

Although COVID-19 continues to keep people apart, a virtual conference recently brought together a diverse group of stakeholders collaborating to improve outcomes for children with rheumatic diseases.

CARRA members participated in a virtual conference on November 16<sup>th</sup> entitled, “Connection, Diversity & Engagement: Navigating Virtually During COVID-19 & Beyond.” The conference was run by a consortium called PARTNERS (Patients, Advocates and Rheumatology Teams Network for Research and Service), which includes CARRA.

Virtual engagement has become a necessity during the pandemic, but it’s not a novel concept to families living with rheumatic disease. When parents can’t find anyone in their community with their child’s disease, they rely on virtual connections, such as online support groups. These connections were a lifeline for me when our daughter was diagnosed with pan-sclerotic morphea, a rare form of localized scleroderma, and four years later they are still very meaningful to me.

The pandemic has created a new imperative to reach patients (and families) where they are — often at home, immunocompromised and isolated. Although this presents challenges for researchers, it is a welcome opportunity for families. I have been pleased to virtually attend several healthcare and pharmaceutical conferences this year, which previously required an elaborate orchestra of babysitters and carpools, as well as a shuffling of medical appointments.

Taking virtual engagement a step further, reimagining clinical trials amidst COVID-19 could reduce barriers to participation. For example, remote patient monitoring and telehealth visits could facilitate participation of patients who previously would not have enrolled due to geographic or logistical barriers. Further, reducing demands on patients and families could improve adherence to trial protocols.

The PARTNERS webinar featured presentations from thought leaders on strategies for improving inclusiveness in research — from design to post-trial.

Consuelo Wilkins, MD MSCI, vice president for health equity at Vanderbilt University Medical Center, spoke about the importance of integrating different voices into research on many levels.

“Engagement is not recruitment,” Wilkins said. “If you are only including those voices in order to enroll them in a clinical research study, then I don’t consider that to be engagement.”

Daphina Melbourne, MPP, a community engagement associate at University of California San Francisco, spoke about her work with Voices for Birth Justice, which is an example of uplifting those with lived experience as experts.

“Voices brings experts, community advocates and those with lived experience together to collaborate on solutions to address pre-term birth,” Melbourne said.

Nadine J. Barrett, PhD MA MS, an assistant professor in family medicine and community health at Duke University, shared success stories of inclusive research. She also urged researchers to avoid making assumptions about what patients want — and including patients too late in the game.

“Don’t invite me for dessert after you have already had the main course, and don’t assume this is a restaurant I even want to eat at,” Barrett said.

In closing, Wilkins reminded participants of something that is close to the hearts of CARRA families.

“There is no substitute for the lived experience,” she said.

— *Erin Moriarty Wade*

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