

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. PATIENTS WITH 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:

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[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/)

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**Dear Muscular Dystrophy Patient Community,**

On April 3rd, The Speak Foundation had a conference call with the Office of Civil Rights (OCR) with the Department of Health and Human Services. In that call, we asked important questions regarding the status of crisis standards of care around the country in our hospitals. The OCR strongly **condemns** policies where individuals with disabilities are not given the same consideration in hospitals as other individuals. Ad

To be proactive in your community, OCR gave guidance by sharing you might consider contacting your local hospital in advance of your visit to ascertain policy decisions in a rationing of care situation. Instead of waiting until the moment you might develop COVID-19, you ought to find out in advance your hospital's policy. This could help you in terms of choosing your healthcare. The hospital should in fact be forthcoming of this information.

Questions to ask in advance might be:

- How are decisions made at this hospital in the event there is a shortage of resources?
- Will I be given the same priority care in your hospital as any other individual?

The Office for Civil Rights (OCR) at the U.S Department of Health and Human Services (HHS) bulletin issued March 28, 2020 states:

**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/.

**Also, included we have put together a checklist you can use to prepare in the event you have to receive medical care. Please see uploaded document "COVID-19 PREPAREDNESS CHECKLIST."**

**Respectfully,**

**The Speak Foundation**