

111TH CONGRESS
1ST SESSION

H. R. 930

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.

IN THE HOUSE OF REPRESENTATIVES

FEBRUARY 10, 2009

Mr. WU (for himself, Mr. GERLACH, Ms. WASSERMAN SCHULTZ, Mr. PLATTS, Mr. GRIJALVA, Mr. HINOJOSA, Mr. KING of New York, Mr. LARSON of Connecticut, Mr. MCNERNEY, Ms. ZOE LOFGREN of California, Mr. KENNEDY, Mr. BLUMENAUER, Mr. GENE GREEN of Texas, Mr. DELAHUNT, Mr. HOLT, and Mr. BACA) introduced the following bill; which was referred to the Committee on Energy and Commerce

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”.

1 **SEC. 2. TABLE OF CONTENTS.**

2 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.

3 **SEC. 3. FINDINGS.**

4 The Congress finds as follows:

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

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

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

1 (4) Psoriasis goes hand-in-hand with myriad co-
2 morbidities such as Crohn's disease, diabetes, meta-
3 bolic syndrome, obesity, hypertension, heart attack,
4 cardiovascular disease, liver disease, and psoriatic
5 arthritis, which occurs in 10 to 30 percent of people
6 with psoriasis.

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

12 (6) Psoriasis is associated with elevated rates of
13 depression and suicidal ideation.

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

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

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

23 (10) Treating psoriasis and psoriatic arthritis
24 presents a challenge for patients and their health
25 care providers because no one treatment works for

1 everyone, some treatments lose effectiveness over
2 time, many treatments are used in combination with
3 others, and all treatments may cause a unique set
4 of side effects.

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

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

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

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

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

1 (1) IN GENERAL.—The directors of the Na-
2 tional Institute of Arthritis and Musculoskeletal and
3 Skin Diseases and the National Institute of Allergy
4 and Infectious Diseases shall continue to conduct
5 and support research to expand understanding of
6 the causes of, and to find a cure for, psoriasis and
7 psoriatic arthritis, including the following:

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

10 (B) Expansion of molecular biology and
11 immunology studies, including additional animal
12 models.

13 (C) Global association mapping with single
14 nucleotide polymorphisms.

15 (D) Identification of environmental trig-
16 gers and autoantigens in psoriasis.

17 (E) Elucidation of specific immunologic
18 cells and their products involved.

19 (F) Pharmacogenetic studies to understand
20 the molecular basis for varying patient response
21 to treatment.

22 (G) Identification of genetic markers of
23 psoriatic arthritis susceptibility.

1 (H) Research to increase understanding of
2 joint inflammation and destruction in psoriatic
3 arthritis.

4 (I) Investigator-initiated clinical research
5 for the development and evaluation of new
6 treatments, including new biological agents.

7 (J) Research to develop enhanced diag-
8 nostic tests that allow for earlier diagnosis of
9 psoriasis and improved outcomes.

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

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

1 **SEC. 5. PSORIASIS AND PSORIATIC ARTHRITIS DATA COL-**
2 **LECTION AND NATIONAL PATIENT REGISTRY.**

3 The Secretary, acting through the Director of the
4 Centers for Disease Control and Prevention and in col-
5 laboration with a national organization serving people with
6 psoriasis and psoriatic arthritis, shall undertake psoriasis
7 and psoriatic arthritis data collection and develop a psori-
8 asis and psoriatic arthritis patient registry.

9 **SEC. 6. NATIONAL SUMMIT.**

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

1 the Food and Drug Administration, and the National In-
2 stitutes of Health.

3 (b) FOCUS.—The summit convened under this section
4 should focus on—

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

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

11 (3) translational research;

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

14 (5) priorities among the programs and activities
15 of the various Federal agencies involved in psoriasis
16 and psoriatic arthritis and related co-morbidities;
17 and

18 (6) challenges, opportunities, and recommenda-
19 tions for scientists, clinicians, patients, and vol-
20 untary organizations.

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

25 (1) the proceedings at the summit; and

1 (2) recommendations related to the research,
2 treatment, education, and quality-of-life activities
3 conducted or supported by the Federal Government
4 with respect to psoriasis and psoriatic arthritis, in-
5 cluding psoriasis and psoriatic arthritis related co-
6 morbidity.

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

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

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

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

21 (3) Health plan and insurer coverage policies
22 and practices, including life-time caps, and their im-
23 pact on the access of such patients to the best regi-
24 men and most appropriate care for their particular
25 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 the Congress, not later
4 than 18 months after the date of the enactment of this
5 Act, a report containing a description of—

6 (1) the results of the study conducted under
7 this section; and

8 (2) the conclusions and recommendations of the
9 Institute of Medicine regarding each of the issues
10 described in paragraphs (1) through (3) of sub-
11 section (a).

12 **SEC. 8. AUTHORIZATION OF APPROPRIATIONS.**

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

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