



STATE OF VERMONT

MEMORANDUM

To: Legislative Committee on Administrative Rules (LCAR)
From: Sen. Ginny Lyons, Chair of the Senate Committee on Health and Welfare
Rep. Theresa Wood, Chair of the House Committee on Human Services
Date: September 19, 2023
Subject: 23-E08; Amyotrophic Lateral Sclerosis (ALS) Registry
Cc: Brendan Atwood, Public Health Policy Advisor, Vermont Department of Health

Section 4.1 of 23-E08 (pertaining to the ALS Registry) directs a health care provider that “screens for, diagnoses, or provides therapeutic services” to ALS patients to report all patients diagnosed with ALS to the Department of Health (Department). It has been brought to the Department’s attention by both the Office of Legislative Counsel and stakeholders that a provider who screens for ALS may not be the same individual who is providing therapeutic services, potentially resulting in duplicate reporting to the ALS Registry.

The Department expressed an interest in mitigating the risk of duplicate reporting by providers by adding a clause to the effect of “unless the health provider knows that a report has already been made to the Department of Health” to Sec. 4.1 of the emergency rule or the subsequent permanent rule but noted a reluctance and need for further review by the Department’s legal counsel because such an addition diverges from the exact statutory language of 18 V.S.A. § 173. We believe that adding language to the anticipated permanent rule to mitigate the risk of duplicate reporting is within the statutory authority of the Department and consistent with legislative intent.