

# WRITTEN STATEMENT

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**Committee:** House Committee on Foreign Affairs  
(Subcommittee on Global Health, Global Human Rights  
and International Organizations)

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**Title:** Meeting the Challenges of Global Brain Health: Diagnosis and Treatment  
for the 21st Century

## **Introduction**

Chairman Smith, Congressman Wild, and honored members of the committee, it is a privilege to be here.

Hydrocephalus is a common childhood condition that can be devastating or even fatal. The good news is that it can be treated. The bad news is that children in much of the world get suboptimal or no treatment.

## **Definition of hydrocephalus**

The normal brain contains fluid-filled spaces called ventricles that communicate with the fluid space outside the brain. Anything that disrupts this circulation pattern can cause the fluid (called CSF) to accumulate within the ventricles, which then enlarge under pressure. That is hydrocephalus.

## **Causes of hydrocephalus**

There are many causes of infant hydrocephalus, some being congenital, and others resulting from another condition. In resource-poor countries, the two most common causes are neonatal infection and neural tube defects (commonly referred to as spina bifida), which together account for about two-thirds of all cases. Thus, a great deal of hydrocephalus could be prevented by reducing the incidence of neonatal infections and neural tube defects.

## **Prevalence of hydrocephalus**

Hydrocephalus is the most common condition treated by pediatric neurosurgeons, with close to one-half million new cases per year; but it is tragically most common among those children who have the least access to treatment. The incidence of congenital hydrocephalus is highest in Africa and Latin America (145 and 316 per 100,000 births, respectively) and lowest in the United States and Canada (68 per 100,000 births). Including cases related to neonatal infection and neural tube defects, the annual case volume in resource-poor countries is more than 20 times that for high-income countries.

## **Consequences of hydrocephalus**

Infant hydrocephalus, whatever its cause, results in expansion of the brain's ventricles, which stretch and compress the surrounding brain tissue, causing mechanical injury and decreased blood flow. The head enlarges dramatically, and the child suffers from progressive symptoms. About half will die within two years and survivors have severe neurocognitive disabilities, spasticity, and blindness.

## **Economic impact of hydrocephalus and its treatment**

Untreated hydrocephalus is also costly. The estimated annual economic burden of untreated infant hydrocephalus in sub-Saharan Africa is between \$1.4 and \$56 billion USD using the value of a statistical life approach, and the estimated benefit-to-cost ratio for treatment is more than 7 to 1.

## **Treatment of hydrocephalus**

The standard and most widely practiced treatment for infant hydrocephalus is to implant a tube, called a shunt, that allows CSF to escape from the brain's ventricles into the abdominal cavity. But 60% of shunts fail at least once within the first 4 years and the risk of failure, which can be life-threatening, never ends.

A minimally invasive endoscopic brain operation called ETV/CPC, can permanently treat infant hydrocephalus without the need for a shunt in 2 out of 3 infants, and has been shown to be at least as safe and effective as shunts, and with a far lower risk of infection. But unlike shunts, that can fail repeatedly over a lifetime, virtually no ETV/CPC treatment failures will occur after the first 6 months.

This procedure was originally developed and validated in Uganda with the support of funding from USAID and NIH. Its subsequent adoption by major pediatric centers in the US demonstrates how Federal funding of projects abroad can benefit US citizens.

### **The situation in low resource countries**

Countries with the highest volume of hydrocephalus have the fewest neurosurgeons, with around 330 pediatric neurosurgeons caring for a population of 1.2 billion children in low-resource countries, where shunt-dependence is more dangerous. Children with shunt failure and no access to emergency surgery often die. Therefore, training and equipping these neurosurgeons to perform ETV/CPC will substantially reduce the number of shunts placed and save lives, while also reducing the number of repeated shunt revision operations on an over-burdened neurosurgical workforce.

### **NeuroKids**

NeuroKids is a non-profit organization that uniquely focuses on training and equipping these neurosurgeons to perform ETV/CPC using a combination of on-site training in their home institution and subsequent remote mentoring that employs virtual presence technology during surgery. We prioritize partnerships with neurosurgeons in high-volume referral centers and subsequently leverage their training by adding them to our growing international team of neurosurgical mentors. NeuroKids currently works with partner sites in 13 countries of Latin America, Africa, the Middle East, and Southeast Asia.

### **Conclusion**

More funding is needed to accelerate the elimination of untreated pediatric hydrocephalus and to minimize life-threatening shunt-dependence in low-resource countries, thus saving the lives of countless children. As well, public health strategies that reduce neonatal infection and neural tube defects would substantially reduce the number of children throughout the world who are affected by this condition.

Thank you.

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