



Rare Disease Legislative Advocates

POWERED BY THE EVERYLIFE FOUNDATION

TIP SHEET

Starting a State Based Organization

In some states, rare disease advocates have joined together to unite rare disease community stakeholders to increase awareness and impact state policy. The state in which you live dictates the type and quality of care you receive, and the access to resources you have. State community action has the potential to improve access to diagnostics and treatments for the rare disease community locally.

Where Do I Start? Here are impactful ways to take action!

State organizations can advocate for:

- ★ State and federal legislation
- ★ Community coordination
- ★ Rare disease awareness/education

IDEAS ► ACTIONS

Collaboration Brings Innovation

Collaborate with other advocates and organizations to engage on policy issues and to host events by bringing multiple people together with the same mission.

Collaboration can help accomplish goals and grow the organization across the state.

Identify State Needs

Determine the needs of the state's rare disease population through surveys, group meetings, and phone calls with different community members.

Event Planning

Advocacy events can range from informal meet-ups to state wide conferences. Make sure all events are tailored to your state's rare disease community.

For ideas, visit the RDILA State Advocacy website at rareadvocates.org/states.

Audience Selection

Identify the target audience the organization seeks to engage.

Online Presence/Brand

The organization can benefit greatly from a name, logo, website, and social media accounts.

Maintaining an active social media presence is a convenient and accessible way to connect with the state's rare disease population.

Rare Disease Legislative Advocates (RDILA) is a program of the EveryLife Foundation for Rare Diseases to support the advocacy of all rare disease patients and organizations. RDILA 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, contact Shannon von Felden, RDILA Program Director, at svonfelden@everylifefoundation.org.