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H.573 (STONE) VT RARE DISEASE ADVISORY COUNCIL

NORD'S Project RDAC
East | AL, CT, DE, FL, GA, IN, KY, ME, MD, MA, MI, MS, NH, NJ, NY, NC, OH, PA, RI, SC, TN, VT, VA, WV

National Organization for Rare Disorders
2023-2024 Session



Alone we are rare. Together we are strong.®

National Organization for Rare Disorders® Mission Statement

We improve the health and well-being of people with rare diseases by driving advances in care, research and policy.



Rare Disease Advisory Councils (RDAC)

A Rare Disease Advisory Council (RDAC) is an advisory body that gives a platform for the rare community to have a stronger voice in state government.

- RDACs address the needs of rare patients and families by giving stakeholders an opportunity to make recommendations to state leaders on critical issues including the need for increased awareness, diagnostic tools and access to affordable treatments and cures.
- RDACs are organized differently in each state. Some of the distinguishing features include the type of entity that houses the RDAC, the composition and size of the council and the duties and accountability requirements of the council.

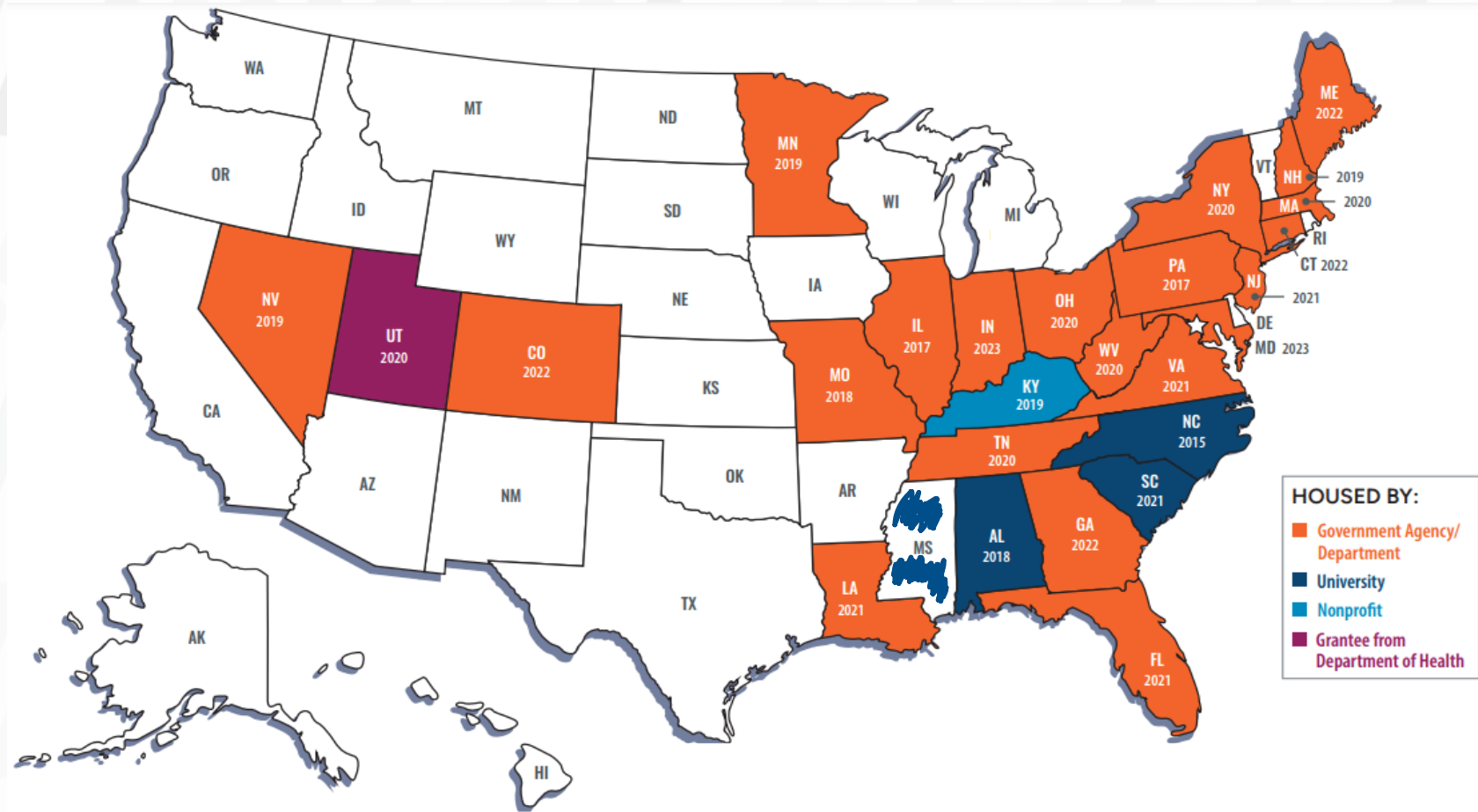
NORD's Project RDAC

GOAL: Optimize existing Rare Disease Advisory Councils (RDACs) and increase the number of RDACs across the country

- Develop resources to guide RDACs at every step of the process:
 - Model Language
 - Webinars and Workshops
 - Toolkits
- Organize diverse coalitions of rare disease community stakeholders in support of establishing new RDACs
- Support existing RDACs in fulfilling their duties
- Create opportunities for existing RDACs to collaborate with each other

Current State of the Union

As of April 2024, there are 28 states with a Rare Disease Advisory Council (RDAC).



RDACs By-the-Numbers

- 28 Councils Nationwide – 22 “active” – remainder in appointments process
 - (1) Grantee from Department of Health | *UT*
 - (1) Nonprofit | *KY*
 - (4) University System | *AL, MS, NC, SC*
 - (22) Gov. Agency or Department

Average Number of Members = 16
(low:high; 11:28)

Funding (9) Councils have language that authorize them to seek and utilize outside funding. | *CO, FL, GA, KY, MD, MA, PA, VA, WV*

CT → \$50,000 (in committee)
MI → \$200,000 (in committee)
MN → \$150,000 (operates as State Agency)
MS → \$250,000 (not passed – DEAD)

2023 Highlights

This is just a small sampling of the amazing accomplishments we've seen from the 27 RDACs across the country!



Survey activity to gather information about state's rare disease landscapes. Launched in **Colorado**, **Tennessee**, & **Massachusetts**. Analysis begins in **Pennsylvania**.



Engagement for Expertise **Colorado's** RDAC engages with the Prescription Drug Affordability Board (PDAB) during affordability reviews.



Minnesota's RDAC was instrumental in passing **HF384/SF1029** to secure robust network access.

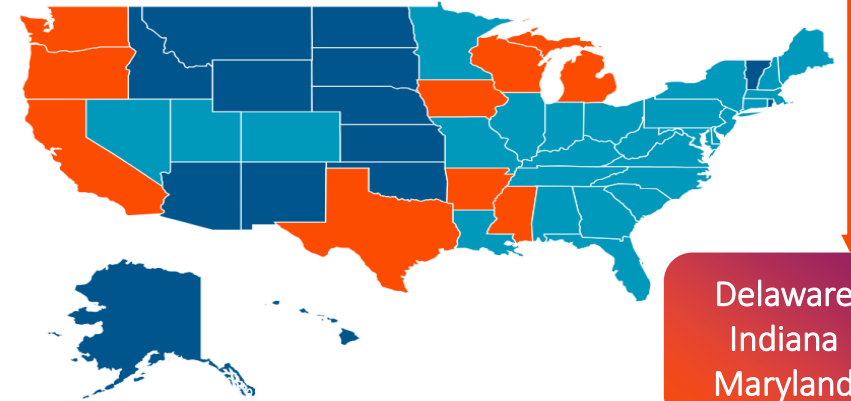


Resources for RDACs **Utah's** RDAC released a policy guide in 2023 titled "Improving the Lives of Rare Disease Patients: 2023 Policy Guide".

Legislative & Pre-Implementation Stage

Indiana	Appointments finalized in record time!
Michigan	Proposed appropriation increase. Passage by the House. Furthest point in the process thus far!
New Jersey	Progress on appointments after significant delays.

27 RDACS NATIONWIDE – 3 SIGNED INTO LAW!



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H.573 (Stone)

An Act relating to the Rare Disease
Advisory Council



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National Organization
for Rare Disorders

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Creation

§1 Subsections (a) & (d) and §2.

The bill creates the **Rare Disease Advisory Council** within the Department of Health effective **July 1, 2024**.

- **PURPOSE:** To provide guidance & recommendations to the public, General Assembly, and other government agencies & departments, as necessary, regarding the needs of individuals living with rare diseases in Vermont.

What is a housing entity?

The Council shall have the administrative, technical, and legal assistance of the Department of Health.

Council Membership

§1 subsection (b)

Government Agencies

Commissioner of Health*	<i>*Chair, per subsection (f) subdivision (2)</i>
Commissioner of Vermont Health Access	
Commissioner of Financial Regulation	
Commissioner of Vermont Health Access	
Director of the Office of Racial Equity	

Appointed Individuals

Membership Role

Appointing Authority

Individual with a Rare Disease	Speaker of the House
Individual with a Rare Disease	Senate Committee on Committees
Representative of an Academic Research Institution , Grant Funded for Rare Disease Research	Speaker of the House
Caregiver of a Person with a Rare Disease	Senate Committee on Committees
Physician Practicing in Vermont with Experience Treating a Rare Disease	Vermont Medical Society
Nurse Practicing in Vermont with Experience Treating a Rare Disease	Vermont Chapter of the American Nurses Association
Representative of Health Insurance Companies Serving Vermonters	Blue Cross Blue Shield of Vermont & MVP Health Care
Representative of Biopharma Industry Doing Business in Vermont	Speaker of the House
Member of the Scientific Community Engaged in Rare Disease Research	Governor
Representative of a Rare Disease Patient Organization Operating in Vermont	Governor

Council Duties

§1 subsection (c)

Develop and disseminate a survey of Vermont's rare disease community.

Provide testimony & comments on pending legislation & rules that impact Vermont's rare disease community.

Develop policy recommendations that:

- Improve access and quality of services provided by specialists.
- Advance affordable and comprehensive health care coverage.
- Provide relevant diagnostic services.

Examine the impact of prior authorization, cost-sharing, tiering, or other utilization management procedures on the provision of treatment & care to individuals with rare diseases.

Evaluate and make recommendations to implement improvements to Vermont's newborn screening program.

Evaluate and make recommendations to improve Medicaid coverage for drugs used by individuals with rare diseases.

Public a list of existing, publicly accessible resources relating to rare diseases on the Advisory Council's website.

Identify and distribute education resources for health care providers.

Research & identify best practices to reduce health disparities and achieve health equity in the research, diagnosis, and treatment of rare diseases in Vermont.

Reporting Requirements

§1 subsection (e)

On an **annual** basis, on or before December 15th the Council must submit a written report to the House Committees on Health Care and on Human Services and the Senate Committee on Health and Welfare on the following:



A description of activities & progress of the Council during the previous year.



Update on the status of the Council's funding needs.

The report must also include findings and recommendations for legislative actions

Meeting Requirements

§1 subsection (f)

As Chair, the Commissioner of Health must call the first meeting. A majority of membership present (8) constitutes a quorum.

During the first year, the Council must meet at least monthly. After its first year, meetings will be by call of the Chair.



Meetings may be held in person or remotely on an electronic platform as determined by the Chair.



The Advisory Council shall maintain a webpage on the Department of Health's website containing notices of upcoming meetings, meeting minutes, public comments, and previous annual reports.

Council Compensation & Reimbursement

§1 subsection (g)

Members of the Council will not be compensated for their role on the Council.

- However, they are entitled to per diem compensation and reimbursement of expenses.
 - For not more than 12 meetings annually.
 - In accordance with existing Vermont law.
- Funds for reimbursement comes from money appropriated to the Department of Health.

Thank You!

Carolyn Sheridan, MPH
State Policy Manager, East

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National Organization for Rare Disorders®

a: 1779 Massachusetts Ave NW., Suite 500, Washington, DC 20036

e: csheridan@rarediseases.org e: rdac@rarediseases.org



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