June 17, 2022

Centers for Medicare & Medicaid Services
Department of Health and Human Services
Attention: CMS-1771-P
P.O. Box 8013
Baltimore, MD 21244-1850

Re: CMS-1771-P: Medicare Program: Hospital Inpatient Prospective Payment Systems; Quality Programs and Medicare Promoting Interoperability Program Requirements, etc.

To whom it may concern,

In service of the limb girdle muscular dystrophy (LGMD) patient community, the undersigned non-profit organizations and disease experts, who collectively serve and represent the LGMD community, thank the Centers for Medicare and Medicaid Services (CMS) and collaborating Federal agencies and departments for proposing ICD-10-CM diagnostic codes for LGMD and certain LGMD subtypes. While we support this proposal under consideration for public comment, we strongly recommend that the ICD-10 Coordination and Maintenance Committee (henceforth referred to as "the Committee") and collaborating agencies and departments also give LGMD 2i/R9 its own distinct subcode as well.

ICD-10 codes for the LGMDs would bring a variety of positive outcomes for the communities that we serve. First, we are all too familiar with individuals with an LGMD who faced a long diagnostic odyssey prior to finally receiving a diagnosis of LGMD or a genetic confirmation of an LGMD subtype. Once diagnosed, an individual with a form of LGMD can receive more precise care from LGMD specialists and join the LGMD community in the variety of services and programs that we collectively provide. We believe the proposed ICD-10 codes for the LGMDs could shorten the diagnostic odyssey and facilitate the targeted care the community needs.

Second, ICD-10 codes for the LGMDs would further accelerate surveillance and epidemiological research. The LGMDs are under-researched diseases with only isolated and nascent efforts to truly capture the true prevalence and incidence of these diseases. Consequently, ICD-10 codes for the LGMDs would substantially accelerate the understanding of LGMD, thus also advancing efforts to better treat these diseases.

Finally, all too often we see individuals with an LGMD mistaken for having other forms of muscle diseases. We also see challenges in accessing critical care due to public and private insurers' unfamiliarity with the LGMDs. The presence of subtype-specific LGMD ICD-10 codes will be critical to accessing subtype-specific treatments, interventions we have long worked to encourage and sometimes even fund.

While we wish all 34 currently identified LGMDs could receive their own ICD-10 code, we recognize a more moderate approach to start is encouraged. That is why we are supportive of the proposed subtype-specific codes for only the most prevalent LGMDs and the LGMDs with active late-preclinical or clinical therapeutic development efforts. But we also strongly encourage the inclusion of LGMD 2i/R9 among the subtypes receiving a subtype-specific code. Our most empirical estimates show that LGMD 2i/R9 is of comparative prevalence to many of the other LGMDs nominated for an ICD-10 code. Furthermore, with three active clinical therapeutic development efforts ongoing specific to LGMD 2i/R9, including one nearing potential marketing approval, LGMD 2i/R9 is actually further along in treatment development as any other nominated subtype.

In conclusion, we thank CMS for proposing to add new ICD-10-CM codes for the LGMDs within the FY23 IPPS proposed rule, and encourage the ICD-10-CM Coordination and Maintenance Committee to further consider LGMD 2i/R9. For questions on our perspectives, and those of the LGMD patient community, please contact Paul Melmeyer, Vice President of Public Policy and Advocacy at the Muscular Dystrophy Association (MDA), at pmelmeyer@mdausa.org.

Sincerely,

Patient Organizations:

Coalition to Cure Calpain 3
CureLGMD2i
Jain Foundation
Kurt+Peter Foundation
LGMD Awareness Foundation
LGMD2i Research Fund
Muscular Dystrophy Association
The Speak Foundation

Medical Experts:

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