



Rare Disease Legislative Advocates

POWERED BY THE EVERYLIFE FOUNDATION

Diversity and Inclusion

TIP SHEET

Diversity at Home

Developing a diverse staff and board that includes underserved communities is imperative and necessary for improving diversity and inclusion. With 47% of new board members for S&P 500 companies coming from diverse backgrounds, according to 2021 study by Spencer Stuart, the need for diversity in leadership and outreach is being realized now more than ever. Reasons include:

- ★ Diversity in background in the boardroom creates diversity in ideas and in resolving challenges
- ★ Diverse individuals understand cultural and linguistic barriers, enabling better outreach to underserved communities

Surveying the Field

Before embarking on any diversity initiatives, it's important to understand how well your organization is performing with underserved communities. In order to build diversity goals and benchmarks, it's necessary to collect ethnicity, racial, and gender data from all programs. Ethnicity responses in registrations should take cues from census groups, with room for additional ethnicity options as needed. Find links and advocacy tools for data collection at <https://rareadvocates.org/advocacy-tools>. Information gathering opportunities include:

- ★ Webinar sign-ups
- ★ Signature or yearly outreach events
- ★ Events involving outside organizations and work groups

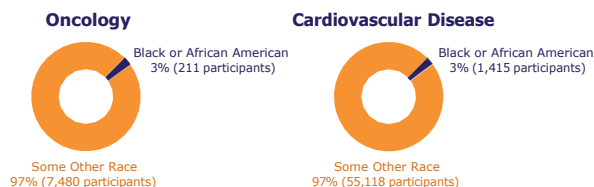
Benchmarking and Targeting

Following data collection, organizations can compare how diverse their programs are to national demographic estimates for minority and underserved communities (i.e. US census data).

- ★ Strategies can then be developed that incorporate tools to overcome possible cultural, linguistic, and corporate barriers
- ★ Benchmarks should be short-term improvement plans with long-term goals and yearly benchmarks that are attainable for underserved participation

Participation of Black/African Americans in Clinical Trials for Oncology and Cardiology

With a limited patient population for rare diseases, and reduced recruiting for clinical trials among diverse groups, the need for diversity advocacy is imperative.



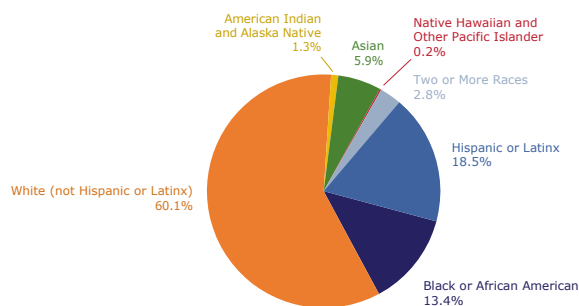
source: Multi-Region Clinical Trials Center Advancing Ethnical Research
2018 National Conference

Importance, Keeping Track, and Tools

To ensure that diversity goals are achieved, it's important to keep measuring the race and ethnicity of program participants after initial sampling. Tools organizations can use to improve diversity include:

- ★ Offering multi-lingual language options for event and project materials
- ★ Press outreach to minority and non-English language newspapers
- ★ Engaging LGBTQ, Minority Health, Ethnically Biased Disease Organizations in increasing engagement with underserved communities

U.S. National Demographic Estimates (2019)*



Rare Disease Legislative Advocates (RDILA) is a program of the EveryLife Foundation for Rare Diseases to support the advocacy efforts of all rare disease patients and organization. RDILA is committed to growing diverse patient advocacy communities and working collaboratively. For additional assistance with Diversity and Inclusion advocacy, contact Shannon von Felden, RDILA Program Director, at svonfelden@everylifefoundation.org.