

An Act

SENATE BILL 22-186

BY SENATOR(S) Ginal and Simpson, Buckner, Cooke, Coram, Fields, Hansen, Jaquez Lewis, Kolker, Lee, Scott, Zenzinger;
also REPRESENTATIVE(S) Mullica and McKean, Bird, Caraveo, Duran, Esgar, Hooton, Kipp, Lindsay, Titone, Young.

CONCERNING THE CREATION OF A COUNCIL TO ADVISE THE STATE ABOUT ISSUES RELATING TO PERSONS LIVING WITH RARE DISEASES, AND, IN CONNECTION THEREWITH, MAKING AN APPROPRIATION.

Be it enacted by the General Assembly of the State of Colorado:

SECTION 1. In Colorado Revised Statutes, **add** part 15 to article 1 of title 25 as follows:

PART 15
COLORADO RARE DISEASE
ADVISORY COUNCIL

25-1-1501. Legislative declaration. (1) THE GENERAL ASSEMBLY FINDS AND DECLARES THAT:

(a) A RARE DISEASE, SOMETIMES CALLED AN "ORPHAN" DISEASE, IS

Capital letters or bold & italic numbers indicate new material added to existing law; dashes through words or numbers indicate deletions from existing law and such material is not part of the act.

A DISEASE THAT AFFECTS FEWER THAN TWO HUNDRED THOUSAND PEOPLE IN THE UNITED STATES;

(b) THERE ARE SEVEN THOUSAND KNOWN RARE DISEASES AFFECTING APPROXIMATELY THIRTY MILLION ADULTS AND CHILDREN IN THE UNITED STATES;

(c) 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;

(d) PEOPLE WITH RARE DISEASES FACE MANY CHALLENGES, INCLUDING DELAYS IN OBTAINING A DIAGNOSIS, MISDIAGNOSIS, SHORTAGES OF MEDICAL SPECIALISTS WHO CAN PROVIDE TREATMENT, AND LACK OF AFFORDABLE ACCESS TO THERAPIES AND MEDICATION USED TO TREAT RARE DISEASES; AND

(e) A COLORADO RARE DISEASE ADVISORY COUNCIL COMPOSED OF QUALIFIED PROFESSIONALS AND PEOPLE LIVING WITH RARE DISEASES COULD EDUCATE MEDICAL PROFESSIONALS, GOVERNMENT AGENCIES, LEGISLATORS, AND THE PUBLIC ABOUT RARE DISEASES AS AN IMPORTANT PUBLIC HEALTH ISSUE AND ENCOURAGE RESEARCH FOR THE DEVELOPMENT OF NEW TREATMENTS FOR RARE DISEASES.

25-1-1502. Definitions. AS USED IN THIS PART 15, UNLESS THE CONTEXT OTHERWISE REQUIRES:

(1) "COUNCIL" MEANS THE COLORADO RARE DISEASE ADVISORY COUNCIL CREATED IN SECTION 25-1-1503.

(2) "DEPARTMENT" MEANS THE DEPARTMENT OF PUBLIC HEALTH AND ENVIRONMENT.

(3) "FACILITATOR" MEANS THE PERSON SELECTED BY THE COUNCIL TO FACILITATE THE WORK OF THE COUNCIL AS DESCRIBED IN SECTION 25-1-1507.

(4) "RARE DISEASE" MEANS A DISEASE THAT AFFECTS FEWER THAN TWO HUNDRED THOUSAND PEOPLE IN THE UNITED STATES.

25-1-1503. Colorado rare disease advisory council - creation. THERE IS CREATED IN THE DEPARTMENT THE COLORADO RARE DISEASE ADVISORY COUNCIL. THE PURPOSE OF THE COUNCIL IS TO STUDY AND MAKE FINDINGS AND RECOMMENDATIONS TO THE GENERAL ASSEMBLY, STATE AGENCIES, AND OTHERS, AS APPROPRIATE, CONCERNING THE NEEDS OF INDIVIDUALS LIVING IN COLORADO WITH RARE DISEASES.

25-1-1504. Council membership. (1) THE APPOINTING AUTHORITIES SHALL CONDUCT THE APPOINTMENT PROCESS IN A TRANSPARENT MANNER TO PROVIDE INTERESTED INDIVIDUALS AN OPPORTUNITY TO APPLY FOR MEMBERSHIP ON THE COUNCIL. ALL MEMBERS OF THE COUNCIL MUST BE FULL-TIME RESIDENTS OF COLORADO.

(2) (a) THE COUNCIL CONSISTS OF TWELVE VOTING MEMBERS APPOINTED AS FOLLOWS:

(I) THE PRESIDENT OF THE SENATE SHALL APPOINT THREE MEMBERS, INCLUDING:

(A) ONE REPRESENTATIVE FROM ACADEMIC RESEARCH IN THE STATE WHO RECEIVES GRANT FUNDING FOR RARE DISEASE RESEARCH;

(B) ONE GENETICIST PRACTICING IN COLORADO; AND

(C) ONE PHYSICIAN LICENSED AND PRACTICING IN COLORADO WITH EXPERIENCE TREATING RARE DISEASES;

(II) THE MINORITY LEADER OF THE SENATE SHALL APPOINT THREE MEMBERS, INCLUDING:

(A) ONE REGISTERED NURSE OR ADVANCED PRACTICE REGISTERED NURSE LICENSED AND PRACTICING IN COLORADO WITH EXPERIENCE TREATING RARE DISEASES;

(B) ONE PHARMACIST WITH EXPERIENCE DISPENSING DRUGS USED TO TREAT RARE DISEASES; AND

(C) ONE PERSON WHO HAS A RARE DISEASE;

(III) THE SPEAKER OF THE HOUSE OF REPRESENTATIVES SHALL

APPOINT THREE MEMBERS, INCLUDING:

(A) ONE REPRESENTATIVE OF A RARE DISEASE PATIENT ORGANIZATION OPERATING IN COLORADO THAT IS NOT AFFILIATED WITH THE FACILITATOR;

(B) ONE REPRESENTATIVE OF THE BIOTECHNOLOGY OR PHARMACEUTICAL INDUSTRY; AND

(C) ONE REPRESENTATIVE OF A HEALTH INSURER; AND

(IV) THE MINORITY LEADER OF THE HOUSE OF REPRESENTATIVES SHALL APPOINT THREE MEMBERS, INCLUDING:

(A) ONE PERSON WHO HAS A RARE DISEASE;

(B) ONE PARENT WHOSE CHILD OR CHILDREN HAVE BEEN DIAGNOSED WITH A RARE DISEASE; AND

(C) ONE CAREGIVER OF A PERSON WITH A RARE DISEASE.

(b) THE DIRECTOR OF THE OFFICE OF HEALTH EQUITY, CREATED IN SECTION 25-4-2204, OR THE DIRECTOR'S DESIGNEE, SHALL SERVE AS AN EX OFFICIO, NONVOTING MEMBER OF THE COUNCIL.

(3) (a) THE APPOINTING AUTHORITIES SHALL MAKE THEIR INITIAL APPOINTMENTS TO THE COUNCIL BY OCTOBER 1, 2022. IN MAKING APPOINTMENTS, TO THE EXTENT PRACTICABLE, THE APPOINTING AUTHORITIES SHALL CONSIDER GENDER, ETHNICITY, GEOGRAPHIC DIVERSITY, AND OTHER CONSIDERATIONS THAT WILL RESULT IN A DIVERSE AND INCLUSIVE COUNCIL.

(b) EACH MEMBER WHO IS APPOINTED PURSUANT TO SUBSECTION (2)(a) OF THIS SECTION SERVES AT THE PLEASURE OF THE OFFICIAL WHO APPOINTED THE MEMBER. ANY VACANCY IN MEMBERSHIP IS FILLED BY THE APPOINTING AUTHORITY.

(c) MEMBERS SHALL SERVE THREE-YEAR TERMS; EXCEPT THAT, IN ORDER TO PROVIDE CONTINUITY AND KNOWLEDGE TRANSFER AMONG COUNCIL MEMBERS, DURING THE INITIAL APPOINTMENTS TO THE COUNCIL

AND FOR ANY MEMBERS APPOINTED IN THE FIRST FIVE YEARS AFTER THE COUNCIL IS ESTABLISHED, MEMBERS MAY SERVE INITIAL TERMS OF UP TO FOUR YEARS.

(4) (a) MEMBERS OF THE COUNCIL SERVE WITHOUT COMPENSATION AND WITHOUT REIMBURSEMENT FOR EXPENSES INCURRED BY THE MEMBERS IN SERVING ON THE COUNCIL OR PARTICIPATING IN COUNCIL ACTIVITIES.

(b) NOTWITHSTANDING SUBSECTION (4)(a) OF THIS SECTION, A COUNCIL MEMBER MAY BE REIMBURSED FOR ACTUAL AND NECESSARY EXPENSES RELATING TO THE COUNCIL'S DUTIES TO THE EXTENT THAT THE COUNCIL RECEIVES GIFTS, GRANTS, OR DONATIONS TO COVER THE COST OF REIMBURSEMENT.

25-1-1505. Activities carried out by the council - duties. (1) THE COUNCIL SHALL CONDUCT THE FOLLOWING ACTIVITIES TO BENEFIT RARE DISEASE PATIENTS IN COLORADO:

(a) CONVENE PUBLIC MEETINGS, MAKE INQUIRIES, AND SOLICIT COMMENTS FROM COLORADANS TO ASSIST THE COUNCIL WITH A SURVEY OF THE NEEDS OF RARE DISEASE PATIENTS, CAREGIVERS, AND PROVIDERS IN THE STATE, TO BE COMPLETED WITHIN EIGHTEEN MONTHS AFTER THE COUNCIL IS ESTABLISHED;

(b) CONSULT WITH EXPERTS ON RARE DISEASES TO DEVELOP POLICY RECOMMENDATIONS TO IMPROVE PATIENT ACCESS TO AND QUALITY OF RARE DISEASE SPECIALISTS, AFFORDABLE AND COMPREHENSIVE HEALTH-CARE COVERAGE, BETTER ACCESS TO CLINICAL TRIALS, RELEVANT DIAGNOSTICS, AND TIMELY TREATMENT;

(c) EDUCATE AND MAKE RECOMMENDATIONS TO STATE AGENCIES AND TO HEALTH INSURERS PROVIDING HEALTH BENEFIT PLANS TO PERSONS WITH RARE DISEASES ON THE IMPACT OF IMPOSING PRIOR AUTHORIZATION, COST-SHARING, TIERING, OR OTHER UTILIZATION MANAGEMENT PROCEDURES ON THE PROVISION OF TREATMENT AND CARE FOR PATIENTS;

(d) RESEARCH AND IDENTIFY BEST PRACTICES TO ENSURE CONTINUITY OF CARE FOR RARE DISEASE PATIENTS TRANSITIONING FROM PEDIATRIC CARE TO ADULT CARE;

(e) ESTABLISH A COLORADO RARE DISEASE COUNCIL WEB PAGE OR WEBSITE, HOUSED ON ITS OWN WEBSITE OR AS PART OF A HOST WEBSITE, AND PUBLISH A LIST OF EXISTING, PUBLICLY ACCESSIBLE RESOURCES ON RESEARCH, DIAGNOSIS, TREATMENT, AND EDUCATIONAL MATERIALS FOR HEALTH-CARE PROVIDERS AND PATIENTS RELATING TO RARE DISEASES; AND

(f) PREPARE AND SUBMIT A REPORT ANNUALLY TO THE GOVERNOR AND TO SPECIFIED COMMITTEES OF THE GENERAL ASSEMBLY PURSUANT TO SECTION 25-1-1509.

(2) PRIOR TO PUBLISHING ANY FINAL RECOMMENDATIONS OF THE COUNCIL, THE COUNCIL SHALL PROVIDE AN OPPORTUNITY FOR PUBLIC COMMENT ON DRAFT RECOMMENDATIONS.

(3) IN ADDITION TO ANY OTHER COUNCIL ACTIVITIES, THE COUNCIL MAY:

(a) ADOPT RULES OF PROCEDURE FOR THE COUNCIL THAT IT DEEMS NECESSARY TO FACILITATE THE ORDERLY CONDUCT OF ITS BUSINESS;

(b) ESTABLISH TASK FORCES OR COMMITTEES OF ITS MEMBERS AND NONMEMBERS TO ASSIST IN THE PERFORMANCE OF THE COUNCIL'S DUTIES;

(c) ACCEPT WRITTEN OR ORAL INPUT FROM THE PUBLIC OR ANY RELEVANT SOURCE;

(d) PUBLICIZE ITS FINDINGS AND RECOMMENDATIONS CONCERNING THE NEEDS OF INDIVIDUALS WITH RARE DISEASES LIVING IN COLORADO AND ADVOCATE ON BEHALF OF THE COUNCIL FOR ITS RECOMMENDED ACTIONS; AND

(e) SEEK, ACCEPT, AND EXPEND GIFTS, GRANTS, AND DONATIONS FOR PURPOSES OF CARRYING OUT THE DUTIES OF THE COUNCIL.

25-1-1506. Department - fiscal agent. (1) THE DEPARTMENT MAY, AS NECESSARY:

(a) ACT AS FISCAL AGENT FOR THE COUNCIL;

(b) RECEIVE GIFTS, GRANTS, OR DONATIONS FROM THE COUNCIL OR

FACILITATOR FOR USE BY THE COUNCIL;

(c) HOST THE COUNCIL'S WEB PAGE OR WEBSITE; AND

(d) PROVIDE MEETING SPACE AND OTHER ADMINISTRATIVE SUPPORTS TO THE COUNCIL.

25-1-1507. Council facilitator - duties. (1) UNLESS THE COUNCIL DETERMINES THAT AN ADMINISTRATOR IS NOT NEEDED, THE COUNCIL SHALL CONTRACT FOR THE SERVICES OF A FACILITATOR TO PROVIDE ASSISTANCE TO THE COUNCIL, AS DETERMINED BY THE COUNCIL, IN AN ANNUAL AMOUNT NOT TO EXCEED FIFTY THOUSAND DOLLARS. THE FACILITATOR'S ASSISTANCE TO THE COUNCIL MAY INCLUDE:

(a) SCHEDULING AND CONDUCTING MEETINGS, PREPARING MEETING MINUTES, AND MANAGING THE COUNCIL'S ONLINE CONTENT;

(b) ORGANIZING THE WORK OF THE COUNCIL;

(c) CONDUCTING RESEARCH AND PROVIDING INFORMATION TO THE COUNCIL CONCERNING ISSUES ADDRESSED BY THE COUNCIL;

(d) CONDUCTING PUBLIC OUTREACH AND SOLICITING PUBLIC FEEDBACK, AS WELL AS PUBLICIZING THE FINDINGS AND RECOMMENDATIONS OF THE COUNCIL;

(e) INVITING AND COORDINATING INTERESTED PERSONS AND EXPERTS TO PROVIDE INFORMATION TO THE COUNCIL;

(f) SOLICITING GIFTS, GRANTS, AND DONATIONS, INCLUDING IN-KIND DONATIONS, FOR THE COUNCIL;

(g) SECURING AND MANAGING THE COUNCIL'S MONEY AND FACILITATING COUNCIL EXPENDITURES; AND

(h) ANY OTHER DUTIES IN SUPPORT OF THE COUNCIL'S ACTIVITIES.

(2) THE FACILITATOR MUST BE A NONPROFIT ENTITY IN COLORADO WITH EXPERIENCE ORGANIZING AND ADVOCATING FOR THE NEEDS OF PERSONS WITH RESPECT TO ALL RARE DISEASES.

25-1-1508. Council meetings - requirements - transparency - information. (1) AT ITS FIRST MEETING, THE COUNCIL SHALL SELECT A CHAIR AND VICE-CHAIR FROM AMONG ITS MEMBERSHIP BY MAJORITY VOTE. UNLESS OTHERWISE DETERMINED BY THE COUNCIL, THE CHAIR AND VICE-CHAIR SERVE TWO-YEAR TERMS. THE CHAIR AND VICE-CHAIR MAY BE REAPPOINTED WITHOUT LIMIT.

(2) (a) THE COUNCIL SHALL HOLD ITS FIRST MEETING WITHIN FORTY-FIVE DAYS AFTER THE FINAL COUNCIL MEMBER IS APPOINTED PURSUANT TO SECTION 25-1-1504.

(b) DURING THE FIRST TWELVE MONTHS AFTER THE COUNCIL IS ESTABLISHED, THE COUNCIL SHALL MEET AT LEAST ONCE PER MONTH. THEREAFTER, THE COUNCIL SHALL MEET AT LEAST ONCE PER QUARTER. COUNCIL MEETINGS MAY BE CONDUCTED IN PERSON OR VIA AN ONLINE PLATFORM.

(3) IN CONDUCTING MEETINGS, THE COUNCIL SHALL:

(a) SCHEDULE MEETINGS IN ADVANCE WITH MEANINGFUL NOTICE TO AFFECTED PERSONS, STAKEHOLDERS, AND THE PUBLIC; AND

(b) PROVIDE OPPORTUNITIES FOR INTERESTED PERSONS TO HEAR UPDATES AND PROVIDE INPUT ON THE COUNCIL'S WORK, INCLUDING THROUGH ONLINE TESTIMONY, IF FEASIBLE.

(4) THE COUNCIL IS SUBJECT TO THE OPEN MEETINGS LAW, PART 4 OF ARTICLE 6 OF TITLE 24, AND THE "COLORADO OPEN RECORDS ACT", PART 2 OF ARTICLE 72 OF TITLE 24.

(5) THE COUNCIL SHALL CREATE AND MAINTAIN, OR PROVIDE CONTENT FOR, A PUBLIC WEBSITE WHERE MEETING NOTICES AND MINUTES ARE POSTED AND PUBLIC COMMENTS MAY BE OFFERED.

25-1-1509. Reporting - recommendations. (1) WITHIN TWELVE MONTHS AFTER THE ESTABLISHMENT OF THE COUNCIL, THE COUNCIL SHALL SUBMIT A REPORT TO THE GOVERNOR, THE PUBLIC AND BEHAVIORAL HEALTH AND HUMAN SERVICES COMMITTEE AND THE HEALTH AND INSURANCE COMMITTEE OF THE HOUSE OF REPRESENTATIVES, AND THE HEALTH AND HUMAN SERVICES COMMITTEE OF THE SENATE, OR THEIR SUCCESSOR

COMMITTEES, CONCERNING:

(a) THE COUNCIL'S ACTIVITIES, INCLUDING PROGRESS ON THE ACTIVITIES DESCRIBED IN SECTION 25-1-1505;

(b) THE STATUS OF COUNCIL FUNDING, INCLUDING:

(I) THE BALANCE OF ANY APPROPRIATIONS MADE TO THE COUNCIL AND ANY GIFTS, GRANTS, OR DONATIONS THAT WERE SOUGHT, ACCEPTED, OR RECEIVED, INCLUDING IN-KIND DONATIONS; AND

(II) THE USE OF MONEY APPROPRIATED TO OR RECEIVED BY THE COUNCIL; AND

(c) RECOMMENDATIONS TO THE GOVERNOR AND THE GENERAL ASSEMBLY TO ADDRESS THE NEEDS OF PEOPLE LIVING WITH RARE DISEASES IN COLORADO.

(2) (a) AFTER THE INITIAL REPORT, THE COUNCIL SHALL REPORT ANNUALLY TO THE GOVERNOR AND TO COMMITTEES OF THE GENERAL ASSEMBLY, AS SPECIFIED IN SUBSECTION (1) OF THIS SECTION.

(b) NOTWITHSTANDING SECTION 24-1-136 (11)(a)(I), THE REPORTING REQUIREMENTS SET FORTH IN SUBSECTION (2)(a) OF THIS SECTION CONTINUE UNTIL THE REPEAL OF THIS PART 15 PURSUANT TO SECTION 25-1-1511.

(3) THE COUNCIL SHALL MAKE ANNUAL REPORTS PUBLIC AND AVAILABLE ON THE COUNCIL'S WEBSITE DESCRIBED IN SECTION 25-1-1505.

25-1-1510. Funding - gifts, grants, or donations. (1) THE GENERAL ASSEMBLY MAY APPROPRIATE MONEY FROM THE GENERAL FUND TO THE DEPARTMENT FOR ALLOCATION TO THE COUNCIL TO CARRY OUT COUNCIL ACTIVITIES AND TO CONTRACT FOR THE SERVICES OF A FACILITATOR.

(2) MEMBERS OF THE COUNCIL AND ANY FACILITATOR MAY SEEK, ACCEPT, AND EXPEND GIFTS, GRANTS, OR DONATIONS FROM PRIVATE OR PUBLIC SOURCES FOR THE PURPOSES OF THIS PART 15.

(3) THE COUNCIL SHALL DEPOSIT ANY MONEY COLLECTED THROUGH

GIFTS, GRANTS, OR DONATIONS IN AN INSURED ACCOUNT AT A COLORADO FINANCIAL INSTITUTION AND OTHERWISE EXERCISE FIDUCIARY RESPONSIBILITIES OVER COUNCIL MONEY.

25-1-1511. Repeal of part - sunset review. THIS PART 15 IS REPEALED, EFFECTIVE SEPTEMBER 1, 2032. BEFORE THE REPEAL, THIS PART 15 IS SCHEDULED FOR REVIEW IN ACCORDANCE WITH SECTION 2-3-1203.

SECTION 2. In Colorado Revised Statutes, 2-3-1203, **add** (24) as follows:

2-3-1203. Sunset review of advisory committees - legislative declaration - definition - repeal. (24) (a) THE FOLLOWING STATUTORY AUTHORIZATIONS FOR THE DESIGNATED ADVISORY COMMITTEES WILL REPEAL ON SEPTEMBER 1, 2032:

(I) THE COLORADO RARE DISEASE ADVISORY COUNCIL CREATED IN SECTION 25-1-1503.

(b) THIS SUBSECTION (24) IS REPEALED, EFFECTIVE SEPTEMBER 1, 2034.

SECTION 3. Appropriation. For the 2022-23 state fiscal year, \$80,567 is appropriated to the department of public health and environment for use by administration and support. This appropriation is from the general fund and is based on an assumption that the department will require an additional 0.4 FTE. To implement this act, the department may use this appropriation for personal services.

SECTION 4. Act subject to petition - effective date. This act takes effect at 12:01 a.m. on the day following the expiration of the ninety-day period after final adjournment of the general assembly; except that, if a referendum petition is filed pursuant to section 1 (3) of article V of the state constitution against this act or an item, section, or part of this act within such period, then the act, item, section, or part will not take effect unless approved by the people at the general election to be held in

November 2022 and, in such case, will take effect on the date of the official declaration of the vote thereon by the governor.



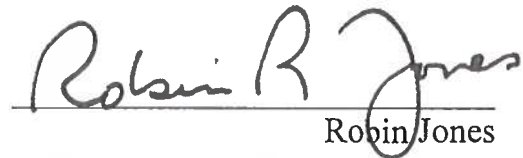
Steve Fenberg
PRESIDENT OF
THE SENATE



Alec Garnett
SPEAKER OF THE HOUSE
OF REPRESENTATIVES



Cindi L. Markwell
SECRETARY OF
THE SENATE

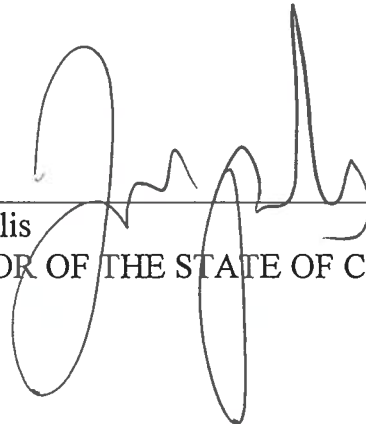


Robin Jones
CHIEF CLERK OF THE HOUSE
OF REPRESENTATIVES

APPROVED

June 8th at 1:35 p.m.

(Date and Time)



Jared S. Polis
GOVERNOR OF THE STATE OF COLORADO