

YA Coalition

It is estimated that more than 30 million Americans are living with one or more rare diseases, the majority of which are diagnosed in childhood. While scientific innovation offers much promise, still more than 93% of the 7,000 known rare diseases have no FDA-approved therapy. Yet, improvements in diagnostics, clinical care, and therapeutic interventions are transforming pediatric rare diseases into 'pediatric-onset' rare diseases and young adults are thriving decades into adulthood. However significant gaps remain as resources to support the transition to adulthood is often overlooked, leaving individuals feeling alone or isolated. The community relies on the resources available to them to help navigate benefit eligibility, the healthcare system, securing and managing caregivers, mental and emotional support, advocacy opportunities, and the general day-to-day challenges that may arise.

Although many resources exist, opportunities for cross-collaboration do not. The Young Adult Representatives of RDLA (YARR) would like to convene partners focused on serving young adults within the rare space. The Young Adult (YA) Coalition will serve as a platform for organization awareness, collaboration and problem solving so that we can all better support young adults with rare diseases.

Goals

- Connect community members to foster an awareness of resources on the national level.
- Create a coalition events calendar to encourage collaboration, promotion, and support for each community event. YA Coalition Event List [here](#).
- Facilitate warm hand-offs by utilizing the personal connections established in the coalition.
- Establish a safe space for sharing best practices amongst organizational leadership.
- Connect young adults across rare disease types so that they can learn about other conditions and broader rare disease issues.

Partnership Organizations will be:

- Involved in the rare disease space, offering resources for young adults ages 16 and above), (may include cross-rare disease organizations, condition-specific rare disease groups, and organizations with both rare and chronic conditions in their mission).
- Based in the United States.
- Represented to the coalition by 1-2 designated representatives.
- Willing to adhere to a *Code of Conduct (link pending)* to maintain open collaboration among partners.

Coalition members are encouraged to attend three quarterly calls each year. YARR will schedule the calls and host the virtual platform and other logistics. Meeting minutes logged [here](#).

Timeline for 2021/2022

- Nov 12, 2021 - Preliminary YA Coalition Call
- March 11, 2022 – Q1 YA Coalition Call @ 2pm ET
- June 10, 2022 – Q2 YA Coalition Call @ 2pm ET
- September 9, 2022 – Q3 YA Coalition Call @ 2pm ET

Organization Sign-on

Please send all referrals to join the YA Coalition to lcundiff@everylifefoundation.org



**OUR
ODYSSEY**



**ADULT ADVISORY
COMMITTEE**



**HUNTINGTON'S DISEASE
YOUTH ORGANIZATION**

