

2nd World Congress on RARE DISEASES

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Enhancing patient engagement in the medical arena

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Patient Engagement programs have been discussed on varying levels throughout the medical arena. There are two essential elements of Patient Inclusion within the Rare Disease Arena and the medical industry. First, and foremost, is an enhanced awareness of the symptoms and challenges patients incur, as this can lead to an earlier diagnosis. The diagnostic journey for those in the Rare Disease Community can be a long and arduous, ranging on average 7 - 10 years before diagnosis. Many in these communities suffer irreparable harm due to late diagnosis. Inclusion of patient advocates, patient led organizations and organizations conducting Rare Disease research is a necessity. We need to create a space of inclusivity to share these findings to enhance the medical treatments and earlier diagnosis of related diseases.

The second, but no less important, aspect of Patient Engagement, reverts to the inclusion of the patients in their medical treatments. More often than not, the patient is partially, if at all included in the medical treatment plan. Commonly, many patients are left feeling unheard. Many times, patients are left feeling devalued and excluded from their treatment options.

Inclusion in the treatment plan and inclusion in the diagnostic process can prove to be invaluable, for the patient and the medical industry. Several groups, particularly, research programs are currently involving patients.

Biography

Deborah Vick, is the co-founder and CEO of RareABILITY, Public Speaker, Volunteer Advocate several organizations including the AllStripes, Myasthenia Gravis Foundation Advocacy Committee, Christopher Reeves Foundation and Ehlers Danlos Society. Along side Robin, they work with various organizations to help reduce barriers for patients, advocate for Rare Disease Legislation and use our personal experiences as those of our peers to broaden the conceptual framework of the patient experience. Robin Powers, is the co-Founder and President of RareABILITY, Public Speaker, and Volunteer Advocate with several groups. As well as Rare Champion of Hope and Rare Impact Nominee. She is clinical patient advocate and works tirelessly to share her own arduous diagnostic journey while working on her masters degree. Both presenters have published articles and/or books as well as featured on various Podcasts.

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