

Stricken language would be deleted from and underlined language would be added to present law.

State of Arkansas
94th General Assembly
Regular Session, 2023

A Bill

HOUSE BILL 1357

By: Representative L. Johnson

By: Senator J. Boyd

For An Act To Be Entitled

AN ACT TO CREATE THE RARE DISEASE ADVISORY COUNCIL;
AND FOR OTHER PURPOSES.

Subtitle

TO CREATE THE RARE DISEASE ADVISORY
COUNCIL.

BE IT ENACTED BY THE GENERAL ASSEMBLY OF THE STATE OF ARKANSAS:

SECTION 1. Arkansas Code Title 25, Chapter 10, Subchapter 1, is amended to add an additional section to read as follows:

25-10-146. Rare Disease Advisory Council – Creation – Definition.

(a) As used in this section, "rare disease" means a health condition that is listed as rare by the National Institutes of Health.

(b) There is created the Rare Disease Advisory Council within the Department of Human Services.

(c) The purposes of the council are to provide:

(1)(A) Expert clinical advice and input in writing to the Arkansas Medicaid Drug Utilization Review Board when the board reviews a drug or other treatment for a rare disease.

(B) The board shall:

(i) Seek advice and feedback from the council on drafts of clinical criteria before reviewing any drug or other treatment that treats a rare disease;

(ii) Distribute the advice of the council to the members of the board; and



(iii) Publish the advice of the council in the meeting minutes of the board;

(2) Input and feedback in writing to the department, the Arkansas Medicaid Program, and other state agencies on matters that affect patients who have been diagnosed with a rare disease, including without limitation information regarding:

(A) Access to care, insurance, specialists, and other needed services for patients who have been diagnosed with a rare disease;

(B) The impact on coverage, cost-sharing, tiering, or other utilization management procedures on providing treatment and services to patients who have been diagnosed with a rare disease; and

(C) Pandemic preparedness and response; and

(3) Publicly accessible resources on research, diagnosis, treatment, and education relating to rare diseases in Arkansas.

(d)(1) The council shall consist of the following members:

(A)(i) Four (4) members appointed by the Governor.

(ii) One (1) member appointed by the Governor shall be a representative of the department.

(iii) One (1) member appointed by the Governor shall be a representative of an organization that operates in the state and represents patients who have been diagnosed with a rare disease.

(iv) Two (2) members appointed by the Governor shall be residents of the state who are either:

(a) Eighteen (18) years of age or older and have been diagnosed with a rare disease; or

(b) A parent or caregiver for a child under eighteen (18) years of age who has been diagnosed with a rare disease;

(B)(i) Three (3) members appointed by the President Pro Tempore of the Senate.

(ii) One (1) member appointed by the President Pro Tempore of the Senate shall be a representative from an academic research institution in the state that receives grant funding for rare disease research.

(iii) One (1) member appointed by the President Pro Tempore of the Senate shall be a physician who is licensed and practicing in the state and has experience in researching, diagnosing, or treating rare

diseases.

(iv) One (1) member appointed by the President Pro Tempore of the Senate shall be a geneticist who is licensed and practicing in the state;

(C)(i) Three (3) members appointed by the Speaker of the House of Representatives.

(ii) One (1) member appointed by the Speaker of the House of Representatives shall be a representative from an academic research institution in the state that receives grant funding for rare disease research.

(iii) One (1) member appointed by the Speaker of the House of Representatives shall be a physician who is licensed and practicing in the state and has experience in researching, diagnosing, or treating rare diseases.

(iv) One (1) member appointed by the Speaker of the House of Representatives shall be a registered nurse or advanced practice registered nurse who is licensed and practicing in the state and has experience treating rare diseases;

(D) One (1) member appointed by the Chair of the Senate Committee on Public Health, Welfare, and Labor; and

(E) One (1) member appointed by the Chair of the House Committee on Public Health, Welfare, and Labor.

(2) A member of the council shall not be a current member of the board or any other drug utilization advisory group to the Arkansas Medicaid Program.

(e)(1) The Secretary of the Department of Human Services shall:

(A) Call the first meeting of the council within ninety (90) days of the effective date of this act; and

(B) Serve as chair at the first meeting of the council until the council elects a chair from its membership.

(2)(A) At the first meeting of the council, the members of the council shall elect from its membership a chair, a vice-chair, and any other officers as needed for the transaction of its business.

(B) The council shall hold an annual election to elect a chair, vice-chair, and any other officers deemed necessary.

(3) Meetings of the council shall be held at least one (1) time

every three (3) months but may occur more often at the call of the chair.

(4) The council shall establish rules and procedures for conducting its business.

(f)(1)(A)(i) At the first meeting of the council, the length of the terms of the initial appointees shall be determined by lot.

(ii) Four (4) members shall serve an initial term of one (1) year.

(iii) Four (4) members shall serve an initial term of two (2) years.

(iv) Four (4) members shall serve an initial term of three (3) years.

(B) A member subsequently appointed to the council shall serve a term of three (3) years.

(2)(A) A vacancy on the council shall be filled in the same manner as the initial appointment.

(B) A member appointed to fill a vacancy shall serve for the remainder of the vacated term.

(3) A member may be removed by the appointing official for cause.

(g) The department shall provide staff, meeting space, and materials for the council.

(h)(1) A majority of the membership of the council constitutes a quorum for the purpose of transacting the business of the council.

(2) An affirmative vote of a majority of a quorum present is required for the passage of a motion or other council action.

(3) Members may participate in meetings electronically via teleconference and be considered present.

(i) The council may appoint subcommittees to study, research, and advise the council.

(j) With the exception of members who are employed by the state, members may receive expense reimbursement and stipends under § 25-16-901 et seq.

(k) By July 1, 2024, and by July 1 of each subsequent year, the council shall submit a report to the Governor, the General Assembly, the department, and other relevant agencies that:

(1) Describes the findings, activities, and progress of the

council; and

(2) Provides feedback on ways to address the needs of patients living with a rare disease in the state.