

# National Psoriasis Foundation: A Patient-Centric Approach to Improve Access to Psoriatic Disease Treatment

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**P**soriasis is the most prevalent autoimmune disease in the United States, affecting approximately 3% of the adult US population.<sup>1</sup> Up to 30% of individuals with psoriasis may also develop psoriatic arthritis, an inflammatory form of arthritis that can lead to irreversible joint damage if left untreated.<sup>2</sup> Beyond the physical pain and discomfort of these diseases, individuals living with psoriatic disease also face higher incidence of comorbid health conditions, including cardiovascular disease,<sup>3,4</sup> diabetes,<sup>3,5</sup> hypertension,<sup>5,6</sup> and stroke.<sup>7</sup> A higher prevalence of atherosclerosis,<sup>4</sup> Crohn's disease,<sup>8</sup> cancer,<sup>9</sup> metabolic syndrome,<sup>10,11</sup> obesity,<sup>12</sup> and liver disease<sup>6</sup> are also found in patients with psoriasis compared with the general population. In National Psoriasis Foundation (NPF) surveys, roughly two-thirds of people with psoriasis and/or psoriatic arthritis said their disease made them feel angry, frustrated, and/or helpless. More than half said psoriasis interfered with their ability to enjoy life, nearly 30% suffer from depression, and 88% of family members report the same levels of depression and anxiety as those with psoriasis.<sup>13</sup>

## Psoriasis and Psoriatic Arthritis: The Need for Early, Effective Treatment

As a heterogeneous chronic autoimmune disease, psoriatic disease requires sophisticated medical care. Without the tools to control their symptoms, people with psoriatic disease cycle through periods of intense pain, fatigue, unbearable itching, whole-body inflammation, flaking and bleeding of large swaths of the skin, and joint degradation. Recent research also suggests that the risk for comorbidities may increase with the severity of psoriatic disease, thereby magnifying the critical need for effective treatment options.<sup>14</sup>

The introduction of biological-based therapies more than a decade ago was a “revolution” that has greatly improved the treatment of psoriasis.<sup>15</sup> Today, physicians may choose among topicals, phototherapy, traditional systemic

## ABSTRACT

Psoriasis and psoriatic arthritis are serious autoimmune diseases requiring lifelong management and support. Uncontrolled psoriatic disease wields a significant impact on the lives of those affected, resulting in lowered quality of life, disability, depression, increased risk of related illnesses (eg, heart disease, diabetes), and early mortality. In National Psoriasis Foundation (NPF) surveys, roughly two-thirds of patients with psoriasis and/or psoriatic arthritis said their disease made them feel angry, frustrated, and/or helpless, and more than half said psoriasis interfered with their ability to enjoy life.

The economic burden of psoriasis is equally daunting, and NPF surveys consistently report cost to be a significant barrier to treatment. This challenge is one of many reasons the NPF launched an aggressive strategic plan in 2014 intended to: 1) cut in half the number of patients who report that their condition is a problem in everyday life, 2) increase by 50% the number of patients receiving the right treatment, and 3) double the number of healthcare providers effectively managing patients with psoriasis and psoriatic arthritis. The NPF has launched several large-scale projects—including the development and implementation of solutions that reduce high out-of-pocket costs—intended to significantly increase the number of people with psoriatic disease who are effectively managing their condition.

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medications, biologics, or novel oral therapies—and new therapies remain in the pipeline. Yet, despite the range of disease-altering therapies, most psoriasis patients remain inadequately treated and dissatisfied.<sup>16,17</sup> Access challenges, including limited insurance coverage and prohibitive costs, alongside other factors, enable uncontrolled psoriatic disease to wield a significant, and detrimental, impact on the lives of those affected.<sup>18</sup>

### Costs Negatively Impact Treatment Decisions

Psoriatic disease is an expensive condition. Stark findings released in a January 2015 *JAMA Dermatology* article calculated the economic burden of psoriatic disease at up to \$135 billion a year.<sup>19</sup> Contributing to this total are the expenses paid by patients, which increasingly obstruct them from obtaining the therapy their physician recommends. A 2013 study of data collected from NPF surveys found that although roughly 91% of patients with psoriasis or psoriatic arthritis were covered by insurance, the majority spent more than \$2500 per year in out-of-pocket costs for their disease.<sup>20</sup> In fact, some patients spend upwards of \$8000 per year toward cost-sharing obligations.<sup>19</sup>

The out-of-pocket costs of therapy has helped to make non-treatment and undertreatment of psoriatic disease a significant problem.<sup>16</sup> According to a 2014 study, 55% of patients with moderate-to-severe psoriasis, and 41% of patients with psoriatic arthritis, are not being treated to the established standards of care.<sup>21</sup> The answer of “why” patients are not being treated according to guidelines is multifactorial. NPF annual surveys find that many patients are unable to obtain their first-choice prescription because the insurer would not cover it (21%), the co-pay was too much (18%), or they could not find a provider (8%)—a problem often associated with costs and/or narrow networks. When last asked about following treatment recommendations in the 2013 NPF annual survey, 40% of respondents reported cost was a significant barrier.

### Cost-Sharing Obligations Reduce—or Even Restrict Entirely—Access to Therapies

Biologics, which are used to treat individuals with severe psoriatic disease, offer a particularly devastating example of these cost-based access issues. More and more plans—particularly those offered in the exchanges—place biologics into a drug formulary category requiring higher co-payments or coinsurance. The increasing use of these “specialty tiers” shifts a hefty proportion of the cost of biologics to patients, posing a major financial challenge to many. An Avalere study of marketplace Silver plans charging a coinsurance of more than 30% for specialty medica-

tions found the practice rising from 27% of plans in 2014 to 41% in 2015.<sup>22</sup> Extending beyond the commercial market, new research published in August 2015 uncovered that when Medicare Part D beneficiaries are not supported by low-income subsidies (LIS), they have 70% lower odds of receiving a biologic compared with beneficiaries with LIS.<sup>18</sup>

While demand for specialty drugs is relatively inelastic, patients who cannot afford the high cost of prescriptions are more likely to not fill a prescription, take a drug in smaller doses than prescribed, or take a medication less frequently than prescribed.<sup>23-25</sup> On average, a \$10 increase in co-pays yields a 4% increase in nonadherence, and studies show that prescription abandonment rates increase significantly when the patient cost-share exceeds \$100.<sup>26</sup> These prescription “holidays” can have a dire effect on treatment efficacy, even after a patient is able to restart the drug.

### NPF’s Multi-Faceted Approach: Patient-Centric Solutions Where They Are Needed Most

Serving the 7.5 million Americans with psoriasis and psoriatic arthritis, the NPF’s mission is to drive efforts to cure psoriatic disease and improve the lives of those affected. Nearly 50 years after our organization’s launch, increasingly it is access challenges—chiefly high out-of-pocket costs—that bring patients to the NPF.

In July 2014, the NPF launched an aggressive 5-year strategic plan centered on dramatically improving the health of people with psoriatic disease. Our agenda is driven by the recognition that, no matter how many life-altering therapies exist, they cannot improve health outcomes if patients are unable to access them. During this 5-year plan, the NPF aims to achieve the following: 1) cut in half the number of people who report that their condition is a problem in everyday life, 2) increase by 50% the number of people receiving the right treatment, and 3) double the number of healthcare providers effectively managing patients with psoriasis and psoriatic arthritis.

Accordingly, the NPF has initiated several large-scale projects—including the development and implementation of solutions that reduce high out-of-pocket costs—intended to significantly increase the number of people with psoriatic disease who are effectively managing their condition.

### Legislative and Regulatory Solutions

Working in coalition at the state and federal level, the NPF supports efforts to lower out-of-pocket costs for life-altering therapies and reduce other impediments to accessing care. As a partner in the Coalition for Accessible Treatments, the NPF calls on the 114th Congress to pass the Patients’ Access to Treatments Act (HR 1600), which

would reduce the adverse impact of specialty tiering practices by limiting cost sharing for prescription drugs in a specialty drug tier to the amount for a nonpreferred brand-drug tier. Serving in 2016 as a co-chair of this now 30-plus member coalition, we will continue to provide the patient community opportunities to share their challenges with members of Congress.

At the state level, the NPF has partnered with other patient organizations, provider groups, and members of industry to advance legislation that would cap monthly copayments for therapies at \$150. These bills will help ensure that individuals with psoriasis and other chronic conditions have meaningful access to the therapy that their healthcare provider determines is most appropriate for them.

Our state-level action has already yielded results. Last October, we achieved a major victory when Governor Jerry Brown of California signed into law 3 bills—including one focused on capping out-of-pocket expenses—that will improve access to care for those with psoriatic disease. With 2 full-time staff members dedicated to advocating on the state and local level, the NPF is poised to engage officials in all but 11 states in the coming year.

### Patient Assistance and Support

Despite our hard work to reduce and eliminate the burden of high out of pocket costs, we know that for many patients struggling today, relief cannot come soon enough. For these patients, the NPF operates a patient assistance center. More than half of the calls received by the NPF's patient assistance line each year pertain to access challenges, with cost topping the list. In the first quarter of 2016, the NPF will launch a new Patient Navigation Center that will provide direct service to patients struggling with the range of issues related to disease management, health literacy, access to care, and adherence. Aiming to increase the number of patients reached annually from 3000 to 12,000 patients in 2016 alone, the center will be open to everyone with psoriatic disease, their families, and their caregivers. In addition to these patient services, the Center will also collect blinded, aggregated patient data on the range of issues related to psoriatic disease care to inform priorities and discern needs, such as "hot spots" in communities where barriers to care exist.

### Engagement With Health Insurers

The NPF appreciates that payers provide millions of dollars of benefit to our community each year and recognizes the numerous complexities that go into a payer's coverage decisions. Given the challenging environment, the NPF has taken a positive and proactive approach to working directly

with payers to explore, promote, and advance innovative and cost-effective coverage policies. It is also why more than 3 years ago, we supported leading dermatologists in launching International Dermatology Outcomes Measures to develop and validate patient-centric outcomes measures with an initial focus on psoriatic disease. By creating better tools to compare and assess outcomes, and through creative collaboration with payers, we aim to improve mechanisms to get patients on the right treatment earlier and reduce the downstream impacts of non-treatment.

### Conclusions

Although uncontrolled psoriatic disease yields a significant impact on the lives of those affected, therapies developed in the last 15 years have been life-altering for the psoriatic disease community. Regrettably, increased cost-shifting of therapies onto patients is putting these therapies out of reach. The NPF aims to eliminate cost and other access barriers through legislative and regulatory advocacy, direct patient assistance programs, and engagement with health insurers. Through this multifaceted effort, we strive to reduce the personal, familial, and economic impact of psoriatic disease.

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