

107TH CONGRESS
2D SESSION

H. R. 5031

To expand research regarding inflammatory bowel disease, and for other purposes.

IN THE HOUSE OF REPRESENTATIVES

JUNE 27, 2002

Mrs. KELLY (for herself, Mr. JACKSON of Illinois, and Mr. FLETCHER) introduced the following bill; which was referred to the Committee on Energy and Commerce

A BILL

To expand research regarding 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 Act”.

6 **SEC. 2. FINDINGS.**

7 Congress makes the following findings:

8 (1) Crohn’s disease and ulcerative colitis are se-
9 rious inflammatory diseases of the gastrointestinal
10 tract. Crohn’s disease may occur in any section of

1 the gastrointestinal tract but is predominately found
2 in the lower part of the small intestine and the large
3 intestine. Ulcerative colitis is characterized by in-
4 flammation and ulceration of the innermost lining of
5 the colon. Because Crohn's disease and ulcerative co-
6 litis behave similarly, they are collectively known as
7 inflammatory bowel disease. Both diseases present a
8 variety of symptoms, including severe diarrhea,
9 crampy abdominal pain, fever, and rectal bleeding.
10 There is no known cause of inflammatory bowel dis-
11 ease, or medical cure.

12 (2) It is estimated that up to 1,000,000 people
13 in the United States suffer from inflammatory bowel
14 disease.

15 (3) In 1990, the total annual medical costs for
16 Crohn's disease patients was estimated at
17 \$1,000,000,000 to \$1,200,000,000.

18 (4) In 1990, the total annual medical costs for
19 ulcerative colitis patients was estimated at
20 \$400,000,000 to \$600,000,000.

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

1 **SEC. 3. INFLAMMATORY BOWEL DISEASE RESEARCH EX-**
2 **PANSION.**

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

8 (1) Genetic research on susceptibility for in-
9 flammatory bowel disease, including the interaction
10 of genetic and environmental factors in the develop-
11 ment of the disease.

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

14 (3) Clinical inflammatory bowel disease re-
15 search, including clinical studies and treatment
16 trials.

17 (4) Other research initiatives identified by the
18 scientific document entitled “Challenges in Inflam-
19 matory Bowel Disease”.

20 (b) AUTHORIZATION OF APPROPRIATIONS.—

21 (1) IN GENERAL.—For the purpose of carrying
22 out this section, there are authorized to be appro-
23 priated \$75,000,000 in fiscal year 2003,
24 \$100,000,000 in fiscal year 2004, and such sums as
25 may be necessary for fiscal years 2005 through
26 2006.

1 (2) RESERVATION.—Of the funds authorized to
2 be appropriated under paragraph (1), not more than
3 20 percent of such funds shall be reserved to fund
4 the training of qualified health professionals in bio-
5 medical research focused on inflammatory bowel dis-
6 ease and related disorders.

7 **SEC. 4. INFLAMMATORY BOWEL DISEASE PREVENTION AND**
8 **EPIDEMIOLOGY.**

9 (a) IN GENERAL.—The Director of the Centers for
10 Disease Control and Prevention shall establish a national
11 program of prevention and epidemiology to determine the
12 prevalence of inflammatory bowel disease in the United
13 States, and conduct public and professional awareness ac-
14 tivities on inflammatory bowel disease.

15 (b) AUTHORIZATION OF APPROPRIATIONS.—For the
16 purpose of carrying out this section, there are authorized
17 to be appropriated \$5,000,000 in fiscal year 2003, and
18 such sums as may be necessary for fiscal years 2004
19 through 2006.

20 **SEC. 5. STUDY OF INFLAMMATORY BOWEL DISEASE RE-**
21 **LATED SERVICES.**

22 (a) IN GENERAL.—The Institute of Medicine of the
23 National Academies of Science shall conduct a study on
24 the coverage standards of medicare, medicaid, and the pri-
25 vate insurance market for the following therapies:

- 1 (1) Parenteral nutrition.
- 2 (2) Enteral nutrition formula.
- 3 (3) Medically necessary food products.
- 4 (4) Ostomy supplies.
- 5 (5) Therapies approved by the Food and Drug
- 6 Administration for Crohn's disease and ulcerative
- 7 colitis.

8 (b) CONTENT.—The study shall also take into ac-
9 count the appropriate outpatient or home health care de-
10 livery settings.

11 (c) REPORT.—Not later than 6 months after the date
12 of enactment of this Act, the Institute of Medicine shall
13 submit a report to Congress describing the findings of the
14 study.

15 (d) AUTHORIZATION OF APPROPRIATIONS.—There
16 are authorized to be appropriated to carry out this section,
17 such sums as may be necessary.

18 **SEC. 6. SOCIAL SECURITY DISABILITY FOR INFLAMMATORY**
19 **BOWEL DISEASE PATIENTS.**

20 (a) IN GENERAL.—The General Accounting Office
21 shall conduct a study of the problems patients encounter
22 when applying for disability insurance benefits under title
23 II of the Social Security Act. The study will also include
24 recommendations for improving the application process for
25 inflammatory bowel disease patients.

1 (b) REPORT.—Not later than 6 months after the date
2 of enactment of this Act, the General Accounting Office
3 shall submit a report to Congress describing the findings
4 of the study.

5 (c) AUTHORIZATION OF APPROPRIATIONS.—There
6 are authorized to be appropriated to carry out this section,
7 such sums as may be necessary.

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