Beyond the Unicorn: Finding Ready-to-Engage Patient Representatives

PAYER ENGAGEMENT

As a health plan or state Medicaid agency looking to recruit patient representatives for Beneficiary Advisory Councils or P&T committees, you may wonder where to start.

Where to Find Patient Representatives

The good news? Patient representatives exist and training programs across the nation are supporting their efforts.
Looking to connect with a patient group? Reach out to **info@everylifefoundation.org** for help connecting.

> *"It feels like we're looking for a unicorn — someone who can weigh the clinical information with the costs and represent not only their condition but other conditions and experiences too."*
>
> — PHARMACY DIRECTOR, REGIONAL HEALTH PLAN

Young Adult Rare Representatives (YARRs) Leadership Academy

Prepares the highly motivated young adults (16-30 years old) in the rare disease community for advocacy roles in regulatory processes, drug development, federal and state policy, and public speaking. Learn about the representatives in your state.

EveryLife Foundation for Rare Disease Legislative Advocates (RDLA)

EveryLife Foundation for Rare Disease Legislative Advocates (RDLA) Rare Disease Legislative Advocates, a program of the EveryLife Foundation for Rare Diseases, provides education, tools, and opportunities for the rare disease community to work collaboratively with local, state, and federal policymakers. Training programs, advocacy events, and year-long mentorship programs help patients and caregivers learn to advocate not only for themselves but for others with rare conditions. To find more about this community, contact kjones@everylifefoundation.org.

Additional Resources

National Health Council E-Learning Resources

Provides self-guided resources for engaging patients in policy development, value assessment, medical product development, Medicare Drug Price Negotiation, and quality measurement. View the resources at https://nationalhealthcouncil.org/education/.

University of Maryland PATIENTS Professors Academy

Equips patients to serve on stakeholder advisory boards, federal and state government agencies, and research partnerships through a 5-week program and peer network. The network includes over 300 graduates from 37 states. Complete the PATIENTS Professors Request form to connect with patient advisors.

EVERYLIFE FOUNDATION FOR RARE DISEASES

> *How do you find a patient who can serve that broad purpose to talk about more than one disease state? Do you have a repository of patient representatives?*

— DIRECTOR OF FORMULARY STRATEGY, NATIONAL HEALTH PLAN

What Are the Characteristics of a Strong Patient Representative?

STRONG PATIENT REPRESENTATIVES WILL:

- Willing to listen actively to diverse perspectives and other experiences
- Ability to share their personal experience and ensure broader patient community perspectives are considered
- Respects confidentiality, navigates sensitive discussions, and constructively debates with others
- Thinks beyond personal experience and is committed to balancing clinical, population, and fiduciary responsibilities while advocating for patient perspectives
- Comes prepared and ready to ask insightful questions
- Willing to devote time to preparing for meetings (with caregiving or other support resources available if needed)

Benefits of Engaging Patient Representatives

Moving beyond checking the box for meaningful patient engagement delivers real benefits. Training and programs can help support more effective patient engagement to:

- Gather actionable input grounded in lived experience to strengthen decision-making
- Access trusted contacts more quickly to meet regulatory requirements and best practices
- Align policies and population health strategies with the priorities of your covered members

> *Previously, we assigned a physician to have the patient's perspective. We were checking a box. That won't work now. For the exchange plan, we spent a lot of time looking for someone.*

— VP PHARMACY, INTEGRATED HEALTH PLAN

Your organization doesn't need a unicorn. With resources, patient training programs, and support, patient representatives can help your organization build better benefits, smarter policies, and more patient-relevant care. To connect directly with the EveryLife Foundation for Rare Diseases, don't hesitate to contact policy@everylifefoundation.org

EVERYLIFE FOUNDATION FOR RARE DISEASES

About the EveryLife Foundation

The EveryLife Foundation for Rare Diseases is a 501(c)(3) nonprofit, nonpartisan organization dedicated to empowering the rare disease patient community to advocate for impactful, science-driven legislation and policy that advances the equitable development of and access to lifesaving diagnoses, treatments and cures.
everylifefoundation.org

Developed in partnership with Innov8 Health Policy
Learn more: everylifefoundation.org/patient-engagement-and-payment-decisions | info@everylifefoundation.org