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PATIENT SOLIDARITY DAY

Launch of Health Literacy Campaign Report

20th December, 2011

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A group photo of children suffering from Cancer

Organizers:

Community Health and Information Network (CHAIN)
Uganda Cancer Institute (UCI)
The Uganda Cancer Society (UCS)
Uganda Child Cancer Foundation (UCCF)
Save a Woman Initiative (SAWI)

With Generous Financial Support from:

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1. INTRODUCTION

Community Health And Information Network (CHAIN) in partnership with the Uganda Cancer Society (UCS), Uganda Child Cancer Foundation (UCCF), Uganda Cancer Institute (UCI), Save A Woman Initiative (SAWI) and Makerere University Students' Association with support from Merck & Co. Inc organized the Patient Solidarity Day and launched the National Health Literacy campaign on December 20th, 2011.

The Patients Solidarity Day brought together patients and patient organizations across all diseases including cancer, Diabetes, Heart, Epilepsy, Sickle cell, infertility, and HIV/AIDS etc. The Day was officiated by Representatives from WHO, Ministry of Health, National Drug Authority and in attendance were also Health Care Professionals, Media and the Civil Society. The major aim was to recapitulate on work so far done on patient safety, share testimonies from clients and launch a national Health literacy campaign across in Uganda.

The day was a colorful one punctuated by patients and doctors painting their faces, free interaction with clients, testimonies of patients along various disease spectrums of their treatment status, drama, speeches and general interaction. It was a day for giving hope to patients through gifts and discussing a common agenda aimed at improving health outcomes.

1.1. Welcome Remarks and Climate Setting

By Claire Judith Achieng, Finance Planning and Administrative Manager Save A Women Initiative (SAWI)

Ms Claire welcomed all the participants. She said that the patients' solidarity is a day of interacting and giving hope and compassion to patients. It is a time to know more about patients and their concerns; the event provides an opportunity for key healthcare stakeholders to understand and appreciate the needs of the patients and therefore able to come up with appropriate solutions of improving healthcare service delivery. She took participants through the day's program agenda and activities.

1.2. Patient Solidarity Day- Background and Objectives

By Ben Ikara, Operations Manager, Uganda Child Cancer Foundation (UCCF)

Briefed the participants about the genesis of Patient day and how it transformed into Patient Solidarity Day.

The Child Cancer Foundation (UCCF) started celebrating the patient day inwith special focus on children suffering from cancer and their caretakers. The purpose of the day was to create a fun and relaxing atmosphere for patients to express themselves on the social needs and experiences as they underwent treatment. The interaction revealed that patients needed a lot of therapeutic activities like art and play, nutrition, counseling, guidance and health education on management and control of cancer. It further revealed that the majority of patients and caretakers had very limited knowledge on managing their health. There was a need to celebrate the day every year to address the identified needs.

How did Cancer Patient day translate into Patient Solidarity Day?

During an interaction with patient organizations (Community Health And Information Network (CHAIN), Uganda Child Cancer Foundation (UCCF), Save A Woman Initiative (SAWI), Sickle cell Association, and Morriss Mosses Foundation (MMF),) from Uganda and Kenya, we discussed the common problems we share and the need to promote patient centered healthcare It it was important to come together and share knowledge, experiences on the management and prevention of diseases. Show love and care to the sick by providing them with food and gifts etc.

The patient solidarity day will be an annual event taking place in December. Other countries will be encouraged to join Uganda and Kenya in marking the patient solidarity day and ultimately have it observed as an international day.

He gave the objectives of the day:

- Bring together Patient Organizations, Health Care professionals, and key stakeholders including ministry of health, WHO, National Drug Authority, civil society and the Media and to raise awareness on Health Literacy.
- Increase knowledge of patients and caretakers to better manage their health through health literacy education activities.
- Share knowledge, experiences and good practices in disease control and management.
- Strengthen collaboration among patient organizations and other key stakeholders to improve health care services.
- Provide an enjoyable and relaxing environment for patients through therapeutic activities.

1.3. Patient Solidarity Day – National Health Literacy Agenda

By Regina M.N. Kamoga – Country Manager, CHAIN

Thanking all guests for honoring the patient's day, she pointed out that the day was for sharing experiences and craft ideas on what needs to be done to promote patient centered healthcare and patient safety. She noted that most of the illnesses in Uganda are treatable and preventable but the situation has been worsened by low health literacy levels.

She went to say that a person with low health literacy has no capacity to obtain health information, process it and act upon it, cannot communicate and question.

"People's health literacy shapes their health behavior and choices-ultimately their health and wellbeing". (Health Literacy Action Guide Part 2,"Evidence and Case Studies, 2010)

Explaining why there was a high need for health literacy can be seen from the national statistics that show that 60% of Ugandans don't seek treatment from health facilities. Low levels of health literacy in Uganda has resulted into consumption of poor quality medication and counterfeit medicines; self medication, poor adherence and health seeking behavior, late diagnosis and referrals, seeking alternative healthcare from traditional medicine practitioners leading to increased mortality and morbidity rates.

The patient solidarity day therefore was a call to all patient organizations; line government bodies and ministries, health professionals, development partners, media and the civil society to embrace the health literacy campaign, design appropriate strategies, dedicate efforts and resources to increase the health literacy levels of the general public.

Thanked all patients organizations for their efforts and presence, Merck & Co. Inc for their generous financial support and WHO for steering the international health literacy agenda.

2. SHARING KNOWLEDGE AND EXPERIENCES

2.1 HIV and AIDS

HIVand AIDS by Milly Katana, HIV Advocate

Dr Martin Ssendyona (Ministry of Health) sharing a moment with Regina Kamoga (Country Manager – CHAIN)

She thanked the Cancer Institute and CHAIN for organizing the patients Solidarity day and giving hope to patients. She noted that the patient solidarity is a day for celebrating life, giving patients honor and dignity in a sense that they are loved and the care givers are committed to their care. The day also sends clear messages that such illnesses are manageable and treatable with the current advances in science and technology.

She observed that health is made at home though sometimes we think it is made in the hospitals. “Hospitals are like garages, where broken health is repaired” she added. Being healthy needs partnership between patients, families, communities and health workers. Commenting on HIV&AIDS, she noted that it precipitates communicable and non communicable diseases. At the same time, patients of cancer, epilepsy and other non-communicable diseases can still get HIV and therefore all this calls for partnerships with other service providers to prevent HIV among patients with NCDs. It is possible to live longer with the current treatment available and prevent further spread of NCDS and HIV. What is needed is for the patient organizations to step up health literacy for the people to seek early interventions. She closed by raising a major concern of HIV among children which is a result of non-effective programs to prevent the transmission from mothers to unborn babies. She called upon care givers to always refer pregnant women for HIV prevention services including HIV testing so that those that are found to be HIV positive can receive appropriate care.

Participants at the Patients Solidarity Day

2.2 Breast Cancer

By Margaret Okello, Breast Cancer Survivor and Advocate

Margaret Okello a breast Cancer survivor of four years narrated her cancer experience. A member of cancer association and a volunteer who raises awareness on cancer exhumes a lot of confidence and hope. Narrating her experience, she told participants that she lived a normal health life or so she thought until one day through self examination felt some lamps in her breast. She didn't take this lightly and immediately sought medical advise. An x-ray revealed she had two lamps, Several tests were done including a biopsy. Throught all this process she wasn't feeling any pain and this gave her the false hope that all was ok.

She wasn't prepared for the devastating news. She had breast cancer! Its hard to describe what she felt when the doctor gave her the results. She could only describe it as a traumatizing experience one she wouldn't wish any other person to go through, and that's the major drive for her advocacy work because she knows that its preventable.

She went through a lot of counseling as she underwent her treatment at Mulago hospital, at the Cancer institute. This took five months with a treatment cycle of every two (2) weeks. Fears of prolonged treatment made her lose weight and the side effect of drugs with soars in the mouth and feeling sick all the time did not make life any easier.

The second treatment took her to blood transfusion and this was followed by announcement that her breasts would be cut off. With counseling, she accepted the operation and her two breasts were cut off with ensued breeding and pain. A few days later, she was discharged from the hospital and currently has completed her fourth cycle of treatment. She is currently fine with no major complications. She thanks doctors, parents and friends that gave her support, advice and counseling to get treatment early or else she could not have been treated in time and therefore the disease would have progressed to late stages making it difficult for her to survive.

Her message to everyone is to go for regular check ups and seeking early treatment and for patient organizations to educate the public about the need for early diagnosis and early treatment.

2.3 Epilepsy

By Ndyahika Dickson, *Advocacy Officer, Epilepsy Support Association Uganda*

Due to limited public knowledge and information, people have always culturally associated causal factors of epilepsy with witchcraft. There are several myths about epilepsy in many communities in Uganda that are just myths and need to be dispelled. Dickson informed participants that epilepsy is not caused by witchcraft and can be treated. It is an abnormal dysfunction of the brain and manifests in different ways, based on the affected area in the brain. These affect the type of seizures that a person with epilepsy gets and the presentation of the seizures.

Epilepsy is caused by known and unknown factors which include among other infections, hereditary factors, though these are rare. Some of the causes of epilepsy include: untreated malaria, measles, worms, HIV/AIDS in its last stages, meningitis, accidents, alcohol abuse, drug abuse, trauma, birth trauma.

Dickson narrated an experience where an employee carried his medication to work to ensure adherence, however he did not want any one to see him for fear of losing his job, he would take his medication in the toilet. Epilepsy has a lot of stigma attached to it and many people will not come out openly.

He appreciated the initiative that provided an opportunity to learn and share knowledge on different diseases and their management. He called upon all the patient organizations to sensitize the general public about the problem different diseases cause to the sufferers. “People need to know that epilepsy is treatable like any disease and that they should not wait till the late stages”. Any health Centre 4 at any District can treat epilepsy and so can government hospitals, referral and regional referral hospitals. Epilepsy is not contagious he affirmed and called upon participants in the meeting to share the knowledge acquired.

2.4 Sickle cell disease

By Ruth Mukiibi, Chairperson and Founder - Sickle Cell Association of Uganda

Ruth was diagnosed with sickle cell when she was six (6) months old. She demystified the belief that people with sickle cell disease cannot marry and produce children. She is married with a health child. Ruth '*disappointed*' many people who waited in vain for her to die at the age of 5,10,15,18 and 22 was the maximum…respectively. Ruth is now 37 years old and still very healthy.

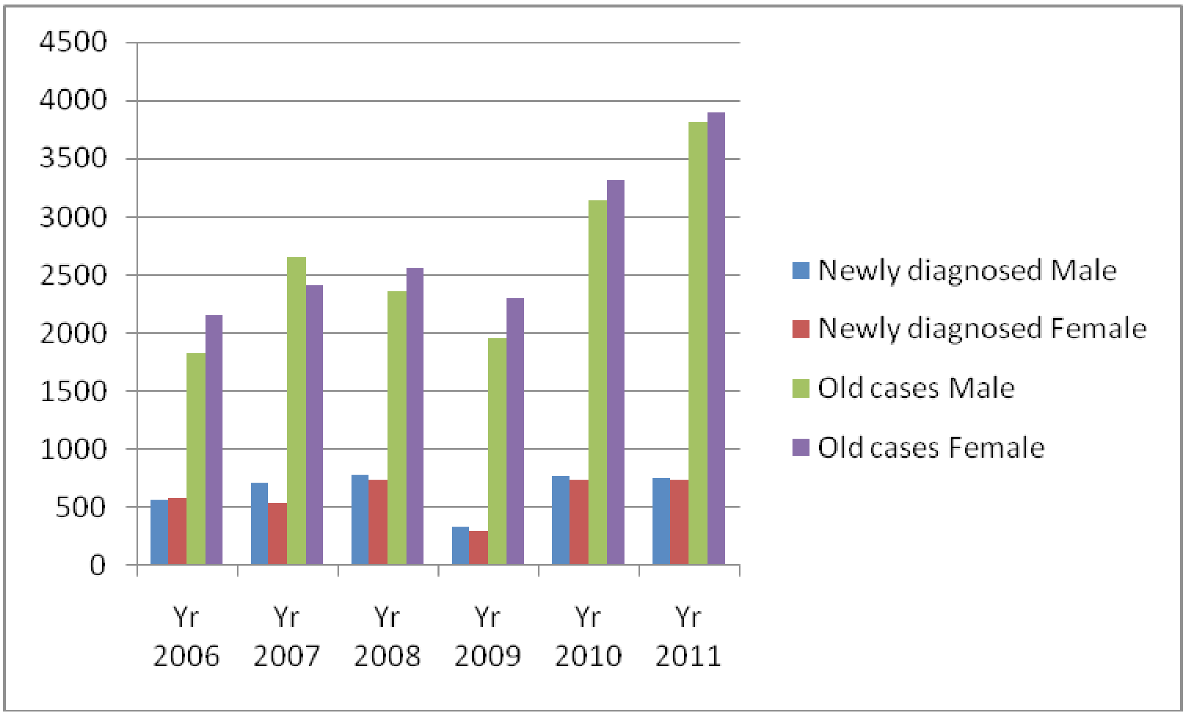
How did her parents know that she had sickle cell disease?

Ruth's fingers and toes were swollen, the parents thought she had been mistreated by the housemaid, a situation that culminated into a maid being dismissed. However, when the condition reoccurred, that's when it they realized that it was a serious issue and took her to hospital where she was diagnosed with sickle cell disease. Both parents also tested and had trait of sickle cell. The doctor advised them to separate to avoid producing more children with the disease and that their blood did not coordinate however the parents loved Ruth that they needed every moment of her life so they did not.

She gave an elaborate explanation of what sickle cell is and the transmission factors. An inherited change in the red blood cells, The red colour of blood is called haemoglobin (Hb).

Normal people have Hb A but in sickle cell they produce Hb S. When oxygen is removed, HbS forms stiff fibers which change the red cell from the normal round shape into the abnormal sickle shape and this is what causes the sickness. Sickle red blood cell is destroyed more quickly in the circulation and may also block flow of blood vessels causing tissue damage and pain. The general condition leads to slow growth and development.

She said that although the number of people with the Sickle cell disease is growing as demonstrated by the data analyzed by Sickle cell Association of Uganda at Mulago Sickle cell clinic(refer to table below; It is still one of the neglected disease. It is not also understood by not only the patients but the health workers, thus putting the life of a sickle cell patient in danger, coupled with increasing incidence of communicable and non communicable diseases eg HIV/AIDS and cancer.



Furthermore the available data on the disease is not update for example in Mulago data available was collected in 1970's. This data put 20% of the Uganda total population having the sickle cell trait, meaning they have a risk of having a sickle cell child. The Bamba people with the highest trait frequency ever registered in the world of 45% and disease frequency of 8% at birth. Basoga, Bagishu, Lugbara, Bakiga 28% trait frequency and 2% disease frequency, Baganda, Acholi, Etesots, and Banyoro 20% trait frequency and 1% disease frequency. Banyankole, Bahima and Karimajong 4% trait frequency and 0.1% disease frequency. The question is what is the situation now, after 32 years ago.This shows the extent to which the disease is neglected. There is urgent need for up to date data and, research is therefore needed to determine the disease burden. date.

Ruth appealed participants to test for the disease and particularly before marriage for them to make informed decisions. The key message to the public and patient organizations is to raise awareness about the sickle cell disease, provide correct information in appropriate way to the general public. People need to know that sickle cell disease can be managed and one can live a health productive life like Ruth.

She has devoted herself to advocate for sickle cell. At policy level, she sits on the technical working committee that formulated the National Health policy and Health Sector Strategic Investment Plan 111 and as a result of this for the first time sickle cell disease is in the National plans and budget.

Ruth is the Founder of Sickle cell Association of Uganda set up in 2000, to educate and counsel sickle cell patients about the management of the disease through outreaches, media activities, scientific conferences, printing of information, education and communication materia

2.5 Diabetes

By Mishati Kisoro-Diabetic Patient

Mishati has lived with diabetes for 33 years, he is strong and doing his work normally. Mishati used to urinate often and would be teased by his friends that he has a weak bladder. He also felt fatigued easily and excessive thirst. It was not until he went to see his doctor that he painfully learnt that he was diabetic. The news was too much for him to bear that his blood pressure went up and had to be admitted in hospital.

He says that being diabetic is not the end of the world.Although it's a life long condition if its managed well one can live a happy life. He cautioned that it requires discipline e.g. adherence to medication, following the doctor's advice. Mishati had to break all his bad habits lke smoking and drinking.

The key message to patients and the general public was go for regular medical checkups. To diabetic patients, developing a healthy life style, regular physical exercises, accepting one's condition and managing it was the best way to deal with diabetes.

2.6 Key Messages from Guest of Honor on the Launch of Health Literacy Campaign

By Dr. Solomon Fisseha Representative from WHO

He thanked the organisers for inviting WHO to a cause of not only a national but an international concern and extended apologies from the WHO Country Representative, Dr. J.Saweka for not being present personally due to other commitments. He noted that Non Communicable Diseases (NCDs) are responsible for 66% of the total global death, according to WHO NDC report 2008The majority of deaths are from developing countries (including Uganda) and 29% of those affected by the disease are 2008 6 years of age. The leading causes of NCDs are from respiratory, cardiovascular, diabetes and cancer and observed that behavior risk factors such as tobacco use and insufficient physical exercise have precipitated the disease.

WHO gives high priority to NCDs on its agenda as it has dedicated resources and time to support countries come up with long lasting but remedial solutions. He acknowledged the testimonies made by patients and noted that it is the role of families, communities to support patients but also patients need to take care for themselves. Nations have to prioritize the health of families through direct prevention programs bearing in mind that prevention is better than cure. Cultural factors have been having a great bearing on halting the needed national energies for combating NCDs and as stakeholders we need to recognize such issues.

The key message from WHO is that the current burden of NCDs to developing countries goes beyond their scope and capacity. Support from wealthiest countries is needed to respond the current level state of nations. As stakeholders including patient organizations, we need to take collective responsibility to lobby governments for services, sensitize and educate the communities while giving hope to families.

Dr Martin Ssendyona (Ministry of Health) sharing a moment with Dr Solomon Fesseha (Representative from WHO)

2.7 Messages from National Drug Authority (NDA)

By David Nahamya – Senior Inspectorate of Drugs- National Drug Authority

He thanked organizers and highlighted the role of NDA saying that it is the only a national drug regulatory agency. He noted all patient testimonies were talking about drugs and the role of NDA is to ensure patients receive the commodity called drugs that is safe and of standard to cure various sicknesses. On the side of NDA, drug supply in public hospitals has increased and patients can access it as a fundamental human right.

He noted that in the region, there are traces of substandard and counterfeit drugs. He briefed the participants about NDA's efforts to curb substandard and counterfeit medicines and unlicensed drug sellers through post market surveillance to ensure patient safety. He appealed to the people to avoid buying medicines from hawkers in the community, markets and buses and requested them to buy medicines only from licensed pharmacies and drug outlets. The public needs to be vigilant and report cases to NDA, as this is the only way NDA can curb illegal sell of drugs and substandard and counterfeit medicines.

He emphasized the role of patient organizations and the need to work with NDA to raise awareness among the public on safe use of medicines. It is through working together that we will all ensure patient safety.

2.8 Remarks from Uganda Cancer Institute

By Dr. Mugisha – Uganda Cancer Institute

Thanked everyone for showing solidarity with the patients. The take home message was that most cancers are curable and the biggest challenge that Uganda faces like other countries is that patients come for treatment when it is very late. Knowledge is power and when one knows what to do in time they suffer less. Everyone needs cancer screening; doctors, engineers, politicians, peasants even when they are not sick. He advised people to go for check ups not only for cancer but also for other diseases such as sickle cell, HIV, diabetes, hepatitis etc. He emphasized the need to work together with all key stakeholders to increase health literacy among the public.

2.9 Closing Remarks

By Dr. Jackson Orem
Director General,
Uganda Cancer
Insitute

He extended his appreciation to all who participated in the event. He noted that the lesson learnt was to appreciate those in agony, provide them with all the support they need. A lot of awareness as echoed by the different patients who shared their experiences was needed. The patient solidarity day has demonstrated an opportunity to work together to respond to issues affecting the patients. We cannot single handedly tackle all the diseases, he said. The ministry of health, WHO, private sector and civil society need to work together to compliment each other's work in order to improve health service delivery for better health outcomes.

The launch of health literacy campaign is a welcome initiative and should be supported by all key stakeholder ". Each one of us has a role a play, lets all ensure we do our part" he said. Doctors can treat but referral for treatment is needed first. The civil society and patient organizations need to sensitize patients, families and communities of the need for early treatment and prevention of disease and in particular NCDs which are on the rise. he echoed others by concluding that prevention is better than cure.

2.10 PICTORIAL

Drama skit showing patient - doctor interaction

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