**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.

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**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

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**QUICK SUMMARY!**

<table>
<thead>
<tr>
<th></th>
<th>Caucus</th>
<th>Advisory Council</th>
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</thead>
<tbody>
<tr>
<td>Established by passing a law?</td>
<td>✓</td>
<td>✓</td>
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<tr>
<td>Works to improve the lives of rare disease patients?</td>
<td>✓</td>
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<td>Holds awareness and education events?</td>
<td>✓</td>
<td>✓</td>
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<td>Can publish statewide resources and conduct studies?</td>
<td>✓</td>
<td>✓</td>
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<td>Builds relationships with legislators?</td>
<td>✓</td>
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<tr>
<td>You can play a part in establishing?</td>
<td>✓</td>
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