Congress of the United States

Washington, DC 20510

August 2, 2024

The Honorable Chiquita Brooks-LaSure Administrator Centers for Medicare and Medicaid Services 200 Independence Avenue SW Washington DC, 20202

Dear Administrator Brooks-LaSure,

We write today out of concern for the thousands of low-income and disabled Americans who are being denied Medicaid drug coverage for the treatment of vitiligo. The denials are happening in a handful of states and are based on an erroneous classification of vitiligo as a cosmetic condition. In order to correct this mistake, we request that the Centers for Medicaid and Medicaid Services (CMS) issue guidance to State Medicaid Directors clarifying that treatments indicated for vitiligo are **not** considered cosmetic, which would create parity with Medicare.

Classifying vitiligo as a cosmetic condition contradicts clinical consensus that vitiligo is a chronic autoimmune condition. The disease is characterized by progressive loss of melanocytes, leading to cutaneous depigmentation. It often emerges in adolescence or later, occurring in an estimated 1% of the world's population.

Despite medical consensus, we understand that at least eleven state Medicaid agencies or their managed care plans are currently denying Medicaid drug coverage of the first Food and Drug Administration (FDA) approved vitiligo treatment based on a "cosmetic" exclusion. We are glad to know that our state, Massachusetts, currently covers treatment for vitiligo, but are concerned that some states that are currently covering treatment for vitiligo in accordance with the statute could reverse course if other states continue to deny coverage.

This determination is contrary to the CMS's long-established position in guidance issued to Medicare Part D plan sponsors. Specifically, the *Medicare Prescription Drug Benefit Manual*, clarifies that "treatments indicated for...vitiligo are NOT considered cosmetic." (emphasis in original). Given the fact that Medicaid drug coverage and Medicare Part D coverage are both governed by section 1927(d)(2) of the Social Security Act (SSA), it seems inconsistent that state Medicaid agencies are denying coverage, especially when CMS has issued a definitive interpretation of this language. We respectfully request that CMS consistently apply this section of the SSA by issuing a letter to state Medicaid Directors clarifying that treatments indicated for vitiligo are not considered cosmetic.

Studies show a lack of access to vitiligo treatment (most commonly due to financial barriers and lack of insurance coverage) may increase health disparities among already-marginalized groups,

such as children and adults of darker skin phototypes.⁸ Even the Department of Veteran's Affairs, which has also issued policy stating that vitiligo it not cosmetic⁹, has additional language stating that vitiligo can "have profound detrimental psychosocial effects on quality of life, social interactions, self-esteem, and discrimination against the patient."¹⁰

CMS has demonstrated an impressive commitment to health equity.¹¹ A letter to State Medicaid Directors is a critical step to help to improve health care coverage for underserved populations, specifically members for people with darker skin pigmentation. These individuals have more noticeable differences in skin coloration between affected and normal areas.¹²

We appreciate your consideration to ensure consistent interpretation of the Social Security Act and ensuring that CMS plays an important role in improving health disparities for marginalized populations.

Sincerely,

James P. McGovern

Member of Congress

Ayanna Pressley Member of Congress

Stephen F. Lynch

Member of Congress

Lori Trahan

Member of Congress

CFU Ruxolitinib OPZELURA Cream in Nonsegmental Vitiligo Criteria Jun 2023.pdf

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¹ https://www.niams.nih.gov/health-topics/vitiligo

² https://www.aad.org/public/diseases/a-z/vitiligo-medical-condition

³ https://www.jaad.org/article/S0190-9622(15)01985-4/fulltext

⁴ https://www.ncbi.nlm.nih.gov/books/NBK559149/

⁵ https://jamanetwork.com/journals/jamadermatology/fullarticle/2785895

⁶ States that have formal exclusion policies: <u>AZ, HI, IA, NH, NY, RI, VA</u>. Additionally, patients or providers have also received denial letters for Medicaid coverage in: AL, ND, SD, WV

⁷ https://www.cms.gov/medicare/prescription-drug-coverage/prescriptiondrugcovcontra/downloads/part-d-benefits-manual-chapter-6.pdf

⁸ https://onlinelibrary.wiley.com/doi/epdf/10.1111/pde.14714

⁹https://www.va.gov/formularyadvisor/DOC_PDF/

¹⁰https://www.va.gov/formularyadvisor/DOC_PDF/

¹¹ https://www.cms.gov/files/document/cms-framework-health-equity-2022.pdf

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