

110TH CONGRESS
1ST SESSION

H. R. 1113

To expand the research, prevention, and awareness activities of the National Institute of Diabetes and Digestive and Kidney Diseases and the Centers for Disease Control and Prevention with respect to inflammatory bowel disease, and for other purposes.

IN THE HOUSE OF REPRESENTATIVES

FEBRUARY 16, 2007

Mr. JACKSON of Illinois (for himself and Mr. CASTLE) introduced the following bill; which was referred to the Committee on Energy and Commerce

A BILL

To expand the research, prevention, and awareness activities of the National Institute of Diabetes and Digestive and Kidney Diseases and the Centers for Disease Control and Prevention with respect to inflammatory bowel disease, 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.**

4 This Act may be cited as the “Inflammatory Bowel
5 Disease Research Enhancement Act”.

6 **SEC. 2. FINDINGS.**

7 The Congress finds as follows:

1 (1) Crohn’s disease and ulcerative colitis are se-
2 rious inflammatory diseases of the gastrointestinal
3 tract.

4 (2) Crohn’s disease may occur in any section of
5 the gastrointestinal tract but is predominately found
6 in the lower part of the small intestine and the large
7 intestine. Ulcerative colitis is characterized by in-
8 flammation and ulceration of the innermost lining of
9 the colon. Complete removal of the colon in patients
10 with ulcerative colitis can potentially alleviate and
11 cure symptoms.

12 (3) Because Crohn’s disease and ulcerative coli-
13 tis behave similarly, they are collectively known as
14 inflammatory bowel disease. Both diseases present a
15 variety of symptoms, including severe diarrhea; ab-
16 dominal pain with cramps; fever; and rectal bleeding.
17 There is no known cause of inflammatory bowel dis-
18 ease, or medical cure.

19 (4) It is estimated that up to 1,400,000 people
20 in the United States suffer from inflammatory bowel
21 disease, 30 percent of whom are diagnosed during
22 their childhood years.

23 (5) Children with inflammatory bowel disease
24 miss school activities because of bloody diarrhea and
25 abdominal pain, and many adults who had onset of

1 inflammatory bowel disease as children had delayed
2 puberty and impaired growth and have never
3 reached their full genetic growth potential.

4 (6) Inflammatory bowel disease patients are at
5 high risk for developing colorectal cancer.

6 (7) The total annual medical costs for inflam-
7 matory bowel disease patients is estimated at more
8 than \$2,000,000,000.

9 **SEC. 3. NATIONAL INSTITUTE OF DIABETES AND DIGES-**
10 **TIVE AND KIDNEY DISEASES; INFLAMMATORY**
11 **BOWEL DISEASE RESEARCH EXPANSION.**

12 (a) IN GENERAL.—The Director of the National In-
13 stitute of Diabetes and Digestive and Kidney Diseases
14 shall expand, intensify, and coordinate the activities of the
15 Institute with respect to research on inflammatory bowel
16 disease, with particular emphasis on the following areas:

17 (1) Genetic research on susceptibility for in-
18 flammatory bowel disease, including the interaction
19 of genetic and environmental factors in the develop-
20 ment of the disease.

21 (2) Research targeted to increase knowledge
22 about the causes and complications of inflammatory
23 bowel disease in children.

24 (3) Animal model research on inflammatory
25 bowel disease, including genetics in animals.

1 (4) Clinical inflammatory bowel disease re-
2 search, including clinical studies and treatment
3 trials.

4 (5) Expansion of the Institute’s Inflammatory
5 Bowel Disease Centers program with a focus on pe-
6 diatric research.

7 (6) Other research initiatives identified by the
8 scientific document entitled “Challenges in Inflam-
9 matory Bowel Disease” and the research agenda for
10 pediatric gastroenterology, hepatology, and nutrition
11 entitled “Chronic Inflammatory Bowel Disease”.

12 (b) AUTHORIZATION OF APPROPRIATIONS.—

13 (1) IN GENERAL.—For the purpose of carrying
14 out subsection (a), there are authorized to be appro-
15 priated \$80,000,000 for fiscal year 2008,
16 \$90,000,000 for fiscal year 2009, and \$100,000,000
17 for fiscal year 2010.

18 (2) RESERVATION.—Of the amounts authorized
19 to be appropriated under paragraph (1), not more
20 than 20 percent shall be reserved for the training of
21 qualified health professionals in biomedical research
22 focused on inflammatory bowel disease, including pe-
23 diatric investigators.

1 **SEC. 4. AMENDMENT TO THE PUBLIC HEALTH SERVICE**
2 **ACT.**

3 Part B of title III of the Public Health Service Act
4 (42 U.S.C. 243 et seq.) is amended by inserting after sec-
5 tion 317S the following:

6 **“SEC. 317T. PEDIATRIC INFLAMMATORY BOWEL DISEASE**
7 **REGISTRY.**

8 “(a) ESTABLISHMENT.—

9 “(1) IN GENERAL.—Not later than 6 months
10 after the receipt of the report described in sub-
11 section (b)(3), the Secretary, acting through the Di-
12 rector of the Centers for Disease Control and Pre-
13 vention and in consultation with a national voluntary
14 patient organization with experience serving the pop-
15 ulation of individuals with pediatric inflammatory
16 bowel disease and organizations representing physi-
17 cians and other health professionals specializing in
18 the treatment of this population, shall—

19 “(A) develop a system to collect data on
20 pediatric IBD; and

21 “(B) establish a national registry, to be
22 known as the National Pediatric IBD Registry,
23 for the collection and storage of such data.

24 “(2) PURPOSES OF REGISTRY.—The National
25 Pediatric IBD Registry—

1 “(A) shall include a population-based reg-
2 istry of cases of pediatric IBD in the United
3 States;

4 “(B) shall be used to gather data con-
5 cerning—

6 “(i) pediatric IBD, including the inci-
7 dence and prevalence of pediatric IBD in
8 the United States;

9 “(ii) the genetic and environmental
10 factors that may be associated with pedi-
11 atric IBD;

12 “(iii) the age, race or ethnicity, gen-
13 der, and family history of individuals who
14 are diagnosed with pediatric IBD;

15 “(iv) treatment approaches and out-
16 comes; and

17 “(v) other matters as recommended
18 by the Advisory Committee established
19 under subsection (b); and

20 “(C) shall be used to establish a secure
21 method to put patients in contact with sci-
22 entists studying the environmental and genetic
23 causes of pediatric IBD or conducting clinical
24 trials on pediatric IBD.

25 “(b) ADVISORY COMMITTEE.—

1 “(1) ESTABLISHMENT.—Not later than 90 days
2 after the date of the enactment of this section, the
3 Secretary, acting through the Director of the Cen-
4 ters for Disease Control and Prevention, shall estab-
5 lish a committee to be known as the Advisory Com-
6 mittee on Pediatric Inflammatory Bowel Disease.

7 “(2) MEMBERS.—The members of the Advisory
8 Committee shall be appointed by the Secretary, act-
9 ing through the Director of the Centers for Disease
10 Control and Prevention, and shall include at least
11 one representative of each of the following:

12 “(A) A national voluntary patient organi-
13 zation that focuses on pediatric IBD and has
14 demonstrated experience in pediatric IBD re-
15 search, care, and patient services.

16 “(B) A professional pediatric gastro-
17 enterology organization with expertise in pedi-
18 atric research, care, and patient services.

19 “(C) The National Institutes of Health.

20 “(D) If recommended by the Director of
21 the National Institutes of Health—

22 “(i) the National Institute of Diabetes
23 and Digestive and Kidney Diseases;

24 “(ii) the National Institute of Allergy
25 and Infectious Diseases;

1 “(iii) the National Institute of Child
2 Health and Human Development; and

3 “(iv) any other appropriate national
4 research institute or national center.

5 “(E) The Centers for Disease Control and
6 Prevention.

7 “(F) Pediatric gastroenterologists and
8 other clinicians who have experience with data
9 registries.

10 “(G) Epidemiologists who have experience
11 with data registries.

12 “(H) Geneticists or experts in genetics who
13 have experience with the genetics of pediatric
14 IBD.

15 “(I) Other individuals with an interest in
16 developing and maintaining the National Pedi-
17 atric IBD Registry.

18 “(3) STUDY.—The Advisory Committee shall
19 conduct a study and make recommendations on—

20 “(A) the development and maintenance of
21 the National Pediatric IBD Registry;

22 “(B) the type of information to be col-
23 lected and stored in the Registry;

24 “(C) the manner in which such data is to
25 be collected; and

1 “(D) the use and availability of such data
2 including guidelines for such use.

3 “(4) REPORT.—Not later than 6 months after
4 the date on which the Advisory Committee is estab-
5 lished, the Advisory Committee shall submit a report
6 to the Secretary and the Congress on the results of
7 the study conducted under paragraph (3), including
8 the recommendations of the Advisory Committee
9 with respect to such results.

10 “(c) GRANTS.—The Secretary, acting through the
11 Director of the Centers for Disease Control and Preven-
12 tion, may award grants to, and enter into contracts and
13 cooperative agreements with, public or private nonprofit
14 entities for the collection, analysis, and reporting of data
15 on pediatric IBD.

16 “(d) COORDINATION WITH EXISTING REGISTRIES
17 AND DATA REPOSITORIES.—

18 “(1) IN GENERAL.—In establishing the Na-
19 tional Pediatric IBD Registry under subsection (a),
20 the Secretary, acting through the Director of the
21 Centers for Disease Control and Prevention, shall
22 identify, build upon, expand, and coordinate among
23 existing public and private surveillance systems, and
24 registries concerning pediatric IBD.

1 “(2) COORDINATION WITH NIH.—The Secretary
2 shall ensure that epidemiological and other types of
3 information obtained under subsection (a) are made
4 available to the National Institutes of Health.

5 “(e) DEFINITIONS.—In this section:

6 “(1) The term ‘Advisory Committee’ means the
7 Advisory Committee on Pediatric Inflammatory
8 Bowel Disease established under subsection (b).

9 “(2) The terms ‘national research institute’ and
10 ‘national center’ have the meanings given to those
11 terms in section 401(g).

12 “(3) The term ‘national voluntary patient orga-
13 nization’ means a national non-profit patient organi-
14 zation with chapters in States throughout the
15 United States.

16 “(4) The term ‘pediatric IBD’ means pediatric
17 inflammatory bowel disease.

18 “(f) AUTHORIZATION OF APPROPRIATIONS.—To
19 carry out this section, there are authorized to be appro-
20 priated \$5,000,000 for fiscal year 2008 and such sums
21 as may be necessary for each of fiscal years 2009 and
22 2010.”.

1 **SEC. 5. CENTERS FOR DISEASE CONTROL AND PREVEN-**
2 **TION; NATIONAL INFLAMMATORY BOWEL DIS-**
3 **EASE ACTION PLAN.**

4 (a) IN GENERAL.—

5 (1) PREPARATION OF PLAN.—The Director of
6 the Centers for Disease Control and Prevention, in
7 consultation with the inflammatory bowel disease
8 community, shall prepare a comprehensive plan to
9 address the burden of inflammatory bowel disease in
10 both adult and pediatric populations (which plan
11 shall be designated by the Director as the “National
12 Inflammatory Bowel Disease Action Plan”).

13 (2) REPORT TO CONGRESS.—Not later than 12
14 months after the date of the enactment of this Act,
15 the Director of the Centers for Disease Control and
16 Prevention shall submit the Plan referred to in para-
17 graph (1) to the Committee on Energy and Com-
18 merce and the Committee on Appropriations of the
19 House of Representatives and to the Committee on
20 Health, Education, Labor and Pensions and the
21 Committee on Appropriations of the Senate.

22 (b) CONTENT.—

23 (1) IN GENERAL.—The National Inflammatory
24 Bowel Disease Action Plan shall address strategies
25 for determining the unique demographic, geographic,
26 and environmental-exposure characteristics of the in-

1 inflammatory bowel disease population through the ex-
2 pansion of appropriate epidemiological activities.

3 (2) CERTAIN REQUIREMENTS.—The Plan re-
4 ferred to in paragraph (1) shall—

5 (A) focus on strategies for increasing
6 awareness about inflammatory bowel disease
7 within the general public and the health care
8 community in order to facilitate more timely
9 and accurate diagnoses; and

10 (B) address mechanisms designed to pre-
11 vent the progression of the disease and the de-
12 velopment of complications, such as colorectal
13 cancer, and other strategies and activities as
14 deemed appropriate.

15 (c) AUTHORIZATION OF APPROPRIATIONS.—For the
16 purpose of carrying out this section, there is authorized
17 to be appropriated \$750,000 for fiscal year 2008.

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