
**CURE Children's Hospital of Uganda
Press Release
World Spina Bifida and Hydrocephalus Day**

The World Spina Bifida and Hydrocephalus Day is held every year on 25 October. It is an opportunity to raise awareness about Spina Bifida and Hydrocephalus and the ways in which these disabilities can be reduced through primary prevention and access to treatment. It is also a means to advocate and promote the rights of persons living with these impairments.

The First World Spina Bifida and Hydrocephalus Day will be officially celebrated on 25 October 2012 under the theme "Unlocking their Potential." It will be marked by an exhibition organised by the CURE Children's Hospital of Uganda and its member association IF Child Help, in collaboration with the Mr. Patrick Bitature. The Exhibition will take place on the 25th October 2012 at the Protea Hotel, Kololo. Initiatives and activities will be organised by CURE and IF member associations all over the world.

The Executive Director of the CURE Children's Hospital of Uganda, Mr. Derek B Johnson, states "Our patients' successes and testimonies showcase what can happen when we invest in them. With proper access to care and basic human rights, they can lead active and fulfilling lives."

The 2012 Day highlights unmet needs across the globe. While medical and healthcare advances have greatly improved the lives of some people with these disabilities, significant challenges and issues still need to be tackled. The 2012 World Spina Bifida and Hydrocephalus Day conveys three major messages: **1-** The rights of children with Spina Bifida and or Hydrocephalus to proper care and treatments should be respected; Unfortunately, in many countries around the world, many children die because of non access to basic treatments and proper care. **2-** Young people with Spina Bifida and/or Hydrocephalus should be provided with specialised and comprehensive healthcare; Young people with Spina Bifida and/or Hydrocephalus often find that appropriate multidisciplinary healthcare is not available and they have to bear the complications and additional costs related to their basic healthcare. **3-** Schools need to be disability-friendly to facilitate integration and participation for children with Spina Bifida and Hydrocephalus.

For more information about the World Spina Bifida and Hydrocephalus Day, go to: www.worldspinabifidahydrocephalusday.com

For more information about CURE or Spina Bifida and Hydrocephalus go to: www.cure.org/hydrocephalus

Infant Hydrocephalus: A Global Health Concern

Infant hydrocephalus is one of the most common congenital abnormalities affecting the nervous system of children around the globe. Commonly referred to as "water on the brain," infant hydrocephalus can be congenital (existing from birth) or acquired. Hydrocephalus is an abnormal medical condition that develops when the normal flow and absorption of cerebrospinal fluid (CSF) in the brain is hindered or blocked resulting in excessive accumulation of fluid in the ventricles of the brain. This excessive accumulation of CSF creates severe and harmful pressure on the brain and eventual swelling of the head.

Left untreated, in addition to pain and suffering, infant hydrocephalus leads to significant brain damage, severe developmental delays, blindness, and ultimately death.

Hydrocephalus is a life-threatening medical condition that goes vastly untreated in developing countries because neurosurgical care is simply not available. This year alone, CURE

conservatively estimates that nearly **400,000 newborns** (3/1,000 births) will suffer from congenital or acquired hydrocephalus around the globe and over **310,000** (79%) of these children will be born in the developing world with limited or no access to critical life-saving care (Appendix I). Over the next five years, as many as **1.5 million infants** in the developing world will die from hydrocephalus.

Children suffering from hydrocephalus in the developing world have not been a significant priority for many nations' Ministries of Health, major international actors in global health, or other international development groups to date. CURE International has launched a global initiative, **CURE Hydrocephalus**, to address the needs of these underserved children and expand the medical infrastructure necessary for addressing this significant global health concern.

Spina bifida is a neural tube birth defect (NTD) which occurs within the first three weeks of pregnancy. The spinal column fails to develop properly resulting in varying degrees of permanent damage to the spinal cord and nervous system. Approximately 70% of people with Spina Bifida develop Hydrocephalus.

Hydrocephalus is a condition in which the primary characteristic is excessive accumulation of fluid in the brain. Although hydrocephalus was once known as "water on the brain," the "water" is actually cerebrospinal fluid (CSF) -- a clear fluid surrounding the brain and spinal cord. The excessive accumulation of CSF results in an abnormal dilation of the spaces in the brain called ventricles. This dilation causes potentially harmful pressure on the tissues of the brain.

Primary Prevention: Worldwide, over 300,000 newborns are affected by Neural Tube Defects such as Spina Bifida every year and much more are affected by Hydrocephalus. Spina Bifida can lead to severe malformations. Yet 70% of pregnancies affected with Spina Bifida can be prevented if women take daily folic acid supplements at the right time. According the World Health Organisation, women of child bearing age should take 0.4 mg of folic acid per day two months before conception and during the first three months of pregnancy.

CURE Children's Hospital of Uganda

Established in 2000 as the first pediatric neurosurgical hospital in Sub-Saharan Africa, CURE Children's Hospital of Uganda (CURE Uganda) is a specialty teaching hospital focused on treating the neurosurgical needs of children with an emphasis on hydrocephalus, neural tube defects such as spina bifida, epilepsy and brain tumors. Located in Mbale, Uganda, CURE Uganda is a 40-bed children's hospital with 100 employees including a staff of 5 doctors and 30 nurses who annually serve approximately 7,000 patients and perform 1,000 surgeries.

CURE Uganda has emerged as the global leader and center of excellence for the treatment and management of children with hydrocephalus in the developing world. **Over the past ten years, CURE Uganda has provided surgical care to over 4,500 children suffering with hydrocephalus, more than any other hospital in the world.**

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