

ADVOCACY WORKS!

Road Map

Advocacy can be done in many different ways



Advocacy is an activity by an individual or group that aims to influence decisions.

Advocacy empowers, advocacy creates change, advocacy works!

1 On behalf of a diagnosis

- Diagnostic process and genetic testing
- Standard of care for the diagnosis
- Participate in registries, natural history studies and clinical trials



2 On behalf of state and community services and support

- Insurance including private, state, and federal plans
- Home and community-based services (often called Medicaid waivers)
- Rare Disease Advisory Councils



3 On behalf of patient groups

- Volunteer
- Fundraise
- Mentor
- Share your story
- Advisory Boards



4 On behalf of legislation

- Speak with your state and federal representatives
- Speak with the Food and Drug Administration (FDA), Centers for Disease Control and Prevention (CDC), Centers for Medicare & Medicaid Services (CMS), National Institutes of Health (NIH)



Connect with resources to help guide you through this journey



- 1-833-PTC-HOPE (1-833-782-4673), or in Spanish 1-833-PTC-VIDA (1-833-782-8432)
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