June 7, 2019

The Honorable Diana DeGette
2111 Rayburn House Office Building
Washington, D.C. 20515

The Honorable Donald Beyer
1119 Longworth House Office Building
Washington, D.C. 20515

Dear Representative DeGette and Representative Beyer,

On behalf of the more than eight million Americans living with psoriasis and psoriatic arthritis, the National Psoriasis Foundation (NPF) writes today in support of H.R. 3030, the Patient-Centered Outcomes Research Extension Act of 2019. NPF strongly supports this legislation and appreciates your commitment to funding comparative clinical effectiveness research (CER) studies.

The Patient-Centered Outcomes Research Institute (PCORI) is a non-profit organization that was authorized by Congress to fund CER. Since 2010, PCORI has awarded more than $2.4 billion in grants to over 600 research-related projects to assess prevention, diagnosis and treatment options, improve healthcare systems, and communicate and disseminate research.¹ Patients with psoriatic disease often have their choices in treatment and therapy dictated by out-of-pocket costs and other cost burdens rather than the efficacy of the treatment. Thus, PCORI research into CER is of particular importance to those with psoriasis and psoriatic arthritis and providers when prescribing treatments to manage their disease.

To this end, the NPF and PCORI have identified opportunities to collaborate on patient-focused research to reduce barriers to care and increase access to critical treatment options for those living with psoriasis and psoriatic arthritis. In 2017, the University of Pennsylvania, in partnership with the NPF, was awarded a grant to study psoriasis phototherapy treatment options, which aims to compare home-based phototherapy and phototherapy that requires visiting a doctor’s office. Psoriasis symptoms and response to treatments vary from patient to patient; therefore, it is critical that various treatment options are available. Phototherapy is an important part of the treatment armamentarium and access issues related to this safe and effective therapy are of great importance to our organization and patient community. The study is funded through PCORI’s Pragmatic Clinical Studies Initiative, an effort to produce results that are broadly applicable to a diverse range of patients and care situations, and can be quickly integrated into routine clinical practices. The data resulting from this trial will help address the uncertainty often faced by patients, dermatologists and payers regarding this treatment approach.

Additionally, NPF has received PCORI’s support through the Pipeline to Proposal program, which enabled the NPF to establish Citizen Pscientist, an online patient research community, and the Eugene Washington PCORI Engagement Award, which funded the creation of the NPF Psoriatic Disease Research

¹ [https://www.pcori.org/sites/default/files/PCORI-Research-Funding.pdf](https://www.pcori.org/sites/default/files/PCORI-Research-Funding.pdf)
Ambassador program—both initiatives support the mission of driving comparative effectiveness research in support of patients living with psoriatic disease.

On behalf of all Americans who live with psoriatic disease, we appreciate your attention to this critically important issue and welcome the opportunity to work together to increase funding for clinical effectiveness research, reduce out-of-pocket costs for patients, and remove barriers for patients to access the treatment options necessary to manage their conditions. Should you wish to reach us to discuss this topic please contact Matthew Moran, Federal Government Relations & Health Policy Manager at mmoran@psoriasis.org.

Sincerely,

Patrick Stone
Vice President, Government Relations & Advocacy