

REFERENCE TITLE: rare disease advisory council

State of Arizona  
House of Representatives  
Fifty-sixth Legislature  
Second Regular Session  
2024

## **HB 2758**

Introduced by  
Representatives Hernandez A: Gress, Hernandez C, Hernandez M, Mathis,  
Wilmeth; Senators Bravo, Gonzales, Miranda, Shamp

AN ACT

AMENDING TITLE 36, CHAPTER 1, ARTICLE 2, ARIZONA REVISED STATUTES, BY  
ADDING SECTION 36-142.01; RELATING TO THE DEPARTMENT OF HEALTH SERVICES.

(TEXT OF BILL BEGINS ON NEXT PAGE)

1 Be it enacted by the Legislature of the State of Arizona:

2 Section 1. Title 36, chapter 1, article 2, Arizona Revised  
3 Statutes, is amended by adding section 36-142.01, to read:

4 36-142.01. Arizona rare disease advisory council; purpose;  
5 membership; duties; reports

6 A. THE ARIZONA RARE DISEASE ADVISORY COUNCIL IS ESTABLISHED IN THE  
7 DEPARTMENT. THE COUNCIL SHALL PROVIDE GUIDANCE AND RECOMMENDATIONS TO  
8 EDUCATE THE PUBLIC, THE LEGISLATURE AND OTHER GOVERNMENT AGENCIES AND  
9 DEPARTMENTS, AS APPROPRIATE, ON THE NEEDS OF INDIVIDUALS WHO HAVE RARE  
10 DISEASES AND WHO ARE LIVING IN THIS STATE.

11 B. THE COUNCIL'S APPOINTMENT PROCESS SHALL BE CONDUCTED IN A  
12 TRANSPARENT MANNER TO PROVIDE INTERESTED INDIVIDUALS AN OPPORTUNITY TO  
13 APPLY FOR MEMBERSHIP ON THE COUNCIL. ALL MEMBERS OF THE COUNCIL SHALL BE  
14 FULL-TIME RESIDENTS OF THIS STATE, IF PRACTICABLE. MEMBERSHIP SHALL  
15 INCLUDE A DIVERSE SET OF STAKEHOLDERS WHO REPRESENT THE GEOGRAPHIC AND  
16 POPULATION DIVERSITY OF THIS STATE. THE COUNCIL CONSISTS OF THE FOLLOWING  
17 MEMBERS APPOINTED BY THE GOVERNOR:

18 1. ONE PERSON WHO REPRESENTS AN ACADEMIC RESEARCH INSTITUTION IN  
19 THIS STATE THAT RECEIVES GRANT FUNDING FOR RARE DISEASE RESEARCH.

20 2. ONE PERSON WHO REPRESENTS THE DEPARTMENT.

21 3. ONE PERSON WHO REPRESENTS THE ARIZONA HEALTH CARE COST  
22 CONTAINMENT SYSTEM.

23 4. ONE REPRESENTATIVE FROM THE DEPARTMENT OF INSURANCE AND  
24 FINANCIAL INSTITUTIONS.

25 5. ONE REGISTERED NURSE OR ADVANCED PRACTICE REGISTERED NURSE WHO  
26 IS LICENSED AND PRACTICING IN THIS STATE AND WHO HAS EXPERIENCE TREATING  
27 RARE DISEASES.

28 6. TWO PHYSICIANS WHO ARE PRACTICING IN THIS STATE AND WHO HAVE  
29 EXPERIENCE TREATING PATIENTS WITH RARE DISEASES, ONE OF WHOM HAS  
30 EXPERIENCE WORKING WITH PEDIATRIC POPULATIONS.

31 7. ONE GENETICIST OR GENETIC COUNSELOR.

32 8. ONE HOSPITAL ADMINISTRATOR, OR THE HOSPITAL ADMINISTRATOR'S  
33 DESIGNEE, FROM A HOSPITAL IN THIS STATE THAT PROVIDES CARE TO PERSONS  
34 DIAGNOSED WITH RARE DISEASES.

35 9. AT LEAST ONE PATIENT WHO HAS A RARE DISEASE.

36 10. AT LEAST ONE CAREGIVER OF A PERSON WITH A RARE DISEASE.

37 11. ONE PERSON WHO REPRESENTS A RARE DISEASE PATIENT ORGANIZATION  
38 THAT OPERATES IN THIS STATE.

39 12. A PHARMACIST WITH EXPERIENCE DISPENSING DRUGS USED TO TREAT  
40 RARE DISEASES.

41 13. ONE REPRESENTATIVE OF THE BIOPHARMA INDUSTRY.

42 14. ONE REPRESENTATIVE OF A HEALTH INSURER.

43 15. ONE MEMBER OF THE SCIENTIFIC COMMUNITY WHO IS A MEDICAL  
44 RESEARCHER WITH EXPERIENCE CONDUCTING RESEARCH ON RARE DISEASES.

1           16. ONE MENTAL HEALTH PROVIDER WITH EXPERIENCE TREATING PATIENTS  
2 WITH RARE DISEASES IN THIS STATE.

3           C. THE INITIAL MEETING OF THE COUNCIL SHALL OCCUR WITHIN NINETY  
4 DAYS AFTER THE EFFECTIVE DATE OF THIS SECTION. DURING THE FIRST YEAR, THE  
5 COUNCIL SHALL MEET AT LEAST ONCE PER MONTH. THE COUNCIL MAY MEET IN  
6 PERSON OR VIA AN ONLINE MEETING PLATFORM. THE COUNCIL SHALL PROVIDE  
7 OPPORTUNITIES FOR THE PUBLIC TO HEAR UPDATES ON THE COUNCIL'S WORK AND TO  
8 PROVIDE INPUT. THE COUNCIL SHALL DEVELOP AND MAINTAIN A PUBLIC WEBSITE ON  
9 WHICH MEETING MINUTES AND MEETING NOTICES MAY BE POSTED AND PUBLIC  
10 COMMENTS MAY BE SUBMITTED.

11           D. COUNCIL MEMBERS SHALL SERVE THREE-YEAR TERMS. COUNCIL MEMBERS  
12 ARE NOT ELIGIBLE TO RECEIVE COMPENSATION BUT ARE ELIGIBLE FOR  
13 REIMBURSEMENT OF EXPENSES PURSUANT TO TITLE 38, CHAPTER 4, ARTICLE 2.

14           E. THE COUNCIL SHALL CONDUCT THE FOLLOWING ACTIVITIES TO BENEFIT  
15 THOSE IMPACTED BY RARE DISEASES IN THIS STATE:

16           1. CONVENE PUBLIC HEARINGS, MAKE INQUIRIES AND SOLICIT COMMENTS  
17 FROM THE PUBLIC IN THIS STATE TO ASSIST THE COUNCIL WITH A FIRST-YEAR  
18 LANDSCAPE OR SURVEY OF THE UNMET NEEDS OF RARE DISEASE PATIENTS,  
19 CAREGIVERS AND PROVIDERS IN THIS STATE.

20           2. PROVIDE TESTIMONY AND COMMENTS ON PENDING LEGISLATION AND RULES  
21 THAT IMPACT THIS STATE'S RARE DISEASE COMMUNITY.

22           3. CONSULT WITH EXPERTS ON RARE DISEASES TO DEVELOP POLICY  
23 RECOMMENDATIONS THAT IMPROVE PATIENT ACCESS TO, AND QUALITY OF, RARE  
24 DISEASE SPECIALISTS, AFFORDABLE AND COMPREHENSIVE HEALTH CARE COVERAGE,  
25 RELEVANT DIAGNOSTICS, TIMELY TREATMENT AND OTHER NEEDED SERVICES.

26           4. RESEARCH AND MAKE RECOMMENDATIONS TO STATE AGENCIES AND HEALTH  
27 INSURERS THAT PROVIDE SERVICES TO PERSONS WITH RARE DISEASES REGARDING THE  
28 IMPACT OF ORPHAN DRUG PRICING, PRIOR AUTHORIZATION, COST-SHARING OR OTHER  
29 BARRIERS TO PROVIDING TREATMENT AND CARE FOR PATIENTS.

30           5. EVALUATE AND MAKE RECOMMENDATIONS TO IMPROVE THE ARIZONA HEALTH  
31 CARE COST CONTAINMENT SYSTEM AND STATE-REGULATED PRIVATE HEALTH INSURANCE  
32 COVERAGE OF DRUGS FOR RARE DISEASE PATIENTS, INCLUDING ENGAGING WITH THE  
33 STATE DRUG UTILIZATION REVIEW BOARD AND THE PHARMACY AND THERAPEUTICS  
34 COMMITTEE, TO IMPROVE COVERAGE OF DIAGNOSTICS AND FACILITATE ACCESS TO  
35 NECESSARY HEALTH CARE PROVIDERS WITH EXPERTISE IN TREATING RARE DISEASES.

36           6. IDENTIFY AND DISTRIBUTE EDUCATIONAL RESOURCES FOR HEALTH CARE  
37 PROVIDERS TO FOSTER RECOGNITION AND OPTIMIZE TREATMENT OF RARE DISEASES IN  
38 THIS STATE.

39           F. ON OR BEFORE DECEMBER 1 OF EACH YEAR, THE COUNCIL SHALL SUBMIT A  
40 REPORT TO THE GOVERNOR AND THE CHAIRPERSONS AND RANKING MEMBERS OF THE  
41 HEALTH AND HUMAN SERVICES COMMITTEES OF THE SENATE AND THE HOUSE OF  
42 REPRESENTATIVES, OR THEIR SUCCESSOR COMMITTEES. BEFORE SUBMISSION, A DRAFT  
43 OF THE ANNUAL REPORT SHALL BE MADE AVAILABLE FOR PUBLIC COMMENT AND  
44 DISCUSSED AT AN OPEN PUBLIC MEETING. THE ANNUAL REPORT SHALL:

