



September 11, 2023

Lila Cummings  
Executive Director  
Colorado Prescription Drug Affordability Board  
Division of Insurance  
1560 Broadway, Suite 850  
Denver, CO 80202

Dear Ms. Cummings,

On behalf of the more than 30 million Americans living with one of the over 7,000 known rare diseases, the National Organization for Rare Disorders (NORD) would like to thank you for your commitment to ensuring that all Coloradans have access to affordable medications. We are writing today with a request to actively participate in the work of the Prescription Drug Affordability Board (PDAB) as it performs its first set of affordability reviews and potential upper payment limit setting. We understand the enormity of the task and believe we are well suited to lend our expertise as the PDAB continues its work.

NORD is a unique federation of non-profits and health organizations dedicated to improving the health and well-being of people living with rare diseases. NORD was founded 40 years ago, after the passage of the Orphan Drug Act, to formalize the coalition of patient advocacy groups that were instrumental in passing that landmark law. Our mission has always been, and continues to be, to improve the health and well-being of people with rare diseases by driving advances in care, research, and policy.

NORD is encouraged that a drug's orphan status will be considered when the PDAB is conducting affordability reviews. NORD believes consideration of orphan status should ultimately reflect a delicate balance between affordable patient access to often life-changing therapies, and vital incentives for continued research in rare disease drug development. However, we are concerned about the lack of clarity in the statute regarding how orphan drug status will be considered. The fact that a product treats orphan diseases can factor into PDAB considerations in a number of nuanced ways. Given our extensive experience supporting the rare disease community and their need for access to safe, effective and affordable orphan products, we would welcome the opportunity to help provide input on how orphan drug status may be factored into your considerations as the PDAB conducts affordability reviews.

NORD is an umbrella organization for more than 330 rare disease-specific patient advocacy groups and does not engage in disease-specific or treatment-specific policy or advocacy work. Therefore, NORD is not seeking an opportunity to discuss the specifics of any of the five selected products, but wants to more broadly discuss issues such as data scarcity that can make it challenging to conduct a comprehensive affordability review and/or set an upper payment limit, the access challenges many of our patients face, as well as the significant unmet medical need that necessitates continued investment in drug development. We hope that we can be a resource in determining how to best factor these realities into the determination of affordability and upper payment limits.

Moreover, NORD has been instrumental in establishing Rare Disease Advisory Councils (RDACs) across the country, including in Colorado. We would be more than happy to help facilitate an introduction to the chair of the Colorado RDAC so that the PDAB might use them as an additional resource as the PDAB continues its work this fall.

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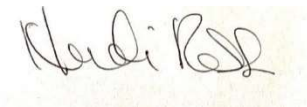
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NORD is uniquely positioned to provide data and to connect patients directly to stakeholder opportunities. We are eager to serve as a resource to the PDAB it conducts its work throughout the affordability review process. As you develop patient stakeholder opportunities such as surveys and listening sessions, we would welcome the opportunity to meet with you and provide resources that will assist in your review. Please contact Heidi Ross, Vice President of Policy and Regulatory Affairs, at [HRoss@rarediseases.org](mailto:HRoss@rarediseases.org), Mason Barrett, Policy Analyst, at [MBarrett@rarediseases.org](mailto:MBarrett@rarediseases.org), or Lindsey Viscarra, State Policy Manager, at [LViscarra@rarediseases.org](mailto:LViscarra@rarediseases.org) to schedule a meeting at your earliest convenience.

Thank you for your consideration of our request, and we look forward to hearing from you.

Sincerely,



Heidi Ross  
Vice President, Policy and Regulatory Affairs  
National Organization for Rare Disorders



Mason Barrett  
Policy Analyst  
National Organization for Rare Disorders



Lindsey Viscarra  
State Policy Manager  
National Organization for Rare Disorders

CC: Members of the Colorado Prescription Drug Affordability Board

