112TH CONGRESS
1ST SESSION

S. 1107

To authorize and support psoriasis and psoriatic arthritis data collection, to express the sense of the Congress to encourage and leverage public and private investment in psoriasis research with a particular focus on interdisciplinary collaborative research on the relationship between psoriasis and its comorbid conditions, and for other purposes.

IN THE SENATE OF THE UNITED STATES

MAY 26, 2011

Mr. MENENDEZ 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 authorize and support psoriasis and psoriatic arthritis data collection, to express the sense of the Congress to encourage and leverage public and private investment in psoriasis research with a particular focus on interdisciplinary collaborative research on the relationship between psoriasis and its comorbid conditions, 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 2011".

1 **SEC. 2. FINDINGS.**

2 Congress finds the following:

3 (1) Psoriasis and psoriatic arthritis are auto-
4 immune, chronic, inflammatory, painful, and dis-
5 abling diseases that require lifelong timely and ap-
6 propriate medical intervention and care and have no
7 cure.

8 (2) Current studies indicate that the prevalence
9 of psoriasis in the United States ranges between two
10 and three percent, affecting approximately 7.5 mil-
11 lion men, women, and children of all ages, approxi-
12 mately 17,000 individuals in each congressional dis-
13 trict, and has an adverse impact on the quality of
14 life for virtually all affected.

15 (3) Psoriasis often is overlooked or dismissed
16 because it is not typically a direct cause of death.
17 Psoriasis is commonly and incorrectly considered by
18 insurers, employers, policymakers, and the public as
19 a mere annoyance—a superficial problem, mistak-
20 enly thought to be contagious, due to poor hygiene,
21 or both. As such, treatment for psoriasis is often in-
22 correctly categorized as ''cosmetic'' and not ''medi-
23 cally necessary''.

24 (4) Psoriasis is connected with an elevated risk
25 for other serious, chronic, and life-threatening co-
26 morbid conditions, including cardiovascular disease,

1 diabetes, stroke, and cancer. A higher prevalence of
2 stroke, atherosclerosis, chronic obstructive pul-
3 monary disease (COPD), Crohn's disease,
4 lymphoma, metabolic syndrome, and liver disease are
5 also found in people with psoriasis as compared to
6 the general population. Up to 30 percent of people
7 with psoriasis also develop potentially disabling pso-
8 riatic arthritis.

9 (5) The National Institute of Mental Health
10 (NIMH) funded a study that found that psoriasis
11 may cause as much physical and mental disability as
12 other major chronic diseases, including cancer, ar-
13 thritis, hypertension, heart disease, diabetes, and de-
14 pression.

15 (6) Psoriasis is associated with elevated rates of
16 depression, anxiety, and suicidality (suicidal
17 thoughts, suicide attempts, and completed suicides).
18 Individuals with psoriasis are twice as likely to have
19 thoughts of suicide as people without psoriasis or
20 with other chronic conditions.

21 (7) The risk of premature death is 50 percent
22 higher for people with severe psoriasis. This trans-
23 lates to people with severe psoriasis dying four years
24 earlier, on average, than people without psoriasis.

1 (8) The economic consequences of psoriasis,
2 both for individuals and the health care system, are
3 significant. Total direct and indirect health care
4 costs of psoriasis are calculated at $11,250,000,000
5 with work loss accounting for 40 percent of the cost
6 burden. People with psoriasis have significantly
7 higher health care resource utilization and costs
8 than the general population. Additionally, psoriasis
9 patients with comorbidities are more likely to experi-
10 ence urgent care, have greater rates of hospitaliza-
11 tion, more frequent outpatient visits, and incur
12 greater costs than psoriasis patients without
13 comorbidities.
14 (9) Early diagnosis and treatment of psoriatic
15 arthritis may help prevent irreversible joint damage.
16 (10) Treating psoriasis and psoriatic arthritis
17 presents a challenge for patients and their health
18 care providers. A wide range of treatment options is
19 available; however, adverse side effects and success
20 varies from patient to patient. The same treatments
21 do not work for every patient and a treatment that
22 may have been effective for a period of time can stop
23 working.
24 (11) Despite a number of recent breakthroughs
25 that have led to some new treatments, too many peo-

ple with psoriasis and psoriatic arthritis still cannot live normal lives. For many of these individuals, existing treatments are not effective or appropriate or may not be accessible due to cost and insurance barriers.

(12) Psoriasis and psoriatic arthritis constitute a significant national health issue that deserves a comprehensive and coordinated response by States and the Federal Government with involvement of the health care provider, patient, and public health communities.

SEC. 3. NATIONAL PSORIASIS AND PSORIATIC ARTHRITIS DATA COLLECTION.

(a) IN GENERAL.—The Secretary of Health and Human Services, acting through the Director of the Centers for Disease Control and Prevention, is authorized to undertake psoriasis and psoriatic arthritis data collection efforts, including incorporating questions into public health surveys, questionnaires, and other databases in existence as of the date of the enactment of this Act to collect information, with respect to psoriasis and psoriatic arthritis, regarding—

(1) the prevalence of psoriasis and psoriatic arthritis in the United States;

(2) the age of onset;

1 (3) health-related quality of life;
2 (4) health care utilization;
3 (5) burden of such disease (such as with respect
4 to employment);
5 (6) direct and indirect costs;
6 (7) health disparities, including with respect to
7 age, gender, race, and ethnicity; and
8 (8) comorbidities and the natural history of
9 such disease.
10 Such data collection efforts may include the consideration
11 and development of a patient registry, which would include
12 individuals of all ages.
13 (b) AUTHORIZATION OF APPROPRIATIONS.—To carry
14 out subsection (a), there are authorized to be appropriated
15 $1,500,000 for each of fiscal years 2012 through 2017.

16 **SEC. 4. SENSE OF CONGRESS FOR COLLABORATIVE INTER-**
17 **DISCIPLINARY RESEARCH ON PSORIASIS AND**
18 **PSORIATIC ARTHRITIS AND COMORBID CON-**
19 **DITIONS.**

20 It is the sense of the Congress that—
21 (1) the psoriasis research community has made
22 significant strides in proving the seriousness of pso-
23 riasis as an autoimmune disease and in advancing
24 the identification of commonalities between psoriasis
25 and other diseases;

1 (2) the nonprofit and private sector psoriasis
2 research communities are to be commended for plan-
3 ning a multidisciplinary scientific meeting in 2012 to
4 discuss future directions of psoriasis and comorbid
5 research, identify initiatives necessary to fill any
6 gaps, leverage public and private investments in pso-
7 riasis research, and facilitate progress in inter-
8 disciplinary research related to psoriasis and its co-
9 morbid conditions;
10 (3) the National Institutes of Health is encour-
11 aged to continue to work with the organizations and
12 private sector stakeholders who convene the multi-
13 disciplinary scientific meeting to discuss future di-
14 rections of psoriasis and comorbid research;
15 (4) the nonprofit and private sector meeting
16 conveners should disseminate to the public, Con-
17 gress, and other relevant public and private policy-
18 making and research entities a report that includes
19 findings from the scientific meeting and suggestions
20 regarding next steps, including recommendations
21 from the National Institutes of Health and other rel-
22 evant Federal agencies; and
23 (5) utilizing the information produced by the
24 scientific meeting regarding future directions of pso-
25 riasis and comorbid research, the Secretary of

1 Health and Human Services, acting through the Di-
2 rector of the National Institutes of Health, and in
3 conjunction with the National Institute for Arthritis,
4 Musculoskeletal, and Skin Diseases and other insti-
5 tutes and centers of the National Institutes of
6 Health, is encouraged to explore the development of
7 a virtual Center of Excellence for Collaborative Dis-
8 covery in Psoriasis and Comorbid Research or some
9 other mechanism through which public and private
10 sector findings regarding psoriasis and its comorbid
11 conditions can be regularly shared and leveraged.

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