



Our Mission: To drive efforts to cure psoriatic disease and improve the lives of those affected.

## Public Comment

By: Leah Howard, J.D., on behalf of the National Psoriasis Foundation  
ICER New England CEPAC Meeting

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*Good morning. My name is Leah Howard, and I am the National Psoriasis Foundation's Chief Operating Officer. As is indicated in your materials, I have no personal conflicts, however, as an employee of the NPF I do want to disclose that we engage with every manufacturer that has a presence in our space.*

*On behalf of the more than 8 million Americans living with psoriatic disease, I appreciate the opportunity to again be with you as you deliberate and vote on the effectiveness and value of targeted immunomodulators for the treatment of moderate-to-severe plaque psoriasis.*

*My aim is to offer a few perspectives on behalf of individuals living with psoriasis and the unique challenges that frustrate the clinical experts who specialize in caring for the psoriatic disease community.*

*It was not all that long ago that NPF's VP of Research, Dr. Mike Siegel stood before the New England CEPAC in Boston to share the perspectives of the National Psoriasis Foundation during ICER's first review of therapies for plaque psoriasis. (If you missed them, his comments are still up on ICER's homepage. I checked the other day!) During his remarks, you heard about the heterogeneity, complexity and uncertainty of living with this disease. Dr. Siegel spoke to the complex genetic architecture that underlies psoriasis, the complex layer of immunology that drives the disease, and the uncertainty about what drives the progress of psoriasis. He talked about plaques presenting in different severities, various body locations, and the uncertainty related to the dizzying number of comorbidities associated with psoriatic disease. And finally treatments and the complex decisions that providers and patients face with regard to treating a chronic disease such as psoriasis for the entire lifetime.*

*What he ended his remarks with was this sentiment – that while there is a lot of uncertainty, we know from NPF survey data that the burden of psoriatic disease remains. We know that the majority of patients report psoriasis to be a problem in their everyday life. We know that the majority report dissatisfaction with their current treatments, and we know that the majority are not treating to the level appropriate to the severity of their disease. So he encouraged an effort like the ICER review to break through that, and to reach those patients and get them the best possible health outcomes.*

*So it has been a year and a half since the first review of psoriasis treatments and Dr. Siegel's remarks. In many ways, our space has not changed all that much. Psoriasis is still a complex disease with much uncertainty. And while we have seen new therapies come to market – something patients*

*and providers are always eager to see – we still have significant room to go in getting patients to treat their disease to target.*

*The mission of the NPF is to find a cure and improve lives. As part of that mission we want all patients treating at a level appropriate to disease severity and for the patient-provider dialog to be at the heart of every treatment decision.*

*For this to work, particularly within such a heterogeneous disease and heterogeneous population, we want as many treatment options accessible to as many patients as possible.*

*Historically, data has shown us that treatment choices, access opportunities, and a need for more knowledge to inform decisions leave a lot to be desired. This is a challenge that NPF works on every day and, the good news, is that we've made a lot of progress from a policy standpoint in the last year and a half to improve access for patients with chronic disease, preserve provider choice and clarify how patient and providers can access more of the tools in their toolbox.*

*As we shared in our written remarks prior to this meeting, we would encourage ICER to be sure that as part of this treatment update, the important role that you play in supporting individuals living with a chronic disease like psoriasis having access to good value therapies not be overlooked.*

*From a patient community standpoint, the 2016 findings were as good as it could get. All the therapies were determined to be of good value, the work reflected patient concerns and included patient input thanks to the work of the NPF and contributions of individual patients, and the policy recommendations accurately captured the challenges of accessing the reviewed therapies.*

*Unfortunately, an analysis of several markets has confirmed what we have heard from patients through our Patient Navigation Center – even with these new therapies coming to market, patients don't have that many more options to choose from when it comes to treating. Most formularies offer only limited numbers of treatments, and as one member of our medical board stated to me, while experienced clinicians know based on data and their clinical experience that some medications are more likely to work "better", he doesn't see the playing field being level enough to make a balanced opinion until there is greater transparency in the process.*

*So as we conclude this condition update, that is the sentiment I would like to leave ICER with – how do we make a value assessment something that is real and meaningful to patients because it positively impacts their health, opens up access to therapies, and helps experienced clinicians take an individual who has been struggling, felt frustrated, angry and helpless, and turn their life around because they are on the right therapy from the beginning.*