RDLA

Rare Disease Legislative Advocates

POWERED BY THE EVERYLIFE FOUNDATION

Comparing State Caucuses and Advisory Councils

TIP SHEET

What is a Rare Disease State Legislative Caucus?

A caucus is a group of members of a state legislature that meet to pursue common legislative objectives such as rare diseases. A caucus:

- ★ Can hold briefings and events to raise awareness and educate legislators about rare diseases and the unmet needs of the rare disease community.
- ★ Is established by one or more state legislators (usually one Democrat and one Republican) and invites other legislators to join the caucus.
- ★ Has a bicameral structure and scope can vary in each state and may include (not limited):
  - Move legislation
  - Seek and secure appropriations
  - Consider policies that affect the rare disease community

Who are the Members?

State legislators make up a state legislative caucus.

QUICK SUMMARY!	**CAUCUS**	**ADVISORY COUNCIL**
Established by passing a law?		✓
Works to improve the lives of rare disease patients?	✓	✓
Holds awareness and education events?	✓	
Can publish statewide resources and conduct studies?		✓
Builds relationships with legislators?	✓	✓
You can play a part in establishing?	✓	✓

What is a Rare Disease Advisory Council?

An advisory council is established through state legislation which is passed by legislators and signed into law by the governor. A council:

- ★ Acts to evaluate and make recommendations to the state on issues related to rare disease families.
- ★ Is effective when advocates are involved in helping administer council.
- ★ Has a structure and duties that vary depending on the state's law and may include (not limited):
  - Act as an informed advisory committee to the state legislature, utilization review boards, and state agencies on policy and best practices for rare disease healthcare delivery.
  - Advise and coordinate efforts to study and subsequently collect data on the incidence and prevalence of rare diseases, and their unmet needs.
  - Coordinate rare disease collaborations with experts across the state.
  - Identify best practices for rare disease diagnosis and treatment.
  - Raise public awareness on rare diseases in the state through published resources and findings.

Who are the Members?

Rare disease advisory council's members may be specified by the state's law or appointed by the chair of the council.

Example members from across the state include (not limited):

- Healthcare providers
- Researchers
- Hospital administrators
- State legislators
- Rare disease patients or caregivers
- Members of the health department
- Biopharmaceutical representatives
- Health insurance plan representatives

Rare Disease Legislative Advocates (RDLA) is a program of the EveryLife Foundation for Rare Diseases to support the advocacy of all rare disease patients and organizations. RDLA is committed to growing the patient advocacy community and working collaboratively, thereby amplifying the patient voice to be heard by local, state and federal policy makers. For additional assistance, please contact Shannon von Felden, RDLA Program Director, at svonfelden@everylifefoundation.org.