

1 State of Arkansas
2 95th General Assembly
3 Regular Session, 2025
4

A Bill

HOUSE BILL 1532

5 By: Representative L. Johnson
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7

For An Act To Be Entitled

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

Subtitle

14 TO CREATE THE ARKANSAS RARE DISEASE
15 ADVISORY COUNCIL.
16

17 BE IT ENACTED BY THE GENERAL ASSEMBLY OF THE STATE OF ARKANSAS:
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19 SECTION 1. Arkansas Code Title 20, Chapter 8, is amended to add an
20 additional subchapter to read as follows:

21 Subchapter 12 – Arkansas Rare Disease Advisory Council
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23 20-8-1201. Legislative findings.

24 The General Assembly finds that:

25 (1) A rare disease, sometimes called an orphan disease, is
26 defined as a disease that affects fewer than two hundred thousand (200,000)
27 people in the United States;

28 (2) There are more than ten thousand (10,000) known rare
29 diseases affecting more than thirty million (30,000,000) Americans with more
30 than half of this number being children;

31 (3) Approximately ninety-five percent (95%) of rare diseases do
32 not have a United States Food and Drug Administration approved treatment;

33 (4) While the exact cause for many rare diseases remains
34 unknown, many rare diseases are genetic in origin and can be linked to
35 mutations in a single gene or in multiple genes that can be passed down from
36 generation to generation;



1 (5) People with rare diseases face many obstacles, including
2 delays in obtaining an accurate diagnosis, finding a healthcare provider with
3 expertise in their condition, and a lack of affordable access to therapies
4 and medication used to treat rare diseases that may result in significant
5 physical, mental, and financial challenges; and

6 (6) A state-based advisory council composed of qualified
7 professionals and persons living with rare diseases and their caregivers
8 could educate or advise medical professionals, government agencies,
9 legislators, and the public about rare diseases as an important public health
10 issue to encourage research or support the development of new and better
11 policies to diagnose and treat rare diseases.

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13 20-8-1202. Arkansas Rare Disease Advisory Council – Creation –
14 Membership.

15 (a) There is created the Arkansas Rare Disease Advisory Council within
16 the Department of Health, to consist of the following eight (8) members:

17 (1) A representative from an academic research institution in
18 the state that receives grant funding for rare disease research;

19 (2) A representative from the Department of Human Services who
20 is knowledgeable about the Arkansas Medicaid Program;

21 (3) A geneticist or genetic counselor, appointed by the
22 Secretary of the Department of Health;

23 (4) At least two (2) patients who have a rare disease, appointed
24 by the secretary;

25 (5) At least one (1) caregiver of a person with a rare disease,
26 appointed by the secretary;

27 (6) A person who is a member of the scientific community, a
28 member of the biopharmaceutical industry, or a pharmacist who has experience
29 with or is engaged in rare disease research, including without limitation a
30 medical researcher with experience conducting research on rare diseases,
31 appointed by the secretary; and

32 (7) A mental health provider, registered nurse, advanced
33 practice registered nurse, or physician with experience treating patients who
34 have rare diseases in this state, appointed by the secretary.

35 (b)(1) All members of the advisory council shall be full-time
36 residents of this state.

1 (2) The membership of the council shall include a diverse set of
2 stakeholders representative of the geographic and population diversity of the
3 state.

4 (c)(1) The secretary shall appoint the Chair of the Arkansas Rare
5 Disease Advisory Council for an initial term of three (3) years.

6 (2) The chair shall not hold a position within the state
7 government.

8 (3) At the end of the initial three (3) year term, and every two
9 (2) years thereafter, the members of the council shall appoint, by a majority
10 vote, a new chair.

11 (d)(1) Members shall serve no longer than three (3) years.

12 (2) However, during the initial five (5) years after the
13 establishment of the council, members may serve up to four (4) years.

14 (e) If a vacancy occurs, the secretary shall fill the vacancy in a
15 timely manner and based on the requirements under subsection (a) of this
16 section.

17 (f)(1) The initial meeting of the council shall occur within the first
18 ninety (90) days after the effective date of this section.

19 (2) During the first year after the effective date of this
20 section, the council shall meet no less than one (1) time per month for a
21 time period determined by the chair either in person or via an online meeting
22 platform.

23 (3) After the first year after the effective date of this
24 section, the council shall meet no less than one (1) time per quarter either
25 in person or via an online meeting platform as determined by the chair.

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27 20-8-1203. Powers and duties.

28 The Arkansas Rare Disease Advisory Council shall:

29 (1) Provide guidance and recommendations to educate the public,
30 the General Assembly, and other government agencies and departments on the
31 needs of individuals with rare diseases living in this state;

32 (2) Convene public hearings, make inquiries, and solicit
33 comments from the general public in this state to assist the Arkansas Rare
34 Disease Advisory Council with a first-year landscape or survey of the needs
35 of rare disease patients, caregivers, and providers in the state;

36 (3) Provide testimony and comments on pending legislation and

1 rules before the General Assembly, or the Legislative Council when not in a
2 legislative session, and other state agencies that impact the rare disease
3 community in this state;

4 (4) Consult with experts on rare diseases to develop policy
5 recommendations to improve patient access to, and the quality of, rare
6 disease specialists, affordable and comprehensive healthcare coverage,
7 relevant diagnostics, timely treatment, and other needed services;

8 (5) Research and make recommendations to state agencies and
9 insurers that provide services to persons with a rare disease on the impact
10 of orphan drug pricing, prior authorization, cost-sharing, or other barriers
11 to the provision of treatment and care for patients;

12 (6) Establish best practices and protocols to include in state
13 planning related to natural disasters, public health emergencies, or other
14 emergency declarations to enable continuity of care for rare disease patients
15 and ensure safeguards against discrimination for rare disease patients are in
16 place;

17 (7) Evaluate and make recommendations to improve the Arkansas
18 Medicaid Program and state-regulated private health insurance coverage of
19 drugs for rare disease patients to improve coverage of diagnostics and
20 facilitate access to necessary healthcare providers with expertise in the
21 treatment of rare diseases;

22 (8) Publish a list of existing, publicly accessible resources on
23 research, diagnosis, treatment, and education relating to the rare diseases
24 on the website of the Department of Health;

25 (9) Identify areas of unmet need for research and opportunities
26 for collaboration across stakeholders and other state rare disease advisory
27 councils that can inform future studies and work done by the Arkansas Rare
28 Disease Advisory Council;

29 (10) Identify and distribute educational resources for
30 healthcare providers to foster recognition and optimize treatment of rare
31 diseases in this state;

32 (11) Research and identify best practices to reduce health
33 disparities and achieve health equity in the research, diagnosis, and
34 treatment of rare diseases in this state; and

35 (12) Provide opportunities for the public to hear updates and
36 provide input into the work of the Arkansas Rare Disease Advisory Council.

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20-8-1204. Reports.

(a)(1) The Arkansas Rare Disease Advisory Council shall submit a report to the Governor and the Legislative Council within one (1) year of enactment of the Arkansas Rare Disease Advisory Council and annually thereafter.

(2) Before submission of the report under subdivision (a)(1) of this section, a draft of the report shall be made available for public comment and discussed at an open public meeting.

(b) The report under subsection (a) of this section shall:

(1) Describe the activities and progress of the Arkansas Rare Disease Advisory Council;

(2) Provide an update on the status of funding of the Arkansas Rare Disease Advisory Council, including without limitation the grants that were sought out, accepted, or used, and the remaining balance of funds of the Arkansas Rare Disease Advisory Council; and

(3) Provide recommendations to the Governor and the General Assembly on ways to address the needs of people living with rare diseases in this state.

20-8-1205. Funding.

(a) The members of the Arkansas Rare Disease Advisory Council may solicit funds on behalf of the council.

(b) The council shall:

(1) Set up a method to securely hold and distribute funds to support the functioning of the council; and

(2) Report funding sources in report required under § 20-8-1203.