

114TH CONGRESS
1ST SESSION

H. R. 1468

To galvanize United States Government programs in support of brain health for global victims of autism, hydrocephalus and Alzheimer's and other forms of dementia, and for other purposes.

IN THE HOUSE OF REPRESENTATIVES

MARCH 19, 2015

Mr. SMITH of New Jersey (for himself, Mr. FATTAH, and Ms. MAXINE WATERS of California) introduced the following bill; which was referred to the Committee on Foreign Affairs, and in addition to the Committee on Energy and Commerce, for a period to be subsequently determined by the Speaker, in each case for consideration of such provisions as fall within the jurisdiction of the committee concerned

A BILL

To galvanize United States Government programs in support of brain health for global victims of autism, hydrocephalus and Alzheimer's and other forms of dementia, and for other purposes.

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

3 **SECTION 1. SHORT TITLE.**

4 This Act may be cited as the “Global Brain Health
5 Act of 2015”.

1 **SEC. 2. FINDINGS.**

2 Congress finds the following:

3 (1) The brain is the center of the human nervous system, exerting centralized control over all
4 other organs of the body.

5 (2) Abnormalities in sections of the brain—
6 namely the corpus callosum (which facilitates communication between the two hemispheres of the
7 brain), the amygdala (which affects emotion and social behavior) and the cerebellum (which is involved
8 with motor activity, balance and coordination)—usually occur during prenatal development.

9 (3) Three main brain disorders are autism, hydrocephalus and Alzheimer's and other forms of dementia.
10 They impact people in both the developed and developing world, but weigh more heavily on
11 sufferers in developing countries due to lack of effective health care, lack of access to health care or cultural influences that inhibit treatment of sufferers of
12 one of these conditions.

13 (4) Autism is a complex neurological disorder
14 that affects an individual in the areas of social interaction and communication. Because it is a spectrum
15 disorder, it affects each individual differently and to varying degrees of severity. People with autism process
16 and respond to information in unique ways. In

1 some cases, coexisting medical issues and aggressive
2 or self-injurious behavior may be present.

3 (5) The occurrence of autism spectrum dis-
4 orders (ASD) has increased during the past decade
5 from an estimated one in 500 to an estimated one
6 in 110, according to data released by the Centers for
7 Disease Control and Prevention (CDC) in December
8 2009. CDC classified as suffering from ASD chil-
9 dren whose behaviors were consistent with the
10 DSM-IV-TR criteria for Autistic Disorder,
11 Asperger Disorder, and Pervasive Developmental
12 Disorder—Not Otherwise Specified (PDD-NOS).

13 (6) The increased number of children diagnosed
14 with autism is a growing and urgent concern for
15 families, health care professionals, and educators, as
16 the health and education systems struggle to re-
17 spond to the needs of this population in a com-
18 prehensive manner.

19 (7) The prevalence of autism in developing
20 countries is also growing rapidly, and health and
21 education systems in these countries are particularly
22 ill-equipped to deal with these issues. According to
23 the World Health Organization, tens of millions of
24 individuals in Africa are affected by autism.

1 (8) Children with autism who receive intensive
2 and appropriate educational services before age 5
3 often make significant functional improvements. In
4 the United States, significant efforts are being pur-
5 sued to expand early diagnosis and the provision of
6 these services. In a report on the identification, eval-
7 uation and management of children with autism, the
8 American Academy of Pediatrics recommended in
9 November 2007 that all children should be screened
10 for autism twice by the age of two, even if they have
11 no symptoms. Early screening and services for au-
12 tism are sorely lacking in most of the developing
13 world. An opportunity exists to use United States
14 expertise to significantly aid children and families in
15 developing countries, for relatively small costs.

16 (9) Hydrocephalus, also known as “water on
17 the brain”, is a medical condition in which an abnor-
18 mal accumulation of cerebrospinal fluid in the ven-
19 tricles or cavities of the brain causes increased
20 intracranial pressure inside the skull and progressive
21 enlargement of the head. If left untreated, hydro-
22 cephalus leads to physical and mental disabilities
23 and eventually death.

24 (10) Hydrocephalus is an extremely painful
25 condition that most commonly occurs in infants and

1 young children as a result of a congenital abnor-
2 mality (anatomic abnormality, aqueductal stenosis,
3 spina bifida or encephalocele), or post-infectious hy-
4 drocephalus (PIH) caused by infections acquired
5 after birth, such as meningitis, that attack the
6 brain.

7 (11) Three to five out of every 1,000 newborns
8 in developing countries are either born with hydro-
9 cephalus or acquire it due to neonatal infections in
10 the first few months of life. It is conservatively es-
11 timated that more than 300,000 children are born
12 with or acquire hydrocephalus in the developing
13 world each year.

14 (12) Children with hydrocephalus who are not
15 effectively treated or who are not treated in the early
16 stages of the condition suffer from cognitive defi-
17 ciencies or physical disabilities or both.

18 (13) Families of children who have hydro-
19 cephalus in developing countries rarely know that it
20 is a treatable condition, where to go for treatment,
21 or how to care for a child suffering from the condi-
22 tion.

23 (14) Many children with hydrocephalus in de-
24 veloping countries are abandoned, ostracized, or

1 abused due to their appearance and physical and
2 mental disabilities.

3 (15) Hydrocephalus can be treated, and ad-
4 vances in innovative medical procedures such as
5 ETV/CPC have the potential to save thousands of
6 lives annually and prevent or mitigate physical and
7 mental disabilities in thousands of children in devel-
8 oping countries.

9 (16) A number of international studies show
10 that between 3.5 to 15 percent of all patients diag-
11 nosed with Alzheimer's or another form of dementia
12 actually have Normal Pressure Hydrocephalus. Such
13 significant incidents of misdiagnosis illustrate the
14 need for greater awareness among members of the
15 medical profession and the general public of adult
16 hydrocephalus, as well as the need for adopting a
17 holistic approach towards brain health instead of a
18 siloed one.

19 (17) Dementia is a degenerative condition
20 caused by disease of the brain—usually of a chronic
21 or progressive nature in which there is disturbance
22 of multiple higher cortical functions, including mem-
23 ory, thinking, orientation, comprehension, calcula-
24 tion, learning capacity, language and judgment. Be-

1 tween 5 to 7 percent of the world's population age
2 60 and above are estimated to have dementia.

3 (18) Dementia can be caused by various fac-
4 tors, including traumatic or localized brain injury, a
5 temporary interruption of the brain's supply of blood
6 or oxygen, infection, stroke, brain hemorrhage, pro-
7 longed seizures or even excessive alcohol use.

8 (19) According to Alzheimer's Disease Inter-
9 national, more than 44,000,000 people worldwide
10 are suffering from Alzheimer's or dementia, a figure
11 that will expand to more than 75,000,000 people by
12 2030 and more than 115,000,000 people by 2050 if
13 the current trajectory of the disease remains un-
14 changed. Globally, a new case of dementia occurs
15 every four seconds. More than 62 percent of people
16 with dementia globally live in low-to-middle income
17 countries, and by 2050 this percentage will exceed
18 70 percent.

19 (20) Alzheimer's disease and related dementias
20 impose a devastating, unsustainable and rapidly
21 growing toll on the health and fiscal well-being of
22 the United States and all countries. In 2010, the an-
23 nual global societal economic cost of Alzheimer's and
24 dementia was estimated to be \$604,000,000,000,

1 about 1 percent of the world's Gross Domestic Prod-
2 uct (GDP).

3 **TITLE I—GLOBAL AUTISM
4 ASSISTANCE**

5 **SEC. 101. GLOBAL AUTISM ASSISTANCE PROGRAM.**

6 (a) ESTABLISHMENT AND PURPOSE.—The Adminis-
7 trator for the United States Agency for International De-
8 velopment shall establish and administer a health and edu-
9 cation grant program to be known as the “Global Autism
10 Assistance Program” to—

11 (1) support activities under subsection (c)(2) by
12 nongovernmental organizations and other service
13 providers, including advocacy groups, focused on au-
14 tism in developing countries; and

15 (2) establish a “teach the teachers” program
16 under subsection (d) to train health and education
17 professionals working with children with autism in
18 developing countries.

19 (b) DESIGNATION OF ELIGIBLE REGIONS.—Not later
20 than 120 days after the date of the enactment of this Act,
21 the Administrator, in consultation with knowledgeable au-
22 tism organizations such as the World Autism Organiza-
23 tion, the Autism Society of America, and Autism Speaks,
24 shall designate not fewer than two regions in developing
25 countries that are determined to—

1 (1) require assistance in dealing with autism;

2 and

3 (2) have sufficient familiarity with issues re-
4 lated to autism to make effective use of the Global
5 Autism Assistance Program.

6 (c) SELECTION OF IMPLEMENTING NGO.—

7 (1) IN GENERAL.—Not later than 180 days
8 after the designation of eligible regions pursuant to
9 subsection (b), the Administrator shall select and
10 award a grant under this section to a nongovern-
11 mental organization with experience in autism-re-
12 lated issues to implement the Global Autism Assist-
13 ance Program through selection and awarding of
14 grants to local service providers and advocacy groups
15 focused on autism.

16 (2) ACTIVITIES.—A local service provider or ad-
17 vocacy group that receives a grant under paragraph
18 (1) may use such grant to carry out any of the fol-
19 lowing activities (including, as appropriate, the
20 translation into local languages of relevant English-
21 language publications):

22 (A) EDUCATION AND OUTREACH TO THE
23 PUBLIC.—Use public service announcements
24 and other public media to help the public be-
25 come more aware of the signs of autism so that

1 children with autism can be diagnosed and
2 treated earlier.

3 (B) SUPPORT TO FAMILIES.—Development
4 of resources for families, such as online web re-
5 source centers in local languages, dissemination
6 of materials to parents of newly diagnosed chil-
7 dren, such as information contained in the Cen-
8 ters for Disease Control and Prevention's publi-
9 cation entitled "Learn the Signs, Act Early", or
10 other suitable alternatives, and dissemination of
11 educational aids and guides to help parents
12 with their children's development.

13 (C) SUPPORT TO EDUCATIONAL INSTITU-
14 TIONS.—Funding for schools or other edu-
15 cational institutions, focusing on teachers of the
16 youngest students, and including the distribu-
17 tion of equipment or of the materials referred
18 to in subparagraph (B).

19 (D) SUPPORT TO CLINICS AND MEDICAL
20 CENTERS.—Provision of funding to clinics and
21 medical centers with proven records in address-
22 ing autism to assist with operating expenses, in-
23 cluding personnel, equipment supplies, and fa-
24 cilities, development of assessment testing for
25 autism, and acquisition of specialized equip-

1 ment, such as augmentative communication de-
2 vices.

3 (3) APPLICATIONS FOR GRANTS.—

4 (A) SUBMISSION OF APPLICATIONS.—To
5 be eligible to receive a grant from the imple-
6 menting nongovernmental organization, a local
7 service provider or advocacy group shall submit
8 to such implementing nongovernmental organi-
9 zation an application at such time, in such
10 manner, and containing such information as
11 such implementing nongovernmental organiza-
12 tion may require.

13 (B) ESTABLISHMENT OF SCREENING
14 BOARD.—

15 (i) IN GENERAL.—The implementing
16 nongovernmental organization responsible
17 for implementing the Global Autism Assis-
18 tance Program shall establish a screening
19 board to be known as the “Project Advi-
20 sory Board” to review for content and ap-
21 propriateness applications from local serv-
22 ice providers or advocacy groups submitted
23 in accordance with subparagraph (A).

24 (ii) MEMBERSHIP.—The members of
25 the Project Advisory Board shall be ap-

(II) A member of the Project Ad-
visory Board may continue to serve
after the expiration of the term of
such member until such time as a suc-
cessor is appointed.

(III) Membership of the Project
Advisory Board shall include at least seven voting members who are members of autism advocacy groups, professionals working with autism, or otherwise associated with the autism community. Among the voting members of the Board shall be at least two parents from different families of individuals with autism, one medical professional working with autism, one teacher of individuals with autism,

1 and one individual who has autism.
2 Efforts shall be made to include on
3 the Project Advisory Board individ-
4 uals with experience working in the
5 developing world.

10 (V) Membership of the Project
11 Advisory Board shall be chosen so as
12 to ensure objectivity and balance and
13 to reduce the potential for conflicts of
14 interest.

20 (d) TEACH THE TEACHERS.—The implementing non-
21 governmental organization, acting on behalf of the Admin-
22 istrator, in consultation with the Project Advisory Board,
23 shall establish a program, to be known as the “Teach the
24 Teachers Program”, to—

1 (1) identify health and education professionals
2 to receive specialized training for teaching and work-
3 ing with youth with autism, including training con-
4 ducted in two- or three-day workshops at locations
5 within one of the two regions designated pursuant to
6 subsection (b); and

7 (2) conduct training through two- or three-day
8 biomedical conferences in the two regions designated
9 pursuant to subsection (b), including bringing med-
10 ical and psychological specialists from the United
11 States to train and educate parents and health pro-
12 fessionals who deal with autism, including training
13 related to biomedical interventions that can affect
14 autism, how nutrition and various metabolic issues
15 can impact behavior, the role of applied behavioral
16 analysis, and various occupational and speech thera-
17 pies in fighting autism.

18 (e) FUNDING.—To carry out this title, the Adminis-
19 trator shall allocate amounts that have been appropriated
20 or otherwise made available to the United States Agency
21 for International Development.

22 (f) AUTISM DEFINED.—For purposes of this title, the
23 term “autism” means all conditions consistent with au-
24 tism spectrum disorders described in section 2(5).

1 **TITLE II—INTERNATIONAL HY-**
2 **DROCEPHALUS TREATMENT**
3 **AND TRAINING**

4 **SEC. 201. ASSISTANCE TO TREAT HYDROCEPHALUS AND**
5 **TRAIN SURGEONS.**

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

8 (1) by redesignating the second section 135 (as
9 added by section 5(a) of the Senator Paul Simon
10 Water for the Poor Act of 2005 (Public Law 109–
11 121; 119 Stat. 2536)) as section 136; and

12 (2) by adding at the end the following:

13 **“SEC. 137. ASSISTANCE TO TREAT HYDROCEPHALUS AND**
14 **TRAIN SURGEONS.**

15 “(a) PURPOSES.—The purposes of assistance author-
16 ized by this section are—

17 “(1) to ensure that life-saving treatment of hy-
18 drocephalus is an important priority of United
19 States bilateral foreign assistance, including through
20 promotion of innovative treatments and training of
21 medical practitioners from the developing world in
22 the latest treatment protocols and best practices for
23 the treatment of hydrocephalus, including—

24 “(A) surgery and post-surgery care in de-
25 veloping countries;

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

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

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

8 “(b) AUTHORIZATION.—To carry out the purposes of
9 subsection (a), the President is authorized to provide assistance to support a network of trained medical practitioners to treat hydrocephalus in children at pediatric hospitals and hydrocephalus treatment centers in developing
10 countries with a high incidence of hydrocephalus.

11 “(c) ACTIVITIES SUPPORTED.—

12 “(1) COMPREHENSIVE PROGRAM.—

13 “(A) IN GENERAL.—Assistance provided
14 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

1 of performing endoscopic surgery in developing
2 countries.

3 “(B) ADMINISTRATION.—The program de-
4 scribed in subparagraph (A) shall be adminis-
5 tered by health care executives and neuro-
6 surgeons with expertise in the treatment of hy-
7 drocephalus.

8 “(C) RESPONSIBILITIES.—The responsibil-
9 ties of the administrators described in subpara-
10 graph (B) shall include—

11 “(i) developing an appropriate edu-
12 cation and training curriculum;

13 “(ii) establishing quality control
14 standards;

15 “(iii) instituting safety guidelines and
16 standards; and

17 “(iv) developing monitoring and eval-
18 uation protocols.

19 “(2) TRAINING HOSPITAL.—

20 “(A) IN GENERAL.—Assistance provided
21 under subsection (b) shall, to the maximum ex-
22 tent practicable, be used to establish a surgeon
23 training program within a pediatric hospital
24 based in a developing country with a high inci-
25 dence of hydrocephalus with the goal of training

1 four surgeons annually and a total of 20 sur-
2 geons over a 5-year period to treat hydro-
3 cephalus utilizing the ETV/CPC technique.

4 “(B) TIMELINE.—To the maximum extent
5 practicable, the surgeon training program de-
6 scribed in subparagraph (A) should be oper-
7 ational no later than 1 year after the date of
8 enactment of this section.

9 “(C) TRAINING ADMISSIONS CRITERIA.—
10 Candidates for the surgeon training program
11 established under subparagraph (A) shall—

12 “(i) have a demonstrated commitment
13 to providing medical assistance in the de-
14 veloping world; and

15 “(ii) certify that the candidate intends
16 to remain and practice medicine in the de-
17 veloping world following completion of the
18 program.

19 “(D) TRAINING PROGRAM METHOD-
20 OLOGY.—The surgeon training program estab-
21 lished under subparagraph (A) shall—

22 “(i) be conducted by a neurosurgeon
23 with a minimum of 3 years of full-time op-
24 erating experience in the developing world;

1 “(ii) be a hands-on operating room ex-
2 perience in the developing world;

3 “(iii) utilize a hydrocephalus treat-
4 ment protocol with an emphasis on ETV/
5 CPC as the preferred treatment when
6 medically appropriate; and

7 “(iv) require that each trainee com-
8 plete a minimum of 50 ETV/CPC or ETV
9 procedures and at least 25 VP shunt pro-
10 cedures.

11 “(3) TREATMENT CENTERS.—

12 “(A) IN GENERAL.—Assistance provided
13 under subsection (b) shall, to the maximum ex-
14 tent practicable, be used to establish at least 20
15 hydrocephalus treatment centers located at pub-
16 lic and private hospital in developing countries
17 with a high incidence of hydrocephalus, which
18 shall include treatment costs, endoscopy equip-
19 ment and medical supplies necessary to provide
20 ETV/CPC procedures to treat hydrocephalus.

21 “(B) STAFFING.—The treatment centers
22 described in subparagraph (A) shall be staffed
23 by—

24 “(i) one or more surgeons who have
25 successfully completed the surgeon training

1 program provided pursuant to paragraph
2 (2); and

3 “(ii) a patient care administrator.

4 “(C) TREATMENT.—The treatment centers
5 described in subparagraph (A) shall—

6 “(i) provide surgery to treat hydro-
7 cephalus in children;

8 “(ii) perform at least 50 hydro-
9 cephalus surgeries annually including a
10 minimum of 25 ETV or ETV/CPC sur-
11 geries; and

12 “(iii) provide post-surgery care and
13 support for the children treated in accord-
14 ance with clause (i).

15 “(4) MEDICAL RECORDS AND DATA.—Assist-
16 ance provided under subsection (b) shall, to the
17 maximum extent practicable, include the mainte-
18 nance of medical records which track patient care
19 activities and information about the causes and inci-
20 dence rates of PIH.

21 “(d) DEFINITIONS.—In this section:

22 “(1) CPC.—The term ‘CPC’ means choroid
23 plexus cauterization, a surgical procedure to reduce
24 the production of cerebrospinal fluid in the brain.

1 “(2) ETV.—The term ‘ETV’ means endoscopic
2 third ventriculostomy, a shunt-less surgical proce-
3 dure in which an opening is created in the floor of
4 the third ventricle of the brain allowing cerebro-
5 spinal fluid to bypass any obstruction and flow di-
6 rectly to the basal cisterns.

7 “(3) ETV/CPC.—The term ‘ETV/CPC’ means
8 the shunt-less surgical method for treating hydro-
9 cephalus through the combination of ETV and CPC
10 surgical procedures.

11 “(4) HYDROCEPHALUS.—The term ‘hydro-
12 cephalus’ means a medical condition in which an ab-
13 normal accumulation of cerebrospinal fluid in the
14 ventricles or cavities of the brain causes increased
15 intracranial pressure inside the skull and progressive
16 enlargement of the head.

17 “(5) MEDICAL PRACTITIONERS.—The term
18 ‘medical practitioners’ means physicians, nurses and
19 other clinicians.

20 “(6) PIH.—The term ‘PIH’ means post-infec-
21 tious or acquired hydrocephalus which is the onset
22 of hydrocephalus after birth due to the affects of an
23 infection, such as meningitis, that has attacked the
24 brain.

1 “(7) VP SHUNT.—The term ‘VP shunt’ means
2 a ventriculoperitoneal shunt which is a plastic tube
3 that is regulated by a valve and surgically placed in
4 a brain ventricle that allows the cerebrospinal fluid
5 to flow out of the brain through the tube and into
6 the patient’s abdomen.

7 “(e) AUTHORIZATION OF APPROPRIATIONS.—Of the
8 amounts made available to carry out this chapter for child
9 survival and maternal health programs, there are author-
10 ized to be appropriated to the President such sums as may
11 be necessary for each of the fiscal years 2016 through
12 2020 to carry out this section.”.

13 **TITLE III—INTERNATIONAL ALZ-
14 HEIMER’S DISEASE AND DE-
15 MENTIA PROGRAMS**

16 **SEC. 301. GLOBAL ALZHEIMER’S DISEASE AND DEMENTIA
17 ACTION PLAN.**

18 (a) IN GENERAL.—The Secretary of Health and
19 Human Services shall enter into negotiations with the
20 World Health Organization to develop a plan for address-
21 ing Alzheimer’s Disease and other forms of dementia glob-
22 ally, to be known as the Global Alzheimer’s Disease and
23 Dementia Action Plan, focused on the following areas:

- 24 (1) Research, including—
25 (A) clinical research; and

(B) development of a stable and sustained international commitment to research.

3 (2) Regulatory issues.

4 (3) Clinical care.

(4) Supportive services for patients and caregivers, including supports using innovative technologies.

8 (5) Clinical care.

9 (6) Supportive services for patients and care-
10 givers, including supports using innovative tech-
11 nologies.

12 (7) Prevention and health promotion.

17 (b) INTERNATIONAL PARTNERSHIPS.—

18 (1) IN GENERAL.—In developing the plan under
19 subsection (a), the Secretary of Health Services—

20 (A) shall seek—

21 (i) to enter into partnerships with
22 other nations that have in place national
23 plans for addressing Alzheimer's disease
24 and other forms of dementia; and

19 SEC. 302. GLOBAL ALZHEIMER'S DISEASE AND DEMENTIA
20 FUND.

21 (a) IN GENERAL.—The Secretary of Health and
22 Human Services, working with the Secretary of the Treas-
23 ury, other nations, nongovernmental organizations, and
24 private entities, shall seek to establish a fund, to be known
25 as the Global Alzheimer’s Disease and Dementia Fund,

1 to provide resources to support implementation of the
2 Global Alzheimer's Disease and Dementia Action Plan.

3 (b) EARLY-STAGE EFFORTS.—In the early stages of
4 carrying out subsection (a), the Secretary of Health and
5 Human Services shall establish priority areas of focus and
6 a governance structure for the Global Alzheimer's Disease
7 and Dementia Fund.

8 **SEC. 303. ALZHEIMER'S DISEASE AND DEMENTIA COORDI-
9 NATOR.**

10 The President shall appoint a high-level official to
11 lead and coordinate all efforts of the Federal Government
12 with respect to developing the Global Alzheimer's Disease
13 and Dementia Action Plan and the Global Alzheimer's
14 Disease and Dementia Fund.

15 **SEC. 304. FOREIGN AID IMPLICATIONS.**

16 The Administrator of the United States Agency for
17 International Development, in collaboration with the heads
18 of other relevant Federal departments and agencies,
19 shall—

20 (1) investigate the foreign aid implications of
21 Alzheimer's disease and other forms of dementia;
22 and

23 (2) inform Congress as to the need for possible
24 changes to health care-related foreign assistance.

1 SEC. 305. PUBLIC-PRIVATE PARTNERSHIPS.

2 The President shall encourage and facilitate partner-
3 ships between the Federal Government and the private
4 sector, such as the partnerships in effect between the Na-
5 tional Institutes of Health and pharmaceutical companies,
6 to identify new approaches to treat Alzheimer's disease
7 and other forms of dementia.

