Dear Senator/Representative [LAST NAME]:

As a Limb Girdle Muscular Dystrophy (LGMD) patient, I am writing to urge you to look at the important accessibility needs of so many of us with LGMD.

The last page of this letter tells you what LGMD is about. This background will help you better understand this rare disease that affects 25,000 or fewer people in the United States. But because it is so rare, accessibility issues are critical for all who have this diagnosis.

We are wanting your help in our Right to Access campaign. Specifically, we need access to:

* **Healthcare**
* **Upcoming Advanced Treatments such as Gene Therapy**
* **Personal Care Assistants**
* **Lifesaving Care During a Pandemic**
* **Fair & Equitable Access to Housing**
* **Fair & Equitable Access to Airline Travel**

Continued access to **healthcare** and medical insurance is so important to people with LGMD (and all forms of muscular dystrophy). These are all considered preexisting conditions for all patients with these genetic disorders. It is extremely important that insurance companies are never allowed to discriminate due to a preexisting condition.

We need to maintain access to forthcoming **treatments** by ensuring that private medical insurance companies pay for these new treatments on the horizon. There are amazing new **gene therapies** coming that are very expensive to develop as they are one-time treatments that can potentially CURE the disease and stop it from progressing. These treatments could save lives. It is important that congress advocate for a patient’s right to access these new treatments that could cure these diseases.

We need access to maintain **personal care assistance** for individuals with disabilities. Many people with muscular dystrophy who use wheelchairs require help and assistance with activities of daily living. The cost is, on average, $75 a day to maintain help just for a few hours to get work-ready. The cost is so high, that a person working cannot afford to pay someone to help them get to work! People turn to Medicaid to fund help with personal care, but the rules basically prevent a person from working due to income restrictions. Medicaid limits a person’s income, but it is often the only vehicle to provide personal care assistants. So, many disabled individuals are prevented from working and thus you don’t see as many disabled individuals in the workplace. Also, because being married causes a spouse’s income to be taken into account for Medicaid eligibility, and therefore access to personal care, people with disabilities who need personal care assistance are often prevented from marrying the person they love.

We need equitable treatment and access during the COVID-19 pandemic. In many states, we have seen disabled individuals being treated differently during the pandemic. In some cases, it was reported that disabled individuals were deemed "less likely to recover" from COVID-19 and were not given the same **life-saving treatment** as a non-disabled individual. Our civil rights were at stake on this issue and it was horribly wrong for states to determine resource allocation with a bias against those with disabilities.

We need **fair and equitable access to apartments and housing**. The ADA doesn’t do enough for tenants to have accessible rentals. In most cases, roll-in showers are not put in apartments where a person using a wheelchair needs to use them, an apartment that is supposed to be an ADA apartment. Tenants are required to pay for that modification and cannot afford to put in a roll-in shower in a rental! Landlords and apartment companies are also unwilling to make modifications that are reasonable based on subjective decision making. There must be more protection for the disabled in our rental markets. At least one roll-in shower, 36-inch doors, and 4-foot-wide hallways should be required in all new construction in first floor apartments and in any ADA apartment.

We also need **fair and equitable access to airplane travel**. Many disabled individuals are unable to travel because airlines will not allow a person with a disability to remain in his or her wheelchair while flying.

Instead, a disabled individual is forced out of their wheelchair and then must transfer into the seat on the plane. It is very painful for a person who uses a wheelchair to be transferred in this manner, and so often, a disabled person is injured in the process.

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I would love to hear your perspective on these important issues for LGMD patients.

Thank you for your time and interest, and I look forward to hearing from you soon.

Sincerely,

[NAME/TITLE/INSTITUTION]