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Non-profit 501(c)(3)

February 9, 2017

The Honorable Laurie Monnes Anderson  
State Capitol  
900 Court St, NE  
Salem, OR 97301

Dear Senator Anderson,

Thank you for your leadership on healthcare issues, particularly your support for individuals and families impacted by rare, chronic, and devastating medical conditions. I write you on behalf of the GBS|CIDP Foundation International to express our support for SB 526.

The GBS|CIDP Foundation International is a patient-driven 501c3 founded over 30 years ago. We support the community affected by Guillain-Barré Syndrome (GBS), Chronic Inflammatory Demyelinating Polyneuropathy (CIDP), and related conditions, such as Multifocal Motor Neuropathy (MMN). GBS is an inflammatory disorder of the peripheral nerves outside the brain and spinal cord. CIDP is a rare disorder of the peripheral nerves characterized by gradually increasing weakness of the legs and, to a lesser extent, the arms. MMN is a rare and incurable neurological condition in which multiple motor nerves are attacked by the immune system. Peripheral neuropathies can be progressive, disabling, and even fatal. These conditions can be managed though if they are diagnosed early and patients have appropriate access to innovative therapies.

The recent utilization of step therapy and fail-first protocols by third-party payers is incredibly distressing to our community. These diseases progress quickly and the damage done can be severe and even irreversible if appropriate intervention is not timely. Quite literally, GBS, CIDP, and MMN patients do not have the luxury of “failing first” on a more cost effective medication before moving onto a better treatment. Further, these disease are complex and nuanced, and only the patient and their healthcare provider know the best course of action. Any delay in treatment could result in lingering disability or worse, jeopardizing the patients’ health and the family livelihood.

SB 526 is a common-sense piece of legislation that will preserve the doctor-patient relationship and allow our community in Oregon due recourse in their efforts to quickly access the most effective therapy. Similar legislative efforts in New York and other states have been critical to protecting patients in this regard. Further, the SB 526 requirements that step therapy protocols be established in a transparent manner and that utilization must be based on current clinical evidence will be extremely beneficial in protecting patients moving forward.

Thank you for your time and your consideration of this request.

Sincerely,



Lisa Butler  
Executive Director