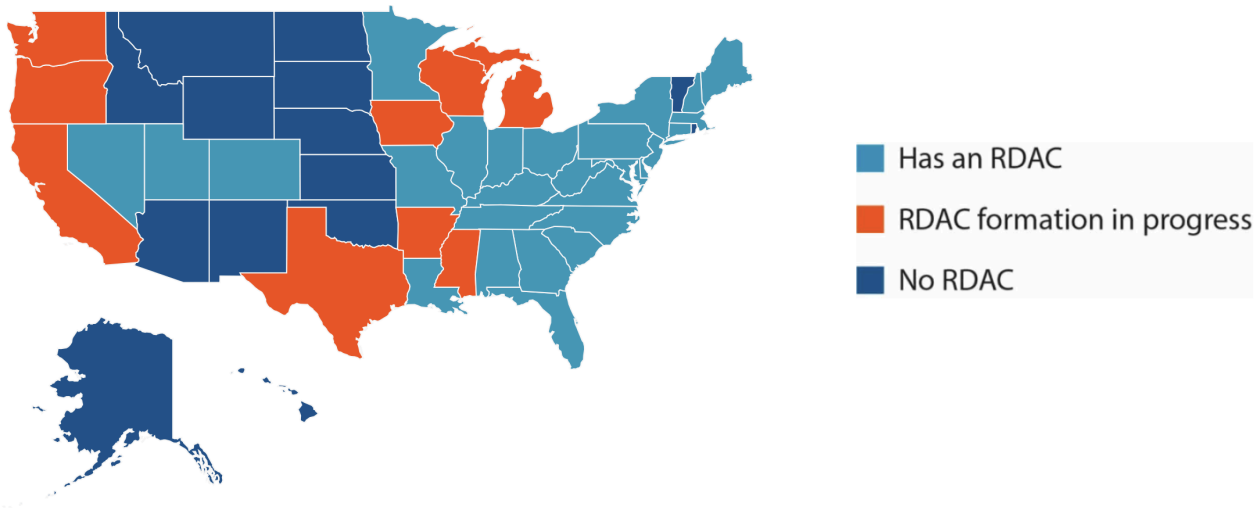


DOES YOUR STATE HAVE A RARE DISEASE ADVISORY COUNCIL?

In 2015, the first rare disease advisory council was created in North Carolina as a result of the rare disease community coming together and demanding a stronger voice in government. With over 7000 rare diseases, it would be impossible for state legislators to understand the challenges rare disease patients face every day around diagnosis, treatment, and access. Additionally, state policies are often determined without consulting the individual disease community that will be directly affected. A state rare disease advisory council provides an avenue for all stakeholders including patients, caregivers, doctors, insurers, drug manufacturers, and researchers to offer insight and recommendations to state elected officials and leaders as those decisions are being considered.



North Carolina sparked similar legislation to be enacted throughout the country. Today, with the support of the [National Organization of Rare Diseases \(NORD\) Project RDAC](#) and other patient organizations like FARA, 26 states have rare disease advisory councils with others currently considering creating one. Kudos to the [states who have acted!](#)

A comparison state program would be a state legislative caucus. A caucus is a group of legislators coming together around a common interest, such as rare disease. To learn more, check out these resources from the EveryLife Foundation.

[Creating a Rare Disease State Legislative Caucus](#)
[Comparing State Caucuses and Advisory Councils](#)