YARR Policy Campaign

A major goal of the Young Adult Rare Representatives (YARR) program is to ensure that young adults have a growing impact on public policy in the rare space. This includes building knowledge of current policies, political literacy for future policies, and advocacy skills and tactics.

To encourage both established and newer YARRs in developing these skills, we developed the YARR Policy Campaign. YARRs will choose a policy area affecting the overall rare disease community and organize advocacy in support of relevant policy proposals throughout the year.

2025 YARR Policy Campaign: Ensuring Access to Approved Treatments

Background	It is a massive effort to get a medication to FDA approval, but the work does not stop there. The next hurdle is ensuring patients can actually access the treatment post-approval. The treatment has to be available, affordable, and covered by insurance plans.
YARR Angle	Young adults can face distinct access barriers due to having less economic stability, moving more often with college and early-career life, and transitioning to new providers. By focusing on the extra challenges that young adults face, we can advocate for improved access for everyone.
Policy Area	Access landscape, including the HELP Copays Act, Safe Step Act, Access to Genetic Counselor Services Act, Accelerating Kids' Access to Care Act, and state-level proposals.

Below is information on the three policy areas that YARR members did not choose for the 2025 YARR Policy Campaign, but that remain critical priorities for the young adult rare disease community.

Strengthening Rare Disease Therapy Development Initiatives

Background	93% to 95% of the more than 10,000 known rare diseases have no U.S. Food and Drug Administration-approved therapies. It can take an average of 15 years for the FDA to approve a new medication. This is much too long for those in the rare disease community to wait.
YARR Angle	Young adults have their own distinct healthcare needs. Sometimes they have been waiting for a treatment since childhood, with their symptoms progressing. Sometimes, they are the youngest of a majority older disease population, with different lifestyle and health needs. Sometimes they are worried about long-term treatment availability and side effects. Their voices matter in the review of new therapies they will hopefully use in the following decades.
Policy Area	FDA regulation, including the Accelerated Approval pathway, Orphan Drug Tax Credit protection, and BENEFIT Act.

Facilitating Support for the Transition from Pediatric to Adult Healthcare

Background	Throughout adolescence and early adulthood, patients undergo a process of healthcare transition. This includes switching to adult providers when possible, aging out of parents' insurance plans or Medicaid waivers, seeking independent insurance, and gaining more independence over medical decision-making in hospital settings.
YARR Angle	Many YARR members have expressed frustration or anxiety over their own healthcare transitions. Young adults are the experts on what it is like to undergo pediatric to adult healthcare transition right now. Policymakers can learn from this lived experience.
Policy Area	Transitional healthcare, including federal funding for transition resources and regulations providing support and exceptions for rare disease patients in the transition process.

Reducing and Eliminating the Diagnostic Odyssey

Background	The EveryLife Foundation released a study in September 22023 on "The Cost of Delayed Diagnosis in Rare Disease." On average, it takes rare disease patients 6.3 years and 16.9 specialists to receive a diagnosis. In that time, patients can suffer significant economic, physical, and social consequences. A delayed diagnosis worsens outcomes and has a significant financial impact on families, including paying for doctor visits, medical equipment, prescriptions, and transportation that could have been avoided. This economic impact is up to $517,000 per patient in avoidable costs.
YARR Angle	YARR members have a wide range of experiences with diagnosis. Even relatively young advocates may have gone many years without a proper diagnosis or still be fighting for an accurate diagnosis. Perceptions of some patients as "too young" to have certain conditions, or "too young" to understand the science of their lifelong genetic conditions, can exacerbate health outcomes.
Policy Area	Timely diagnosis, including newborn screening, access to genetic and diagnostic testing, and economic trends highlighted in the National Economic Burden of Rare Disease Study considered through the lens of young adult experience.

YARR Policy Campaign History

The YARR Policy Campaign began in late 2021. For the inaugural 2022 YARR Policy Campaign, YARR members chose to advocate for the Speeding Therapy Access Today (STAT) Act. YARRs discussed the STAT Act during the YARR legislative breakout session at Rare Disease Week 2022, Hill meetings with legislators, patient conferences, EveryLife webinars, and more.

The 2023 and 2024 YARR Policy Campaign also focused on "Ensuring Access to Approved Treatments." It is a testament to this effort's importance that YARR members have once again selected it as their priority. We will continue to build on our momentum in 2025!

If you have questions about the YARR Policy Campaign, please email Laura Romano at lromano@everylifefoundation.org.