



ARIZONA HOUSE OF REPRESENTATIVES

Fifty-sixth Legislature
Second Regular Session

HB 2758: rare disease advisory council

Sponsor: Representative Hernandez A, LD 20
Committee on Health & Human Services

Overview

Establishes the Arizona Rare Disease Advisory Council (RDAC) to gather public testimony, educate and recommend to the Legislature and government entities on the needs of individuals with rare diseases living in Arizona. Outlines RDAC membership and duties and contains legislative findings.

History

The [Arizona Department of Health Services \(DHS\)](#) aims to promote, protect and improve the health and wellness of individuals and communities in Arizona. The agency strives to set the standard for personal and community health through direct care, science, public policy and leadership. DHS operates programs from the following areas: 1) disease prevention and control; 2) health promotion; 3) community public health; 4) environmental health; 5) maternal and child health; 6) emergency preparedness; and 7) regulation of healthcare intuitions and facilities.

Currently, there are 26 states that have established an RDAC. These states include: Alabama Colorado, Connecticut, Delaware, Florida, Georgia, Illinois, Indiana, Louisiana, Maine, Maryland, Massachusetts, Minnesota, Missouri, Nevada, New Hampshire, New Jersey, New York, North Carolina, Ohio, Pennsylvania, South Carolina, Tennessee, Utah, Virginia and West Virginia ([National Organization for Rare Disorders](#)).

Provisions

1. Establishes the RDAC within DHS to provide guidance and recommendations to educate the public, Legislature and other government agencies and departments, as appropriate, on the needs of individuals who have rare diseases and living in Arizona. (Sec. 1)
2. Requires the appointment process to be conducted in a transparent manner to provide interested individuals an opportunity to apply for RDAC membership. (Sec. 1)
3. Requires all RDAC members to be full-time residents of Arizona, if practicable. (Sec. 1)
4. Requires RDAC membership to include a diverse set of stakeholders who represent the geographic and population diversity of this state. (Sec. 1)
5. Lists the types of members to be appointed to the RDAC. (Sec. 1)
6. Requires the initial meeting of the RDAC to occur within 90 days after the effective date. (Sec. 1)
7. Directs the RDAC to meet at least once a month, during the first year. (Sec. 1)
8. Allows RDAC to meet in person or via an online meeting platform. (Sec. 1)

<input type="checkbox"/> Prop 105 (45 votes)	<input type="checkbox"/> Prop 108 (40 votes)	<input type="checkbox"/> Emergency (40 votes)	<input type="checkbox"/> Fiscal Note
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9. Requires RDAC to provide opportunities for the public to hear updates on their work and provide input. (Sec. 1)
10. Instructs RDAC to develop and maintain a public website on which meeting minutes and notices will be posted and public comments can be submitted. (Sec. 1)
11. Requires RDAC members to serve three-year terms. (Sec. 1)
12. Specifies that RDAC members are not eligible to receive compensation but are eligible for reimbursement of expenses. (Sec. 1)
13. Requires the RDAC to do the following:
 - a) convene public hearings, make inquiries and solicit comments from the public to assist the RDAC with a first-year landscape or survey of the unmet needs of rare disease patients, caregivers and providers in the state;
 - b) provide testimony and comments on pending legislation and rules that impact the state's rare disease community;
 - c) consult with experts to develop policy recommendations that improve patient access to, and quality of, rare disease specialists, affordable and comprehensive health care coverage, relevant diagnostics, timely treatment and other needed services;
 - d) research and make recommendations to state agencies and health insurers that provide services to persons with rare diseases regarding the impact of orphan drug pricing, prior authorization, cost-sharing or other barriers to providing treatment and care for patients,
 - e) evaluate and make recommendations to improve the Arizona Health Cost Containment System and state-regulated private health insurance coverage of drugs for rare disease patients,
 - f) engage with the state Drug Utilization Review Board and the Pharmacy and Therapeutics committee, to improve coverage of diagnostics and facilities access to necessary health care providers with expertise in treating rare diseases; and
 - g) identify and distribute educational resources for health care providers to foster recognition and optimize treatment of rare diseases. (Sec. 1)
14. Requires RDAC to submit a report to the Governor and chairpersons and ranking members of the Health and Human Services Committee of the Senate and the House of Representatives, or their successor committee annually on December 1. (Sec. 1)
15. Specifies that a draft of the annual report must be made available for public comment and discussed at an open public meeting before submission. (Sec. 1)
16. Requires the annual report to:
 - a) describe RDAC's activities and progress; and
 - b) provide recommendations to the Governor and Legislature on ways to address the needs of people living in Arizona with rare diseases. (Sec. 1)
17. Allows the RDAC to solicit gifts, grants and donations for operations, activities and initiatives. (Sec. 1)
18. Outlines initial terms for RDAC members. (Sec. 2)
19. Requires the Governor to make all subsequent appointments as prescribed by statute. (Sec. 2)
20. Contains legislative findings. (Sec. 3)