



NATIONAL  
**PSORIASIS**  
FOUNDATION®

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# REPORT

## on the Psycho-Social Impacts of Psoriasis

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Psoriasis and work

Psoriasis and well-being

Impact on women, minorities and young people

Impact on uninsured

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## National Psoriasis Foundation Report on the Psycho-Social Impacts of Psoriasis

### Summary

This report is the culmination of the largest longitudinal study to date of the psycho-social impacts of psoriasis on individuals. Over a period of six years, the National Psoriasis Foundation collected responses to questions about the emotional and social effects of psoriatic diseases from nearly 5,000 people with psoriasis and/or psoriatic arthritis. The results of this study highlight sharp differences in the negative impact psoriasis has on various populations including women, minorities and young people. The National Psoriasis Foundation will use this information to design and deliver programs and services that continue to assist these populations in coping with and managing their condition.

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## Introduction

**P**soriasis is a noncontagious genetic disease that results when faulty signals in the immune system prompt skin cells to regenerate too quickly, causing red, scaly lesions that can crack and bleed. It is the most common autoimmune disorder in the United States, affecting as many as 7.5 million people, or about 2 percent of the population. Up to 30 percent of people with psoriasis also develop psoriatic arthritis, an inflammatory disease which causes pain, stiffness and swelling in and around the joints.

The National Psoriasis Foundation is the world's largest organization serving people with psoriasis and psoriatic arthritis. In addition to assisting approximately 1.5 million people annually through educational programs and services, the Psoriasis Foundation is the largest psoriasis patient advocacy organization and charitable funder of psoriatic disease research worldwide.

Each spring and fall from 2004 to 2009, the National Psoriasis Foundation conducted telephone and Internet surveys of people diagnosed with psoriasis and/or psoriatic arthritis. The study collected data on the extent and severity of the respondents' disease(s); age at onset; concurrence with other diseases; treatments and treatment success; insurance coverage; and psycho-social aspects of the diseases, as well as basic demographic information.

The large body of data acquired through these surveys reveals patterns that add to the urgency of dedicating more resources to addressing this serious disease.

In addition to reinforcing scientifically identified trends in the occurrence of other serious diseases among people with psoriasis, the survey data reveal the deep impact of psoriasis and psoriatic arthritis on the emotional and social lives of people with the diseases. The survey findings also show striking differences in the psycho-social impacts of the diseases on women, minorities and people without health insurance coverage.

This report summarizes the results of the six years of data collection, and concludes with recommendations for policymakers and health care practitioners on steps to address the issues highlighted by this study.

**6 YEARS**  
**OF SUMMARIZED**  
**DATA IN**  
**THIS REPORT**

# Introduction

## Methodology

The data discussed in this report were obtained from telephone and Internet surveys conducted in 11 waves beginning in the spring of 2004 and ending in the spring of 2009. **The researchers obtained 4,725 valid survey responses.**

The survey panel contained core questions asked in each wave and specialty questions asked sporadically, based on the information needs of the Psoriasis Foundation or survey partners. Potential respondents were randomly selected from the National Psoriasis Foundation database, and included members and nonmembers.

Respondents were screened so that 75 percent had moderate to very severe disease (based on expected body surface area [BSA] coverage of 3 percent or greater without medication). The remaining 25 percent of the respondents had mild disease (under 3 percent BSA). Quotas were also established for a gender split and an approximate normal distribution of age.

## Demographics of Survey Respondents

**GENDER:** The survey respondents were **59 percent female, 41 percent male.** The prevalence of psoriasis in the general population is evenly split.<sup>1</sup>

**AGE:** Seventy-three percent of survey respondents were over age 40; 17 percent ages 30 to 39; 9 percent ages 20 to 29; and less than 1 percent ages 10-19.

**RACE AND ETHNICITY:** Eighty-seven percent of respondents identified their race as Caucasian; 2 percent African American; 2 percent Asian American; 4 percent Hispanic/Latino/Mixed ethnicity and 1 percent Native American. Clinical findings indicate that psoriasis prevalence varies with ethnicity and is lower in people of Asian and some African descents.<sup>2</sup>



1. National Institutes of Health/ National Institute of Arthritis and Musculoskeletal and Skin Diseases, [http://www.niams.nih.gov/Health\\_Info/Psoriasis/default.asp](http://www.niams.nih.gov/Health_Info/Psoriasis/default.asp), August 24, 2009.
2. van de Kerkhof, Peter, Textbook of Psoriasis, Second Edition. Malden, Mass.: Blackwell, 2003. p. 58.

# Introduction

**INCOME:** The median household income of survey respondents was \$62,500. The income information was not adjusted for inflation when averaged across the response years. This median income was significantly higher than the median household income reported by the U.S. Census Bureau of \$50,233 in 2007.<sup>3</sup>

**EDUCATION:** The educational attainment of the survey respondents was generally greater than the general population. Only 2 percent of respondents did not graduate high school, compared with 16 percent of the general population; 30 percent of respondents had a high school diploma or equivalency, twice the rate of attainment of the general population; 29 percent of respondents had a bachelor's or associate degree, compared with 25 percent of the general population; and 21 percent of the respondents had some postgraduate training compared with 10 percent of the general population.<sup>4</sup>

## Disease characteristics

The average age of onset for psoriasis among respondents was about 28 years for both males and females. This is consistent with a range of average ages found in scientific literature about psoriasis.<sup>5</sup> The average age of onset for psoriatic arthritis was 38 years for males, nearly 40 years for females.

**62%** HAD PSORIASIS ALONE  
**38%** ALSO HAD PSORIATIC ARTHRITIS

Of the 4,725 people responding to the survey, 62 percent (n=2,952) had psoriasis alone; 38 percent (n=1,773) also had psoriatic arthritis.

3. DeNavis-Walt, Carmen, et al, Income, Poverty and Health Insurance Coverage in the United States, 2007. United States Census Bureau, 2008. p. 6. <http://www.census.gov/prod/2008pubs/p60-235.pdf>. August 24, 2009.
4. United States Census Bureau, 2005-2007 American Community Survey 3-year estimates. [http://factfinder.census.gov/servlet/STTable?\\_bm=y&-qr\\_name=ACS\\_2007\\_3YR\\_G00\\_S1501&-geo\\_id=01000US&-ds\\_name=ACS\\_2007\\_3YR\\_G00\\_&-lang=en&-format=&-CONTEXT=st](http://factfinder.census.gov/servlet/STTable?_bm=y&-qr_name=ACS_2007_3YR_G00_S1501&-geo_id=01000US&-ds_name=ACS_2007_3YR_G00_&-lang=en&-format=&-CONTEXT=st). August 25, 2009.

# Introduction

## Key Findings: The psycho-social aspects of psoriasis

A number of recent scientific reports have identified significant comorbidity between psoriasis and other life-threatening diseases including diabetes mellitus, heart disease, high cholesterol, obesity, hypertension and depression. The associated diseases are more likely to occur in people with psoriasis than in the general population even when behavioral risk factors are factored out.<sup>6</sup>

The data from the 2004-2009 survey panels corroborate these findings, in particular the incidence of obesity and high cholesterol in psoriasis patients. Of survey respondents, 68 percent reported being overweight or obese, compared with 63.2 percent of the general population<sup>7</sup> ; and 24 percent reported having elevated cholesterol levels, compared with about 17 percent of adult Americans.<sup>8</sup> In addition, 28 percent of respondents stated they have another chronic, inflammatory disease such as lupus, Crohn's disease or multiple sclerosis.

In addition to its physical impact, psoriasis affects patients socially, emotionally and professionally. Scientific studies have identified links between psoriasis and depression and suicidal ideation. The data collected in these survey panels paint a vivid picture of the day-to-day impact of living with this disease.

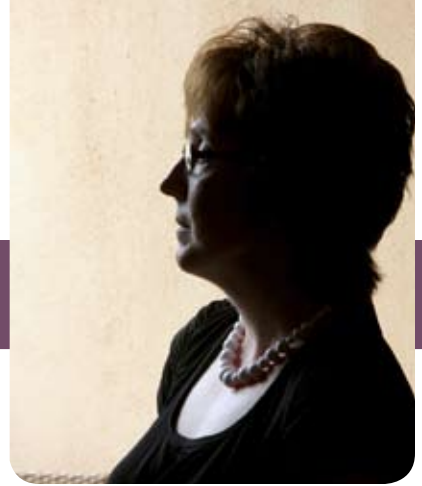
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**28%** OF RESPONDENTS STATED THEY HAVE ANOTHER CHRONIC, INFLAMMATORY DISEASE SUCH AS LUPUS, CROHN'S DISEASE OR MULTIPLE SCLEROSIS.

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5. van de Kerkhof, p. 59
  6. Kimball, Alexa B., et al. National Psoriasis Foundation clinical consensus on psoriasis comorbidities and recommendations for screening. *Journal of the American Academy of Dermatology*, Volume 58, Issue 6, pp. 1031-1042
  7. Centers for Disease Control and Prevention/National Center for Chronic Disease Prevention & Health Promotion Behavioral Risk Factor Surveillance System. Prevalence and Trends Data Overweight and Obesity (BMI) – 2008, <http://apps.nccd.cdc.gov/brfss/list.asp?cat=OB&yr=2008&qkey=4409&state=All>. August 25, 2009
  8. Centers for Disease Control and Prevention, <http://www.cdc.gov/cholesterol/>. August 25, 2009

## Psoriasis and work



**S**ixty percent of survey respondents were working full or part time at the time of the surveys. This is equal to the rate of employment of the general population around the time of the surveys (2005-2007 average). However it is likely lower than work-force participation among a segment of the general population with similar educational attainment.

Furthermore, of those who are not working, more than a quarter reported that this was due wholly or in part to their psoriasis and/or psoriatic arthritis. The effect of psoriatic arthritis on work-force participation was particularly pronounced: Among respondents with psoriatic arthritis who are not working, 44 percent said this was due wholly or in part to their disease(s).

**44%** **RESPONDENTS WITH PSORIATIC ARTHRITIS WHO ARE NOT WORKING SAID THIS WAS DUE WHOLLY OR IN PART TO THEIR DISEASE(S).**

disease(s) and among those with very severe disease (more than 20 percent BSA), 47 percent who were not working said it was to some extent because of their disease(s).

The severity of the disease(s) also appears to affect participation in the work force. Among respondents with severe (more than 10 percent BSA) psoriasis or psoriatic arthritis who are not working, 32 percent said this was due wholly or in part to their

# Psoriasis and well-being



Survey responses make it clear that psoriasis and psoriatic arthritis have significant impact on the quality of life for people with these diseases.

## Impact on appearance and self-esteem

- 73 percent of respondents said they feel **SELF-CONSCIOUS** about their psoriasis.
- 68 percent said they feel **EMBARRASSED** with regard to their psoriasis.
- 65 percent said that psoriasis makes their appearance unsightly.
- 54 percent said their **PSORIASIS IS DISFIGURING**.
- 41 percent said they change their choice of clothing to conceal psoriasis.

## Emotional impact

- 73 percent of respondents said they **FEEL ANGRY OR FRUSTRATED** with regard to their psoriasis.
- 71 percent said they **FEEL HELPLESS** with regard to their psoriasis.
- 56 percent said psoriasis interferes with their capacity to enjoy life.
- 63 percent said psoriasis impacts their overall emotional well being.

**63%** SAID PSORIASIS IMPACTS THEIR OVERALL EMOTIONAL WELL BEING

## Quality of life impact

- 72 percent of respondents suffer from **ITCHING**, 70 percent from **PHYSICAL IRRITATION**, and 59 percent from **PHYSICAL PAIN** from psoriasis.
- 59 percent said psoriasis was a large problem in their everyday lives.
- An additional 17 percent said the disease is a **VERY LARGE PROBLEM** in their everyday lives.

## Pronounced impacts on women, minorities and young people



Many of the impacts described on the previous page were more pronounced for women than for men, for younger people with the disease, and for non-white respondents.

### Impacts on women

Psoriasis appears to have a greater impact on women's lives across all the psycho-social measures used in this survey. In addition, **women with psoriasis are three times more likely than men to suffer from several comorbid diseases, such as lupus and multiple sclerosis.**

**Psoriasis has a greater OVERALL IMPACT on women's day-to-day well-being:**

- Twenty percent of women said psoriasis is a very large problem in their everyday lives, compared with just 12 percent of men.
- Women were 26 percent less likely than men to describe psoriasis as "just an annoyance," (23 percent vs. 31 percent).
- Women were 17 percent more likely than men to report that they experience itching, 16 percent more likely to report physical irritation, and 24 percent more likely to report pain from psoriasis.

**20% WOMEN SAID PSORIASIS IS A VERY LARGE PROBLEM IN THEIR EVERYDAY LIVES**

**12% MEN SAID PSORIASIS IS A VERY LARGE PROBLEM IN THEIR EVERYDAY LIVES**

## Impacts on women, cont'd.



### Psoriasis has a greater **EMOTIONAL IMPACT** on women than on men.

- Two-thirds of women (67 percent) said that psoriasis negatively affects their overall emotional well-being, compared with 57 percent of men.
- More than three-quarters (77 percent) of women said they feel angry or frustrated in regard to their psoriasis, compared with 68 percent of men.
- Women were also more likely than men to say they feel embarrassed (71 percent vs. 65 percent) and helpless (73 percent vs. 69 percent) in regard to their psoriasis.
- Women were 12 percent more likely than men to say psoriasis interferes with their capacity to enjoy life (59 percent vs. 52 percent).

### Women are particularly sensitive to the **EFFECT OF PSORIASIS ON THEIR APPEARANCE.**

- 57 percent of women said their psoriasis is disfiguring, compared with 48 percent of men.
- 68 percent of women said psoriasis makes their appearance unsightly compared with 61 percent of men.
- Women were 33 percent more likely to say they alter their clothing choices to conceal psoriasis (48 percent vs. 32 percent).

**33%** NUMBER OF WOMEN MORE LIKELY THAN MEN TO SAY THEY ALTER THEIR CLOTHING CHOICES TO CONCEAL PSORIASIS

( **48%** WOMEN  
**32%** MEN )

## Impacts on minorities



Like women, minority respondents reported a greater impact of psoriasis and psoriatic arthritis on their daily lives. These differences may be due in part to the greater prevalence of very severe disease in the minority respondent group. While only 8 percent of Caucasians had very severe psoriasis, 10-23 percent in other racial groups had very severe psoriasis. Nearly a quarter of African American (23 percent) respondents had very severe psoriasis.

- 72 percent of minority respondents said psoriasis interfered with their capacity to enjoy life, compared with just 54 percent of Caucasian respondents.
- 75 percent said psoriasis impacted their overall emotional well-being, compared with 62 percent of Caucasian respondents.
- Minority respondents were also more likely than Caucasian respondents to feel self-conscious (86 percent vs. 72 percent), embarrassed (79 percent vs. 67 percent), angry or frustrated (82 percent vs. 72 percent) and helpless (79 percent vs. 70 percent).
- Like women, minority respondents were more likely to say that psoriasis made their appearance unsightly (77 percent vs. 64 percent), that their psoriasis was disfiguring (65 percent vs. 52 percent), and that they choose clothing to conceal psoriasis (53 percent vs. 40 percent).

**72%** MINORITY RESPONDENTS SAID PSORIASIS INTERFERED WITH THEIR CAPACITY TO ENJOY LIFE

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**54%** CAUCASIAN RESPONDENTS SAID PSORIASIS INTERFERED WITH THEIR CAPACITY TO ENJOY LIFE

## Impacts on younger people



The emotional and social impacts from the disease also appear to be more pronounced for people under age 40 than for older respondents. Most strikingly:

- 84 percent of those aged 20 to 39 said they felt angry or frustrated with regard to psoriasis, compared with 69 percent of respondents over 40.
- 81 percent of those aged 20 to 39 said they felt embarrassed with regard to psoriasis, compared with 64 percent of respondents over 40.
- 83 percent of those aged 20 to 39 said they felt helpless with regard to psoriasis, compared with 67 percent of respondents over 40.
- 74 percent of those aged 20 to 39 said psoriasis had a large impact on their overall emotional well-being, compared with 59 percent of respondents over 40.
- 43 percent of those aged 20 to 29 said the statement “it is a social embarrassment” best described their psoriasis, compared with just 17 percent of those over 40.

**43%** : Ages 20-29

VS.

**17%** : Ages 40+

**SAID THE STATEMENT “IT IS  
A SOCIAL EMBARRASSMENT”  
BEST DESCRIBED THEIR  
PSORIASIS**

## Uninsured report greater impacts from psoriasis and psoriatic arthritis



The survey results also indicate that having no health insurance makes managing psoriasis and its related health issues even tougher. Respondents without health insurance were likely to report more extensive body coverage with psoriasis plaques, more pain and irritation, and greater psycho-social impacts than respondents who did have insurance.

### Inadequate care

- 17 percent of people with no insurance have not seen a doctor for their psoriasis in the past two years, compared with 7 percent of those who did have insurance.
- 70 percent reported that this is due to cost.
- More than half (51 percent) of those who lacked insurance were dissatisfied with the care they have received.

### Unemployment and income

- A quarter of respondents with no insurance are out of work.
- The uninsured are twice as likely to report that they are not working due totally or in part to their psoriatic disease (50 percent vs. 27 percent).
- Uninsured survey respondents had a median income of \$22,500, 36 percent of the median income of insured respondents.

**17%** OF PEOPLE WITH NO INSURANCE HAVE NOT SEEN A DOCTOR FOR THEIR PSORIASIS IN THE PAST TWO YEARS

**7%** OF PEOPLE WITH INSURANCE HAVE NOT SEEN A DOCTOR FOR THEIR PSORIASIS IN THE PAST TWO YEARS

**70%**  
REPORTED THAT THIS IS  
DUE TO COST.

# Uninsured report greater impacts from psoriasis and psoriatic arthritis, cont'd.

## Physical and emotional impacts

Overall, 86 percent of uninsured respondents reported that psoriasis is a “somewhat” to “very large” problem in their lives, compared with 75 percent of those with insurance. These respondents endure greater physical, emotional and social impacts than their insured peers.

### Physical impacts:

- 35 percent of those without insurance reported extensive to very extensive psoriasis coverage at the time of the survey, compared with 25 percent of patients with insurance.
- The uninsured were more likely than those with insurance to report itching (86 percent vs. 70 percent), physical irritation (83 percent vs. 69 percent), and physical pain (71 percent vs. 57 percent) from their disease.

### Emotional and social impacts:

- Three-quarters of patients without insurance said psoriasis interferes with their capacity to enjoy life, compared with 54 percent of those with insurance.
- 79 percent of uninsured respondents said their psoriasis impacts their overall emotional well-being, compared with 61 percent of those with insurance.
- Those without insurance felt more helpless (85 percent vs. 69 percent) and angry (86 percent vs. 71 percent) than insured respondents with regard to their psoriasis.
- They also felt more embarrassed (84 percent vs. 66 percent), self-conscious (86 percent vs. 71 percent), and were more likely to choose clothing that concealed their psoriasis (57 percent vs. 39 percent).

**57%** Uninsured

VS.

**17%** Insured

**WERE MORE LIKELY TO  
CHOOSE CLOTHING THAT  
CONCEALED THEIR PSORIASIS**

## Conclusions and recommendations

The results presented here draw from the most extensive data collection effort conducted to date on the psycho-social aspects of psoriasis and psoriatic arthritis.

While many of the effects described above are well-known anecdotally, the data highlight the particular difficulties of living with diseases that can both disable and disfigure, diseases that are neither well-known nor well-understood. Taken together, these findings reveal an interconnected web of issues:

- The extent of emotional distress revealed by these data has implications for the progression and treatment of the diseases themselves, as stress is a documented trigger for flares of both psoriasis and psoriatic arthritis.
- **EMOTIONAL DISTRESS IS VERY LIKELY A TRIGGER** for mental health comorbidities such as **DEPRESSION AND SUICIDAL THOUGHTS**.
- Absence from the work force due to psoriasis may result in not only lost productivity and potential financial hardship, but in further emotional and mental distress.
- The emotional and social **IMPLICATIONS OF THE DISEASE ARE GREATEST FOR WOMEN AND MINORITIES**—classes of people who already bear the burdens of difference and discrimination.

**The findings have significant implications for psoriasis treatment, research and activism.**

- People with psoriasis **NEED ADEQUATE MEDICAL CARE** to manage their condition, and **INSURANCE COVERAGE** that ensures that care. Successful disease management is likely to lessen both the physical and emotional toll of psoriasis and psoriatic arthritis.
- Support and tools for managing the emotional stress that both results from and contributes to their physical disease should be a part of psoriasis and psoriatic arthritis treatment plans.
- Particular attention should be paid to ensuring that women and minorities receive the care they need for the physical and emotional aspects of the disease.
- **SUPPORT FROM PEER GROUPS** such as those found in the National Psoriasis Foundation's Internet chat rooms, local support groups and disease mentor program have been shown to **REDUCE THE STRESS** associated with these diseases. These programs require adequate funding and support to continue and expand.

## Conclusions and recommendations, cont'd.

### How the National Psoriasis Foundation is addressing these issues

Ultimately, the psycho-social issues highlighted by this data will persist until a cure is discovered for psoriasis and psoriatic arthritis. The National Psoriasis Foundation is working to find a cure and improve life for people with psoriasis and psoriatic arthritis by:

- **INVESTING IN RESEARCH** that will lead most directly and swiftly lead to a cure.
- **ADVOCATING FOR INCREASED FEDERAL SUPPORT** for psoriasis research from the National Institutes of Health (NIH).
- **WORKING WITH HEALTH CARE INSURERS**, government and individuals to end harmful health insurance policies and procedures.
- **EDUCATING INDIVIDUALS** and health care practitioners about the most current developments in treating psoriasis and psoriatic arthritis.
- **PROVIDING EDUCATIONAL RESOURCES** and support to people with psoriasis and psoriatic arthritis.

To achieve this ambitious agenda, the National Psoriasis Foundation relies on a network of thousands of volunteers working in communities across the country. For more information go to [www.psoriasis.org](http://www.psoriasis.org) or call 800.723.9166.