

# What is RAN?



## **What is the Rare Action Network<sup>SM</sup> (RAN)?**

The Rare Action Network<sup>SM</sup> (RAN) mission is to connect and empower a unified network of individuals and organizations with tools, training, and resources to become effective advocates for rare diseases through national and state based initiatives across the United States. RAN is the nation's leading rare disease advocacy network working to improve the lives of the 30 million Americans impacted by rare disease. The goal of RAN is to ensure that the rare disease community is represented and supported in all 50 states. RAN serves as a broad spectrum of stakeholders ranging from patients, to their families, caregivers, and friends; from researchers to industry; to physicians and academia. While working on both the national and state level, RAN filters information to help address issues of national concern and engage rare communities to take action through policy, awareness and education initiatives in their state and local communities. The goal of RAN is to ensure that the rare disease community is represented and supported in all 50 states.

Members of the Rare Action Network<sup>SM</sup> are part of 30+ million person community working towards improving the lives of patients with rare diseases. RAN members will positively improve the quality of life for rare disease patients and their families by ensuring rare diseases become a national priority through policy, education and awareness.

## **Policy**

NORD has always been on the forefront of rare disease advocacy and policy, starting in 1983 with its founding roots with the Orphan Drug Act. NORD's policy team is proud to present its side of RAN, offering multiple ways to enable members such as:

- Learn about new legislation and regulations in congress and your state that may affect you
- Influence federal and state policy decisions
- Connect with other rare disease advocates in your community
- Learn more about rare diseases and the legislative process to become an even better advocate
- Work directly with volunteer State Ambassadors and NORD staff to develop new policy initiatives
- Find tools and guides to support the advocacy work you are already doing

**Not all rare disease issues can be resolved through policy. RAN was designed to extend beyond legislative action to include other important activities:**

## **Awareness**

Creating awareness for the 30 million Americans affected by rare diseases is essential to creating and fostering change! Toolkits, videos, and how-to guides have been developed to help RAN members hold small-scale awareness campaigns all year long. RAN prepares members to:

- Host Awareness events and activities in their local community
- Connect and find support with other members within their state network to develop year round initiatives
- Enlist with one of NORD's 250+ patient organization members through their various volunteer opportunities

## **Education**

RAN has tools and trainings to educate RAN members on how to become an effective advocate within their community and resources to get them started. Education also takes the form in NORD's Student Club, a program that aspiring medical professionals can form at their college or university to discuss, educate, and raise awareness for rare diseases.

- Learn how to Connect with individuals and organizations within states and how to become effective advocates through RAN on-demand training's and resources including:
  - Learn about effective ways to utilize Social Media
  - Learn how to engage with local media within your community
- Take action and educate your local community clubs and organizations on rare diseases
- Create a NORD Rare Disease Student Club at local colleges or universities