

111TH CONGRESS  
1ST SESSION

# H. R. 2275

To support research and public awareness activities with respect to  
inflammatory bowel disease, and for other purposes.

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## IN THE HOUSE OF REPRESENTATIVES

MAY 6, 2009

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

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## A BILL

To support research and public awareness activities 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 and Awareness 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; arthritic joint pain,  
17          inflammation of the eye, and rectal bleeding. There  
18          is no known cause of inflammatory bowel disease, or  
19          medical cure.

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

24          (5) Children with inflammatory bowel disease  
25          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 are estimated at more  
9 than \$2,000,000,000.

10 (8) The average time from presentation of  
11 symptoms to diagnosis in children is three years.

12 (9) Delayed diagnosis of inflammatory bowel  
13 disease frequently results in more-active disease as-  
14 sociated with increased morbidity and complications.

15 (10) The National Institutes of Health National  
16 Commission on Digestive Diseases issued com-  
17 prehensive research goals related to inflammatory  
18 bowel disease in its April 2009 report to Congress  
19 and the American public entitled “Opportunities and  
20 Challenges in Digestive Diseases Research: Rec-  
21 ommendations of the National Commission on Di-  
22 gestive Diseases”.

1 **SEC. 3. ENHANCING CDC'S PUBLIC HEALTH ACTIVITIES ON**  
2 **INFLAMMATORY BOWEL DISEASE.**

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 320A the following:

6 **“SEC. 320B. INFLAMMATORY BOWEL DISEASE EPIDEMI-**  
7 **LOGY RESEARCH AND PEDIATRIC PATIENT**  
8 **REGISTRY PROGRAM.**

9 “(a) IN GENERAL.—The Secretary, acting through  
10 the Director of the Centers for Disease Control and Pre-  
11 vention, shall conduct, support, and expand epidemiology  
12 research on inflammatory bowel disease in both pediatric  
13 and adult populations and establish a registry of pediatric  
14 IBD patients.

15 “(b) COOPERATIVE AGREEMENT.—In carrying out  
16 subsection (a), the Secretary shall enter into a cooperative  
17 agreement with a nonprofit organization with expertise  
18 and experience in conducting inflammatory bowel disease  
19 research to develop and administer the epidemiology re-  
20 search and registry program, including—

21 “(1) expansion of existing IBD epidemiology  
22 program research activities within the National Cen-  
23 ter for Chronic Disease Prevention and Health Pro-  
24 motion; and

25 “(2) establishment, within one year of enact-  
26 ment of this section, of a population-based registry

1 of pediatric IBD patients for the purposes of data  
2 collection, research, and patient services.

3 “(c) PEDIATRIC IBD REGISTRY.—

4 “(1) FOCUS.—The pediatric IBD registry es-  
5 tablished under this section shall focus on, but not  
6 be limited to, data collection, storage and analysis  
7 regarding—

8 “(A) the incidence and prevalence of pedi-  
9 atric IBD in the United States;

10 “(B) genetic and environmental factors as-  
11 sociated with pediatric IBD;

12 “(C) age, race or ethnicity, gender, and  
13 family history of individuals diagnosed with pe-  
14 diatric IBD; and

15 “(D) treatment approaches and outcomes  
16 in pediatric IBD.

17 “(2) ADDITIONAL REQUIREMENTS.—In estab-  
18 lishing the pediatric IBD registry under this section,  
19 the Secretary shall—

20 “(A) identify, build-upon, and coordinate  
21 with existing public and private surveillance  
22 systems related to pediatric IBD; and

23 “(B) establish a secure communication  
24 mechanism within the registry to facilitate pa-  
25 tient contact with researchers studying the envi-

1           ronmental and genetic causes of pediatric IBD  
2           or conducting clinical trials on pediatric IBD.

3           “(d) DEFINITION.—In this section, the term ‘IBD’  
4 means inflammatory bowel disease.

5           “(e) AUTHORIZATION OF APPROPRIATIONS.—To  
6 carry out this section, there is authorized to be appro-  
7 priated \$3,500,000 for each of the fiscal years 2010  
8 through 2014.

9           **“SEC. 320C. INCREASING PUBLIC AWARENESS OF INFLAM-**  
10                                   **MATORY BOWEL DISEASE AND IMPROVING**  
11                                   **HEALTH PROFESSIONAL EDUCATION.**

12           “(a) IN GENERAL.—The Secretary, acting through  
13 the Director of the Centers for Disease Control and Pre-  
14 vention, shall award grants to eligible entities for the pur-  
15 pose of increasing awareness of inflammatory bowel dis-  
16 ease among the general public and health care providers.

17           “(b) USE OF FUNDS.—The Secretary may not award  
18 a grant under this section to an eligible entity unless the  
19 entity agreed to use the grant to develop educational mate-  
20 rials and conduct awareness programs focused on inflam-  
21 matory bowel disease, including with respect to the fol-  
22 lowing subjects:

23                   “(1) Crohn’s disease and ulcerative colitis and  
24           their symptoms.

1           “(2) Testing required for appropriate diagnosis  
2           and the importance of accurate and early diagnosis.

3           “(3) Key differences between pediatric and  
4           adult disease.

5           “(4) Specific physical and psychosocial issues  
6           impacting pediatric patients, including stunted  
7           growth, malnutrition, delayed puberty, and depres-  
8           sion.

9           “(5) Treatment options for both adult and pedi-  
10          atric patients.

11          “(6) The importance of identifying aggressive  
12          disease in children at an early stage in order to im-  
13          plement the most effective treatment protocol.

14          “(7) Complications of inflammatory bowel dis-  
15          ease and related secondary conditions, including  
16          colorectal cancer.

17          “(8) Federal and private information resources  
18          for patients and physicians.

19          “(9) Incidence and prevalence data on pediatric  
20          and adult inflammatory bowel disease.

21          “(c) REPORT TO CONGRESS.—Not later than Sep-  
22          tember 30, 2010, the Secretary shall report to the Com-  
23          mittee on Energy and Commerce of the House of Rep-  
24          resentatives, the Committee on Health, Education, Labor,  
25          and Pensions of the Senate, and the Committees on Ap-

1 appropriations of the House of Representatives and the Sen-  
2 ate regarding the status of activities under this section.

3 “(d) ELIGIBLE ENTITY.—To carry out this section,  
4 the term ‘eligible entity’ means a nonprofit patient or pro-  
5 fessional organization with experience in serving adults  
6 and children with inflammatory bowel disease.

7 “(e) AUTHORIZATION OF APPROPRIATIONS.—For the  
8 purpose of carrying out this section, there is authorized  
9 to be appropriated \$2,000,000 for each of fiscal years  
10 2010 through 2014.”.

11 **SEC. 4. SENSE OF CONGRESS ON EXPANSION OF BIO-**  
12 **MEDICAL RESEARCH ON INFLAMMATORY**  
13 **BOWEL DISEASE.**

14 It is the sense of the Congress that—

15 (1) the Secretary, acting through the Director  
16 of the National Institutes of Health and the Director  
17 of the National Institute of Diabetes and Digestive  
18 and Kidney Diseases (in this section referred to as  
19 the “Institute”) should aggressively support basic,  
20 translational, and clinical research designed to meet  
21 the research goals for inflammatory bowel disease  
22 (in this section referred to as “IBD”) included in  
23 the National Institutes of Health National Commis-  
24 sion on Digestive Diseases report entitled “Opportu-  
25 nities and Challenges in Digestive Diseases Re-

1 search: Recommendations of the National Commis-  
2 sion on Digestive Diseases”, including by—

3 (A) establishing an objective basis for de-  
4 termining clinical diagnosis, detailed phenotype,  
5 and disease activity in IBD;

6 (B) developing an individualized approach  
7 to IBD risk evaluation and management based  
8 on genetic susceptibility;

9 (C) modulating the intestinal microflora to  
10 prevent or control IBD;

11 (D) effectively modulating the mucosal im-  
12 mune system to prevent or ameliorate IBD;

13 (E) sustaining the health of the mucosal  
14 surface;

15 (F) promoting regeneration and repair of  
16 injury in IBD;

17 (G) providing effective tools for clinical  
18 evaluation and intervention in IBD; and

19 (H) ameliorating or preventing adverse ef-  
20 fects of IBD on growth and development in  
21 children and adolescents;

22 (2) the Institute should support the training of  
23 qualified health professionals in biomedical research  
24 focused on IBD, including pediatric investigators;  
25 and

1           (3) the Institute should continue its strong col-  
2           laboration with medical and patient organizations  
3           concerned with IBD and seek opportunities to pro-  
4           mote research identified in the scientific agendas  
5           “Challenges in Inflammatory Bowel Disease Re-  
6           search” (Crohn’s and Colitis Foundation of Amer-  
7           ica) and “Chronic Inflammatory Bowel Disease”  
8           (North American Society for Pediatric Gastro-  
9           enterology, Hepatology and Nutrition).

10 **SEC. 5. BIENNIAL REPORTS.**

11           Section 403(a)(5) of the Public Health Service Act  
12 (42 U.S.C. 283(a)(5)) is amended—

13           (1) by redesignating subparagraph (L) as sub-  
14           paragraph (M); and

15           (2) by inserting after subparagraph (K) the fol-  
16           lowing:

17                           “(L) Inflammatory bowel disease.”.

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