

Ask the Experts

Session Key Learnings

June 18th, 2022
www.icanresearch.org/videos

Summary:

Dr. Anthony Chang, CHOC, AIMED, iSPI, discusses his education and experience of “What Does It Mean to Be Rare?”. Special Guest Rhiannon Perry, Chair, iCAN Young Adult Professionals joined the discussion to share insight of her own personal journey.

- Rare Disease, while made up of often small population/orphan conditions, when combined, comprises about 8% of the total population. The Rare Disease population includes infants through adult; both with genetic and non-genetic markers. There may be a distinction of a Rare Disease Syndrome (a cluster of diagnosis) vs. a Rare Disease Condition—but it should be emphasized that all Rare Disease needs to be supported equally.
- Anyone from anywhere may have been diagnosed or know someone diagnosed with a Rare Disease. It is critical to find support networks to help with advocacy, healthcare needs, and other resources. iCAN supports Rare Disease at www.icanresearch.org.
- How do you decide to tell someone that you have a rare disease? It is a personal decision and while not required, it can provide mentorship and support by sharing your story. For example, sharing your story to a college roommate can be helpful in creating a safety net.
- How can Rare Disease receive more clinical research support? One of the best ways is to also share your story. By sharing your story, researchers and doctors are made aware of the need for support and can help by creating projects to better understand that specific disease/condition, ultimately leading to better treatments and a cure.
- For advocacy to work, it needs to be adopted by communities. iCAN is a community, but there are also disease specific communities, family support and patient groups. Joining together can help to spotlight the need to create more clinical research and provide areas for awareness and fundraising.
- Join the 2022 iCAN Summit presented by Jumo Health for a week-long series of sessions focused on ‘Rare Disease’ - to learn more, visit www.icanresearch.org/2022-summit.

With Dr. Anthony Chang