February 19, 2019

The Honorable Seema Verma
Administrator
Centers for Medicare and Medicaid Services
Department of Health and Human Services
200 Independence Avenue, S.W. Washington, D.C. 20201

Re: Patient Protection and Affordable Care Act; HHS Notice of Benefit and Payment Parameters for 2020 (CMS-9926-P)

Dear Administrator Verma,

On behalf of the more than eight million Americans living with psoriasis and psoriatic arthritis, the National Psoriasis Foundation (NPF) appreciates the opportunity to comment on the HHS Notice of Benefit and Payment Parameters for 2020 (CMS-9926-P). As the patient advocacy organization for the psoriatic disease community for more than 50 years, the NPF is keenly aware of the improvements in health outcomes that have resulted from advances in treatment innovation. Therefore, the NPF remains committed to ensuring beneficiaries with psoriasis and psoriatic arthritis have access to the full range of treatments and therapies necessary to successfully manage their disease.

Understanding that cost can be one of the biggest barriers to this critical access, we commend the Administration for its focus on reducing the financial burden for our community. Upon review of this proposed rulemaking, we have highlighted some areas of agreement and some areas that we believe require further detail and explanation as this rulemaking process advances.

**Premium Adjustment Formula and Out-of-Pocket Costs**

In the Notice of Benefit and Payment Parameters for 2020 (NBPP), CMS proposed several changes to the premium adjustment factor formula which is used to determine the annual alterations to subsidies, the cap on out-of-pocket spending and other costs for beneficiaries. We are concerned that the proposed changes to the premium measure will result in rapid growth of premiums paid by our community on the Exchanges and an increase in the maximum out-of-pocket (MOOP) growth limit. The proposal estimates an increase of $400¹ per year in expected out-of-pocket costs and $220² per year increase in premiums for individuals and families. Additionally, HHS estimates that the proposed changes to the premium

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¹ 84 Fed. Reg. page 288
adjustment formula will result in overall net premium increases of over $180 million per year and a
decline of approximately 100,000 marketplace enrollees in 2020.³

Unfortunately, patients with psoriatic disease are all too familiar with the burden that comes with the high cost of treatment, which can result in reduced access, outcomes and overall well-being. A 2018 NPF Advocacy survey of NPF members found that nearly 50 percent of psoriasis and psoriatic arthritis patients, many of whom live on a fixed income, experienced financial strain due to the cost of their treatment. Equally alarming, almost one in four patients with psoriatic disease spend more than $150 per month in out-of-pocket costs to access treatment needed to manage their chronic condition.

As evidenced by the survey referenced above, patients with psoriatic disease already face significant financial challenges in managing their condition. The proposed changes to the premium adjustment formula will further strain their budget which may cause patients to abandon critical treatments. Foregoing or receiving inadequate treatment can cause disease progression and, in the case of psoriatic arthritis, irreversible joint damage, ultimately leading to higher healthcare costs.

Due to the increase in expected out-of-pocket costs, anticipated loss of coverage by individuals on the Exchange, and the potential for negative health outcomes, we encourage CMS to make meaningful revisions to increase protections for communities impacted by serious chronic conditions like psoriasis and psoriatic arthritis.

Silver Loading for 2020

We commend CMS’s decision to encourage participation in the individual market and permit “silver loading” for 2020. As CMS noted in the preamble to the NBPP:

“On January 20, 2017, the President issued an Executive Order which stated that, to the maximum extent permitted by law, the Secretary of HHS and heads of all other executive departments and agencies . . . should exercise all authority and discretion available to them to waive, defer, grant exemptions from, or delay the implementation of any provision or requirement of the PPACA that would impose a fiscal burden on any state or a cost, fee, tax, penalty, or regulatory burden on individuals, families, health care providers, health insurers, patients, recipients of health care services, purchasers of health insurance, or makers of medical devices, products, or medications.”⁴

NPF endorses CMS’s approach in upholding the practice of “silver loading” and honoring the January 2017 Executive Order to reduce the financial burden for patients, individuals and families – especially those with chronic illnesses. A future ban on silver loading would result in up to seven million non-subsidized enrollees paying more for their health insurance with no additional benefits in return.⁵ Until a

³ 84 Fed. Reg. page 308
⁴ 84 Fed. Reg. page 228
permanent solution is achieved to cost-sharing reduction payment (CRS) payments, we urge CMS to continue allowing “silver loading” in future years to help stabilize the marketplace and increase patient access for our patients with psoriasis or psoriatic arthritis.

**Essential Health Benefits**

Psoriasis and psoriatic arthritis are heterogeneous chronic immune-mediated diseases that require sophisticated medical care. As psoriatic disease presents differently across the population, tailored treatment regimens often include a combination of systemic treatments, phototherapy, and/or topicals. Higher rates of comorbid conditions also expand the types of medical services patients need to stay healthy. The varied nature of the disease and treatment options make Essential Health Benefits (EHB) protections critically important to our community. Specifically, EHB protections facilitate patient access to the type of comprehensive care necessary to ensure patients can properly manage their condition and be full members of society. Given the importance of EHB protections, the NPF is very concerned about several of the proposed EHB changes included in the proposed rule. To strengthen the EHB policies outlined within this proposal, we urge consideration of polices that increase access to care, including ensuring that patients have access to expedited appeals and exception processes and allowing patient’s out-of-pocket costs associated with “excluded” drugs to count towards the annual out-of-pocket maximum. Overall, as currently constructed, we believe these changes will lead to a weakening of EHB protections and diminished access to care for the psoriatic disease community.

**Navigator Program**

NPF is concerned that the proposed rule would make several changes to the Navigator program that would be detrimental to our patient community. Specifically, the NBPP would no longer require Navigators to engage with beneficiaries on post-enrollment activities such as increasing health literacy, assisting with plan renewals and education on how to avoid disenrollment for non-payment. The proposed rule would make these vital tools optional for Navigator programs. Navigators would also no longer need to receive guidance on the 20 currently mandated training topics. Moreover, in recent years, CMS has drastically reduced Navigator funding awards for the federal marketplace — compared to 2016, federal Navigator funding for 2018-2019 was reduced by 84 percent. We are concerned that these changes and the lack of funding would limit the ability for the psoriatic disease community to access the informed guidance and assistance programs many need to make smart choices about their health care coverage.

Psoriasis and psoriatic arthritis are complex, chronic conditions that require comprehensive care to ensure individuals are receiving the full suite of health services needed to properly manage their health. When choosing insurance products, members of the psoriatic disease community must weigh premiums against out-of-pocket costs associated with specialty physician visits, co-insurance rates for specialty tier

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therapies, and a host of other care needs. This can make the process of choosing the best health plan very complicated for even those with high health literacy. For the more vulnerable members of our community, including but not limited to the elderly and those in rural areas, accessing the critical services provided by Navigators can make all the difference in ensuring they select a health plan that meets their individual needs.

Our NPF Patient Navigation Center hears regularly from patients regarding health insurance selection questions and engages in multiple proactive educational campaigns during open enrollment periods. In fact, in October 2017, our center saw a significant increase in users due to an exponential increase in questions around health care coverage and enrollment. Through this experience, we know that having in-person assistance and the kind of nuanced and tailored advice provided by community-based nonprofits is critical to ensuring patients are making smart choices. The elimination of the requirement that each Exchange engage patients in post-enrollment activities could hurt those most in need. We encourage you to reconsider this change and maintain the existing requirements.

**Direct Enrollment**

NPF is worried about CMS’s proposal to expand direct enrollment beyond Healthcare.gov and allow insurers and web-brokers to enroll consumers in an insurance plan directly. We are also deeply troubled that this proposal would not require an insurer or web-broker to list out all available plans when advising consumers on their health insurance options. As mentioned above, patients with psoriasis and psoriatic arthritis face complex challenges in managing their disease and this proposal could diminish access and quality of care for our community. This proposal is particularly dangerous to patients with psoriatic disease due to the expansion of Short-Term, Limited-Duration (STLD) insurance plans and the potential that insurers and web-brokers could enroll our patient community in these skimpy plans. The expanded use of STLD insurance plans could be disastrous for patients who enroll in these plans or existing plan members who receive a psoriasis or psoriatic arthritis diagnosis during the plan year. The paltry nature of these plans and the ability for issuers to charge more for, or deny care to, individuals with pre-existing conditions makes these plans unsuitable for those with significant healthcare needs and expenditures.

The lack of patient protections means that if a plan member were to develop a condition while on such a plan, he or she may be unable to renew the plan because of an absence of prohibitions on discriminating against persons based on their health status. Relatively, there is the potential for plan rescissions or plan cancellation if a member submits too many claims, on top of the ability to deny coverage of claims that the plan deems related to a pre-existing condition. Combined, these factors would be very problematic for patients with complex, chronic diseases, like psoriatic disease, who rely on health insurance to provide meaningful coverage for medically necessary services.

We strongly urge that this provision is not adopted in the final rule.

**Special Enrollment Periods**

We applaud the proposal to establish a special enrollment period for individuals with “off-Exchange” coverage who experience mid-year income changes. This proposal will ensure that our community, in
the event of an income change, has access to affordable health care when they become eligible for advance payment of premium tax credits. We commend HHS for this proposal and encourage the agency to maintain this language in the final rule.

**Auto Renewal**

NPF strongly encourages CMS retain the policy of automatically re-enrolling consumers in plans offered through the Exchange or State-Based Exchanges (SBE). As you know, currently consumers are automatically re-enrolled in their plan if they do not take any action to change their plan. In 2018, approximately 25 percent of consumers were automatically renewed in their plan, which totaled 1.8 million individuals that were re-enrolled for the 2019 plan year. We are concerned about removing auto-renewal, which could result in gaps in coverage and pose significant challenges to our community’s ability to manage their condition and live more comfortably with psoriatic disease. Should CMS move forward with discontinuing or putting restrictions on automatic renewal we encourage a consistency across all markets. We would suggest CMS adopt in this space the policy confirmed in the STLD rulemaking, which provided that short term plans may be automatically renewed for no longer than 36 months.

**Limiting the use of manufacturer coupons**

CMS has proposed to exclude any form of direct manufacturer cost-sharing support from calculations toward applicable annual limitations on out-of-pocket costs when it is offered in connection with a specific prescription brand drug that has a generic equivalent. The topic of co-pay assistance and the significant increase in the use of co-pay accumulators in the employer space presents a complex situation to those who advocate for health care access reform but are also acutely aware of the role manufacturer assistance programs play in masking the true cost of a medication. Ultimately what we want to see is consistency across different markets. This is positive for all of those involved. We recommend that CMS limit its scrutiny of manufacturer assistance to instances where the copayment support is connected to a specific brand product, and generic substitution is appropriate for the specific patient. We greatly discourage CMS from restricting assistance from being applied to a deductible. This could have a significant financial impact on enrollees, particularly those in High Deductible Health Plans (HDHP) who could be subjected to the entirety of their deductible in the first quarter of the year. As numerous studies show, any significant increase in out of pocket cost and cost sharing can lead to a decrease in adherence.

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7 [https://www.wsj.com/articles/trumps-proposed-aca-rules-could-lift-costs-for-millions-of-people-11547775475?emailToken=774bc4bebc0f134eb1cbdb62929ce2755lrsaMajxYsOlrBrHt2PV0GkFvF/RER9kVfVE2/R4UuP5GtaR04vGls+Q+2suU34h6a/7caWwp7yvncdNJf4A8I8U8HSze7rRRnF/utKpV9ZDyiA8UuvgTODvn3OvxPwaA8J&reflink=article_email_share](https://www.wsj.com/articles/trups-proposed-aca-rules-could-lift-costs-for-millions-of-people-11547775475?emailToken=774bc4bebc0f134eb1cbdb62929ce2755lrsaMajxYsOlrBrHt2PV0GkFvF/RER9kVfVE2/R4UuP5GtaR04vGls+Q+2suU34h6a/7caWwp7yvncdNJf4A8I8U8HSze7rRRnF/utKpV9ZDyiA8UuvgTODvn3OvxPwaA8J&reflink=article_email_share)

8 [https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3278192](https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3278192)
Conclusion

We appreciate your attention to the comments made by NPF on behalf of the millions of Americans who live with psoriatic disease. Should you wish to reach us to discuss any of our suggestions please contact Patrick Stone, VP of Government Relations & Advocacy at pstone@psoriasis.org.

Sincerely,

Patrick Stone
Vice President, Government Relations & Advocacy