



April 15, 2021

The Honorable Ron Wyden
Chairman
Committee on Finance
United States Senate
219 Dirksen Senate Office Building
Washington, D.C. 20510

The Honorable Mike Crapo
Ranking Member
Committee on Finance
United States Senate
219 Dirksen Senate Office Building
Washington, D.C. 20510

Dear Chairman Wyden, Ranking Member Crapo, and Members of the Senate Finance Committee,

The National Organization for Rare Disorders, Inc. (NORD) writes to express our support for the nomination of Chiquita Brooks-LaSure as the next Administrator of the Centers for Medicare and Medicaid Services (CMS). NORD is a unique federation of over 325 voluntary health organizations dedicated to helping the 25-30 million Americans living with a rare disease. NORD is committed to the identification, treatment, and cure of rare disorders through programs of education, advocacy, research, and patient services. We believe that all patients should have access to quality, accessible, and affordable health coverage that is appropriate for their medical needs.

Ms. Brooks-LaSure is a health policy expert with an extensive and diverse background that makes her well suited to be the next CMS Administrator. As a Professional Staff Member for the House Ways and Means Committee, Ms. Brooks-LaSure played a central role in the crafting and passage of the Affordable Care Act (ACA). She then spent many years overseeing the implementation of the ACA's coverage and insurance reform provisions at the Department of Health & Human Services (HHS) as Director of Coverage Policy, and as Deputy Director for Policy at the Center for Consumer Information and Insurance Oversight (CCIIO) within CMS. Since leaving the federal government, Ms. Brooks-LaSure has continued to be a thought leader within the health policy community.

The breadth and complexity of the challenges faced by CMS mean that it is more important than ever to have leadership in place with significant experience in Medicare, Medicaid and insurance policy. CMS oversees programs that affect more than 150 million Americans—including many patients with rare and chronic conditions. State Medicaid programs and subsidized coverage through the individual marketplaces in particular serve as an invaluable safety net for rare disease patients who often find their financial lives upended by the debilitating nature of their disease. NORD looks forward to working with Ms. Brooks-LaSure and CMS to develop policies that ensure that health care is accessible, comprehensive, and affordable for patients with rare disorders.

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Upon confirmation, we urge Ms. Brooks-LaSure to enact policies that support the integration of telehealth into our broader health care system enable better patient health outcomes for rare disease patients in a post-COVID-19 pandemic. In addition, over the past several years, many essential guardrails that protect patients and their families have been eroded while insurance practices that disproportionately discriminate against patients with pre-existing conditions have proliferated. CMS must take action to halt the spread of non-compliant insurance-like products that do not provide adequate coverage. Finally, CMS, and the entire Department must take decisive action to address systemic racism and pervasive inequality within our health care system.

We are confident that Chiquita Brooks-LaSure's extensive experience will enable to her to effectively lead CMS and support the implementation of policies that can help address the pressing health needs of the rare disease community. We urge this committee to take swift action to advance Ms. Brooks-LaSure's nomination before the full Senate so that the critical work of CMS may proceed without any delay.

Sincerely,

A handwritten signature in black ink, appearing to read "Peter L. Saltonstall". The signature is fluid and cursive, with a prominent "P" and "L".

Peter L. Saltonstall
President and Chief Executive Officer

