

1 State of Arkansas  
2 94th General Assembly  
3 Regular Session, 2023  
4

# A Bill

HOUSE BILL 1357

5 By: Representative L. Johnson  
6 By: Senator J. Boyd  
7

## For An Act To Be Entitled

9 AN ACT TO CREATE THE RARE DISEASE ADVISORY COUNCIL;  
10 AND FOR OTHER PURPOSES.  
11

## Subtitle

12  
13 TO CREATE THE RARE DISEASE ADVISORY  
14 COUNCIL.  
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18 BE IT ENACTED BY THE GENERAL ASSEMBLY OF THE STATE OF ARKANSAS:  
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20 SECTION 1. Arkansas Code Title 25, Chapter 10, Subchapter 1, is  
21 amended to add an additional section to read as follows:

22 25-10-146. Rare Disease Advisory Council – Creation – Definition.

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

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

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

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

31 (B) The board shall:

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

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



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

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

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

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

12                   (C) Pandemic preparedness and response; and

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

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

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

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

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

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

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

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

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

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

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

1 diseases.

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

1 council; and

2 (2) Provides feedback on ways to address the needs of patients

3 living with a rare disease in the state.

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