

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

State of Arkansas  
95th General Assembly  
Regular Session, 2025

# A Bill

HOUSE BILL 1532

By: Representative L. Johnson

## For An Act To Be Entitled

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

## Subtitle

TO CREATE THE ARKANSAS RARE DISEASE  
ADVISORY COUNCIL.

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

SECTION 1. Arkansas Code Title 20, Chapter 8, is amended to add an additional subchapter to read as follows:

Subchapter 12 – Arkansas Rare Disease Advisory Council

20-8-1201. Legislative findings.

The General Assembly finds that:

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

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

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

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



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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

20-8-1203. Powers and duties.

The Arkansas Rare Disease Advisory Council shall:

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

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

(3) Provide testimony and comments on pending legislation and

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

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

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

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

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

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

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

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

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

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

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.