



Rare Disease Legislative Advocates

POWERED BY THE EVERYLIFE FOUNDATION

Creating a Rare Disease State Legislative Caucus

TIP SHEET

What is a state legislative caucus?

A caucus is a group of members of a state legislature that meets to pursue common legislative objectives. A caucus can hold briefings to raise awareness on an issue such as rare disease.

How is a legislative caucus formed?

A caucus is a great way to bring awareness and attention to rare diseases. An issue caucus is officially formed by members of the legislature, usually by co-chairs from both political parties (one Democrat and one Republican), but advocates can be instrumental in organizing support.

What can an advocate do to help create a caucus?

★ PLAN AND ORGANIZE

Preparation is the key to success. Write a letter to state legislators on its purpose and goals. Create a website to keep track of the legislators in the caucus and post information on briefings. Organize an email list to reach advocates and state representatives.

★ FIND CAUCUS LEADERS

Advocates should ask their own state legislator for their support and to co-chair a rare disease caucus. Other potential co-chairs of a rare disease caucus could be a member of the Health Committee, or a state legislator who has been active and vocal on health care or rare disease issues.

★ RECRUIT LEGISLATORS

Once there are co-chairs of the caucus, the next step is to ask other legislators to join. Advocates should ask their own legislators to join the caucus and encourage other rare disease advocates, community members, family, and friends from across the state to contact their legislators.

How do advocates reach out to state legislators?

There are many ways to communicate with your legislators to invite them to join the caucus. Legislators have offices in the state capitol as well as in their district with staff in each office. Constituents can call either of these offices to speak to staff. Advocates should share their story succinctly and request the legislator to join the caucus. In addition, you can write and email your legislator. If you do not receive a response, follow up with the staff and the legislator.

There is a rare disease caucus! Now what?

Thank the co-chairs for founding the new caucus and legislators for joining the caucus! The advocacy community will need to coordinate efforts to recruit new members for the caucus and work with the caucus co-chairs to schedule and organize briefings. A caucus can hold briefings and other awareness events to bring rare disease education to your state capitol.

The awareness and relationships being built between legislators and rare disease advocates is an invaluable resource as legislators consider policies that affect the rare disease community.

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 with creating a state rare disease caucus, contact Shannon von Felden, RDLA Program Manager, at svonfelden@everylifefoundation.org.