

February 11, 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 (NORD) writes to express our support for the nomination of Xavier Becerra as the next Secretary of the Department of Health and Human Services (HHS). 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 best suited to their medical needs.

Attorney General Becerra has spent a career in both Washington and California advancing policies that have improved access to affordable and comprehensive health care. As a member of Congress for more than 20 years, Representative Becerra served on the House Ways and Means Committee, where he focused on strengthening the programs that patients with rare diseases depend on and played an integral role in the passage of the Affordable Care Act (ACA). Mr. Becerra has continued to act has a champion for patients as Attorney General of California, spearheading efforts to safeguard the patient protections enshrined within the ACA, including leading a coalition of 17 states to defend the law before the Supreme Court. We are confident that his experience will enable to him to effectively lead HHS and support the implementation of policies that can help address pressing health needs of the rare disease community.

Should Attorney General Becerra be confirmed, he will be tasked with addressing many of our nation's most urgent health challenges. 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. Upon confirmation, Attorney General Becerra and the Department must take immediate steps to restore protections and resources that help patients get high-quality insurance coverage that meets their needs. In addition, we hope Attorney General Becerra will strengthen the vital Medicaid and Medicare programs upon which so many in the rare disease community rely. Medicaid, in particular, is an invaluable safety net for rare disease patients who often find their

1779 MASSACHUSETTS AVENUE NW, SUITE 500 WASHINGTON, DC 20036 T 202-588-5700 F 202-588-5701 T 203

55 KENOSIA AVENUE DANBURY, CT 06810 T 203-744-0100 ■ F 203-263-9938

1900 CROWN COLONY DRIVE, SUITE 310 QUINCY, MA 02169 T 617-249-7300 F 617-249-7301

rarediseases.org • orphan@rarediseases.org

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financial lives upended by the debilitating nature of their diseases, but its core objective of serving the health and wellness needs of its beneficiaries has been undermined in recent years through federal government approval of several harmful Section 1115 waivers. NORD looks forward to working with HHS to reinforce the objectives of the Medicaid program and continue to develop new and innovative payment models to reward the delivery of high-quality care to patients.

This nomination is occurring during an unprecedented national public health crisis. The devastating impact of COVID-19 means that it is more important than ever that the Department of Health and Human Services has strong and continuous leadership. In addition to overseeing the distribution of vaccines for COVID-19 and coordinating our public health agencies, as Secretary, Attorney General Becerra must address the systemic racism and pervasive inequality within our health care system that has only been exacerbated by this crisis. The COVID-19 pandemic has been particularly challenging for the rare disease community, as many rare disease patients are immune-compromised, putting them at high risk of infection and serious illness. Our community cannot afford for there to be any interruption in the operations of the Department during this pandemic.

NORD believes that Attorney General Becerra's lifetime of public service and commitment to patients with pre-existing conditions makes him the right candidate for this role. We look forward to working alongside Attorney General Becerra to ensure that health care is accessible, comprehensive, and affordable for patients with rare disorders. We urge this committee to take swift action to advance Mr. Becerra's nomination before the full Senate so that the critical work of the Department may proceed without any delay. For questions regarding NORD or our support, please contact Rachel Sher, Vice President of Policy and Regulatory Affairs, at rsher@rarediseases.org, or 202-588-5700.

Sincerely,

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Peter L. Saltonstall President and Chief Executive Officer