



June 17, 2022

Chiquita Brooks-LaSure  
Administrator  
Centers for Medicare & Medicaid Services  
Department of Health and Human Services  
Attention: CMS-1771-P  
Mail Stop C4-26-05  
7500 Security Blvd.  
Baltimore, MD 21244-1850

**Re: FY 2023 Hospital Inpatient Prospective Payment Systems for Acute Care Hospitals (CMS-1771-P) – NORD Rare Disease Centers of Excellence Program**

Dear Administrator Brooks-LaSure:

On behalf of the 25 to 30 million Americans 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 the Agency's proposed rule captioned above (Proposed Rule).<sup>1</sup> NORD is a unique federation of voluntary health organizations dedicated to helping people with rare "orphan" diseases and assisting the organizations that serve them. NORD is committed to the identification, treatment, and cure of rare disorders through programs of education, policy and advocacy, research, and patient services. Together with over 300 disease-specific member organizations, more than 18,000 Rare Action Network advocates across all 50 states, and national and global partners, NORD delivers on its mission to improve the lives of those impacted by rare diseases.

NORD appreciates CMS' attention and efforts to promote access to care among beneficiaries diagnosed with rare diseases. We agree with CMS that treating patients with rare diseases may "involve more resource use than other cases in their respective MS-DRG"<sup>2</sup> and we support CMS' solicitation of stakeholder input on ways to improve Medicare reimbursement for hospitalized beneficiaries with rare diseases. NORD believes that any effort to improving access to care for rare disease patients must take into account the multi-specialty clinical care that such patients require.

Our comments highlight our new NORD Rare Disease Centers of Excellence (RD CoE) Program, which is dedicated to identifying medical centers that offer the best possible coordinated multi-specialty clinical care and diagnostic opportunities for rare diseases. The NORD RD CoE network is working in partnership to share expertise, advance education, define standards and protocols, and shape the field of rare disease care, ultimately enabling rare disease patients to better navigate their diagnostic journey and find qualified medical homes for their complex medical conditions. NORD offers the RD CoE Program to inform CMS' efforts going forward on supporting access to quality rare disease clinical care through, including but not limited to, reimbursement reform.

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<sup>1</sup> 87 Fed. Reg. 28108 (May 10, 2022).

<sup>2</sup> *Id.* at 28197.

## The NORD Centers of Excellence Program

People with rare diseases face many challenges, but one of the most difficult phases is at the outset, as it takes a rare disease patient an average of 5-7 years to an accurate diagnosis. This stage of the rare disease journey has become so common, it has a name: the “diagnostic odyssey” and refers to the lengthy period during which patients undergo a multitude of medical visits, tests, and procedures to try to identify their condition. Unfortunately, for many rare disease patients, they frequently get multiple wrong diagnoses and ultimately experience significant delays in obtaining appropriate care and treatment, resulting in the progression of their disease and irreversible damage in the delay or absence of effective treatment.

Relatedly, patients have complained that even when they are appropriately diagnosed, their provider is ill-equipped to treat their rare disease, either because of technical limitations or because they lack the knowledge and experience to treat such rare conditions. Adding to a patient’s frustration is that there is no objectively verified and evidence-based directory for providers that patients can use to access care that best meets their rare medical needs.

On November 4, 2021, NORD announced the designation of 31 NORD Rare Disease Centers of Excellence (RD CoEs) across the United States.<sup>3</sup> The RD CoE network comprises of a unique network of medical centers, clinics, and institutions that are on the frontlines of advancing care and expanding access for rare disease patients. The goal of the NORD RD CoEs is to promote outstanding treatment for rare diseases regardless of disease or geography, elevate collaboration across the network, improve standards of care, advance research, and increase awareness about rare diseases in the broader medical and patient communities.

Each RD CoE was selected by NORD through a competitive application process requiring evidence of staffing with experts across multiple specialties to meet the needs of rare disease patients. NORD also considered an applicant’s contributions to rare disease patient education, physician training, and rare disease research. Through our rigorous selection process, NORD hopes to pool the expertise of specialists across the network to identify the best existing treatment guidelines or develop new guidelines where there are currently none. Similarly, we will facilitate the sharing of diagnostic expertise across the RD CoEs to help solve difficult cases and shorten the diagnostic odyssey of these patients, while also facilitating communication between centers to disseminate the latest and most advanced treatment guidelines.

In short, patients can be referred to a NORD RD CoE when they need help with diagnosis, for treatment recommendations, or to have the center serve as a multispecialty “medical home” for their rare disease care, while maintaining communication and coordination with their local physician(s).

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<sup>3</sup> NORD. Committing to Care, Access, Equity and Research: NORD Announces 31 Rare Disease Centers of Excellence. (November 4, 2022) <https://rarediseases.org/committing-to-care-access-equity-and-research-nord-announces-31-rare-disease-centers-of-excellence/>

**CMS should consider the role that standardized and collaborative rare disease programs, like NORD's RD CoE, may play in improving access to care for Medicare beneficiaries diagnosed with rare conditions.**

In the Proposed Rule, CMS solicits comments from stakeholders on how the agency could improve reimbursement mechanisms for hospitalized Medicare beneficiaries that support these providers' ability to furnish quality rare disease care that is often more costly than non-rare disease care. We agree with CMS that reforms to the existing reimbursement system could better support providers' ability to adequately care for their rare disease patients. Currently, the existing MS-DRG system inadvertently punishes hospitals that specialize in furnishing rare disease care because such patient episodes are usually more costly than the "average" episode that MS-DRG-based payments are intended to reflect. Further compounding these hospitals' reimbursement challenges is that because these patient episodes are "rare" by definition and represent a small proportion of the total volume of cases assigned to that particular MS-DRG, rare disease patient episodes do not have tangible impact on the recalibration of MS-DRGs year-over-year, thereby perpetuating under-reimbursement for rare disease patient care.

NORD also believes, however, that CMS should consider all potential avenues to improve access to rare disease care, including those that are not patently monetary on their face. NORD's RD CoE represents a valuable resource that could inform reimbursement reform considerations. The NORD RD CoE program will systemically collect and aggregate patient data in order to apply it to the treatment of rare diseases, leveraging the best diagnostic algorithms and treatment protocols that could be used to inform both clinical education and awareness of rare disease more broadly. A collaborative and standardized, evidence-based approach to care delivery for rare diseases is particularly valuable given the diverse array of rare diseases and multi-disciplinary standards of care.

We believe that the NORD RD CoEs, could help CMS better study, target, and/or evaluate reimbursement reforms that the agency pursues, and which are intended to support providers who treat patients with rare conditions. NORD encourages CMS to make use of this network when working to identify ways to address the complex care needs of rare disease patients and ensure optimal health outcomes.

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NORD appreciates the opportunity to comment on the FY 2023 IPPS Proposed Rule. Should you have any questions or wish to discuss anything in these comments, please contact Corinne Alberts at [calberts@rarediseases.org](mailto:calberts@rarediseases.org).

Sincerely,



Heidi Ross  
Vice President, Policy & Regulatory Affairs