



GETTING INVOLVED IN CAREGIVING ADVOCACY

The nature of being a caregiver to a child with a rare and/or serious illness means that the caregiver will more likely than not become an advocate in some way.

When the child is young, the caregiver is their voice to their health care team, advocating for tests and treatments; as the child grows older, the caregiver supports them in their decisions and needs. While caring for a child with a rare and/or serious illness can take up a lot of time and energy, sharing the family's experiences and perspectives as a caregiver can help advance advocacy efforts to improve the experiences of families across the rare disease community. Actions such as telling the family's story, making others aware of the child's illness, or simply exchanging useful tips to other caregivers are all forms of advocacy that can encourage broader support and positively impact other families.

There are several ways for caregivers to engage in advocacy. Sharing a life story creates awareness and highlights what needs to be changed by policy. Defining goals or specific changes to advocate for provides focus to begin supporting and engaging in work that will create positive change. Acknowledging the unique

challenges facing rare and/or serious illness caregivers, specific changes that caregivers can elevate both personally and with policy makers include:

- Expanding and enhancing Centers of Excellence (COE) programs within healthcare institutions to provide expertise care in rare and serious diseases.
- Ensuring that health care for rare and/or serious illnesses is not negatively impacted by overt or implicit bias based on race, color, sex, national origin, religion, orientation, age, disability, or socioeconomic status.
- Increasing funding for clinical research for rare and/or serious illnesses, including the development of innovative therapies and increased participation in clinical trials by underrepresented populations, such as minorities.
- Increasing services and supports to help caregivers efficiently navigate the health system, including providing qualified respite, skilled nursing and home care options, and developing a centralized resource for identifying expert health professionals in rare and/or serious illnesses.

- Streamlining the insurance claim process for reimbursement of services and equipment, including improving the caregiver's understanding of treatment procedures and availability for rare and/or serious illnesses.
- Facilitating health care coordination and collaboration across providers for rare and/or serious illnesses by eliminating silos in care.
- Training health care providers to: 1) communicate with parents and guardians with respect; 2) acknowledge their roles as caregivers; and 3) deliver health care and social support services using culturally competent approaches.
- Increasing caregivers' access to appropriate training in providing proper health care for rare and/or serious illnesses within the home environment.
- Helping parents and guardians of children with rare and/or serious illnesses locate services and support by encouraging them to recognize their caregiving roles and to identify as caregivers.
- Assisting caregivers in navigating the health care system by expanding networks of qualified case managers, health professionals, and health care facilities to have the necessary expertise and resources to manage rare and serious diseases.
- Protecting families' financial security through increased eligibility for and access to state and federal programs, health insurance coverage, and payment assistance programs to cover or offset the high costs of care and treatment for rare and/or serious illnesses.
- Reducing the financial impacts of caregiving through refundable tax credits, helping families cover out-of-pocket expenses, paid family and medical leave policies, and flexible work arrangements.



Connecting with advocacy groups provides support and resources. It also provides an avenue for caregivers, if and when they are ready, to connect with lawmakers and elected officials who have the ability to make progressive change.

The following are good starting points for advocacy resources:

Genetic and Rare Diseases Information Center Advocacy Organizations Database

www.rarediseases.info.nih.gov/search?keyword=contentType%3Dorganization

Global Foundation for Peroxisomal Disorders

www.thegfpd.org/

National Alliance for Caregiving

www.caregiving.org

National Organization for Rare Disorders

www.rarediseases.org/for-patient-organizations/ways-partner-advocacy/

Rare Diseases Clinical Research Network

www.rarediseasesnetwork.org/pags



Rare Disease Day

www.rarediseaseday.org

The main objective of Rare Disease Day is to raise awareness among the public and decision makers about rare diseases and their impact on patients' lives. Started in 2008 by EURORDIS, today there are numerous partners across the United States who hold events to promote awareness for rare diseases. The event is held on the last day of February each year.

Rare Disease Week

www.everylifefoundation.org/rare-advocates/rare-disease-week/

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