

111TH CONGRESS  
1ST SESSION

# S. 571

To strengthen the Nation’s research efforts to identify the causes and cure of psoriasis and psoriatic arthritis, expand psoriasis and psoriatic arthritis data collection, and study access to and quality of care for people with psoriasis and psoriatic arthritis, and for other purposes.

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## IN THE SENATE OF THE UNITED STATES

MARCH 11, 2009

Mr. MENENDEZ (for himself, Mr. WYDEN, Mr. KERRY, Mr. CASEY, and Mr. DODD) 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 strengthen the Nation’s research efforts to identify the causes and cure of psoriasis and psoriatic arthritis, expand psoriasis and psoriatic arthritis data collection, and study access to and quality of care for people with psoriasis and psoriatic arthritis, 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 “Psoriasis and Psoriatic  
5       Arthritis Research, Cure, and Care Act of 2009”.

6       **SEC. 2. TABLE OF CONTENTS.**

7       The table of contents for this Act is as follows:

- Sec. 1. Short title.
- Sec. 2. Table of contents.
- Sec. 3. Findings.
- Sec. 4. Expansion of biomedical research.
- Sec. 5. Psoriasis and psoriatic arthritis data collection and national patient registry.
- Sec. 6. National summit.
- Sec. 7. Study and report by the Institute of Medicine.
- Sec. 8. Authorization of appropriations.

### 1 **SEC. 3. FINDINGS.**

2       The Congress finds as follows:

3           (1) Psoriasis and psoriatic arthritis are auto-  
 4       immune, chronic, inflammatory, painful, disfiguring,  
 5       and life-altering diseases that require lifelong sophis-  
 6       ticated medical intervention and care and have no  
 7       cure.

8           (2) Psoriasis and psoriatic arthritis affect as  
 9       many as 7,500,000 men, women, and children of all  
 10      ages and have an adverse impact on the quality of  
 11      life for virtually all affected.

12          (3) Psoriasis often is overlooked or dismissed  
 13      because it does not cause death. Psoriasis is com-  
 14      monly and incorrectly considered by insurers, em-  
 15      ployers, policymakers, and the public as a mere an-  
 16      noyance, a superficial problem, mistakenly thought  
 17      to be contagious and due to poor hygiene. Treatment  
 18      for psoriasis often is categorized, wrongly, as “life-  
 19      style” and not “medically necessary.”

20          (4) Psoriasis goes hand-in-hand with myriad co-  
 21      morbidities such as Crohn’s disease, diabetes, meta-

1       bolic syndrome, obesity, hypertension, heart attack,  
2       cardiovascular disease, liver disease, and psoriatic  
3       arthritis, which occurs in 10 to 30 percent of people  
4       with psoriasis.

5           (5) The National Institute of Mental Health  
6       funded a study that found that psoriasis may cause  
7       as much physical and mental disability as other  
8       major diseases, including cancer, arthritis, hyper-  
9       tension, heart disease, diabetes, and depression.

10          (6) Psoriasis is associated with elevated rates of  
11       depression and suicidal ideation.

12          (7) The risk of premature death is 50 percent  
13       higher for individuals with severe psoriasis than for  
14       individuals without any form of psoriasis.

15          (8) Total direct and indirect health care costs  
16       of psoriasis are calculated at over \$11,250,000,000  
17       annually with work loss accounting for 40 percent of  
18       the cost burden.

19          (9) Early diagnosis and treatment of psoriatic  
20       arthritis may help prevent irreversible joint damage.

21          (10) Treating psoriasis and psoriatic arthritis  
22       presents a challenge for patients and their health  
23       care providers because no one treatment works for  
24       everyone, some treatments lose effectiveness over  
25       time, many treatments are used in combination with

1 others, and all treatments may cause a unique set  
2 of side effects.

3 (11) Although new and more effective treat-  
4 ments finally are becoming available, too many peo-  
5 ple do not yet have access to the types of therapies  
6 that may make a significant difference in the quality  
7 of their lives.

8 (12) Psoriasis and psoriatic arthritis constitute  
9 a significant national health issue that deserves a  
10 comprehensive and coordinated response by Federal  
11 and State governments with involvement of the  
12 health care provider, patient, and public health com-  
13 munities.

14 **SEC. 4. EXPANSION OF BIOMEDICAL RESEARCH.**

15 (a) IN GENERAL.—The Secretary of Health and  
16 Human Services (in this Act referred to as the “Sec-  
17 retary”), acting through the Director of the National In-  
18 stitutes of Health, shall continue to expand and intensify  
19 research and related activities of the Institutes with re-  
20 spect to psoriasis and psoriatic arthritis.

21 (b) RESEARCH BY NATIONAL INSTITUTE OF ARTHRI-  
22 TIS AND MUSCULOSKELETAL AND SKIN DISEASES.—

23 (1) IN GENERAL.—The directors of the Na-  
24 tional Institute of Arthritis and Musculoskeletal and  
25 Skin Diseases and the National Institute of Allergy

1 and Infectious Diseases shall continue to conduct  
2 and support research to expand understanding of  
3 the causes of, and to find a cure for, psoriasis and  
4 psoriatic arthritis, including the following:

5 (A) Basic research to discover the patho-  
6 genesis and pathophysiology of the disease.

7 (B) Expansion of molecular biology and  
8 immunology studies, including additional animal  
9 models.

10 (C) Global association mapping with single  
11 nucleotide polymorphisms.

12 (D) Identification of environmental trig-  
13 gers and autoantigens in psoriasis.

14 (E) Elucidation of specific immunologic  
15 cells and their products involved.

16 (F) Pharmacogenetic studies to under-  
17 stand the molecular basis for varying patient  
18 response to treatment.

19 (G) Identification of genetic markers of  
20 psoriatic arthritis susceptibility.

21 (H) Research to increase understanding of  
22 joint inflammation and destruction in psoriatic  
23 arthritis.

1 (I) Investigator-initiated clinical research  
 2 for the development and evaluation of new  
 3 treatments, including new biological agents.

4 (J) Research to develop enhanced diag-  
 5 nostic tests that allow for earlier diagnosis of  
 6 psoriasis and improved outcomes.

7 (K) Research to increase understanding of  
 8 the epidemiology and pathophysiology of co-  
 9 morbidities associated with psoriasis, including  
 10 shared molecular pathways.

11 (2) COORDINATION WITH OTHER INSTI-  
 12 TUTES.—In carrying out paragraph (1), the direc-  
 13 tors of the National Institute of Arthritis and Mus-  
 14 culoskeletal and Skin Diseases and the National In-  
 15 stitute of Allergy and Infectious Diseases shall co-  
 16 ordinate the activities of such Institutes with the ac-  
 17 tivities of other national research institutes and  
 18 other agencies and offices of the National Institutes  
 19 of Health relating to psoriasis or psoriatic arthritis.

20 **SEC. 5. PSORIASIS AND PSORIATIC ARTHRITIS DATA COL-**  
 21 **LECTION AND NATIONAL PATIENT REGISTRY.**

22 The Secretary, acting through the Director of the  
 23 Centers for Disease Control and Prevention and in col-  
 24 laboration with a national organization serving people with  
 25 psoriasis and psoriatic arthritis, shall undertake psoriasis

1 and psoriatic arthritis data collection and develop a psori-  
2 asis and psoriatic arthritis patient registry.

3 **SEC. 6. NATIONAL SUMMIT.**

4 (a) IN GENERAL.—Not later than one year after the  
5 date of the enactment of this Act, the Secretary is encour-  
6 aged to convene a summit on the Federal Government’s  
7 current and future efforts, and the initiatives necessary  
8 to fill any gaps, with respect to the conduct or support  
9 of psoriasis and psoriatic arthritis research, treatment,  
10 education, quality-of-life, and data collection activities.  
11 The summit should also address psoriasis and psoriatic  
12 arthritis related co-morbidities and should include re-  
13 searchers, public health professionals, representatives of  
14 voluntary health agencies and patient advocacy organiza-  
15 tions, representatives of academic institutions, representa-  
16 tives from the pharmaceutical and medical research indus-  
17 try, and Federal and State policymakers, including rep-  
18 resentatives of the Agency for Healthcare Research and  
19 Quality, the Centers for Disease Control and Prevention,  
20 the Food and Drug Administration, and the National In-  
21 stitutes of Health.

22 (b) FOCUS.—The summit convened under this section  
23 should focus on—

1           (1) a broad range of research activities relating  
2           to biomedical, epidemiological, psychosocial, and re-  
3           habilitative issues;

4           (2) clinical research for the development and  
5           evaluation of new treatments, including new biologi-  
6           cal agents;

7           (3) translational research;

8           (4) information and education programs for  
9           health care professionals and the public;

10          (5) priorities among the programs and activities  
11          of the various Federal agencies involved in psoriasis  
12          and psoriatic arthritis and related co-morbidities;  
13          and

14          (6) challenges, opportunities, and recommenda-  
15          tions for scientists, clinicians, patients, and vol-  
16          untary organizations.

17          (c) REPORT TO CONGRESS.—Not later than 180 days  
18          after the first day of the summit convened under this sec-  
19          tion, the Secretary shall submit to the Congress and make  
20          publicly available a report that includes a description of—

21               (1) the proceedings at the summit; and

22               (2) recommendations related to the research,  
23          treatment, education, and quality-of-life activities  
24          conducted or supported by the Federal Government  
25          with respect to psoriasis and psoriatic arthritis, in-



1 including psoriasis and psoriatic arthritis related co-  
2 morbidities.

3 **SEC. 7. STUDY AND REPORT BY THE INSTITUTE OF MEDI-**  
4 **CINE.**

5 (a) IN GENERAL.—The Secretary shall enter into an  
6 agreement with the Institute of Medicine to conduct a  
7 study on the following:

8 (1) The extent to which public and private in-  
9 surers cover prescription medications and other  
10 treatments for psoriasis and psoriatic arthritis.

11 (2) The payment structures, such as deductibles  
12 and co-payments, and the amounts and duration of  
13 coverage under health plans and their adequacy to  
14 cover the costs of providing ongoing care to, and en-  
15 sure access for, patients with psoriasis and psoriatic  
16 arthritis.

17 (3) Health plan and insurer coverage policies  
18 and practices, including lifetime caps, and their im-  
19 pact on the access of such patients to the best regi-  
20 men and most appropriate care for their particular  
21 disease state.

22 (b) REPORT.—The agreement entered into under  
23 subsection (a) shall provide for the Institute of Medicine  
24 to submit to the Secretary and the Congress, not later

1 than 18 months after the date of the enactment of this  
2 Act, a report containing a description of—

3 (1) the results of the study conducted under  
4 this section; and

5 (2) the conclusions and recommendations of the  
6 Institutes of Medicine regarding each of the issues  
7 described in paragraphs (1) through (3) of sub-  
8 section (a).

9 **SEC. 8. AUTHORIZATION OF APPROPRIATIONS.**

10 To carry out this Act, there are authorized to be ap-  
11 propriated such sums as may be necessary for each of fis-  
12 cal years 2010 through 2014.

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