

109TH CONGRESS
1ST SESSION

H. R. 3616

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.

IN THE HOUSE OF REPRESENTATIVES

JULY 29, 2005

Mrs. KELLY (for herself, Mr. CARDIN, Mr. JACKSON of Illinois, Ms. SCHAKOWSKY, Mr. WEINER, Mr. McNULTY, Mr. MORAN of Virginia, Mr. HINCHEY, Ms. KAPTUR, Mr. TAYLOR of Mississippi, Ms. JACKSON-LEE of Texas, Mr. BERRY, and Mr. CUNNINGHAM) 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.

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 Act”.

1 **SEC. 2. FINDINGS.**

2 The Congress finds as follows:

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

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

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

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

25 (5) Children with inflammatory bowel disease
26 miss school activities because of bloody diarrhea and

1 abdominal pain, and many adults who had onset of
2 inflammatory bowel disease as children had delayed
3 puberty and impaired growth and have never
4 reached their full genetic growth potential.

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

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

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

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

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

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

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

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

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

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

14 (b) AUTHORIZATION OF APPROPRIATIONS.—

15 (1) IN GENERAL.—For the purpose of carrying
16 out subsection (a), there are authorized to be appro-
17 priated \$75,000,000 for fiscal year 2006,
18 \$85,000,000 for fiscal year 2007, and \$100,000,000
19 for fiscal year 2008.

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

1 **SEC. 4. 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 in the
19 House of Representatives and to the Committee on
20 Health, Education, Labor and Pensions and the
21 Committee on Appropriations in the Senate.

22 (b) CONTENT.—

23 (1) IN GENERAL.—The National Inflammatory
24 Bowel Disease Action Plan shall address strategies
25 for determining the true prevalence of inflammatory
26 bowel disease in the United States, and the unique

1 demographic characteristics of the patient commu-
2 nity through the expansion of appropriate epidemio-
3 logical activities.

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

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

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

16 (c) AUTHORIZATION OF APPROPRIATIONS.—For the
17 purpose of carrying out this section, there is authorized
18 to be appropriated \$750,000 for fiscal year 2006.

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