Michigan Office of Administrative Hearings and Rules

MOAHR-Rules@michigan.gov

AGENCY REPORT TO THE JOINT COMMITEE ON ADMNINISTRATIVE RULES (JCAR)

1. Agency Information

Agency name:

Health and Human Services

Division/Bureau/Office:

Public Health Administration

Name of person completing this form:

Talisa Gauthier

Phone number of person completing this form:

517-241-0048

E-mail of person completing this form:

gauthiert1@michigan.gov

Name of Department Regulatory Affairs Officer reviewing this form:

Mary Brennan

2. Rule Set Information

MOAHR assigned rule set number:

2022-13 HS

Title of proposed rule set:

Amyotrophic Lateral Sclerosis (ALS) Reporting

3. Purpose for the proposed rules and background:

These new rules would establish requirements for reporting ALS to the Michigan Department of Health and Human Services. ALS is a progressive, degenerative, neurological disease. The onset of ALS is typically later in life, peaking between 50 and 75 years of age. The majority of patients with ALS die within 2-5 years of diagnosis. In general, it is believed that the ALS incidence is 2/100,000, so assuming a population size in Michigan of 10 million, that is 200 new cases per year; however, the University of Michigan ALS clinic has been seeing more cases and estimates 300 new cases per year. It is hard to determine the number of missed cases, especially given the lack of ALS clinics in Northern Michigan. The state has the authority under the Public Health Code to obtain, upon request, medical records to investigate, monitor, prevent, and control diseases dangerous to public health. Many of the diseases that are currently reportable to the state have treatments or known prevention strategies, but ALS patients and families have nothing that makes any significant difference. All ALS patients eventually die. The cost of the care for one ALS patient has been estimated at nearly $200,000 per year in some cases, so the prevention of the development of ALS in one life in Michigan would have an economic impact. These rules would establish a statewide ALS case registry based on data collection of patients with ALS, identified by neurologists, hospitals, ALS clinics, and vital records. The ALS case registry would provide data for public health surveillance and provide researchers with standardized and comprehensive data aimed at identifying risk factors and prevention strategies.

4. Summary of proposed rules:

These new rules would establish requirements for reporting Amyotrophic Lateral Sclerosis (ALS) to the Michigan Department of Health and Human Services. ALS is a progressive, degenerative, neurological disease. These rules would establish a statewide ALS case registry based on data collection of patients with ALS, identified by neurologists, hospitals, ALS clinics, and vital records. The ALS case registry would provide data for public health surveillance and provide researchers with standardized and comprehensive data aimed at identifying risk factors and prevention strategies.

5. List names of newspapers in which the notice of public hearing was published and publication dates:

Oakland Press, January 28, 2025; Marquette Mining Journal, January 27, 2025; Battle Creek Enquirer, January 27, 2025.

6. Date of publication of rules and notice of public hearing in Michigan Register:

2/1/2025

7. Date, time, and location of public hearing:

2/12/2025 09:00 AM at South Grand Tower Building Room 1I , 333 South Grand Avenue, Lansing, Michigan 48933

8. Provide the link the agency used to post the regulatory impact statement and cost-benefit analysis on its website:

https://ARS.apps.lara.state.mi.us/Transaction/RFRTransaction?TransactionID=1372

9. List of the name and title of agency representative(s) who attended the public hearing:

Beth Anderson, State Admin Manager, Chronic Disease Epidemiology.

10. Persons submitting comments of support:

Ximena Arcila-Londono, MD Director, 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; Sheri Mark-Slaim RN, JD, President, ALS Center of Excellence, U of M; Michael Ritter, M.D. Managing Director, ALS Center of Excellent, U of M; Doris Allen, Board of Directors, ALS Center of Excellence, U of M; William Allen, M.D., Board of Directors, ALS Center of Excellence, U of M; Christina Clark, Board of Directors, ALS Center of Excellence, U of M; Jon Gerych, Board of Directors, ALS Center of Excellence, U of M; James Hiller, J.D., Board of Directors, ALS Center of Excellence, U of M; Hilary King, Board of Directors, ALS Center of Excellence, U of M; Clifford Lampe, PHD, Board of Directors, ALS Center of Excellence, U of M; Paula Morning-Carter, Board of Directors, ALS Center of Excellence, U of M; Scott Pranger, Board of Directors, ALS Center of Excellence, U of M; Lisa Rosenberg, Board of Directors, ALS Center of Excellence, U of M; Brian Roth, D.O., Board of Directors, ALS Center of Excellence, U of M; John Scarbrough, Board of Directors, ALS Center of Excellence, U of M.

11. Persons submitting comments of opposition:

None.

12. Persons submitting other comments:

None.

13. Identify any changes made to the proposed rules based on comments received during the public comment period:

	Name & Organization	Comments made at public hearing	Written Comments	Agency Rationale for Rule Change and Description of Change(s) Made	Rule number & citation changed
1					

14.Date report completed:

2/21/2025