

**National Psoriasis Foundation**  
**Written Testimony to the House Labor-Health and Human Services**  
**Appropriations Subcommittee**  
**Regarding Fiscal Year 2008 Psoriasis and Psoriatic Arthritis Research Funding**  
**Submitted by: Gail Zimmerman, CEO National Psoriasis Foundation**  
**March 30, 2007**

**Introduction and Overview**

The National Psoriasis Foundation (the Foundation) appreciates the opportunity to submit written testimony for the record regarding federal funding for psoriasis and psoriatic arthritis research for Fiscal Year (FY) 2008. The Foundation serves as the nation's largest patient-driven non-profit voluntary association committed to improving the quality of life for the millions of people affected by psoriasis and psoriatic arthritis.

As part of our mission, we educate health professionals, the public and policymakers to increase public awareness and understanding of the challenges people with psoriasis and psoriatic arthritis face. Moreover, the Foundation maintains a strong commitment to securing public policies and programs that support its focus of education, advocacy and research toward better treatments and a cure. The Foundation specifically seeks to advance public and private efforts to improve treatment of these diseases, identify a cure and ensure that all people with psoriasis and psoriatic arthritis have access to the medical care and treatment options they need to live the highest quality of life possible.

The Foundation stands ready to work with policymakers at the local, state and federal levels to advance policies and programs that will reduce and prevent suffering from psoriasis and psoriatic arthritis. Specifically, the Foundation advocates that the National Institutes of Health (NIH) be given additional resources to support new investigator-initiated research grants for genetic, clinical, and basic research related to the understanding of the cellular and molecular mechanisms of psoriasis and psoriatic arthritis, as well as studies to understand co-morbidities such as obesity, depression, and heart disease that may be associated with inflammation in the skin and joints. Specifically, we respectfully call upon Congress to boost psoriasis and psoriatic arthritis research efforts by allocating a 6.7% increase in FY 2008 to NIH and its institutes and centers that play an integral role in psoriasis and psoriatic arthritis research:

- The National Institute of Arthritis and Musculoskeletal and Skin Diseases (NIAMS);
- The National Institute of Allergy and Infectious Diseases (NIAID);
- The National Human Genome Research Institute (NHGRI);
- The National Institute for Environmental Health Systems (NIEHS);
- The National Institute of Mental Health (NIMH);
- The National Center for Complementary and Alternative Medicine (NCCAM); and
- The National Center for Research Resources (NCRR).

In addition, the Foundation urges the Subcommittee to encourage the Centers for Disease Control and Prevention (CDC) to strengthen patient data collection on psoriasis to improve the knowledge base of the longitudinal impact of these diseases on the individuals they affect. The Foundation believes that a greater investment in NIH, NIAMS, NIAID, NHGRI, NIEHS, NIMH, NCCAM, NCRR, and CDC will lead to the development of new, safe, effective and long-lasting treatments and a cure for psoriasis and psoriatic arthritis.

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**The Impact of Psoriasis and Psoriatic Arthritis**

According to the NIH, as many as 7.5 million Americans have psoriasis – an immune-mediated genetic chronic, inflammatory, painful, disfiguring, and life-altering disease that requires life-long sophisticated medical intervention and care, has no cure and imposes serious adverse effects on the individuals and families affected. On average, 17,000 people with psoriasis live in each Congressional District.

Psoriasis most often first strikes between the ages of 15 and 25 and lasts a lifetime. Unfortunately, psoriasis often is overlooked or dismissed because it typically does not cause death. It is commonly and incorrectly considered by insurers, employers, policymakers, and the public as a mere annoyance – a superficial problem, mistakenly thought to be contagious and/or due to poor hygiene. Yet, together psoriasis and psoriatic arthritis impose significant economic costs on individuals and society. Each year, Americans with psoriasis lose approximately 56 million hours of work and spend \$2 billion to \$3 billion to treat the disease.

There is mounting evidence that people with psoriasis are at elevated risk for myriad other serious, chronic and life-threatening conditions. Although data are still emerging on the relationship of psoriasis to other diseases and their ensuing costs to the medical system, it is clear that psoriasis goes hand-in-hand with co-morbidities such as Crohn's disease, diabetes, metabolic syndrome, obesity, hypertension, heart attack, cardiovascular disease, liver disease and psoriatic arthritis – which occurs in 10 percent to 30 percent of people with psoriasis. Of serious concern is that studies have shown that psoriasis causes as much disability as other major chronic diseases and individuals with psoriasis are twice as likely to have thoughts of suicide as people without psoriasis or with other chronic conditions.

Despite some recent breakthroughs, many people with psoriasis and psoriatic arthritis remain in need of improved quality of life and effective, safe, and affordable therapies, which could be delivered through an increased federal commitment to genetic, clinical and basic research. Research holds the key to improved treatment of these diseases, better diagnosis of psoriatic arthritis and eventually a cure for both conditions.

**Federal Psoriasis and Psoriatic Arthritis Research**

While our nation has benefited from past federal investment in the NIH, unfortunately psoriasis and psoriatic arthritis research progress has not keep pace with other chronic conditions. An analysis of longitudinal federal funding data shows that, on average over the past decade, NIAMS has spent less than \$1 per person with psoriasis per year. At the historical and current rate of psoriasis funding, NIH funding is not keeping pace with research needs.

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While recent correspondence from NIAMS to Congress, indicates that the three principal agencies involved in psoriasis and psoriatic arthritis research are NIAMS, NCRR and NHGRI, the Foundation knows from meetings at NIH that other federal research agencies – such as NIAID, NIEHS, NIMH, and NCCAM – have important roles to play in psoriasis and psoriatic arthritis and understanding their health and psychosocial impact on affected individuals. We hope that the Subcommittee will provide all seven of the aforementioned institutes and centers with increased FY 2008 funding and encourage them to undertake and/or expand psoriasis and psoriatic arthritis research.

The Foundation has joined with the broader health community in advocating \$30.8 billion for the NIH in FY 2008. This level of investment will allow NIH to sustain and build on its research progress resulting from the recent NIH budget doubling effort while avoiding the severe disruption to that progress that would result from a minimal increase. More than ever, a greater investment today in psoriasis and psoriatic arthritis will go farther faster and help the nation turn the corner on finding a cure for these two life-altering, disfiguring diseases.

Specifically, we urge the Subcommittee to provide NIH and the aforementioned institutes and centers with a 6.7% increase in FY 2008 funding so they can undertake the following:

- Genetic, clinical, and basic research related to the understanding of the cellular and molecular mechanisms of psoriasis and psoriatic arthritis research;
- Efforts to identify the major psoriasis gene as well as others that contribute to psoriasis and/or psoriatic arthritis genetic susceptibility;
- Biomarker work to identify psoriasis and psoriatic arthritis genetic susceptibility;
- Studies to understand individual response to particular therapies for psoriasis and psoriatic arthritis to help determine if psoriatic arthritis can be prevented in those who are at risk;
- Examination of joint inflammation and the associated damage caused by psoriatic arthritis;
- Identification and study of immune cells and inflammatory processes involved in psoriasis;
- Studies to increase understanding of the role of inflammation in skin and joints;
- Efforts to understand co-morbidities such as obesity, depression, heart disease and heart attack to be associated with inflammation in the skin and joints and the interplay between inflammation and such co-morbidities found disproportionately among individuals with psoriasis;
- Research to increase the understanding between psoriasis and mental health conditions, such as depression;
- Development/validation of instruments to measure the mental health impact of psoriasis;
- Inter-institute efforts to identify any underlying biological reasons for the high rate of mental health issues among people with psoriasis, and study the impact of the negative social and psychological impact of psoriasis on disease state;

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- Identification of environmental and lifestyle triggers associated with psoriasis onset, flares, and disease state which will help in the development of appropriate therapies and interventions; and
- Evaluation of the effectiveness of complementary and alternative therapies for the treatment of psoriasis and/or psoriatic arthritis.

**The Role of CDC in Psoriasis and Psoriatic Arthritis Research**

The Foundation is concerned that there have been very few efforts to collect epidemiological and other related data on individuals with psoriasis and psoriatic arthritis. Researchers and clinicians continue to be limited in their longitudinal understanding of these conditions and their effects on individual patients. The Foundation hopes that the Subcommittee will encourage the National Center for Health Statistics (NCHS) to add psoriasis and psoriatic arthritis specific components to the 2009-2010 National Health and Nutrition Examination Survey (NHANES). In addition, we ask that the Subcommittee encourage the National Center for Chronic Disease Prevention and Health Promotion (NCCDPHP) within the CDC to examine and develop options and recommendations for the creation of a National Psoriasis and Psoriatic Arthritis Patient Registry in FY 2009. A national patient registry that collects longitudinal patient data will help researchers to learn about key attributes such as response to treatment, substantiating the waxing and waning of psoriasis, understanding associated manifestations like nail disease and arthritis, and the relationship of psoriasis to other public health concerns.

**Conclusion**

On behalf of the Foundation's Board of Trustees and the millions of individuals with psoriasis and psoriatic arthritis who we represent, thank you for this opportunity to submit written testimony regarding the FY 2008 funding levels necessary to ensure that our nation adequately addresses psoriasis and psoriatic arthritis and to make gains in improving therapies and eventually attaining a cure. We thank you in advance for encouraging the NCHS and the NCCDPHP to become more engaged in psoriasis and psoriatic arthritis data collection. We believe that additional research undertaken at the NIH coupled with epidemiologic efforts at the CDC together will help advance the nation's efforts to improve treatments and identify a cure for psoriasis and psoriatic arthritis. Please feel free to contact us at any time; we are happy to be a resource to Subcommittee members and your staff. We very much appreciate the Subcommittee's attention to our requests.