



## Patient Engagement in Research: Why Does It Matter?

Wednesday, August 4, 2021

7 p.m. – 8 p.m. EDT

Presenters: Ari Cedars, MD, and ACHA Peer Mentors Dominique L. and Marissa M.

### About the Webinar

Have you participated in a research study before or are you interested in taking part in one? If so, you don't want to miss this webinar. Dr. Ari Cedars and ACHA Peer Mentors Marissa M. and Dominique L. will bring you up to date about the status of research in ACHD. They will also talk about the vital role patients play as partners in the research process.

**REGISTER NOW:** <https://bit.ly/2TYVmrA>

### About the Presenters

Dr. Ari Cedars is a member of the ACHA Medical Advisory Board and director of the ACHD program at Johns Hopkins Hospital. He has an interest in patient-centered care and care individualization based on the ways that the molecules and genes in the body change in different types of congenital heart disease. He also has an interest in mechanical circulatory support and transplant in ACHD.

Dominique L. is an ACHA Peer Mentor who was born with HLHS, TGA, pulmonary stenosis, an ASD and a VSD. She had three open heart surgeries by the age of three, including the Fontan. She works as a registered behavior technician while receiving her master's in psychology to pursue a career as a behavior analyst. As an H2H Peer Mentor, she advocates for the importance of mindfulness and self-advocacy in others when dealing with chronic illness.

Marissa M. is an ACHA peer mentor who was born with six complex heart defects, including a single ventricle, and had three surgical procedures before the age of two. She is a registered nurse in the pediatric cardiac intensive care unit and is enrolled in a masters nursing program. Marissa lives life to the fullest, and never allows her heart condition to define who she is. As a H2H Peer Mentor, she enjoys empowering others to be their own advocate when they need it the most.

### About the Adult Congenital Heart Association

The Adult Congenital Heart Association (ACHA) is a national not-for-profit organization dedicated to improving the quality of life and extending the lives of adults with congenital heart disease (CHD). ACHA serves and supports the nearly 2 million adults with CHD, their families, and the medical community—working with them to address the unmet needs of the long-term survivors of congenital heart defects through education, outreach, advocacy, and research. For more information about ACHA, contact (888) 921-ACHA or visit [www.achaheart.org](http://www.achaheart.org).

This webinar was made possible in part by an unrestricted educational grant from  
Janssen, Inc. Pharmaceutical Companies of Johnson & Johnson.