House Engrossed

rare disease advisory council

State of Arizona
House of Representatives
Fifty-seventh Legislature
First Regular Session
2025

HOUSE BILL 2380

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)

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

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

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

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

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

1. ONE PERSON WHO REPRESENTS AN ACADEMIC RESEARCH INSTITUTION IN THIS STATE THAT RECEIVES GRANT FUNDING FOR RARE DISEASE RESEARCH.
2. ONE PERSON WHO REPRESENTS THE DEPARTMENT.
3. ONE PERSON WHO REPRESENTS THE ARIZONA HEALTH CARE COST CONTAINMENT SYSTEM.
4. ONE REPRESENTATIVE FROM THE DEPARTMENT OF INSURANCE AND FINANCIAL INSTITUTIONS.
5. ONE REGISTERED NURSE OR ADVANCED PRACTICE REGISTERED NURSE WHO IS LICENSED AND PRACTICING IN THIS STATE AND WHO HAS EXPERIENCE TREATING RARE DISEASES.
6. TWO PHYSICIANS WHO ARE PRACTICING IN THIS STATE AND WHO HAVE EXPERIENCE TREATING PATIENTS WITH RARE DISEASES, ONE OF WHOM HAS EXPERIENCE WORKING WITH PEDIATRIC POPULATIONS.
7. ONE GENETICIST OR GENETIC COUNSELOR.
8. ONE HOSPITAL ADMINISTRATOR, OR THE HOSPITAL ADMINISTRATOR'S DESIGNEE, FROM A HOSPITAL IN THIS STATE THAT PROVIDES CARE TO PERSONS DIAGNOSED WITH RARE DISEASES.
9. AT LEAST ONE PATIENT WHO HAS A RARE DISEASE.
10. AT LEAST ONE CAREGIVER OF A PERSON WITH A RARE DISEASE.
11. ONE PERSON WHO REPRESENTS A RARE DISEASE PATIENT ORGANIZATION THAT OPERATES IN THIS STATE.
12. A PHARMACIST WITH EXPERIENCE DISPENSING DRUGS USED TO TREAT RARE DISEASES.
13. ONE REPRESENTATIVE OF THE BIOPHARMA INDUSTRY.
14. ONE REPRESENTATIVE OF A HEALTH INSURER.
15. ONE MEMBER OF THE SCIENTIFIC COMMUNITY WHO IS A MEDICAL RESEARCHER WITH EXPERIENCE CONDUCTING RESEARCH ON RARE DISEASES.

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

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

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

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

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

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

3. CONSULT WITH EXPERTS ON RARE DISEASES 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.

4. 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.

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

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

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

1. DESCRIBE THE ACTIVITIES AND PROGRESS OF THE COUNCIL PURSUANT TO THIS SECTION.

2. PROVIDE RECOMMENDATIONS TO THE GOVERNOR AND THE LEGISLATURE ON WAYS TO ADDRESS THE NEEDS OF PEOPLE LIVING WITH RARE DISEASES IN THIS STATE.

G. THE COUNCIL MAY SOLICIT GIFTS, GRANTS AND DONATIONS FOR OPERATIONS, ACTIVITIES AND INITIATIVES OF THE COUNCIL.

Sec. 2. Initial terms of members of the Arizona rare disease advisory council

A. Notwithstanding section 36-142.01, Arizona Revised Statutes, as added by this act, the initial terms of members of the Arizona rare disease advisory council are:

1. Five terms ending January 1, 2028.

2. Six terms ending January 1, 2029.

3. Six terms ending January 1, 2030.

B. The governor shall make all subsequent appointments as prescribed by statute.

Sec. 3. Legislative findings

The legislature finds that:

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

2. There are more than seven thousand known rare diseases affecting approximately twenty-five to thirty million Americans, more than half of whom are children.

3. Approximately ninety-five percent of rare diseases do not have a treatment approved by the United States food and drug administration.

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, which 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 health care 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.

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 and encourage research or support the development of new and better policies to diagnose and treat rare diseases.