

108TH CONGRESS  
1ST SESSION

# H. R. 290

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

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IN THE HOUSE OF REPRESENTATIVES

JANUARY 8, 2003

Mrs. KELLY introduced the following bill; which was referred to the Committee on Energy and Commerce

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## 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 2004,  
24 \$100,000,000 in fiscal year 2005, and such sums as  
25 may be necessary for fiscal years 2006 and 2007.

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 2004, and  
18          such sums as may be necessary for fiscal years 2005  
19          through 2007.

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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