

## Rare Condition

## Patient Empowerment: Learning to Expand Your Circle

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**Becoming an empowered patient is an important part of health care. However, managing a care team while living with a rare condition may require some skill, and a toolkit may be helpful in navigating care. Empowerment is a broad term that can encompass elements of self-advocacy, goal-setting, and creating a support network. Embracing these factors may help to create a sense of control over the condition.**

### Persistence Is a Key to Advocacy

Learning to navigate the health care system through self-advocacy takes time and experience. Being confident in asking questions and persistent in receiving answers from health care professionals can be especially beneficial in the rare disease setting. Some ways to grow in self-advocacy include planning ahead for appointments by writing out questions or submitting them via the patient portal, role-playing different scenarios with a friend or partner, clearly stating concerns to providers, and having a plan that includes desired goals and outcomes.

### Setting Intentions in Rare Disease

Treatment goals can be anything from controlling signs and symptoms to being well enough to engage in a favorite activity again. The “treat to target” approach can be helpful. Patients and health care providers can use shared decision making to define goals (the “target”) for treatment and then build a roadmap on how to reach them. Creating objectives provides consistency and ensures that all team members have the same understanding. Communicating goals to health care providers and the wider support system is another facet of self-advocacy that can help to achieve success.

### Anatomy of a Support Network

For those who live with a rare condition, a support network can be crucial in managing the disease and fostering a better quality of life. Creating a circle of support may be overlooked as a part of empowerment

because it can be thought to be a role for family and friends, but it can also be helpful to include patient advocacy groups, mental health professionals, social workers, and other rare disease patients as part of the support structure.

### Insurance Carriers as Team Members

While the orphan drug program has accelerated FDA approvals for rare disease treatments, access remains an issue. Health insurance companies play a large role in accessing care, and rare disease patients will want to engage with their provider early in their disease journey. A proactive approach will help in understanding coverage for specialist visits and therapies in order to better manage out-of-pocket expenses.

### Empowerment Is a Marathon, Not a Sprint

Empowerment doesn't mean that people with rare conditions should navigate their journeys alone. In fact, part of empowerment is cultivating and nurturing relationships both outside of, and within, the disease community. The path to empowerment will look different for everyone, but all paths can lead to a better patient or caregiver experience.

#### Your empowerment toolkit



Self-advocacy



Creating a network



Setting goals



Understanding insurance



Patient Affairs Liaisons are a team of non-sales, non-promotional field-based professionals. Pfizer's Patient Affairs Liaisons are dedicated to serving the rare disease community by connecting patients and caregivers with Pfizer Rare Disease tools, including educational resources, access support, and community events in your area.

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