NORD®
National Organization
for Rare Disorders

June 9, 2023

The Honorable Chiquita Brooks-LaSure
Administrator
Centers for Medicare & Medicaid Services
Department of Health and Human Services
Attention: CMS-1785-P
P.O. Box 8013
Baltimore, MD 21244-8013

Docket No. CMS-1785-P FY 2024 Hospital Inpatient Prospective Payment Systems for Acute Care Hospitals – NORD Comments

On behalf of the more than 25 million Americans living with one of the over 7,000 known rare diseases, the National Organization for Rare Disorders (NORD) thanks the Centers for Medicare & Medicaid Services (CMS) for the opportunity to provide comments on CMS's Fiscal Year 2024 Inpatient Prospective Payment System Proposed Rule (proposed rule).

NORD is a unique federation of non-profits and health organizations dedicated to improving the health and well-being of people with rare diseases by driving advances in care, research, and policy. NORD was founded 40 years ago, after the passage of the Orphan Drug Act (ODA), to formalize the coalition of patient advocacy groups that were instrumental in passing that landmark law. Since that time, NORD has been advancing rare disease research and funding to support the development of effective treatments and cures; raising awareness and addressing key knowledge gaps; and advocating for policies that support the availability of and access to comprehensive, affordable health care services.

NORD thanks the agency for their efforts to continue to refine and improve the current IPPS system and for the opportunity to comment on the proposed rule. Given the unique medical complexity of many rare diseases, NORD appreciates CMS' efforts to incorporate the diverse perspectives of impacted patients, including the unique perspectives of rare disease patients, in the rule-making process. Many rare disease patients face unique barriers to diagnostic and care, and accurately capturing the rare disease patient perspective and ensuring that the proposed rule will work for rare disease patients and their families is a key priority for NORD. Specifically, NORD is pleased to provide the following recommendations to CMS:

1. **CMS should continue to work with all stakeholders to ensure the MS-DRGs provides appropriate reimbursement for the actual cost of rare disease patient care.**

Patients living with a rare disease are often particularly medically complex, and the clinical manifestation of their disease(s) can be highly variable.[1] Moreover, rare diseases are, by definition, rare - and available data are scarce and lack granularity. Oftentimes, rare conditions without ICD-10 codes are assigned an overly broad ICD-10 code that may not carry the appropriate relative weight for the cost of treatment. For instance, a Milliman analysis of Orphanet data in the US commercially insured population found that of the population observed to have a rare disease, only 16% had a diagnosis associated with a specific ICD-10 code. The remaining 84% had codes that were described as "nonspecific or overly broad."[2]

NORD is concerned that the combination of variation in the typical cost of care for a treatment episode, lack of disease-specific ICD-10 codes, and overall data scarcity for rare diseases could lead to insufficient reimbursement and a disincentive for hospitals to treat patients with rare diseases.[3] Rare disease patients already often must travel long distances to seek appropriate care. In fact, a 2019 NORD survey of 800 rare disease patients and caregivers across the US, found that 39% of respondents reported traveling at least 60 miles to receive medical care, and 17% had moved (or were considering relocating) to be closer to care.[4] Inappropriate reimbursement for treating rare disease patients could exacerbate these trends and make it even harder for rare disease patients to access the timely, high-quality healthcare they need.

Additional emphasis should be placed on the appropriateness of coding for rare diseases, and the impact of existing data challenges on the MS-DRG, ensuring it works appropriately for rare disease patients. NORD encourages the agency to continue to work with rare disease providers, patients, and hospitals to develop the most effective tools and approaches to capture the experience and true cost of care for treating rare diseases within the MS-DRG system.

2. NORD strongly supports reimbursing Rural Emergency Hospitals for training medical residents and encourages incentives for the inclusion of more rare disease training.

As mentioned previously, many rare disease patients must travel significant distances to access appropriate care. Moreover, many primary care providers have limited or no experience caring

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[1] Augustine, Erika F et al. "Clinical trials in rare disease: challenges and opportunities." *Journal of child neurology* vol. 28,9 (2013): 1142-50. doi:10.1177/0883073813495959

[2] Kuester, Melanie, et al. "Prevalence of Rare Disease in a Commercial Population Using ICD-10 Diagnostic Codes." *Milliman.Com*, Aug. 2022, www.milliman.com/-/media/milliman/pdfs/2022-articles/8-12-22_rare-disease-research-paper.ashx.

[3] NORD. FY 2023 Hospital Inpatient Prospective Payment Systems for Acute Care Hospitals (CMS-1771-P) – NORD Rare Disease Centers of Excellence Program.(June 17, 2022) https://rarediseases.org/wp-content/uploads/2022/08/NORD-FY-2023-IPPS-Comments.pdf

[4] 6 "Barriers and Facilitators to Rare Disease Diagnosis, Care and Treatment: 30-year Follow-up." National Organization for Rare Disorders, 2020

for rare disease patients which contributes to the reality that too many rare disease patients must endure a very long diagnostic odyssey – often 5 to 7 years – until receiving a correct diagnosis.[5]

NORD appreciates the agency's willingness to reimburse Rural Emergency Hospitals (REHs) for the training of medical residents. The increased incentive will help maintain a pipeline of qualified healthcare providers in rural areas and help rare disease patients in rural areas seek care closer to home. As REHs are "oftentimes… the initial and only accessible point of care for individuals living in rural underserved areas," a potential increase in the resident workforce will help short-staffed REHs provide appropriate care within the community.[6]

NORD also encourages the agency to promote additional education on the treatment and diagnosis of rare conditions by providing supplementary payments to hospitals with medical residents staffed on rare disease cases. NORD's Rare Disease Centers of Excellence (RD CoEs) were ultimately created to make it easier for rare disease patients to access the high-quality care they need. The RD COEs are a network of medical centers, clinics, and institutions across the country with the unique knowledge and passion to diagnose and treat patients with rare diseases most effectively. Participants in NORD's RD CoEs are committed to sharing knowledge and best practices to improve rare disease care and advance rare disease research, including by providing education and support to primary care physicians diagnosing and treating rare disease patients. NORD's CoEs can help support CMS to study reimbursement for rare diseases, as well as help support providers nationally in the treatment and diagnosis of rare diseases.

NORD again thanks the agency for the opportunity to comment on the proposed rule and looks forward to working with CMS on improving care for rare disease patients. We encourage quick finalization of the rule to ensure rare disease patients can benefit from the enhanced provisions as soon as possible. Please contact Mason Barrett, Policy Analyst at mbarrett@rarediseases.org with any questions, and we look forward to work with the agency on this and other policies to improve the ability of rare disease patients to seek appropriate, high-quality healthcare.

Sincerely,

Mason Barrett

Mason Barrett
Policy Analyst

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[5] NORD. FY 2023 Hospital Inpatient Prospective Payment Systems for Acute Care Hospitals (CMS-1771-P) – NORD Rare Disease Centers of Excellence Program.(June 17, 2022) https://rarediseases.org/wp-content/uploads/2022/08/NORD-FY-2023-IPPS-Comments.pdf

[6] 88 Federal Register 26658 (May 1, 2023)