105TH CONGRESS 2D SESSION

H. R. 3661

To require the Secretary of Veterans Affairs and the Secretary of Defense to give greater priority to research on the exposure of veterans of Operation Desert Shield and Operation Desert Storm to biological agents or chemical weapons, other toxic agents such as depleted uranium and organophosphates, pyridostigmine bromide, vaccines, oil well fire pollution, and other potentially hazardous substances, to require the Director of the National Institutes of Health to monitor, through a comprehensive database, the resulting effects of such exposure on those veterans' health and their clinical progress in order to identify and provide appropriate and effective medical treatment, and for other purposes.

IN THE HOUSE OF REPRESENTATIVES

APRIL 1, 1998

Mr. Kennedy of Massachusetts (for himself, Mr. Shays, Mr. Filner, Mr. Quinn, Mr. Moakley, Mr. Sanders, Mr. Gutierrez, Mr. Peterson of Minnesota, Ms. Brown of Florida, Ms. Carson, Mr. Olver, Ms. Rivers, Mr. Markey, Mr. Frank of Massachusetts, Mr. Kennedy of Rhode Island, Mr. Neal of Massachusetts, Mr. Waxman, Mr. McGovern, Mr. Burton of Indiana, Mr. Tierney, Mrs. Maloney of New York, Mr. Delahunt, Mr. Lantos, Mr. Underwood, Mr. Romero-Barceló, Mr. Clement, Mr. Frost, Ms. Slaughter, Mr. Moran of Virginia, Mr. Hastings of Florida, Mr. McIntosh, Mr. Meehan, Mr. Rodriguez, Mr. Davis of Illinois, and Ms. Velázquez) introduced the following bill; which was referred to the Committee on Veterans' Affairs, and in addition to the Committees on National Security, 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 require the Secretary of Veterans Affairs and the Secretary of Defense to give greater priority to research

on the exposure of veterans of Operation Desert Shield and Operation Desert Storm to biological agents or chemical weapons, other toxic agents such as depleted uranium and organophosphates, pyridostigmine bromide, vaccines, oil well fire pollution, and other potentially hazardous substances, to require the Director of the National Institutes of Health to monitor, through a comprehensive database, the resulting effects of such exposure on those veterans' health and their clinical progress in order to identify and provide appropriate and effective medical treatment, and for other purposes.

- 1 Be it enacted by the Senate and House of Representa-
- 2 tives of the United States of America in Congress assembled,
- 3 SECTION 1. SHORT TITLE; TABLE OF CONTENTS.
- 4 (a) SHORT TITLE.—This Act may be cited as the
- 5 "Persian Gulf War Veterans' Health and Medical Re-
- 6 search Act of 1998".
- 7 (b) Table of Contents.—
 - Sec. 1. Short title; table of contents.
 - Sec. 2. Management by National Institutes of Health of research on illnesses of Gulf War veterans.
 - Sec. 3. Database for tracking the health status, clinical progress, and medical treatment of Gulf War veterans.
 - Sec. 4. Semiannual report on research programs.
 - Sec. 5. General Accounting Office annual assessment and report.
 - Sec. 6. Research protocol and training.
 - Sec. 7. Outreach.
 - Sec. 8. Definitions.
- 8 SEC. 2. MANAGEMENT BY NATIONAL INSTITUTES OF
- 9 HEALTH OF RESEARCH ON ILLNESSES OF
- 10 GULF WAR VETERANS.
- 11 (a) National Institutes of Health.—The Direc-
- 12 tor of the National Institutes of Health shall establish and

- 1 manage research activities within the Department of De-
- 2 fense and Department of Veterans Affairs in order to en-
- 3 sure that a greater priority is given to—
- 4 (1) research on finding effective treatment for 5 ill Gulf War veterans; and
- 6 (2) research on exposure to all potentially haz-7 ardous substances and diseases encountered by 8 members of the Armed Forces mobilized or deployed 9 in support of combat operations in the areas of re-10 sponsibility of the United States Central Command 11 and the United States European Command during 12 the period beginning on August 2, 1990, and ending 13 on December 31, 1991, including (among others) 14 chemical and biological warfare agents, 15 pyridostigmine bromide, vaccinations, and any other 16 manmade or naturally occurring toxic substances or 17 disease vectors to which Gulf War veterans were ex-18 posed.
- 19 (b) RESEARCH TIMETABLE.—The Director shall de-20 velop a plan for the research to be carried out pursuant 21 to subsection (a). The Director shall begin to develop the 22 plan not later than 60 days after the date of the enact-23 ment of this Act and shall implement the plan not later 24 than 60 days after the completion of the development of 25 the plan.

- 1 (c) Identification of Substances to Which
- 2 VETERANS MAY HAVE BEEN EXPOSED.—Research to be
- 3 carried out pursuant to subsection (a) shall include identi-
- 4 fication of all potentially hazardous substances, natural or
- 5 manmade (including biological or chemical agents, other
- 6 toxic agents (including, among others, depleted uranium
- 7 and organophosphates), pyridostigmine bromide, and vac-
- 8 cines), to which members of the Armed Forces may have
- 9 been exposed by reason of service in the areas of respon-
- 10 sibility of the United States Central Command and the
- 11 United States European Command during the period be-
- 12 ginning on August 2, 1990, and ending on December 31,
- 13 1991.
- 14 (d) IDENTIFICATION OF ILLNESSES.—Research to be
- 15 carried out pursuant to subsection (a) shall include identi-
- 16 fication of all illnesses (diagnosed and undiagnosed) that
- 17 Gulf War veterans are experiencing. The Director shall re-
- 18 view and summarize the relevant scientific evidence re-
- 19 garding the occurrence of such illnesses among Gulf War
- 20 veterans and among other populations considered appro-
- 21 priate for comparison. Matters to be reviewed and com-
- 22 pared with respect to those illnesses include symptoms,
- 23 mortality rates, and reproductive health problems (includ-
- 24 ing birth defects).

1	(e) List of Chronic Illnesses That Provide
2	VALID MODELS OF SUCCESSFUL TREATMENT.—As part
3	of the management of research under this section, the Di-
4	rector shall compile a list of chronic illnesses for which
5	valid models of successful treatment are provided, as iden-
6	tified by—
7	(1) scientific data and literature;
8	(2) the views of Gulf War veterans of the effi-
9	cacy of the treatment;
10	(3) the views of private-sector medical special-
11	ists involved in researching Gulf War illnesses; and
12	(4) the views of private-sector medical clinicians
13	treating Gulf War veterans.
14	(f) Interagency Agreements.—The Secretary of
15	Defense and the Secretary of Veterans Affairs shall each
16	enter into an agreement with the Secretary of Health and
17	Human Services to provide for the implementation of this
18	section. The agreements shall ensure that the Director of
19	the National Institutes of Health has the authority nec-
20	essary to carry out the responsibilities of the Director
21	under this section.
22	SEC. 3. DATABASE FOR TRACKING THE HEALTH STATUS,
23	CLINICAL PROGRESS, AND MEDICAL TREAT-
24	MENT OF GULF WAR VETERANS.
25	(a) Establishment of the Database.—

- 1 (1) ESTABLISHMENT.—The Director of the Na2 tional Institutes of Health shall establish a single
 3 comprehensive database and monitoring system for
 4 the collection, storage, and analysis of data covering
 5 all Gulf War veterans in order to monitor the health
 6 status and clinical progress of those veterans for the
 7 purpose of identifying appropriate and effective
 8 treatment needed to improve their health.
 - (2) SEPARATE TRACKING FOR VETERANS RE-CEIVING MEDICAL CARE.—In the database under paragraph (1), the Director shall identify and track separately those Gulf War veterans who—
 - (A) are receiving medical care from the Secretary of Veterans Affairs;
 - (B) are receiving medical care from the Secretary of Defense; and
 - (C) are receiving medical care in the private sector.
 - (3) Public availability of information in Database.—With the exception of information protected under section 552b of title 5, United States Code (popularly known as the "Privacy Act"), information in the database shall be made available to the public through the Internet World Wide Web and other appropriate electronic and printed means.

1	(4) REQUIRED CONSULTATION.—The Director
2	shall establish the database in consultation with the
3	Secretary of Veterans Affairs and the Secretary of
4	Defense.
5	(5) Authorization of appropriations.—
6	There are authorized to be appropriated such sums
7	as may be necessary to establish and carry out the
8	database under paragraph (1).
9	(b) Matters To Be Included in Database.—The
10	database shall include—
11	(1) all diagnosed and undiagnosed illnesses.
12	symptoms, and syndromes of Gulf War veterans, in-
13	cluding fibromyalgias, rheumatic ailments, skin ul-
14	cers, sinus diseases, gastrointestinal or digestive dis-
15	eases (especially Crohn's colitis, ulcerative colitis
16	and inflammatory bowel disorders), respiratory dis-
17	eases, neurocognitive disorders, kidney stones, repro-
18	ductive illnesses, abnormalities, and birth defects;
19	(2) relevant medical data on illnesses reported
20	by the spouses and children of Gulf War veterans
21	including, among other matters, reports of reproduc-
22	tive illnesses, abnormalities, and birth defects since
23	1990; and
24	(3) the medical treatment provided Gulf War
25	veterans for—

1	(A) any undiagnosed illness; and
2	(B) any illness for which the Director of
3	the National Institutes of Health (pursuant to
4	section 2) identified a valid model of treatment.
5	(c) Tracking Capacity.—The database shall be de-
6	veloped so that it has the capacity to track and analyze—
7	(1) the illnesses referred to in subsection $(b)(1)$;
8	(2) the treatments referred to in subsection
9	(b)(3); and
10	(3) the progress of the treatments as viewed by
11	Gulf War veterans.
12	(d) Data To Be Included.—The database shall in-
13	clude the following:
14	(1) Information in the Persian Gulf War Veter-
15	ans Health Registry established under section 702 of
16	the Persian Gulf War Veterans' Health Status Act
17	(title VII of Public Law 102–585; 38 U.S.C. 527
18	note).
19	(2) Information in the Comprehensive Clinical
20	Evaluation Program for Veterans established under
21	section 734 of the National Defense Authorization
22	Act for Fiscal Years 1992 and 1993 (10 U.S.C.
23	1074 note).
24	(3) Information derived from other examina-
25	tions and treatment provided to veterans who served

- in the Southwest Asia theater of operations during the period specified in section 8(1).
- (4) Information derived from other examinations and treatment provided current members of
 the Armed Forces (including members on active
 duty and members of the reserve components) who
 served in that theater of operations during that period.
 - (5) Information derived from other examinations and treatment provided to Gulf War veterans who receive medical care in the private sector.
 - (6) Information derived from physicians' Current Procedure Terminology (CPT) and the Department of Health and Human Services-approved International Classification of Diseases with Clinical Modification (ICD-9-CM) codes in the Persian Gulf veterans' medical charges and medical bills, from any medical treatments and examinations provided to Persian Gulf veterans, even if they are not registered in the registry referred to in paragraph (1) and are not covered by the Comprehensive Clinical Evaluation Program for Veterans referred to in paragraph (2).
 - (7) Information pertaining to causes of death, health claims, and diagnoses of Gulf War veterans

- 1 contained in the Department of Veterans Affairs'
- 2 Beneficiary Identification and Records Locator Sub-
- 3 system (BIRLS).

18

(8) Such other information as the Secretary of Veterans Affairs or the Secretary of Defense consid-5 6 ers appropriate for inclusion in the database, includ-7 ing information regarding persons who underwent 8 preparations to deploy to the Southwest Asia theater

of operations but were not deployed.

- 10 (9) Such other information as the Director of 11 the National Institutes of Health, based upon the 12 advice of health professionals, scientists, and epi-13 demiologists, considers appropriate for inclusion in 14 the database, including information regarding per-15 sons who underwent preparations to deploy to the 16 Southwest Asia theater of operations but were not 17 deployed.
- (e) Implementation of Database.—(1) Not later than 90 days after the date of the enactment of this Act, 19 20 the Director of the National Institutes of Health shall sub-21 mit for comment and evaluation a plan for the develop-22 ment of the database to the following:
- 23 (A) The Comptroller General.
- 24 (B) The designated congressional committees.

- 1 (C) Representatives of Gulf War veterans, in-
- 2 cluding (among others) the veterans' service organi-
- 3 zations, with special emphasis on those organizations
- 4 formed on behalf of Persian Gulf veterans.
- 5 (2) The Director of the National Institutes of Health
- 6 shall modify the database plan according to the evalua-
- 7 tions received from the entities specified in subparagraphs
- 8 (A), (B), and (C) of paragraph (1) and shall, not later
- 9 than 60 days after receiving the evaluations, implement
- 10 the plan as modified.
- 11 (3) The Director shall carry out paragraphs (1) and
- 12 (2) in consultation with the Secretary of Veterans Affairs
- 13 and the Secretary of Defense.
- 14 (4) The database shall become operational no later
- 15 than six months after the date of the enactment of this
- 16 Act.
- 17 (f) Compilation and Analysis of Information
- 18 IN DATABASE.—The Director of the National Institutes
- 19 of Health shall compile and analyze, on an ongoing basis,
- 20 all clinical data in the database under subsection (a) that
- 21 is likely to be scientifically useful in determining the asso-
- 22 ciation, if any, between the illnesses (including diagnosed
- 23 illnesses and undiagnosed illnesses) of Gulf War veterans
- 24 covered by such data and exposure to biological or chemi-
- 25 cal agents, other toxic agents (including depleted uranium

1	and organophosphates), pyridostigmine bromide, vaccines,
2	and any other potentially hazardous substance.
3	(g) Annual Report.—Not later than January 31
4	of each year after the database is operational, the Director
5	of the National Institutes of Health shall submit to the
6	designated congressional committees a report contain-
7	ing—
8	(1) with respect to the data compiled in accord-
9	ance with subsection (b) during the preceding year—
10	(A) an analysis of the data;
11	(B) a discussion of the types, incidence,
12	and prevalence of the disabilities and illnesses
13	identified through such data;
14	(C) an explanation for the incidence and
15	prevalence of such disabilities and illnesses;
16	(D) other reasonable explanations for the
17	incidence and prevalence of such disabilities and
18	illnesses; and
19	(E) an analysis of the scientific validity of
20	drawing conclusions from the incidence and
21	prevalence of such disabilities and illnesses, as
22	evidenced by such data, about any association
23	between such disabilities and illnesses, as the
24	case may be, and exposure to biological or
25	chemical agents, other toxic agents (including

1	depleted uranium and organophosphates),
2	pyridostigmine bromide, vaccines, and any other
3	potentially hazardous substance; and
4	(2) with respect to the most current informa-
5	tion regarding treatment models identified under
6	section 2(e)—
7	(A) an analysis of the information;
8	(B) the results of any consultation between
9	such Secretaries regarding the implementation
10	of such treatment models in the health care sys-
11	tems of the Department of Veterans Affairs
12	and the Department of Defense; and
13	(C) in the event either such Secretary de-
14	termines not to implement such treatment mod-
15	els, an explanation for such determination and
16	the views of the Director of the National Insti-
17	tutes of Health regarding such determination.
18	SEC. 4. SEMIANNUAL REPORT ON RESEARCH PROGRAMS.
19	The Secretary of Defense and Secretary of Veterans
20	Affairs shall submit to the designated congressional com-
21	mittees a semiannual joint report on their research
22	progress concerning the health of Gulf War veterans and
23	the health status of the veterans being tracked in the data-
24	base under section 3.

1	SEC. 5. GENERAL ACCOUNTING OFFICE ANNUAL ASSESS-
2	MENT AND REPORT.
3	(a) Annual Assessments.—(1) The Comptroller
4	General shall carry out—
5	(A) an assessment each year of the establish-
6	ment and management of research during the pre-
7	ceding calendar year by the Director of the National
8	Institutes of Health under section 2;
9	(B) an assessment each year to determine
10	whether the Secretary of Veterans Affairs and the
11	Secretary of Defense are effectively and efficiently
12	allocating funds toward research protocols required
13	by the Director of the National Institutes of Health;
14	and
15	(C) an assessment each year of the establish-
16	ment, maintenance, and use during the preceding
17	calendar year of the database established under sec-
18	tion 3.
19	(2) If the Comptroller General finds under paragraph
20	(1)(B) that funds are not being allocated according to the
21	Director's guidelines, the Comptroller General shall make
22	recommendations to the Congress to reappropriate funds
23	or to take such other action as is appropriate and nec-
24	essary to ensure that the research protocols are carried
25	out. The recommendations of the Comptroller General

- 1 shall be stated each year in the annual report under sub-
- 2 section (b).
- 3 (b) Report.—Not later than March 15 each year,
- 4 the Comptroller General shall submit to the designated
- 5 congressional committees a report on the assessments
- 6 under subsection (a) for the preceding calendar year.

7 SEC. 6. RESEARCH PROTOCOL AND TRAINING.

- 8 (a) Treatment Protocols.—The Director of the
- 9 National Institutes of Health shall review the research
- 10 findings under section 2, and the database findings under
- 11 section 3, as those findings become available or not less
- 12 often than annually. The purpose of those reviews shall
- 13 be to develop new treatment protocols for individual and
- 14 multiple toxic exposures. The Director shall provide the
- 15 treatment protocols so developed—
- 16 (1) to the Secretary of Veterans Affairs and the
- 17 Secretary of Defense, who shall ensure that those
- protocols are made available to attending physicians
- in their respective departments; and
- 20 (2) to attending physicians in the private sector
- as provided in section 7(d)(1).
- 22 (b) Training Program.—
- 23 (1) IN GENERAL.—The Director of the National
- Institutes of Health shall provide a program of
- training for physicians of the Department of Veter-

- ans Affairs and Department of Defense to train those physicians in treatment protocols for persons exposed to acute and low-level toxic substances. The Director shall carry out the program through the Director of the National Institute of Environmental Health Sciences.
 - (2) Training entity.—The training program shall be conducted by an appropriate entity outside the Government which is experienced in treating persons exposed to toxic substances.
 - (3) Content of Program.—The Director shall ensure that the training program includes training for the entire range of medical and scientific disciplines in the course curricula as they pertain to diagnosing and treating individual and multiple toxic exposures, with special emphasis placed on understanding the effects of repeated low-level exposures to single and multiple toxic substances.
 - (4) Goal for training.—The Secretary of Veterans Affairs and the Secretary of Defense shall seek to ensure that not less than 15 percent of the attending physicians within their respective departments participate in the training program.
 - (5) TIMETABLE FOR PROGRAM.—The training program shall be implemented not later than one

- 1 year after the date of the enactment of this Act. Not
- 2 later than 90 days after the date of the enactment
- of this Act, the Director shall identify the course
- 4 content for the training program and not later than
- 5 30 days thereafter shall issue a request for proposals
- 6 for a contract for the training program. The Direc-
- 7 tor shall enter into such a contract not later than
- 8 120 days after issuing the request for proposals.
- 9 (c) Renewal of Training Program.—Whenever
- 10 the Director determines that there have been new research
- 11 results that warrant additional training as described in
- 12 subsection (b), the Director shall provide for an additional
- 13 training program to be made available in the same manner
- 14 as provided in subsection (b).
- 15 (d) CONTINUING EDUCATION PROGRAM.—The Direc-
- 16 tor shall ensure that the training program contains a con-
- 17 tinuing education component in order to provide training
- 18 for new attending physicians of the Department of Veter-
- 19 ans Affairs and the Department of Defense.
- 20 (e) Reimbursement.—A training program under
- 21 this section shall be conducted on a reimbursable basis.
- 22 SEC. 7. OUTREACH.
- 23 (a) Outreach Program by Director of Na-
- 24 TIONAL INSTITUTES OF HEALTH.—

1	(1) REQUIRED OUTREACH PROGRAM.—The Di-
2	rector of the National Institutes of Health shall
3	carry out an ongoing program to provide Gulf War
4	veterans the information described in subsection (c).
5	(2) REQUIRED CONSULTATION.—The Director
6	shall carry out the outreach program in consultation
7	with—
8	(A) the Secretary of Veterans Affairs and
9	the Secretary of Defense; and
10	(B) representatives of Gulf War veterans.
11	(b) Ombudsman.—
12	(1) In general.—As part of the outreach pro-
13	gram under subsection (a), the Director shall estab-
14	lish an ombudsman program to facilitate addressing
15	complaints of Gulf War veterans regarding treat-
16	ment for health risks described in subsection $(c)(1)$.
17	(2) Authorization of appropriations.—
18	There are authorized to be appropriated such sums
19	as may be necessary to carry out the ombudsman
20	program under paragraph (1).
21	(c) Covered Information.—Information under
22	this subsection is information relating to—
23	(1) the health risks, if any, resulting from expo-
24	sure to biological or chemical agents, other toxic
25	agents (including depleted uranium and

- 1 organophosphates), pyridostigmine bromide, vac-
- 2 cines, and any other potentially hazardous substance
- due to service in, or mobilization in support of, com-
- 4 bat operations in the areas of responsibility of the
- 5 United States Central Command and the United
- 6 States European Command during the period begin-
- 7 ning on August 2, 1990, and ending on December
- 8 31, 1991; and
- 9 (2) any health services, medical care, or bene-
- fits that are or become available with respect to such
- 11 health risks.
- 12 (d) Public Availability of Research Find-
- 13 INGS.—
- (1) Public availability.—The Director of
- the National Institutes of Health shall ensure that
- all research findings from research activities covered
- by this Act, and all treatment protocols developed
- pursuant to section 6, are made available to the pub-
- lic through the Internet World Wide Web, peer-re-
- viewed medical journals, and other appropriate medi-
- cal channels. The Director shall publish reliable, rel-
- evant, and objective medical data regarding diseases
- of Gulf War veterans. Peer review of that research
- shall include at least one representative from each of
- 25 the veterans' service organizations.

1	(2) REQUIRED CONSULTATION.—The Director
2	shall carry out paragraph (1) in consultation with
3	the Secretary of Veterans Affairs and the Secretary
4	of Defense.
5	SEC. 8. DEFINITIONS.
6	For the purposes of this Act:
7	(1) The term "Gulf War veteran" means a vet-
8	eran or member of the Armed Forces who during
9	the period beginning on August 2, 1990, and ending
10	on December 31, 1991, while serving on active
11	duty—
12	(A) served in the area of responsibility of
13	the United States Central Command or the
14	United States European Command; or
15	(B) while outside either such area of re-
16	sponsibility—
17	(i) received an inoculation in anticipa-
18	tion of deployment to either such area of
19	responsibility; or
20	(ii) handled equipment or supplies re-
21	turned from either such area of respon-
22	sibility after Operation Desert Storm.
23	(2) The term "designated congressional com-
24	mittees" means the following:

1	(A) The Committee on Veterans' Affairs
2	and the Committee on Armed Services of the
3	Senate.
4	(B) The Committee on Veterans' Affairs
5	and the Committee on National Security of the
6	House of Representatives.