

**JCAR PACKAGE WRITTEN  
COMMENTS/DHHS RESPONSE-ALS**

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January 23, 2025

To the Michigan Department of Health and Human Services,

As directors of the major ALS Clinics in the State of Michigan, we are writing to convey our strongest support for making amyotrophic lateral sclerosis (ALS) a reportable disease in Michigan. ALS is a debilitating neurodegenerative disease that involves progressive loss of motor neurons that control voluntary muscle function. Its unrelenting and ultimately fatal nature requires evolving multidisciplinary support as the disease advances, but barriers to acquiring this multidisciplinary care have a significant impact on quality of life for all impacted by ALS.

The data collected by the Michigan Department of Health and Human Services through an ALS registry will provide critical insight into the clinical care needs for individuals with ALS by helping us understand how currently available resources are being utilized and by identifying whether there are underserved areas where access to the required multidisciplinary care is lacking. This knowledge will inform improved care management and have considerable benefits for both those affected by ALS and their caregivers. Notably, the scientific advances made possible by having a comprehensive registry of individuals in our state can likewise enable much-needed diagnostic, prognostic, and therapeutic breakthroughs as well as inform potential prevention strategies.

Once again, we offer our utmost support for making ALS a reportable disease in Michigan. If there is anything else we can do to help facilitate this endeavor, please let us know.

Sincerely,

Ximena Arcila-Londono, MD  
Director, Harry J. Hoenselaar ALS Clinic  
Henry Ford Health Neuroscience



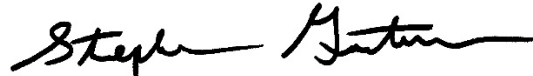
Brian Callaghan, MD, MS  
Director, Multidisciplinary ALS Clinic  
VA Ann Arbor Health System



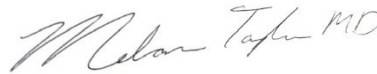
Michelle Crooks, MD  
Medical Director, Bronson Neuroscience  
Bronson



Stephen Goutman, MD, MS  
Director, Pranger ALS Clinic  
University of Michigan Medicine



Melanie Taylor, MD  
Director, Hauenstein Neurosciences ALS Clinic  
Trinity Health



Paul Twydell, DO  
Director, ALS Clinic  
Neurosciences Integrated Care Campus-Beltline  
Corewell Health Medical Group



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January 23, 2025

To the Michigan Department of Health and Human Services,

The National Advisory Board of the ALS Center of Excellence at Michigan Medicine/University of Michigan is writing this letter in full support of the state of Michigan moving forward in making ALS a reportable disease through a formal registry, and with Rule Set 2022-13 HS. We believe that the data collected by this registry will assist ALS physicians and ALS researchers in Michigan in their mission to find identifiable risk factors for the disease, leading to possible effective treatments or prevention. Each member of this Board has had ALS touch their lives in a personal way, so we are very aware of the devastation of this disease and lack of effective treatments to date.

Without data collected by the MDHHS, we will not know where clusters of disease may be occurring, what elements these cases have in common, and where efforts should be centered at for monitoring or preventing ALS.

We are happy to provide support with further letter writing or emails if beneficial.

Sincerely,

Sheri Mark-Slaim RN, JD, President

Hilary King

John Scarbrough

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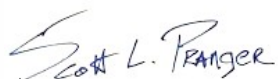
Jon Gerych

Paula Morning-Carter

Brian Roth, DO

A blue ink handwritten signature of Brian Roth, DO, featuring a stylized 'B' and 'R'.

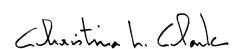
Scott Pranger

A blue ink handwritten signature of Scott L. Pranger, written in a cursive style.

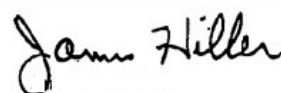
Clifford Lampe, PhD

A blue ink handwritten signature of Clifford Lampe, PhD, consisting of stylized initials 'CL' followed by a horizontal line.

Christina Clark

A blue ink handwritten signature of Christina Clark, written in a cursive style.

James Hiller, JD

A blue ink handwritten signature of James Hiller, written in a cursive style.

**From:** [Anderson, Beth E. \(DHHS\)](#)  
**To:** [Brennan, Mary \(DHHS\)](#)  
**Subject:** FW: Updated letters of support for ALS Rules Set 2022-13 HS  
**Date:** Wednesday, February 12, 2025 9:06:25 AM  
**Attachments:** [UpdatedUM ALS BofD Letter to State of MI1\\_25final.pdf](#)  
[UpdatedClinicDirectorLettertoState1\\_25.pdf](#)

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**From:** Ritter, Mike <denritte@med.umich.edu>  
**Sent:** Thursday, January 23, 2025 12:50 PM  
**To:** Anderson, Beth E. (DHHS) <AndersonB@michigan.gov>; MDHHS-AdminRules <MDHHS-AdminRules@michigan.gov>  
**Subject:** Updated letters of support for ALS Rules Set 2022-13 HS

**CAUTION: This is an External email. Please send suspicious emails to [abuse@michigan.gov](mailto:abuse@michigan.gov)**

Good morning,

Attached are the two letters of support for the forum for public comment – for the Administrative Rules for ALS Reporting (Rule Set 2022-13 HS) – for February 12, 2025.

One is from the 6 ALS Clinic medical directors in the state of Michigan  
The other is from our entire Michigan Medicine National Advisory Board

Thank you for your consideration,  
Mike Ritter MD

**D. Michael Ritter MD**

MANAGING DIRECTOR | ALS Center of Excellence at Michigan Medicine and the Neuronetwork for Emerging Therapies

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