

APPENDIX: RARE DISEASE ADVISORY COUNCILS

| STATE | Council (Yes/No) | RDAC Called | Enacted Date | Council Members | Membership | Appointments Made By | Housed By | Duties | Funding | RDAC Bill |
|-------|------------------|----------------------|--------------|-----------------|--|---|---|---|-------------------------------|--------------------------------------|
| AL | Yes | Council | 2018 | 20(+) | One physician, one pediatrician, one medical researcher, one advanced practice or registered nurse, one pediatric nurse, two hospital administrators (one pediatric, one non-pediatric), one representative from each academic research institution that receives grant funding related to rare disease, one representative from each of the seven congressional districts, the state health officer, two members of the state Senate and two members of the state House of Representatives. | Aside from members of state Senate and House of Representatives, appointments made by Governor. Members of state Senate appointed by President Pro Tempore of the Senate and Senate Minority Leader. Members of State House of Reps appointed by Speaker of state House of Reps and Minority Leader of House of Representatives. | Within the School of Medicine at University of Alabama Birmingham | -Discuss strategies to improve understanding of the diagnosis, treatment, and impact of rare diseases -Collect data on rare diseases -Coordinate rare disease collaborations across the state -Highlight existing collaborations -Report findings to the AL legislature annually with the goal of addressing changes in rare disease policies to positively impact citizens and the state | No information about funding. | HJR 115 (2017) |
| AK | No | N/A | N/A | N/A | N/A | N/A | N/A | N/A | N/A | N/A |
| AZ | No | N/A | N/A | N/A | N/A | N/A | N/A | N/A | N/A | N/A |
| AR | No | N/A | N/A | N/A | N/A | N/A | N/A | N/A | N/A | N/A |
| CA | No | N/A | N/A | N/A | N/A | N/A | N/A | N/A | N/A | N/A |
| CO | No | N/A | N/A | N/A | N/A | N/A | N/A | N/A | N/A | N/A |
| CT | No* | Temporary Task Force | 2017 | 16 | Physicians of various specialties related to the diagnosis, treatment, and management of rare diseases, hospital administrator, registered nurse or advanced practice nurse, one rare disease survivor over the age of 18, one caregiver of a pediatric rare disease survivor, one NORD representative, one hospital representative, one biopharmaceutical representative. | Four appointments each made by each the speaker of the House of Representatives and the president pro tempore of the Senate. Two appointments made by each the majority leader of the House of Representatives and the majority leader of the Senate. Two appointments each made by each the minority leader of the House of Representatives and the minority leader of the Senate. | N/A | -Examine research, diagnoses, treatment, and education related to rare diseases -Make recommendations for the establishment of a permanent group of experts to advise the Department of Public Health on rare diseases | No information about funding. | House Bill 7222 2017 |
| DE | No | N/A | N/A | N/A | N/A | N/A | N/A | N/A | N/A | N/A |
| DC | No | N/A | N/A | N/A | N/A | N/A | N/A | N/A | N/A | N/A |
| FL | Yes | Council | 2021 | 20 | Department of Health representatives, Agency of Healthcare Administration representatives, Office of Insurance Regulation representatives, Department of Education representatives, geneticists, nurses, hospital administrators, pharmacists, biotech industry representatives, health insurance representatives, academic researchers, physicians, rare disease patients, caregivers, and patient organization representatives. | Governor, Senate President, Speaker of the House | Department of Health | -Solicit public comments -Provide recommendations to academic research institutions -Develop recommendations for healthcare providers -Provide input to public and private departments -Submit an annual report to the Governor | Fiscal note of \$127,118 | SB 272 (2021) |
| GA | No | N/A | N/A | N/A | N/A | N/A | N/A | N/A | N/A | N/A |
| HI | No | N/A | N/A | N/A | N/A | N/A | N/A | N/A | N/A | N/A |

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| ID | No | N/A | N/A | N/A | N/A | N/A | N/A | N/A | N/A | N/A |
| IL | Yes | Commission | 2017 | 15 | Residents of the state whose position, knowledge or experience enables them to reasonably represent the interests of those with rare diseases; at least five members must be rare disease patients or caregivers, physicians and/or health care providers; two members of the State Senate; two members of the State House of Representatives. | Eleven appointments made by the Governor. Two members of the State Senate appointed by the President of the Senate and the Senate Minority Leader. Two members of the House of Representatives appointed by the Speaker of the House of Representatives and the House of Representatives Minority Leader. | Department of Health | Make annual recommendations through an annual report through 2023 regarding: -The use of prescription drugs and innovative therapies for children and adults with rare diseases, and recommendations about how this information should be used in state programs which provide assistance or health care coverage -Legislation that could improve the care and treatment of adults or children with rare diseases -Newborn screening in coordination with Genetic and Metabolic Diseases Advisory Committee -Any other issues the Commission deems appropriate | No specific mention of funding within the legislation; states the Department of Public Health shall provide administrative and other support to the Commission. (Until 2026.) | HB 4576 (2016) |
| IN | No | N/A | N/A | N/A | N/A | N/A | N/A | N/A | N/A | N/A |
| IA | No | N/A | N/A | N/A | N/A | N/A | N/A | N/A | N/A | N/A |
| KS | No | N/A | N/A | N/A | N/A | N/A | N/A | N/A | N/A | N/A |
| KY | Yes | Council | 2019 | Not to exceed 20 members | Council Chair and Vice-Chair who then appoint other members of the council | Appointments for Chair and Vice-Chair made by Governor, then all others made by the Council Chair and Vice-Chair; appointments approved with a majority vote of existing members. | Outside Nonprofit | -Act as an advisory body to the General Assembly, the Governor and all relevant state and private agencies -Coordinate with community-based organizations and private entities to ensure greater cooperation regarding the research, diagnosis and treatment of rare diseases -Disseminate the council's research, identified best practices and policy recommendations -Research and determine most appropriate methods to collect information on rare diseases in Kentucky -Research and identify priorities relating to the quality, cost-effectiveness, and access to treatment and services provided to persons with rare diseases -Identify best practices for rare disease care -Develop effective strategies to raise public awareness of rare diseases -Work with state medical schools, Department of Public Health and hospitals to develop a list of existing resources -Report biennially on its activities, findings and recommendations | Grant money from the Federal government, private foundations, and other sources available for programs related to rare diseases (council shall apply for these funds.) | SB 16 (2019) |

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| LA | Yes | Council | 2021 | 12 | One member appointed by the president of the Senate and speaker of the House of Representatives. Governor to appoint one representative from the department, two representatives from academic research institutions in the state that conduct rare disease research, two physicians who are licensed and practicing in state, one geneticist licensed and practicing in the state, one registered nurse who is licensed and practicing in the state who has experience treating rare disease patients, two residents of Louisiana who are 18 years or older who have been diagnosed with a rare disease or who act as a caregiver for a patient with a rare disease, and one representative of a rare disease patient organization operating in the state. | One member appointed by the president of the Senate. One member appointed by the speaker of the House of Representatives. All other members to be appointed by the governor. The governor will also be responsible for determining who serves as the chair and vice chair of the council. | Department of Health | <p>To provide input and feedback to the department and any other state agency on matters that affect a person who has been diagnosed with a rare disease, including, but not limited to all of the following:</p> <ul style="list-style-type: none"> -Pandemic preparedness -Research, education, diagnosis, and treatment relating to rare diseases within the state -Rare diseases in general, the severity of rare diseases, and unmet medical needs associated -The demographics and clinical description of patient populations -Timely access to screening, care, insurance or Medicaid coverage, specialists, and other needed services -The impact that coverage, cost-sharing, tiering, and any other utilization management procedure has on providing treatment and services to a patient -To provide expert and clinical advice to the board in its review of treatments for rare disease -To provide a report to the governor, the Legislature of Louisiana, the department, and any other relevant agency on the findings, activities, and progress of the council and recommendations for addressing the needs of a person living with a rare disease in the state | Advisory council members shall not receive any compensation for serving on the advisory council. | HB 460 (Act 321) |
| ME | No | N/A | N/A | N/A | N/A | N/A | N/A | N/A | N/A | N/A |
| MD | No | N/A | N/A | N/A | N/A | N/A | N/A | N/A | N/A | N/A |

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| MA | Yes | Council | 2020 | 27 | The executive director, or a designee, of the health policy commission; members of the senate, one pharmacist, one geneticist, one nurse, one health plan representative, one genetic counselor, one rehabilitation facility representative, two academic researchers, two physicians, one hospital administrator, two patient organization representatives, one medical researcher, one dietician, two rare disease patients, and one caregiver. | One will be appointed by the minority leader of the senate, two members of the house, or a designee, one of whom shall be appointed by the minority leader of the house, four persons appointed by the senate president, four appointed by the speaker of the house, 15 persons to be appointed by the governor. | Department of Health | <ul style="list-style-type: none"> -Advise the governor, the general court and the department on the incidence of rare disease within the commonwealth and the status of the rare disease community -Undertake a statistical and qualitative examination of the h26 and causes of rare disease to develop a profile of the social and economic burden of rare disease in the commonwealth -Receive and consider reports and testimony from expert individuals, the department, community-based organizations, voluntary health organizations, health care providers and other public and private organizations recognized as having expertise in rare disease care -Develop methods to publicize the profile of the social and economic burden of rare disease in the commonwealth -Determine the human impact and economic implications of early treatment of rare diseases versus delayed or inappropriate treatment -Evaluate the current system of rare disease treatment and available public resources to develop recommendations -Research and determine the most appropriate method for the commonwealth to collect rare disease data -Examine the feasibility of developing a rare disease information and patient support network in the commonwealth -Develop and maintain a comprehensive rare disease plan for the commonwealth -Annually file a report with the clerks of the House of Representatives and the Senate and the Executive Office for Administration and Finance | The advisory council may accept and solicit funds. | S 2984 (2020) |
| MI | No | N/A | N/A | N/A | | N/A | N/A | N/A | N/A | N/A |

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| MN | Yes | Council | 2019 | 2020 | Three physicians including one pediatrician; one registered nurse or advanced practice nurse; two hospital administrators; three adults who either have a rare disease or are a caregiver of a person with a rare disease; a representative of a rare disease patient organization; a social worker with experience providing services to a person with a rare disease; a pharmacist; a dentist with rare disease experience; a representative of the biotech industry; a representative of health plan companies; a medical researcher with experience conducting research on rare diseases; a genetic counselor; and four members of the State Legislature. | Four members of the Minnesota Legislature appointed by the Majority and Minority Leaders of each the State Senate and State House of Representatives. Other members appointed by the Board of Regents of the University of Minnesota. | University of Minnesota | -Developing resources or recommendations relating to quality of and access to treatment and services in the state for people with rare diseases including: -A list of existing publicly accessible resources on research, diagnosis, treatment and education relating to rare diseases -Identifying best practices for rare disease care -Identifying problems faced by rare disease patients when switching health plans and recommendations on how to improve obstacles -Identifying best practices to ensure health care providers are informed -Advising, consulting, and cooperating with the Department of Health the Advisory Committee on Heritable and Congenital Disorders, and other agencies of state government in developing information and programs for the public and the health care community relating to diagnosis, treatment and awareness of rare diseases | \$50,000 in FY2020 and \$50,000 in FY2021 appropriated for the council | SF 973 (2019) |
| MS | No | N/A | N/A | N/A | N/A | N/A | N/A | N/A | N/A | N/A |
| MO | Yes | Council | 2018 | 15 | Two physicians with private schools of medicine; two physicians who holds a doctor of osteopathy; two medical researchers; one registered nurse; one pharmacist; one professor; one individual with a rare disease; one member who represents a rare disease foundation; one representative from a rare disease center located within the state's pediatric hospital; Chair of the Joint Committee on Life Sciences; and Chairperson of the DUR board. | Appointments made by the Director of the Department of Social Services. | Montana Health Net Division | The DUR board will seek the input of the council on rare diseases, the severity of rare diseases, unmet medical needs, impact of particular coverage, cost-sharing, tiering, utilization management, prior authorization, therapy management or other Medicaid policies. An assessment of the benefits and risks of therapies to treat diseases, whether beneficiaries have adequate access to needed therapies, demographics and the clinical description of the patient population. | No funding information. | HB 1953/SB718 (2018) |
| MT | No | N/A | N/A | N/A | N/A | N/A | N/A | N/A | N/A | N/A |
| NE | No | N/A | N/A | N/A | N/A | N/A | N/A | N/A | N/A | N/A |

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| NV | Yes | Council | 2019 | 16 | Chair of the State of Nevada Advisory Council on Palliative Care and Quality of Life, Appointed by Director: Not more than three physicians; two nurses; not more than two hospital administrators; one rep from the Division who provide education; one employee from the Division responsible for epidemiology services; two patients; two parents/guardians; and two patient organization representatives (one from Northern Nevada and one from Southern Nevada). | Members appointed by the Director | Department of Health | -Perform a statistical/qualitative exam of the incidence of rare diseases -Receive/consider reports/testimony from the community; increase awareness; identify evidence-based strategies; determine the effects of delayed treatments; study early treatment; increase awareness among providers; evaluate the delivery system for rare diseases; establish a comprehensive plan for the management of rare diseases in the state; develop a registry; and compile an annual report/post on Department website | Department shall provide administrative support. | SB three15 (2019) |
| NH | Yes | Council | 2019 | 12 | Two members of the State House of Representatives; one member of the State Senate; the Commissioner of the Department of Health; one physician; one advanced practice registered nurse; an APRN; one representative of the New Hampshire Hospital Association; one representative from a health insurer; one parent/guardian of a child with a rare disease; and two adult people living with rare diseases. | Members of House of Representatives appointed by Speaker of the House; members of State Senate appointed by Senate President; physician appointed by New Hampshire Medical Society; APRN appointed by New Hampshire Nurse Practitioner Association; representative of New Hampshire Hospital Association appointed by the Association; and remaining members appointed by the Governor. | Department of Health | -Advise the Legislature and the Department of Health on rare diseases -Coordinate with other states' rare disease advisory bodies, community-based organizations, and other public and private organizations for the purpose of ensuring greater cooperation between state and Federal activities related to the research, diagnosis and treatment of rare diseases -Review data on rare diseases collected in New Hampshire -Raise public awareness of rare diseases in New Hampshire -Make an annual report detailing findings, including recommendations for legislation on or before December 2020 | Aside from payment of legislative members of the council, no information regarding funding in the text. | HB 2three7 (2019) |
| NJ | Yes | Council | 2021 | 20 | Commissions on banking and insurance, HHS, members of the Senate, nurse, epidemiologist, physician, academic research institution, biotech caregivers, genetic counselor, health plan, researchers, assembly members. | Governor, President of the Senate, Minority Leader of the Senate, two members of General Assembly, Speaker of General Assembly, Minority Leader of the General Assembly | Department of Health | Conduct studies related to the quality of care and access to care for rare disease patients (including the link between COVID-19 and rare diseases), develop standards of care recommendations for healthcare providers, make recommendations to improve the state's NBS program and state medicaid coverage. | None | S2682/A4016 (2021) |
| NM | No | N/A | N/A | N/A | N/A | N/A | N/A | N/A | N/A | N/A |

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| NY | Yes | Work Group | 2020 ch amend, extension bill passed in 2021 | 21 | Physicians; nurses and other health care professionals; scientific community; health insurance industry; patients, caregivers; and patient organizations. | Department of Health in collaboration with the department of financial services shall convene the workgroup. | Department of Health and Department of Financial Services | Focus on but not limited to: identify best practices that could improve the awareness of rare diseases and referral of people with potential rare diseases to specialists/evaluate barriers to treatment, including financial barriers on access to care. The Department of Health shall prepare a written report summarizing the opinions and recommendations from the work group which includes a list of existing publicly accessible resources on research, diagnosis, treatment, and coverage options/education related to rare diseases. Must be submitted by two years and posted to Department of Health website. | No funding information. | AB A5762 (2020) |
| NC | Yes | Council | 2015 | 7+ | One physician; one medical researcher; one registered nurse or advanced practice registered nurse; one rare disease survivor; one member who represents a rare disease foundation; one representative from each academic foundation in the state receiving rare disease related grant funding; the Chairs of the Joint Legislative Oversight Committee on Health and Human Services. | Members appointed by the Secretary of the Department of Health upon recommendation from the Dean of the School of Medicine at University of North Carolina Chapel Hill. | School of Medicine at University of North Carolina Chapel Hill | -Advise on coordinating statewide efforts for the study of the incidence and prevalence of rare diseases within the state and the status of the rare disease community -Report to the Secretary, Governor, and the Committee on Health and Human Services on behalf of the General Assembly on its findings and recommendations regarding rare disease care and research in North Carolina, including any recommendations for statutory changes | Per diem and necessary travel and subsistence expenses from the state; all other administrative and other support from the School of Medicine at UNC Chapel Hill. | HB 823 (2015) |
| ND | No | N/A | N/A | N/A | N/A | N/A | N/A | N/A | N/A | N/A |
| OH | Yes | Council | 2020 | 25 | One medical researcher, one academic researcher, one licensed physician, one licensed nurse, one genetic counselor, three rare disease patients, one patient org representative, one representative from a rare disease foundation, two representatives from the Department of Health, one representative from the Department of Medicaid, one representative from the Department of Insurance, one representative from the commission on minority health, one representative from the Ohio Hospital Association, one health insurer, bioOhio, one representative from health commissioner, one pharmaceutical representative, two members of Senate, two members of House of Representatives. | Appointments are made by the Governor | Department of Health | -Prior the expiration of each term, the council shall be responsible for submitting a report on the following: 1) The coordination of statewide efforts for studying the incidence of rare disease in the state; 2) The council's findings and recommendations regarding rare disease research and care in the state; 3) Efforts to promote collaboration among rare disease organizations, clinicians, academic research institutions, and the general assembly to better understand the incidence of rare diseases in the state. | N/A | HB 412 (2020) |
| OK | No | N/A | N/A | N/A | N/A | N/A | N/A | N/A | N/A | N/A |
| OR | No | N/A | N/A | N/A | N/A | N/A | N/A | N/A | N/A | N/A |

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| PA | Yes | Council | 2017 | 24+ (can add members at any time to help carry out the duties) | The Secretary or a designee; heads of state agencies related to care of people with rare diseases (at a minimum, Secretary of Health and Secretary of Education); the insurance commissioner or a designee; three physicians (one pediatrician); two registered nurses; one epidemiologist; two representatives from hospitals (one must be research hospital); two representatives from the bio-pharmaceutical industry; two representatives of the scientific community engaged in rare disease research; two parents of different families who have a child with a rare disease; two individuals with rare diseases; and representatives of two rare disease-specific patient organizations that operate within the state. | Appointments outside of the state officials acting in their roles made by the Secretary of the Department of Health and Human Services. | Department of Health | <ul style="list-style-type: none"> -Coordinate statewide efforts for the study of the incidence and prevalence of rare diseases within the state and the status of the rare disease community -Advise the General Assembly and all relevant state and private agencies that provide services to, or are charged with the care of, people with rare diseases -Coordinate the performance of the advisory council -Duties with those of other rare disease advisory bodies, community-based organizations and other private and public organizations to improve coordination between state and Federal agencies regarding the research, treatment and diagnosis of rare diseases. -Disseminate the outcomes of the council's research, including best practices and policy recommendations -Research and determine the most appropriate method to collect rare disease data, and information concerning individuals with rare diseases including conducting comprehensive surveys of the rare disease community -Research and identify priorities relating to the quality and cost-effectiveness of and access to treatment and other services provided to individuals with rare diseases in the state and develop policy recommendations on those issues -Identify best practices in other states and at the national level for rare disease management, monitoring and surveillance, education, detection, diagnosis, information and care to improve these capabilities -Develop effective strategies to raise awareness of rare diseases in the state -Develop a task force to facilitate the development and publication of a rare disease report | Department of Health and Human Services will reimburse for travel and other miscellaneous expenses necessary to perform their duties with the limits of funds made available to the advisory council for its purposes. | HB 239 (2017) |
| RI | No | N/A | N/A | N/A | N/A | N/A | N/A | N/A | N/A | N/A |
| SC | Yes | Council | 2021 | 15 | DHEC, DHHS, MUSC member, biopharma, researcher, patients, patient org, researcher | DHEC, DHHS, Hospital Association, Primary Healthcare Association, MUSC staff (Dean, MUSC President) | Medical University of South Carolina (MUSC) | Distribute educational resources on rare disease, consult with experts on how to improve access to care, identify ways to address health disparities, publish list of publicly available resources. | N/A | Proviso |
| SD | No | N/A | N/A | N/A | N/A | N/A | N/A | N/A | N/A | N/A |

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| TN | Yes | Council | 2020 | 11 | One representative from TennCare, two from academic research institutions, two physicians one geneticist, one nurse, one patient 18+, one caregiver, one representative from a rare disease organization. | Governor appoints: one rep from TennCare; two researchers; two physicians; one geneticist; and one nurse, caregiver/patient. Speaker appoints. | Attached to TennCare for administration purposes | -Advise the DUR, PAC and other state entities; the DUR and PAC shall seek the input of the council on rare diseases and personalized medicine to address the following (not limited): rare diseases, severity of rare diseases, unmet medical needs, impact of coverage, cost-sharing, tiering, utilization management and other policies -Whether beneficiaries who need treatment from or consultation with a rare disease specialist have adequate access, the demographics/ the clinical description of the patient population | No funding information. | SB 2124 (2020) |
| TX | No | N/A | N/A | N/A | N/A | N/A | N/A | N/A | N/A | N/A |
| UT | Yes | Council | 2020 | At least 6 | A representative from the Department; researchers/physicians (at least one from University of Utah); two individuals/caregivers with rare diseases; and two representatives from patient organizations. | Appointments made by the Department of Health. | Department of Health/Grantee | -Advise the Legislature and state agencies; make recommendations to the Legislature on improving access/ treatment; identify best practices (before November 2021; and before November 30 on odd years after report findings to the Health/Human Services interim communications.) | \$9500 from general fund. Rest from outside funders. UT BIO had agreed to verbally support as the grantee. | HB 106 (2020) |
| VT | No | N/A | N/A | N/A | N/A | N/A | N/A | N/A | N/A | N/A |
| VA | Yes | Council | 2021 | 21 | Patient organization, DHHS, Department of Education, Department of Medical Assistance, academic research institution, nurse, physician, hospital admin, patients, caregivers, pharmacist, biotech, health plan, researcher. | Governor, RDAC Chair | Department of Health | -Focus on improving access to care for rare disease patients, solicit comments from the general public, publish list of publicly available resources | \$42,716 annual fiscal note | HB 1995 |
| WA | No | N/A | N/A | N/A | N/A | N/A | N/A | N/A | N/A | N/A |
| WV | Yes | Council | 2020 | 12 voting members | Secretary of Health or designee; three physicians; three rare disease patients/caregivers; nurse; person with an advanced public health or other health related field degree and three representatives from patient groups. | Made by Governor. | Department of Health | -Coordinate statewide efforts of incidence; act as an advisory board to the secretary/legislature on research, treatment and education related to rare diseases; research and identify priorities related to the quality of, access to, and treatment of person with rare diseases; develop policy recommendations in conjunction with state's medical schools; advise agencies; identify best practices; develop strategies to raise awareness; develop recommendations for best practices for ensuring health care providers are sufficiently informed of the most effective strategies for recognizing and treating rare diseases; and report to the Governor, Secretary and Legislature no later than January 1, 2021 | Created a fund so the council can accept outside gifts/donations. | SB 269 (2020) |
| WI | No | N/A | N/A | N/A | N/A | N/A | N/A | N/A | N/A | N/A |
| WY | No | N/A | N/A | N/A | N/A | N/A | N/A | N/A | N/A | N/A |

