

110TH CONGRESS
1ST SESSION

S. 1459

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, study access to and quality of care for people with psoriasis and psoriatic arthritis, and for other purposes.

IN THE SENATE OF THE UNITED STATES

MAY 23, 2007

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

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, 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 2007”.

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. National patient registry.
 Sec. 6. National summit.
 Sec. 7. Study and report by the Institute of Medicine.

1 **SEC. 3. FINDINGS.**

2 The Congress finds as follows:

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

8 (2) Psoriasis and psoriatic arthritis affect as
 9 many as 7.5 million 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 a myriad
 21 of co-morbidities such as Crohn’s disease, diabetes,
 22 metabolic syndrome, obesity, hypertension, heart at-

1 tack, cardiovascular disease, liver disease, and psori-
2 atic arthritis, which occurs in 10 to 30 percent of
3 people with psoriasis.

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

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

11 (7) Each year the people of the United States
12 lose approximately 56 million hours of work and
13 spend \$2 billion to \$3 billion to treat psoriasis.

14 (8) Early diagnosis and treatment of psoriatic
15 arthritis may help prevent irreversible joint damage.

16 (9) Treating psoriasis and psoriatic arthritis
17 presents a challenge for patients and their health
18 care providers because no one treatment works for
19 everyone, some treatments lose effectiveness over
20 time, many treatments are used in combination with
21 other treatments, and all treatments may cause a
22 unique set of side effects.

23 (10) Although new and more effective treat-
24 ments finally are becoming available, too many peo-
25 ple do not yet have access to the types of therapies

1 that may make a significant difference in the quality
2 of their lives.

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

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

10 (a) IN GENERAL.—The Secretary of Health and
11 Human Services (in this Act referred to as the “Sec-
12 retary”), acting through the Director of the National In-
13 stitutes of Health, shall expand and intensify research and
14 related activities of the Institutes with respect to psoriasis
15 and psoriatic arthritis.

16 (b) RESEARCH BY NIAMS.—

17 (1) IN GENERAL.—The Director of the National
18 Institute of Arthritis and Musculoskeletal and Skin
19 Diseases shall conduct or support research to expand
20 understanding of the causes of, and to find a cure
21 for, psoriasis and psoriatic arthritis. Such research
22 shall include the following:

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

1 (B) Expansion of molecular genetics and
2 immunology studies, including additional animal
3 models.

4 (C) Global association mapping with single
5 nucleotide polymorphisms.

6 (D) Identification of environmental trig-
7 gers and autoantigens in psoriasis.

8 (E) Elucidation of specific immune recep-
9 tor cells and their products involved.

10 (F) Pharmacogenetic studies to understand
11 the molecular basis for varying patient response
12 to treatment.

13 (G) Identification of genetic markers of
14 psoriatic arthritis susceptibility.

15 (H) Research to increase understanding of
16 joint inflammation and destruction in psoriatic
17 arthritis.

18 (I) Clinical research for the development
19 and evaluation of new treatments, including
20 new biological agents.

21 (J) Research to develop improved diag-
22 nostic tests.

23 (K) Research to increase understanding of
24 co-morbidities and psoriasis, including shared
25 molecular pathways.

1 (2) COORDINATION WITH OTHER INSTI-
2 TUTES.—In carrying out paragraph (1), the Director
3 of the National Institute of Arthritis and Musculo-
4 skeletal and Skin Diseases shall coordinate the ac-
5 tivities of the Institute with the activities of other
6 national research institutes and other agencies and
7 offices of the National Institutes of Health relating
8 to psoriasis or psoriatic arthritis.

9 **SEC. 5. NATIONAL PATIENT REGISTRY.**

10 (a) IN GENERAL.—The Secretary, acting through the
11 Director of the Centers for Disease Control and Preven-
12 tion and in collaboration with an eligible national organi-
13 zation, shall establish a national psoriasis and psoriatic
14 arthritis patient registry.

15 (b) COOPERATIVE AGREEMENTS.—In carrying out
16 subsection (a), the Secretary shall enter into cooperative
17 agreements with an eligible national organization and ap-
18 propriate academic health institutions to develop, imple-
19 ment, and manage a system for psoriasis and psoriatic ar-
20 thritis patient data collection and analysis, including the
21 creation and use of a common data entry and management
22 system.

23 (c) LONGITUDINAL DATA.—In carrying out sub-
24 section (a), the Secretary shall ensure the collection and
25 analysis of longitudinal data related to individuals of all

1 ages with psoriasis and psoriatic arthritis, including in-
 2 fants, young children, adolescents, and adults of all ages
 3 including older Americans.

4 (d) ELIGIBLE NATIONAL ORGANIZATION.—In this
 5 section, the term “eligible national organization” means
 6 a national organization that—

7 (1) has expertise in the epidemiology of psori-
 8 asis and psoriatic arthritis; and

9 (2) maintains an established patient registry or
 10 biobank.

11 (e) AUTHORIZATION OF APPROPRIATIONS.—To carry
 12 out this section, there are authorized to be appropriated
 13 \$1,000,000 for fiscal year 2008 and \$500,000 for each
 14 of fiscal years 2009 through 2012.

15 **SEC. 6. NATIONAL SUMMIT.**

16 (a) IN GENERAL.—Not later than one year after the
 17 date of enactment of this Act, the Secretary shall convene
 18 a summit on the current activities of the Federal Govern-
 19 ment to conduct or support research, treatment, edu-
 20 cation, and quality-of-life activities with respect to psori-
 21 asis and psoriatic arthritis, including psoriasis and psori-
 22 atic arthritis related co-morbidities. The summit shall in-
 23 clude researchers, public health professionals, representa-
 24 tives of voluntary health agencies and patient advocacy or-

ganizations, representatives of academic institutions, and
Federal and State policymakers.

(b) FOCUS.—The summit convened under this section
shall focus on—

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

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

(3) translational research;

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

(5) priorities among the programs and activities
of the various Federal agencies involved in psoriasis
and psoriatic arthritis and psoriasis and psoriatic ar-
thritis related co-morbidities; and

(6) challenges and opportunities for scientists,
clinicians, patients, and voluntary organizations.

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

(1) the proceedings at the summit; and

1 (2) the research, treatment, education, and
2 quality-of-life activities conducted or supported by
3 the Federal Government with respect to psoriasis
4 and psoriatic arthritis, including psoriasis and psori-
5 atic arthritis related co-morbidities.

6 (d) AUTHORIZATION OF APPROPRIATIONS.—To carry
7 out this section, there are authorized such sums as may
8 be necessary for each of fiscal years 2008 through 2010.

9 **SEC. 7. STUDY AND REPORT BY THE INSTITUTE OF MEDI-**
10 **CINE.**

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

14 (1) The extent to which public and private in-
15 surers cover prescription medications and other
16 treatments for psoriasis and psoriatic arthritis.

17 (2) The payment structures, such as deductibles
18 and co-payments, and the amounts and duration of
19 coverage under health plans and their adequacy to
20 cover the costs of providing ongoing care to patients
21 with psoriasis and psoriatic arthritis.

22 (3) Health plan and insurer coverage policies
23 and practices and their impact on the access of such
24 patients to the best regimen and most appropriate
25 care for their particular disease state.

1 (b) REPORT.—The agreement entered into under
2 subsection (a) shall provide for the Institute of Medicine
3 to submit to the Secretary and Congress, not later than
4 18 months after the date of the enactment of this Act,
5 a report containing a description of the results of the
6 study conducted under this section and the conclusions
7 and recommendations of the Institutes of Medicine regard-
8 ing each of the issues described in paragraphs (1) through
9 (3) of subsection (a).

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