



May 10, 2021

ICD-10 Coordination and Maintenance Committee
National Center for Health Statistics
3311 Toledo Road
Hyattsville, MD, 20782

Re: Nomination of Limb Girdle Muscular Dystrophies for ICD-10-CM Codes

Dear Members of the ICD-10 Coordination and Maintenance Committee,

In service of the limb girdle muscular dystrophy (LGMD) patient community, the undersigned non-profit organizations, who collectively serve and represent the LGMD community, support the nomination of LGMD and certain LGMD subtypes for ICD-10-CM codes. While we support the nomination under consideration for public comment, we strongly recommend that the ICD-10 Coordination and Maintenance Committee (henceforth referred to as “the Committee”) 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 ICD-10 codes for the LGMDs under consideration 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 this proposal to offer subtype-specific codes to only the most prevalent LGMDs and the LGMDs with active late-preclinical or clinical therapeutic development efforts. But we also strongly encourage you to include 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, and with three active clinical therapeutic development efforts ongoing, LGMD 2i/R9 is easily as far along in treatment development as any other nominated subtype.

In conclusion, we thank the ICD-10 Coordination and Maintenance Committee for considering this nomination and encourage the Committee to accept this proposal with the addition of 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,

Coalition to Cure Calpain 3
CureLGMD2i
Jain Foundation
LGMD Awareness Foundation
The LGMD1D DNAJB6 Foundation
LGMD2i Research Fund
Muscular Dystrophy Association
The Speak Foundation