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Hydrocephalus Treatment in Uganda: Leading the Way to Help Children

*Africa, Global Health and Human Rights Subcommittee
Excerpts of Remarks by Chairman Chris Smith
August 2, 2011*

Thank you for joining us this afternoon for this hearing on a serious – and seriously neglected - health condition, and a relatively inexpensive, technologically-sophisticated advancement for curing it, created, designed and perfected by one of our distinguished witnesses, Dr. Benjamin Warf.

I had the opportunity to learn more about hydrocephalus when I was traveling in Africa last March. Children who suffer from it characteristically have heads that are far out of proportion to the size of their small bodies. I was horrified to learn that in Africa, where superstitions still are widespread, hydrocephalus is commonly perceived as a curse or caused through witchcraft. A child may be subjected to horrific abuse, and even killed, as a result. It was therefore a real eye-opener for me to see the cultural context of hydrocephalus in Africa, and the extraordinary efforts of a number of courageous, compassionate individuals to address it.

The human brain normally produces cerebrospinal fluid which surrounds and cushions it. The fluid also delivers nutrients to and removes waste away from the brain. This fluid is drained away from the brain and absorbed into blood vessels as new fluid is produced.

Hydrocephalus occurs when this draining process no longer functions properly. The fluid levels inside the skull rise, causing increased pressure that compresses the brain and potentially enlarges the head. Symptoms include headaches, vomiting, blurred vision, cognitive difficulties, imbalance, convulsions, brain damage, and ultimately, death.

Hydrocephalus can occur in adults, but most commonly is present at birth. Our witnesses will testify that there are believed to be more than 4,000 new cases of infant hydrocephalus in

Uganda, and 100,000 to 375,000 new cases in sub-Saharan Africa, each year. By comparison, in the United States, hydrocephalus occurs in 1 out of every 500 births. Another 6,000 children under the age of 2 develop hydrocephalus annually. The U.S. National Institutes of Health estimates that 700,000 Americans have hydrocephalus, and it is the leading cause of brain surgery for children in this country.

A major difference between the United States and sub-Saharan Africa is the number of neurosurgeons available to treat this condition. The U.S. has 3,500 neurosurgeons, whereas Uganda, for instance, has only four.

Another major difference between the United States and sub-Saharan Africa is the methodology used to treat hydrocephalus. In the Western world, doctors surgically insert a shunt into the brain in order to drain the fluid through the neck and into another part of the body where the fluid can be absorbed. A shunt is only a temporary solution, and there is always a danger that any one of a number of things may go wrong. For example, the tube may become blocked, an infection may develop, catheters may break or malfunction due to calcification, or the valve may drain too much or too little fluid. In almost half of all cases, shunts fail within the first two years. And when they do, the patient must have immediate access to a medical facility and a doctor who can correct the problem.

This precarious situation must be a constant source of concern and stress for people in the United States who suffer from hydrocephalus and their families. However, in a place like sub-Saharan Africa, a shunt is fundamentally impractical. Trained neurosurgeons, as I noted, are extremely few in Africa, as are properly equipped hospitals. And roads and transportation systems on the African continent make travel arduous and long for the vast majority of people under even the best of circumstances. A hydrocephalic child in a place like Uganda, even if he or she could be treated with a shunt, would have little hope of living for more than a couple of years.

In March of this year, I had the privilege of meeting Dr. John Mugamba, one of the four neurosurgeons in Uganda. With the help of a video such as we will be viewing during this hearing, Dr. Mugamba explained the fascinating surgical procedure that he is performing several times daily in Uganda to cure small children of hydrocephalus. This treatment being provided at CURE Children's Hospital of Uganda is not only overcoming a medical barrier that children afflicted with the condition face; it is also serving to educate Ugandan communities that the condition is not the result of a curse and is not a reason to kill the child. Parents whose children have been cured are helping other parents to identify the condition early in an infant's life, and to know where to go for treatment.

One of our witnesses, Dr. Benjamin Warf, was the first to identify neonatal infection as the chief cause of pediatric hydrocephalus in a developing country. He also developed the new surgical technique, a combined endoscopic third ventriculostomy with bilateral choroid plexus cauterization (ETV/CPC), which holds great promise not only for the children of Africa but potentially for children in developed countries as well. As Dr. Warf will soon testify, hydrocephalus has never been a public health priority in developing countries. Most infants in Africa do not receive treatment, and even when treated, they often succumb to a premature death

or suffer severe disabilities. It is imperative that we find the causes in order to develop public health prevention strategies.

I am very pleased to welcome our distinguished witnesses who will explain this innovative procedure, efforts being undertaken to determine the causes of hydrocephalus, and initiatives to end the suffering caused by this life-threatening condition. I plea with all stakeholders who care about the children of Africa, including African Ministries of Health, non-governmental organizations, and our own U.S. Agency for International Development, to urgently provide tangible support to these efforts and initiatives.