Seeking ACHD Care When There is No Local Center

Wednesday, August 18, 2021
7 p.m. – 8 p.m. EDT

Presenters: Jeremy Nicolarsen, MD, FACC, Susan Fernandes, LP.D, PA-C, and Tarrin Weber

About the Webinar
Living with congenital heart disease can be difficult. It can even be harder if you don’t live near an Adult Congenital Heart Association (ACHA) Adult Congenital Heart Disease (ACHD) Accredited Program or board certified ACHD specialist. What can an ACHD patient in these areas do to get specialized care? When is traveling for care necessary? How can you form a care partnership with your local team and a remote ACHD provider? Join Jeremy Nicolarsen, MD, FACC, Sue Fernandes, LP.D., PA-C, and Tarrin Weber, an ACHD patient without a local team, as they discuss these challenges and more. You’ll also learn about the role of virtual office visits, best practices for seamless communication, and the importance of self-advocacy.

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About the Presenters
Dr. Susan Fernandes is a member of the ACHA Medical Advisory Board. She is also the Program Director of the Adult Congenital Heart Program at Stanford, a nationally accredited ACHA ACHD Comprehensive Care Center in California. She has been caring for ACHD patients for more than 25 years as a physician assistant, while also being involved in ACHD research and patient advocacy. A main focus of Dr. Fernandes’ work is increasing access to specialized care for ACHD patients.

Dr. Jeremy Nicolarsen is a member of the ACHA Medical Advisory Board. He is also the Director of the Providence Adult and Teen Congenital Heart Program (PATCH), a nationally accredited ACHA ACHD Comprehensive Care Center in Spokane, WA, that serves the Inland Northwest, including eastern and southern WA, western MT, and the ID panhandle. Dr. Nicolarsen is no stranger to traveling long distances to provide outreach care to more than 1,800 patients. He is interested in improving access to ACHD care for all through a telehealth enterprise being developed specifically for the Providence program called ePATCH.

Tarrin Weber is an ACHD patient who currently resides in a small farming community along the Washington-Idaho border with her spouse and four children. She has lived in rural regions of the Pacific Northwest throughout her life. First diagnosed with CHD in her teens, Tarrin has navigated through barriers related to accessible care for more than 20 years, often finding herself as the educator for her specific conditions within the community in which she lives. Specific barriers that have affected her care include traveling for service, coordination of care, changes in healthcare insurance, coordination of care needs related to pregnancy, and screening for biological children. Tarrin is honored to share her experience with fellow ACHD patients in hopes of supporting their journey.

About the Adult Congenital Heart Association
The Adult Congenital Heart Association (ACHA) is a national not-for-profit organization dedicated to supporting individuals and families living with congenital heart disease and advancing the care and treatment available to our community. ACHA empowers the more than nearly 2 million adults with CHD, their families, and the medical community by advancing access to resources and specialized care that improve patient-centered outcomes. For more information about ACHA, contact (888) 921-ACHA or visit www.achaheart.org.

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