

109TH CONGRESS  
1ST SESSION

# S. 1930

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.

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## IN THE SENATE OF THE UNITED STATES

OCTOBER 27, 2005

Mr. REID (for himself and Mr. COCHRAN) introduced the following bill; which was read twice and referred to the Committee on Health, Education, Labor, and Pensions

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## 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”.

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 \$75,000,000 for fiscal year 2006,  
16           \$85,000,000 for fiscal year 2007, and \$100,000,000  
17           for fiscal year 2008.

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. 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 such sums as may be necessary for fis-  
19 cal year 2006.

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