for more equitable and better access to treatment and care for all children with cancer which is in accordance with the UN rights of a child. Therefore, as we commemorate this day, it’s important to recall Article 24(1) of the UN Convention on the rights of a child which emphasizes that; “Children have the right to the enjoyment of the highest attainable standard of health and to facilities for the treatment of illness and rehabilitation of health.”

Defining a child according to the UN Convention on the rights of a child as a human being below the age of 18 years, this year’s ICCD unified message: “Better access to care for children and adolescents with cancer everywhere” captures both children and adolescents alike.

Indeed, the unified message is cognizant of the UN rights of a child and befits the description of need given the circumstances and challenges surrounding childhood cancer globally and in the Low and Middle Income Countries (LMICs) in particular.

Adopted from: http://www.internationalchildhoodcancerday.org/

Globally, about 150,000 children are diagnosed with cancer each year. Nonetheless, with early detection and access to quality care, it’s estimated that 80% of children diagnosed with cancer can survive, living full and healthy lives. Sadly, over 90% of childhood cancer deaths occur in LMICs primarily because children with cancer in these low resource settings do not receive adequate and or complete care.

Uganda just like the rest of the world recognizes the burden of childhood cancer. Unfortunately, there is limited nationally representative data indicating incidence and prevalence of childhood cancer. However, some information exists. Studies have in the past indicated arise in childhood cancer within the central region of Uganda as assessed from information captured in the Kampala Cancer Registry (KCR). Between the two periods 1960-1971 and 1991-1997, childhood cancer incidence increased from 97.8 per one million to 169.7 per one million within the central region of Kyadondo County where Kampala Capital City is located. Lymphomas remain relatively more frequent, with Burkitt’s Lymphoma (BL) being the most frequently diagnosed cancer among children with the peak age of between 5–9 years. At the Uganda Cancer Institute (UCI), childhood cancer accounts for 40% (700) of the 1700 new cancer patients seen each year. This figure cannot be undermined as it indicates a close to 50% odds in all new cancer cases seen at UCI annually being children.

Nonetheless, some efforts have been made towards childhood cancer control and prevention. As such, it’s important to recognize and appreciate current efforts by Government and other actors in cancer and childhood cancer control in particular. Uganda Cancer Institute has a functioning pediatric oncology department with a dedicated and qualified
staff comprising of pediatric oncologists and nurses and a fully-fledged and well equipped pharmacy. There is also a separate and dedicated pediatric floor (floor no.3) in the new cancer Institute’s building to accommodate the pediatric ward and an outpatient clinic and infusion area. Government of Uganda through UCI is set to establish regional clinics as a way to decentralize services in cancer management. A regional clinic is already operational in Mayuge district to function as a cancer treatment centre for Eastern Uganda and serve as a model for the establishment of other regional centres in Mbarara, Arua, Gulu and Mbale. [7] At a national level, the launch of the national Human Papilloma Virus (HPV) vaccination program on 26th November, 2015 for eligible adolescent girls to guard against cervical cancer is a positive intervention towards reducing the burden of cervical cancer in women. [8] It must be recalled that cervical cancer remains the most diagnosed and leading cancer killer among women of reproductive age in Uganda. [9] Also the passage of the National Tobacco Control Act, 2015 is a major government commitment towards curbing tobacco use and exposure to second hand smoke as a major cancer risk factor which disproportionately affects children and women. [10] Similarly, the growth of palliative care supported by government policy allowing prescription of morphine by specially trained nurses and clinical officers to patients in need goes a long way in fostering palliative care in Uganda. [11]

But despite the above efforts, Uganda just like many other LMICs still faces numerous challenges in childhood cancer control. Among others the following can be recounted; limited awareness on childhood cancer among communities, centralization of cancer services, and absence of supportive legal environment for cancer control in general, shortage of specialists in childhood cancer, a poor economy with limited resources at both government and patient levels affecting the quality of treatment and undermining treatment outcomes and survival rates are some of the challenges in childhood cancer control in Uganda.

This therefore calls for concerted efforts in terms of creating an enabling environment through enactment of comprehensive national policies on cancer control and the establishment of UCI as an autonomous body through an Act of Parliament. This can work hand in hand with intensified creation of awareness on childhood cancer that reaches all citizens and acquisition of knowledge through research to better interventions and treatment outcomes. Government also needs to commit more resources to adequately address existing resource gaps for cancer control.

Cognizant of all the above, the Uganda Cancer control community led by Uganda Cancer Society together with the Uganda Cancer Institute joined the rest of the world to commemorate ICCD on 15th Feb, 2016. This commemoration was meant to appreciate the burden, recognize efforts and encourage more action towards childhood cancer control through awareness creation. Therefore, this report comes to highlight activities conducted by the Uganda Cancer Control community in commemoration of ICCD 2016.

3. Objective of ICCD commemoration

The objective of commemorating ICCD 2016 was to bring together Uganda’s stakeholders to share information and raise awareness on the burden of childhood cancer while appreciating efforts made and recognizing challenges faced in the fight against this burden.

4. Activities conducted to mark ICCD
The following activities were conducted in commemoration of ICCD 2016 by the Ugandan cancer control community;

4.1 Breakfast dialogue meeting

The Breakfast dialogue was intended to provide a platform for information sharing on issues relating to childhood cancer. In this breakfast dialogue meeting, Government through UCI and Mulago Adolescent Clinic was represented. Also, Civil Society under the UCS/UCCF umbrella was represented as well as the media and children/adolescents were also part of the meeting. In total, 16 organizations in both government and civil society were present, and 12 media houses were present plus other members of the public making the total number of participants 54. The program for the breakfast dialogue involved presentations including: a Civil Society submission represented by UCCF, a submission from the Head of Pediatric Oncology at UCI, submission from Mulago adolescent clinic and a submission from UCI Managing Director who then invited and the Head Comprehensive Community Cancer Awareness Program at UCI. These submissions were followed by an open dialogue discussion involving questions from the audience and finally a vote of thanks was given by the Executive Director Kawempe Home Care to close the day.

4.1.1 Welcome Remarks

The breakfast dialogue meeting started at 9:00am with opening remarks from the Program Director of Uganda Cancer Society, Mr. Paul Ebusu who also doubled as the session moderator. Ebusu called the meeting to order and welcomed the participants. He thanked them for sparing time amidst their busy schedules even on short notice. Ebusu re-echoed the unifying message of the ICCD: “Better access to care for children and adolescents in cancer everywhere”.

He then wished the participants fruitful deliberations before welcoming the Team Leader - Uganda Child Cancer Foundation (UCCF), Mr. Ben Ikara to make a submission on behalf of Civil Society.

4.1.2 Submission by UCCF Team Leader, Mr. Ben Ikara on behalf of Civil Society

Mr. Ikara gave a brief background about UCCF saying that UCCF’s establishment was premised on creating awareness on childhood cancer in Uganda. Mr. Ikara highlighted the challenges faced in childhood cancer control including given UCCF’s own experiences which included the following:

- High level of ignorance among the communities. People do not know that even children can get cancer. It is still a strong belief among the population that cancer is a disease of only the old. Dispelling this myth requires intensified awareness creation which is challenged by limited resources to wider areas in the country.
• Childhood cancer is unique and requires special interventions. Much care is needed when dealing with children as opposed to adults. Most times parents bring patient children from upcountry and end up having to sleep on the verandas due to limited accommodation at UCI. This also predisposes the children to other related infections which further undermine cancer treatment outcomes.

• Childhood cancer progresses much faster. Its acute nature has far reaching effects not only to the patient but also to the family and the larger community both socially and economically.

• There is also the challenge of limited knowledge and information for advocacy and awareness creation by Civil Society Organizations coupled with some sections of un-informed health workers.

The UCCF Team leader therefore appealed for appropriate interventions from all stakeholders if the childhood cancer burden is to reduce. Some of his proposed areas of intervention were:

• Government should devise strategies to ensure health workers are well trained to handle childhood cancers for proper handling of children.

• CSOs should get back to the basics and practicalities of advocacy and awareness creation by developing messages and information which is easily communicated for better understanding since the target audience is the children and parents.

“Good news is that Uganda has woken up early enough to control cancer unlike was the case with HIV/AIDS” – Mr. Ben Ikara, UCCF

5.1.3. Submission by Head Pediatric Oncologist Uganda Cancer Institute, Doctor Joyce Balagadde

Dr. Joyce starting by projecting the childhood cancer burden globally indicating that it is a growing threat. She stated that in North America, childhood cancer accounts for only 1% of the burden of cancer. However in Uganda, childhood cancer remains a growing burden just like in most LMICs. Dr. Balagadde further explained that basing on the trend over the past 5 years, and according to the Kampala Cancer Registry, cases of childhood cancer are growing each year. She added that in the developed countries, 80% of childhood cancer cases survive but due to poverty, the case is different in low income countries including Uganda.

The following are some of the most common childhood cancers; Burkits Lymphoma, Acute leukemia, Cancer of the kidney and Kaposis Sarcoma which is common among those infected with HIV/AIDS.

Dr. Balagadde added that since 1967, UCI has taken tremendous studies in childhood cancer and this has involved over 4,000 children leading to the following;
• Formation of a dedicated children service team in 2012 which includes two medical doctors and 12 nurses plus a fully-fledged department of pharmacy which has the best services in the country.

• Establishment of a well-equipped laboratory which provides free imaging services.

• Setting up of a tumor board by a group of specialists.

• In 2013, UCI acquired a separate pediatric outpatient floor to accommodate the ward.

• In 2016, a pediatric outpatient clinic and infusion area was opened.

Dr. Balagadde stated that the UCI is now focusing among other things on; equipping more health workers with knowledge on childhood cancer especially the nurses and collaborations with CSOs to construct hostels for children to solve the accommodation challenge.

But despite all the progress being made in controlling childhood cancer, UCI faces some challenges including

• Few specialists (Currently there is only one oncologist).

• Limited accommodation and yet most of the children come from rural areas and their treatment takes between six months to four years. Dr. Balagadde says these forces the children to seek unsafe shelter which exposes them to many other risk factors.

5.1.4 Submission by Head of Mulago Adolescent Clinic, Dr. Sabrina Kitaka

Dr. Sabrina Kitaka recognized the efforts of the UCI Director, Dr. Jackson Orem and the Oncologist, Dr. Joyce Balagadde saying that they have done remarkably well and she is impressed with the overall progress at the institute.

Dr. Kitaka further appreciated the CSOs for playing a big role in cancer control in Uganda saying that Civil Society is part of the health agenda. She said that she is part of Civil Society and was actively involved in pushing for the introduction of the Human Papilloma Virus (HPV) vaccine against cervical cancer and since then this has increased the number of girls receiving the vaccination.

Dr. Kitaka added that with the establishment of the Adolescent Clinic in Mulago which carries out HPV vaccination every Friday, government is making progress in controlling cervical cancer saying that this targets girls between the ages of 10 to 13 years. She said the vaccine responds to women of up to 26 years but due to limited resources, the age has been limited to 13 years. Dr. Kitaka said it is hoped that this will be reviewed in the future depending on the availability of resources. She called on adolescents and parents to embrace the vaccination exercise saying that children may not get cervical cancer at 12 years but they are likely to get it at their later years if they missed out on the vaccination.
Dr. Orem noted that cancer control efforts have been falling short when it comes to children and adolescents. He said that miss-match occurs between 15 to 18 years because people within this age group are many times not considered children and yet when they go to adult clinics they are also not considered adults. He says UCI will work closely with the Adolescent Clinic to see how to address some of the challenges.

Dr. Orem noted that there is no emphasis put on childhood cancer and this is equivalent to condoning the scourge in children and yet childhood cancer is preventable. He appealed to government and law makers to invest in prevention and treatment of childhood cancer. Dr. Orem further pointed out several gaps that need to be addressed including:

- Establishment of a childhood cancer registry.
- HPV vaccination efforts should be stepped up and this should include both boys and girls.
- There is need to improve on treatment because the survival rate which is currently at 30% should be increased.

Dr. Kitaka revealed that the Adolescent Clinic offers services beyond cancer screening including HIV testing and counseling. This is because some cancers are common in HIV/AIDS patients. She therefore advised parents to talk to their children to avoid risky behaviors to avoid contracting HIV/AIDS. She also urged people to get the Hepatitis B vaccine to avoid liver cancer.
• Mechanism of procurement and distribution of drugs should be refined because cancer control is about timing of treatment.

• There should be increased involvement of children in research saying that the UCI plans to develop another vaccine: Extern ber virus and this will involve research.

• Emphasis should be put on prevention of HIV/AIDS since some cancers are common in children living with the HIV/AIDS virus.

• There is need for strong collaboration from all stakeholders with the UCI.

He concluded by generally thanking everyone in attendance and especially the organizers for the great efforts put.

4.1.6 Open discussion with Q&A

During this session which was moderated by UCS Program Director, Paul Ebusu, participants directed their questions to the panelists while others made comments/suggestions. The following questions/submissions from the audience were asked and or raised.

• What is being done to screen children in rural areas
• What progress has UCI done in terms of training more specialists to boost the gap of having one oncologist?
• How is the registry going to work? Can leukemia and Burkitts Lymphoma be incorporated?
• How will the challenge of getting consent from parents for research on children be addressed?
• Is there a repeat shot of the HPV vaccine?
• What happened to the mobile cancer van?

Responses from the panelists to the questions

From left to right: Panelists during the ICCD breakfast dialogue meeting at UCI, Head of Mulago Adolescent clinic: Dr. Sabrina Kitaka, UCI Managing Director: Dr. Jackson Orem, Head Pediatric Oncology: Dr. Joyce Balagadde and Head Community Cancer Program UCI: Dr. Noleb Mugisha
Dr. Joyce Balagadde

Dr. Balagadde said that taking screening services closer to the rural communities requires partnerships with CSOs involving parents and health workers. She also said that UCI is developing Information, Education and Communication (IEC) materials specifically for children.

In regards to training more specialists, Dr. Balagadde said that UCI is working closely with Makerere University to train health workers engaged in the areas of cancer to improve on their knowledge and level of awareness. She said the target will be Doctors working in Health Centers 3 and 4. She added that UCI has designed a local training for specialists to help in pediatric oncology because acquiring this education outside Uganda is expensive.

Dr. Jackson Orem

Dr. Orem informed members that there is already a registry for adults and this will be customized for children and it will be expanded. He added that UCI will start a community cancer registry beginning with the Eastern region.

There is also a plan to improve on the cervical cancer screening technology from Pap smear to HPV DNA and this will allow women take kits home to carry out tests.

In regard to training more specialists, there will be a fellowship program to train nurses in oncology and train health workers to detect cancer.

Dr. Sabrina Kitaka

Dr. Kitaka clarified that the HPV vaccine requires two shots. She also informed members that the Hepatitis B vaccine in children is repeated 3 times, (at 6 weeks, 10 weeks and at 14 weeks). But she said that some children missed out because this was an intervention which started in 2012. But said screening should be done and those found negative should get the vaccine.

Dr. Mugisha Noleb

Dr. Mugisha informed members that UCI has rolled out training of health workers countrywide. This has been done in Kabale and next will be Arua. Dr. Mugisha called on CSOs to participate during these trainings. He asked participants to promote government interventions like HPV vaccination and help government implement policies and not go against them. He informed participants that the mobile cancer van is still working although its operations are limited by resources. He added that the institute will soon have a much more equipped van.
4.1.7 Closing Remarks by Executive Director Kawempe Home Care, (KHC), Dr. Sammuel Guma

Dr. Guma applauded UCCF saying that the organization in partnership with other CSOs have done a lot in creating awareness on childhood cancer. But he said that there is still more that CSOs need to do. Dr. Guma further noted Dr. Kitaka’s contribution in the reducing the burden of childhood cancer. He said that Dr. Kitaka’s passion in ensuring the introduction of HPV vaccine and the adolescent clinic in Mulago cannot go without mention. He also recognized the fact that Dr. Balagadde has done a great job despite being the only oncologist at the UCI. Dr. Guma applauded Dr. Orem for all his initiatives at UCI saying that this has enabled the institute work closely with the Ministry of Health (MoH) and other partners in cancer control. He recommended that Doctors in cancer control should be given medals of Honor for their tireless efforts. He said the call for partnerships and collaboration from UCI should be taken seriously.

4.2 T-shirt branding for adolescents

A group of over 20 girls between 9-10 years received t-shirts and participated in painting them. This involved writing personal messages on childhood cancer on the t-shirts. This was in preparation for the HPV vaccination.
4.3. HPV vaccination for eligible adolescent girls

The concept behind the vaccination exercise was to encourage adolescent girls to get the HPV vaccination against cervical cancer as a way to reducing the high levels of cervical cancer which is the most common among women. The vaccination exercise was done by the Mulago Adolescent Clinic at UCI and it ran from morning into the afternoon. The exercise saw over 186 girls between 10-19 years vaccinated against cervical cancer. The girls were accompanied by their parents to receive the vaccine.

![A health worker registers one of the adolescent girls for the HPV Vaccination while giving her information about the vaccination](image)

5.4 Blood donation drive

The blood donation drive was premised on the fact that on several occasions, the Uganda Cancer Institute’s blood bank is not sufficient enough given that blood transfusions are done regularly. In a bid to try and bridge this gap, a blood donation drive was carried out by Nakasero blood bank and the exercise saw a number of people donate blood to this just course.

5. Conclusion

To a greater extent, the objective for commemoration of ICCD was achieved despite the limited time in preparations. The breakfast dialogue not only left participants with deeper insights on childhood cancer, but also gave them an opportunity to get fresh ideas on advocacy and in awareness creation on childhood cancer. The adolescent girls and their parents were able to realize their role in reducing the cervical cancer burden by accepting to get vaccinated. The blood donation drive was an exhibition that demonstrated the wider community’s commitment in the fight against cancer and childhood cancer in particular. In the future, it is recommended that better and early arrangements need to be considered to create a balance and prevent WCD commemoration overshadowing that of ICCD.
References


