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113TH CONGRESS
1ST SESSION

H. R. 3525

To amend the Foreign Assistance Act of 1961 to provide assistance for the treatment of hydrocephalus in children in developing countries, to train surgeons and other medical practitioners in innovative methods to treat and cure hydrocephalus, to fund related research, and for other purposes.

IN THE HOUSE OF REPRESENTATIVES

NOVEMBER 18, 2013

Mr. SMITH of New Jersey introduced the following bill; which was referred to the Committee on Foreign Affairs

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A BILL

To amend the Foreign Assistance Act of 1961 to provide assistance for the treatment of hydrocephalus in children in developing countries, to train surgeons and other medical practitioners in innovative methods to treat and cure hydrocephalus, to fund related research, and for other purposes.

Be it enacted by the Senate and House of Representatives of the United States of America in Congress assembled,

SECTION 1. SHORT TITLE.

This Act may be cited as the ''International Hydrocephalus Treatment and Training Act''.

SEC. 2. FINDINGS.

Congress finds the following:

(1) Hydrocephalus, also known as ''water on the brain'', is a medical condition in which an abnormal accumulation of cerebrospinal fluid in the ventricles or cavities of the brain causes increased intracranial pressure inside the skull and progressive enlargement of the head.

(2) If left untreated, hydrocephalus leads to physical and mental disabilities and eventually death.

(3) Hydrocephalus is an extremely painful condition that most commonly occurs in infants and young children as a result of a congenital abnormality (anatomic abnormality, aqueductal stenosis, spina bifida or encephalocele), or post-infectious hydrocephalus (PIH) caused by infections acquired after birth, such as meningitis, that attack the brain.

(4) PIH is the most common cause of hydrocephalus globally, accounting for approximately 60 percent of all cases.

(5) Three to five out of every 1,000 newborns in developing countries are either born with hydrocephalus or acquire it due to neonatal infections in the first few months of life.

(6) It is conservatively estimated that more than 300,000 children are born with or acquire hydrocephalus in the developing world each year.

(7) Children with hydrocephalus who are not effectively treated or who are not treated in the early stages of the condition suffer from cognitive deficiencies or physical disabilities or both.

(8) Families of children who have hydrocephalus in developing countries rarely know that it is a treatable condition, where to go for treatment, or how to care for a child suffering from the condition.

(9) Many children with hydrocephalus in developing countries are abandoned, ostracized, or abused due to their appearance and physical and mental disabilities.

(10) Hydrocephalus can be treated, and advances in innovative medical procedures such as ETV/CPC have the potential to save thousands of lives annually and prevent or mitigate physical and mental disabilities in thousands of children in developing countries.

(11) The current standard treatment for hydrocephalus is the VP shunt which often requires up to 5 surgical revisions before a child reaches adulthood

to remedy blockages in the shunt and to account for the child's growth. Blockages can be expected during the life of the patient and can lead to death, particularly in developing countries where access to the requisite medical expertise often is not available.

(12) Due to the need for multiple replacements of a VP shunt, this treatment is expensive and creates an increased burden on fragile health systems, patients, and families.

(13) ETV/CPC is a shunt-less surgery for hydrocephalus that does not require a VP shunt and has been shown to be appropriate in at least two-thirds of the cases of infants with hydrocephalus. Of those cases, ETV/CPC is 93 percent effective in eliminating hydrocephalus.

(14) Few hospitals with the expertise and capacity to treat hydrocephalus exist in developing countries, and the demand for treatment far exceeds the capacity of health systems in those countries.

(15) Neurosurgical care for hydrocephalus in developing countries is widely unavailable due to a lack of trained neurosurgeons. In East Africa, there is only 1 neurosurgeon per 10,000,000 people. In many developing countries there are no trained neurosurgeons.

(16) Hundreds of thousands of cases of hydrocephalus in children in developing countries could be successfully treated if adequate resources are devoted to training surgeons in new techniques, such as ETV/CPC, and many future cases could be prevented if adequate resources are devoted to research means to mitigate the preventable causes of hydrocephalus.

(17) Adoption of innovative new techniques to treat hydrocephalus, such as ETV/CPC, are more cost effective in the long term than current treatment methods since only one surgery is required in most cases, thus limiting the impact on overburdened health systems in developing countries.

SEC. 3. ASSISTANCE TO TREAT HYDROCEPHALUS AND TRAIN SURGEONS.

Chapter 1 of part I of the Foreign Assistance Act of 1961 (22 U.S.C. 2151 et. seq.) is amended—

(1) by redesignating the second section 135 (as added by section 5(a) of the Senator Paul Simon Water for the Poor Act of 2005 (Public Law 109–121; 119 Stat. 2536)) as section 136; and

(2) by adding at the end the following:

"SEC. 137. ASSISTANCE TO TREAT HYDROCEPHALUS AND TRAIN SURGEONS.

''(a) PURPOSES.—The purposes of assistance authorized by this section are—

''(1) to ensure that life-saving treatment of hydrocephalus is an important priority of United States bilateral foreign assistance, including through promotion of innovative treatments and training of medical practitioners from the developing world in the latest treatment protocols and best practices for the treatment of hydrocephalus, including—

''(A) surgery and post-surgery care in developing countries;

''(B) the creation of a comprehensive hydrocephalus training program based in the developing world for surgeons and key members of their medical team; and

''(C) the training of medical practitioners based in the developing world in ETV/CPC and other appropriate treatment protocols; and

''(2) to promote research to reduce the incidence of PIH epidemiology, pathophysiology, and disease burden, and to improve treatment of hydrocephalus.

''(b) AUTHORIZATION.—To carry out the purposes of subsection (a), the President is authorized to provide as-

sistance to support a network of trained medical practitioners to treat hydrocephalus in children at pediatric hospitals and hydrocephalus treatment centers in developing countries with a high incidence of hydrocephalus.

''(c) ACTIVITIES SUPPORTED.—

''(1) COMPREHENSIVE PROGRAM.—

''(A) IN GENERAL.—Assistance provided under subsection (b) shall, to the maximum extent practicable, be used to establish a comprehensive program to administer global hydrocephalus treatment and training activities utilizing a network of pediatric hospitals capable of performing endoscopic surgery in developing countries.

''(B) ADMINISTRATION.—The program described in subparagraph (A) shall be administered by healthcare executives and neurosurgeons with expertise in the treatment of hydrocephalus.

''(C) RESPONSIBILITIES.—The responsibilities of the administrators described in subparagraph (B) shall include—

''(i) developing an appropriate education and training curriculum;

''(ii) establishing quality control standards;

''(iii) instituting safety guidelines and standards; and

''(iv) developing monitoring and evaluation protocols.

''(2) TRAINING HOSPITAL.—

''(A) IN GENERAL.—Assistance provided under subsection (b) shall, to the maximum extent practicable, be used to establish a surgeon training program within a pediatric hospital based in a developing country with a high incidence of hydrocephalus with the goal of training four surgeons annually and a total of 20 surgeons over a 5-year period to treat hydrocephalus utilizing the ETV/CPC technique.

''(B) TIMELINE.—To the maximum extent practicable, the surgeon training program described in subparagraph (A) should be operational no later than 1 year after the date of enactment of this Act.

''(C) TRAINING ADMISSIONS CRITERIA.—Candidates for the surgeon training program established under subparagraph (A) shall—

''(i) have a demonstrated commitment to providing medical assistance in the developing world; and

''(ii) certify that the candidate intends to remain and practice medicine in the developing world following completion of the program.

''(D) TRAINING PROGRAM METHODOLOGY.—The surgeon training program established under subparagraph (A) shall—

''(i) be conducted by a neurosurgeon with a minimum of 3 years of full-time operating experience in the developing world;

''(ii) be a hands-on operating room experience in the developing world;

''(iii) utilize a hydrocephalus treatment protocol with an emphasis on ETV/CPC as the preferred treatment when medically appropriate; and

''(iv) require that each trainee complete a minimum of 50 ETV/CPC or ETV procedures and at least 25 VP shunt procedures.

''(3) TREATMENT CENTERS.—

''(A) IN GENERAL.—Assistance provided under subsection (b) shall, to the maximum extent practicable, be used to establish at least 20 hydrocephalus treatment centers located at public and private hospital in developing countries with a high incidence of hydrocephalus, which shall include treatment costs, endoscopy equipment and medical supplies necessary to provide ETV/CPC procedures to treat hydrocephalus.

''(B) STAFFING.—The treatment centers described in subparagraph (A) shall be staffed by—

''(i) one or more surgeons who have successfully completed the surgeon training program provided pursuant to paragraph (2); and

''(ii) a patient care administrator.

''(C) TREATMENT.—The treatment centers described in subparagraph (A) shall—

''(i) provide surgery to treat hydrocephalus in children;

''(ii) perform at least 50 hydrocephalus surgeries annually including a minimum of 25 ETV or ETV/CPC surgeries; and

''(iii) provide post-surgery care and support for the children treated in accordance with clause (i).

''(4) MEDICAL RECORDS AND DATA.—Assistance provided under subsection (b) shall, to the maximum extent practicable, include the maintenance of medical records which track patient care activities and information about the causes and incidence rates of PIH.

''(d) DEFINITIONS.—In this section:

''(1) CPC.—The term 'CPC' means choroid plexus cauterization, a surgical procedure to reduce the production of cerebrospinal fluid in the brain.

''(2) ETV.—The term 'ETV' means endoscopic third ventriculostomy, a shunt-less surgical procedure in which an opening is created in the floor of the third ventricle of the brain allowing cerebrospinal fluid to bypass any obstruction and flow directly to the basal cisterns.

''(3) ETV/CPC.—The term 'ETV/CPC' means the shunt-less surgical method for treating hydrocephalus through the combination of ETV and CPC surgical procedures.

''(4) HYDROCEPHALUS.—The term 'hydrocephalus' means a medical condition in which an ab-

normal accumulation of cerebrospinal fluid in the ventricles or cavities of the brain causes increased intracranial pressure inside the skull and progressive enlargement of the head.

''(5) MEDICAL PRACTITIONERS.—The term 'medical practitioners' means physicians, nurses and other clinicians.

''(6) PIH.—The term 'PIH' means post-infectious or acquired hydrocephalus which is the onset of hydrocephalus after birth due to the affects of an infection, such as meningitis, that has attacked the brain.

''(7) VP SHUNT.—The term 'VP shunt' means a ventriculoperitonea shunt which is a plastic tube that is regulated by a valve and surgically placed in a brain ventricle that allows the cerebrospinal fluid to flow out of the brain through the tube and into the patient's abdomen.

''(e) AUTHORIZATION OF APPROPRIATIONS.—Of the amounts made available to carry out this chapter for child survival and maternal health programs, there are authorized to be appropriated to the President such sums as may be necessary for each of the fiscal years 2014 through 2018 to carry out this section.''.

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