

THE GRASP LGMD CONSORTIUM IS COMPRISED OF EXPERTS IN THE FIELD OF LIMB GIRDLE MUSCULAR DYSTROPHY AND OTHER FORMS OF MUSCULAR DYSTROPHY. THEY HAVE PUT TOGETHER THIS STATEMENT IN SUPPORT OF INDIVIDUALS WITH MUSCULAR DYSTROPHY.

**WE REPRESENT A CONSORTIUM OF NEUROLOGISTS THROUGHOUT THE UNITED STATES WHO ARE EXPERTS ON LIMB GIRDLE MUSCULAR DYSTROPHY AND OTHER MUSCULAR DYSTROPHIES CAN LEAD PRODUCTIVE, FULFILLING LIVES. WE FEEL STRONGLY THAT PATIENTS WITH THIS DIAGNOSIS SHOULD NOT BE EXCLUDED FROM RECEIVING LIFESAVING TREATMENTS FOR COVID-19 AND OTHER ACUTE CONDITIONS.**

THE ABOVE STATEMENT APPROVED AND SUPPORTED BY THE FOLLOWING WORLD RECOGNIZED NEUROLOGISTS:

NICHOLAS E. JOHNSON, MD  
KATHERINE MATHEWS, MD  
MATTHEW P. WICKLUND, MD  
CONRAD C. WEIHL, MD, PHD  
PETER B. KANG, MD  
VOLKER STRAUB, MD, PHD  
TAHSEEN MOZAFFAR, MD  
ANTHONY A. AMATO, MD  
JEFFREY STATLAND, MD  
LINDA PAX LOWES, PT, PHD

[HTTPS://STRONGLY.MDA.ORG/MDA-FUNDS-CREATION-LIMB-GIRDLE-MUSCULAR-DYSTROPHY-CLINICAL-RESEARCH-NETWORK/](https://strongly.mda.org/mda-funds-creation-limb-girdle-muscular-dystrophy-clinical-research-network/)

[HTTPS://VIMM.VCU.EDU/LABORATORY-GROUPS/NICHOLAS-E-JOHNSON-MD-MSCI-FAAN/](https://vimm.vcu.edu/laboratory-groups/nicholas-e-johnson-md-msci-faan/)

WE ARE ALL IN THIS TOGETHER



**Dear Health Care Provider,**

Thank you from the bottom of our hearts for all you are doing to help patients with COVID-19. **We were prompted to write this letter as individuals with Limb Girdle Muscular Dystrophy (LGMD) and other forms of Muscular Dystrophy have become alarmed as some states around the country have issued crisis standards of care that are outdated and illegal to hospitals. Some of these crisis standards of care regarding the allocation of resources during a health crisis have supported the idea of excluding disabled individuals from having access.** In some states, civil rights laws are being violated by classifying certain physically disabled individuals as less "viable" to receive care during crisis situations where resources are scarce.

Our federal government has issued a directive from the Office of Civil Rights (OCR) and from the Department of Health and Human Services (HHS) **condemning** the practice of classifying disabled individuals as less worthy to receive life saving treatments or ICU care. The OCR and HHS issued this directive on March 28, 2020:

The Office for Civil Rights enforces Section 1557 of the Affordable Care Act and Section 504 of the Rehabilitation Act which prohibit discrimination on the basis of disability in HHS funded health programs or activities. These laws, like other civil rights statutes OCR enforces, remain in effect. **Persons with disabilities should not be denied medical care on the basis of stereotypes, assessments of quality of life, or judgments about a person's relative "worth" based on the presence or absence of disabilities.**

<https://www.hhs.gov/sites/default/files/ocr-bulletin-3-28-20.pdf>

Contact: HHS Press Office 202-690-6343 [media@hhs.gov](mailto:media@hhs.gov).

**Limb-girdle muscular dystrophy (LGMD) is a diverse group of disorders with many subtypes categorized by disease gene and inheritance.** Onset may occur in childhood, adolescence, young adulthood, or even later. The disease causes weakness which affects the voluntary muscles around the hips and shoulders. **An individual with muscular dystrophy may have the same chances to improve as anyone else with COVID-19.**

**Respectfully,  
The Speak Foundation**

The Speak Foundation | [www.thespeakfoundation.com](http://www.thespeakfoundation.com)  
COVID-19 Care Statement for Limb Girdle Muscular Dystrophy and other forms of Muscular Dystrophies