

























November 18, 2019

The Honorable Nancy Pelosi Speaker of the House United States House of Representatives Washington, D.C. 20515 The Honorable Kevin McCarthy Minority Leader United States House of Representatives Washington, D.C. 20515

Re: Support for the Access to Genetic Counselor Services Act of 2019 (H.R. 3235)

Dear Speaker Pelosi and Minority Leader McCarthy,

On behalf of the neuromuscular disease (NMD) patient community, the undersigned patient organizations write to you in support of the *Access to Genetic Counselor Services Act of 2019* (H.R. 3235). This bi-partisan legislation, introduced by Representatives Dave Loebsack (IA-02) and Mike Kelly (PA-16), would authorize reimbursement for professional services delivered to Medicare beneficiaries by certified genetic counselors. These providers would be reimbursed at 85% of the physician pay rate, which is consistent with the rate of pay for nurse practitioners.

While some neuromuscular diseases can be identified and diagnosed reasonably soon after symptoms present, many others are only identified after lengthy and complicated diagnostic odysseys for the patients and families who live with them. Obtaining definitive genetic results is often critical as the diagnoses allow physicians to treat individuals with neuromuscular diseases with more accuracy. Certified genetic counselors are important partners to physicians in providing guidance to patients, but they currently are not recognized as Medicare practitioners even though genetic counseling is a covered benefit under Medicare.

Allowing certified genetic counselors to be reimbursed by Medicare for the services they provide would enable more individuals living with neuromuscular conditions to receive the information and services they need to access genetic testing, which is oftentimes essential to ensuring that they can get the right treatment and participate in clinical trials. Additionally, certified genetic counselors can assist in crafting innovative treatment approaches and avoiding unnecessary additional testing.

As representatives of the neuromuscular disease patient community, we support H.R. 3235 as it will increase access to more affordable and patient-centric diagnoses and care strategies within the Medicare program. We call on all Members of Congress to support this legislation and ensure its swift passage. For questions or other information, please contact Brittany Johnson Hernandez, Senior Director of Policy and Advocacy for the Muscular Dystrophy Association, at <a href="mailto:bhernandez@mdausa.org">bhernandez@mdausa.org</a>. Thank you.

## Sincerely,

ALS Association
Charcot-Marie-Tooth Association
Coalition to Cure Calpain 3
Cure CMD
Cure VCP Disease
CureDuchenne
Hereditary Neuropathy Foundation
Jain Foundation
Les Turner ALS Foundation
Little Hercules Foundation
MitoAction
Muscular Dystrophy Association
Myasthenia Gravis Foundation of American