

Congenital Heart
INITIATIVE

ANNUAL REPORT

MESSAGE FROM THE TEAM



In December 2018, more than 30 patients, physicians, health scientists, and researchers representing more than a dozen organizations met in Washington, D.C., to embark on the process of creating a patient-powered registry for adult congenital heart disease. For far too long, significant barriers have existed in conducting surveillance and long-term outcomes research on this patient population. The lack of a longitudinal registry in the US and heterogeneity of ACHD patients has resulted in an inability to fully characterize the U.S. ACHD population and attain baseline quality of life data on ACHD patients.

This working group, fueled by seed funding from Children's National and the Heart Research Alliance (UCSF), came together to address these issues and create an accessible, useable, and transparent registry. The Congenital Heart Initiative's mission is to create a digital hub that gathers health data from ACHD patients to realize a shared understanding of research needs and medical outcomes of the ACHD patient population. After two years of effort, including countless hours of volunteer effort from patients, providers, and researchers, the Congenital Heart Initiative launched in December 2020. In the past year, we have demonstrated the feasibility of the registry as a tool that unites patients, providers, and researchers to improve the lives of adults living with congenital heart defects.

Hopefully, this is our first report of many that will help shine light and characterize the ACHD patient population and drive research and innovation in the field. We believe the Congenital Heart Initiative is an essential tool for helping to deliver improved outcomes for all ACHD patients, and we will continue to work diligently to deliver on that promise.

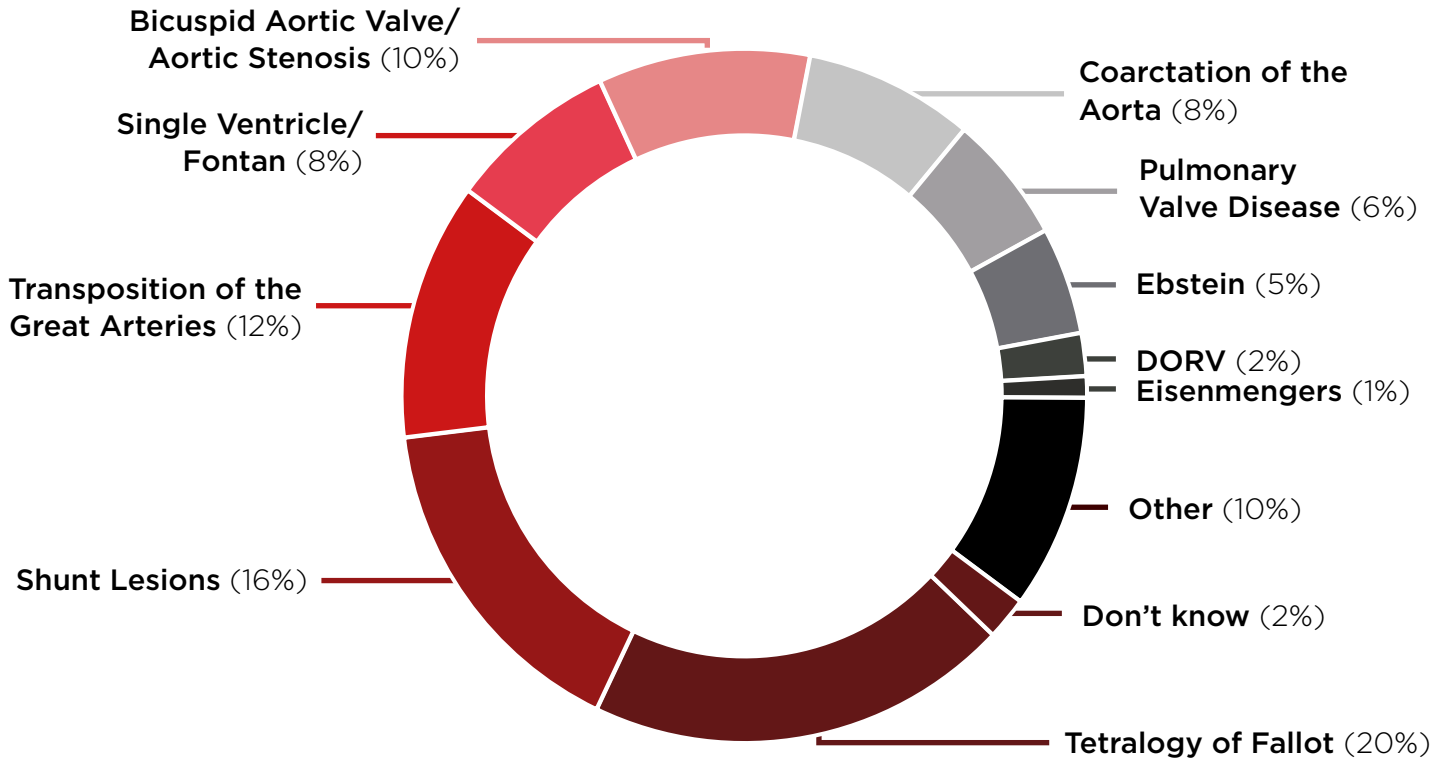
- DR. ANITHA JOHN

Medical Director, Washington Adult Congenital Heart Program

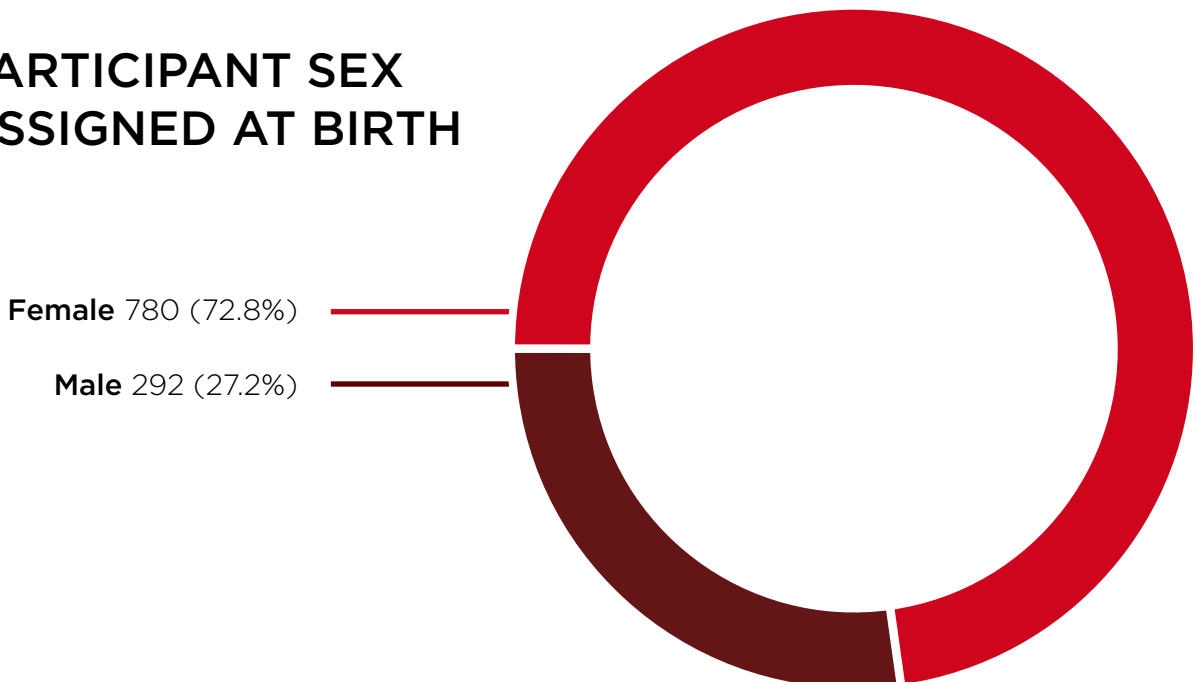


KEY STATISTICS

PARTICIPANT DIAGNOSIS

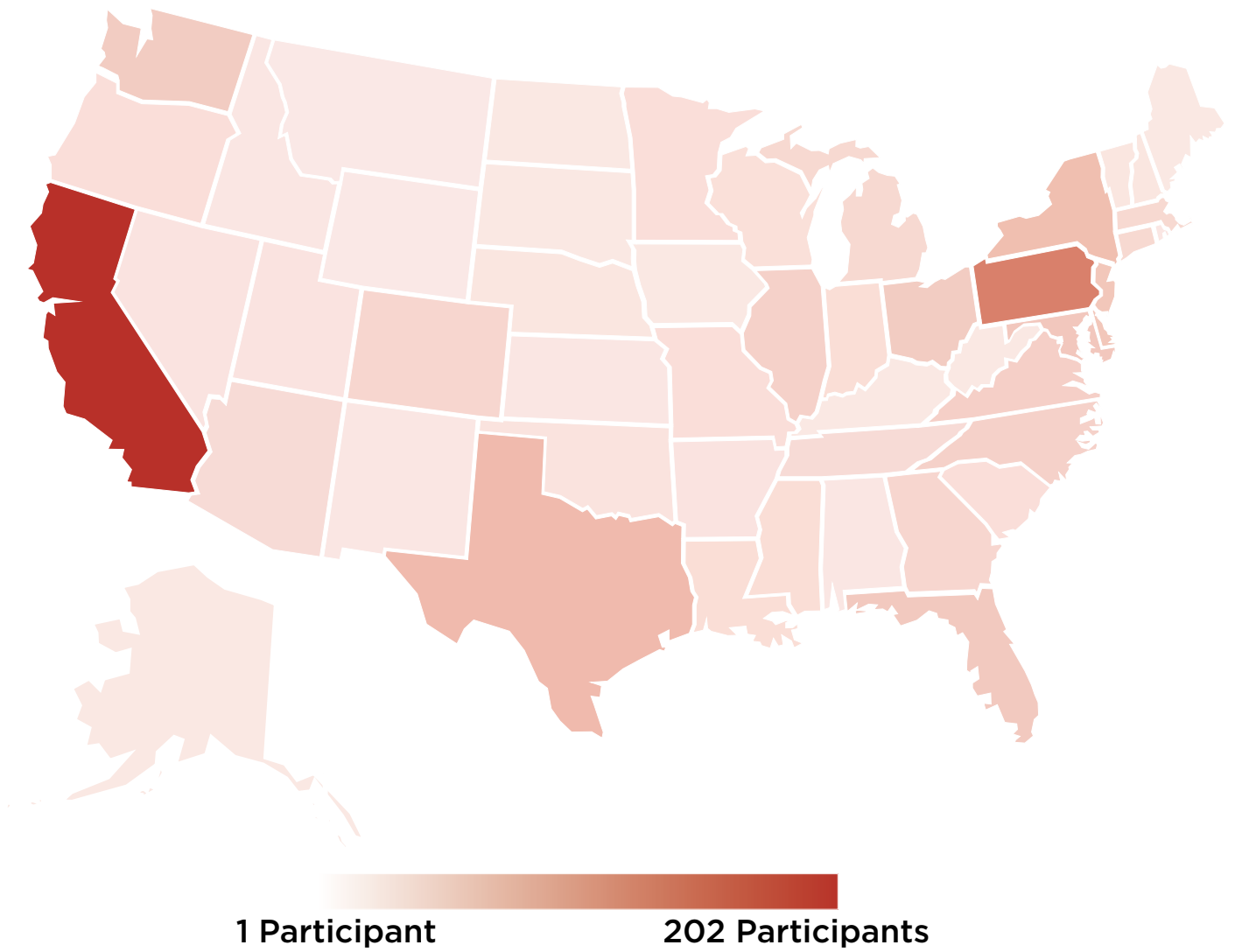


PARTICIPANT SEX ASSIGNED AT BIRTH



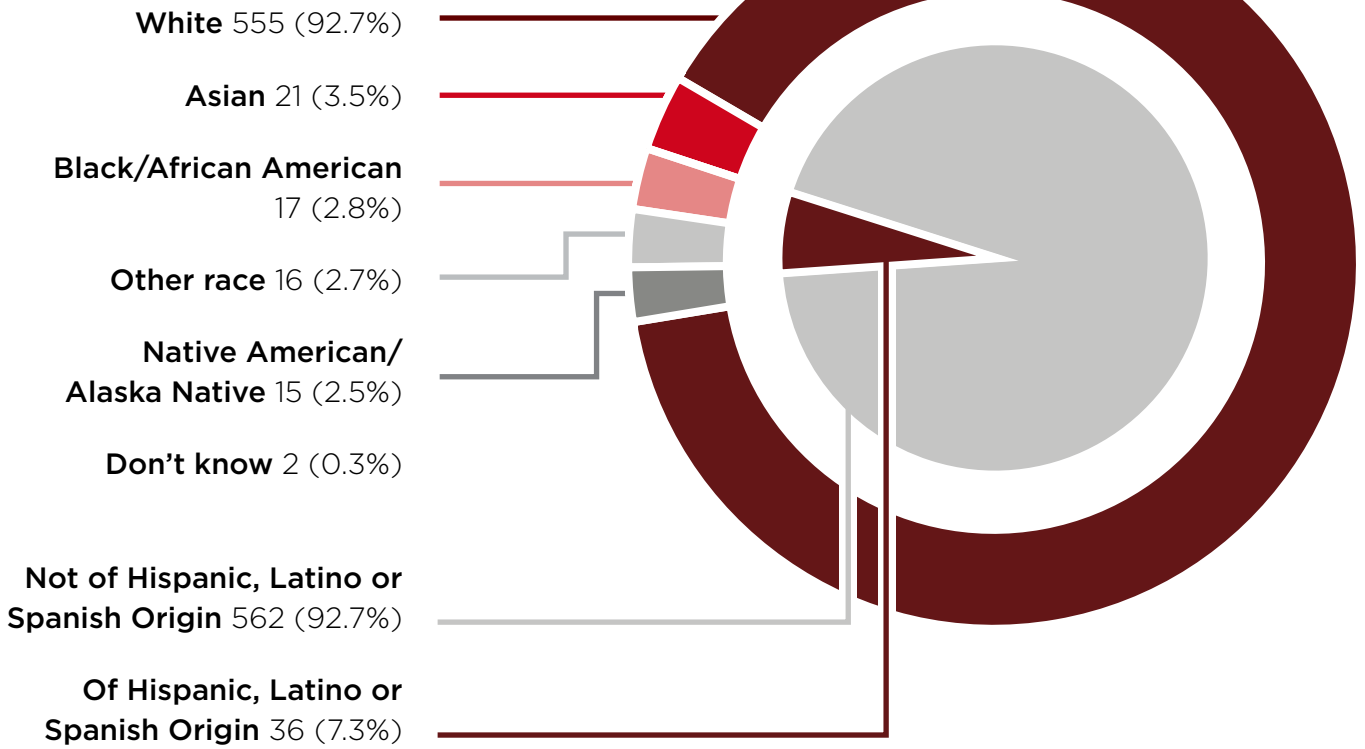
KEY STATISTICS

PARTICIPANT STATE OF RESIDENCE

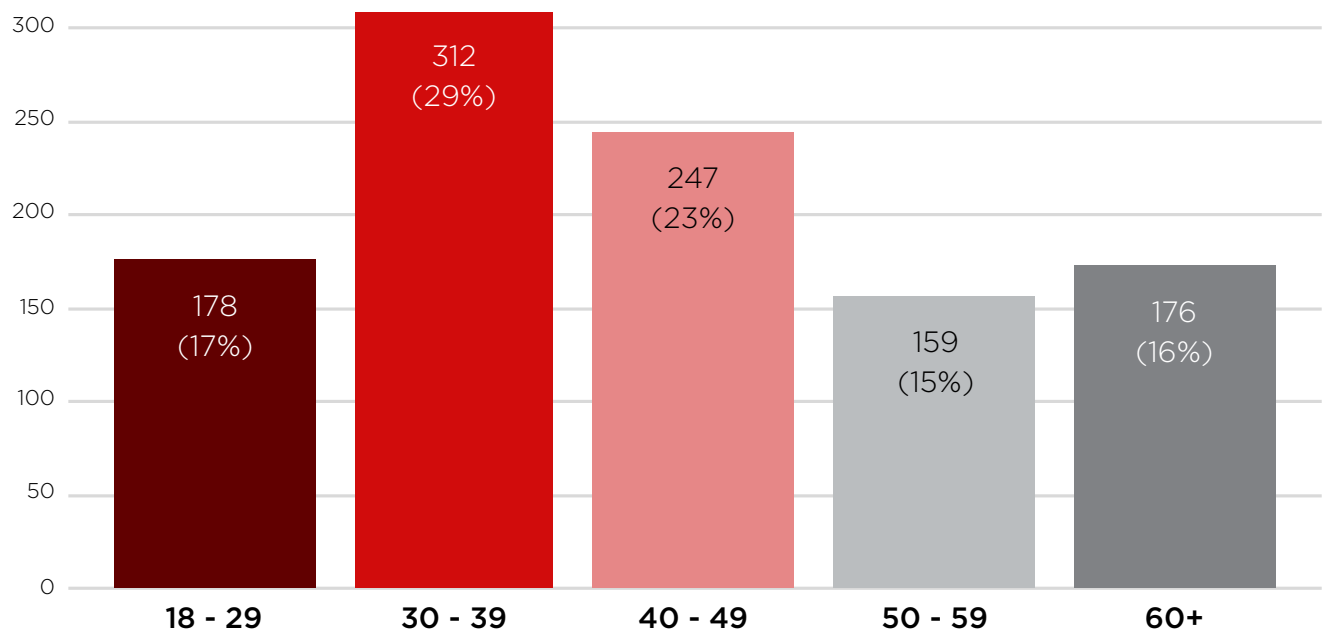


KEY STATISTICS

PARTICIPANT RACE

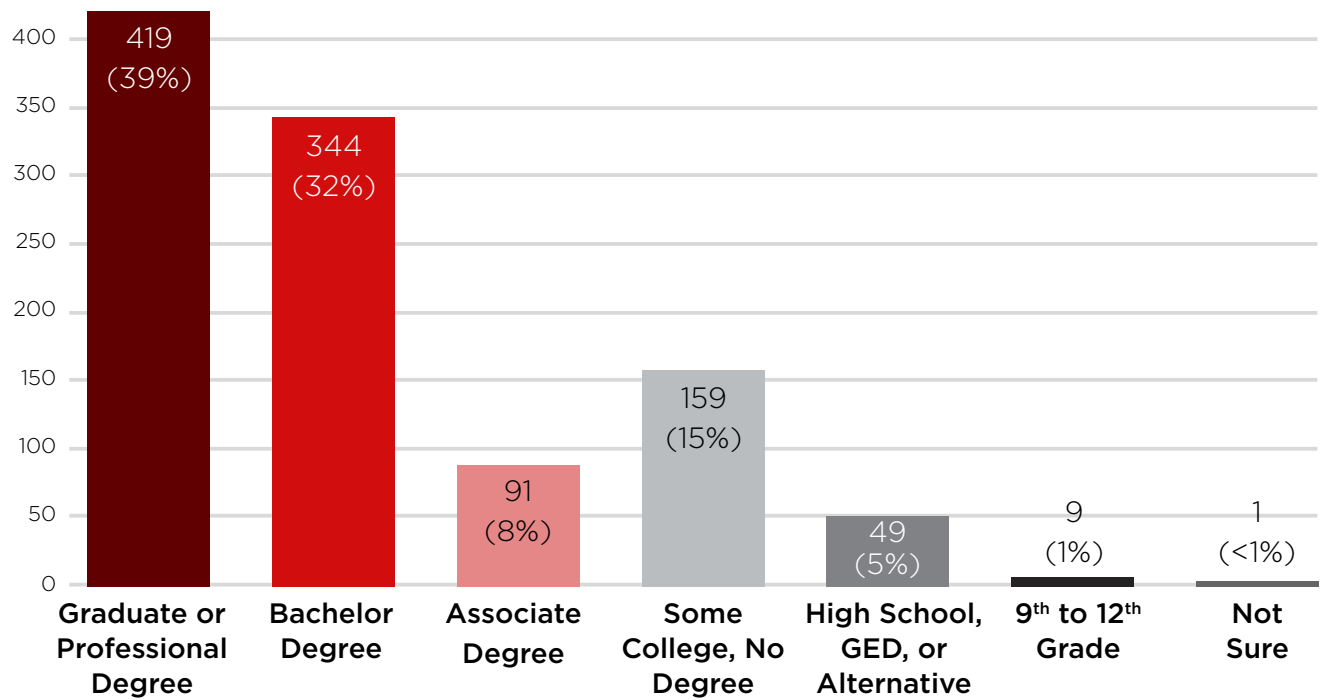


PARTICIPANT AGE RANGE

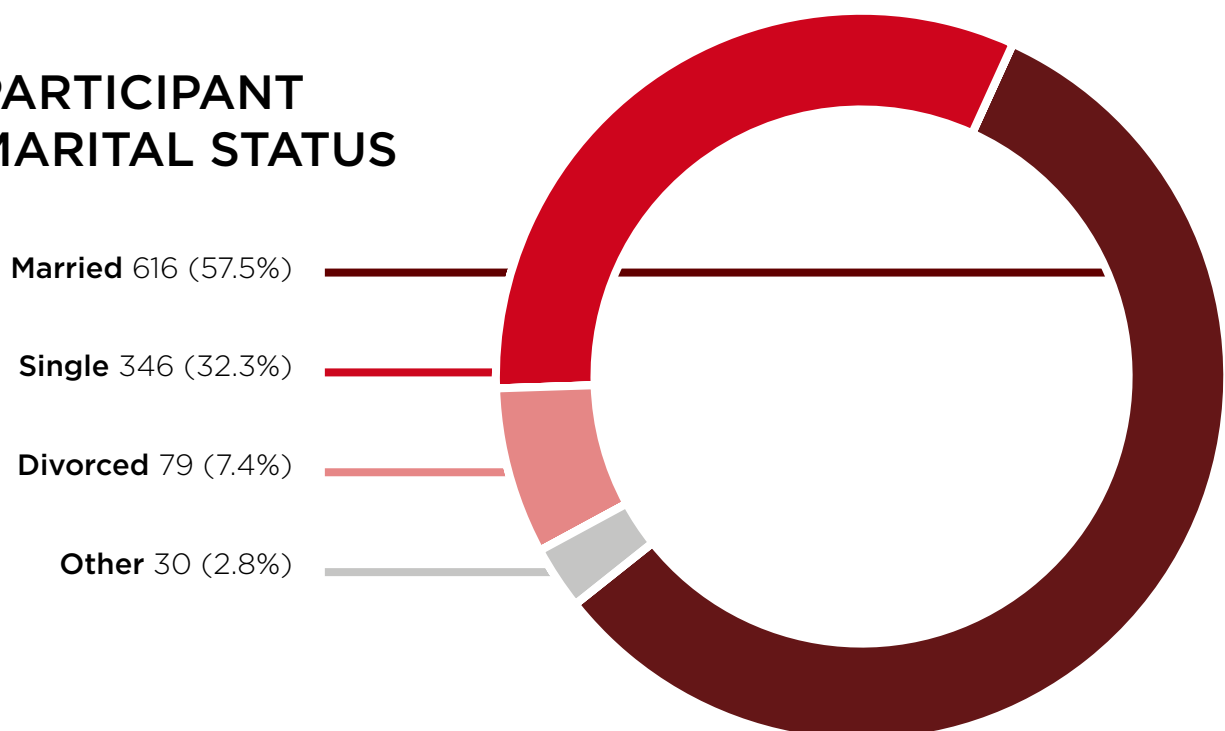


KEY STATISTICS

PARTICIPANT EDUCATION ATTAINMENT

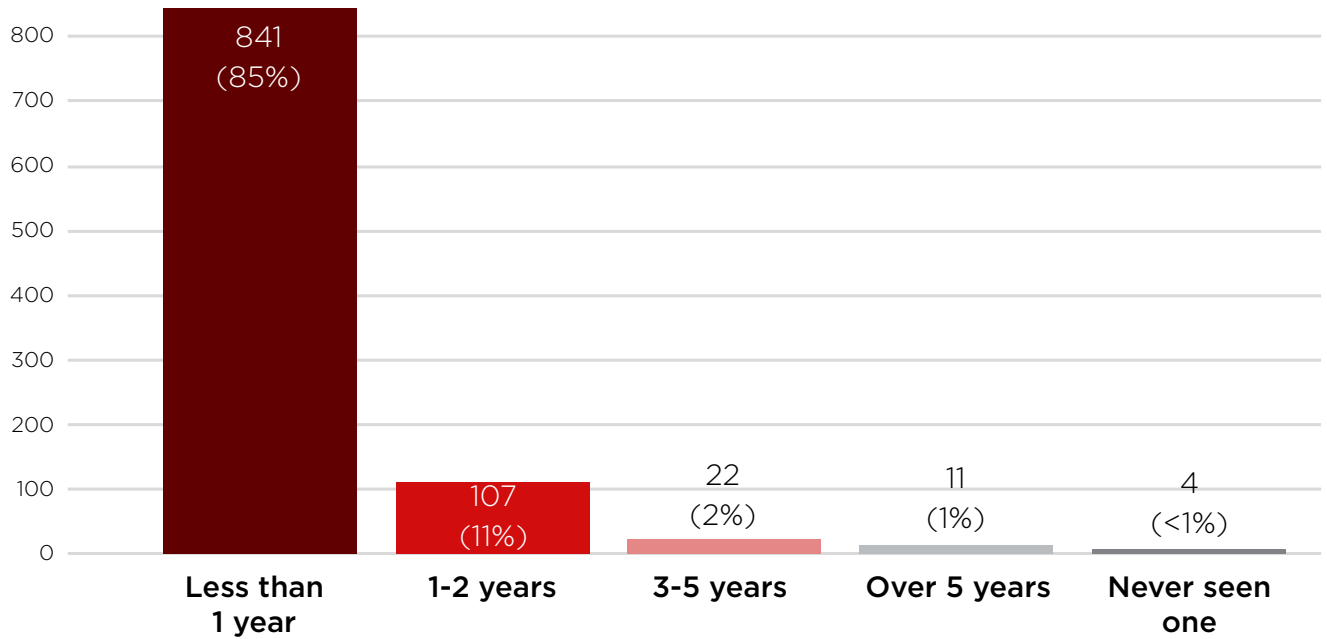


PARTICIPANT MARITAL STATUS

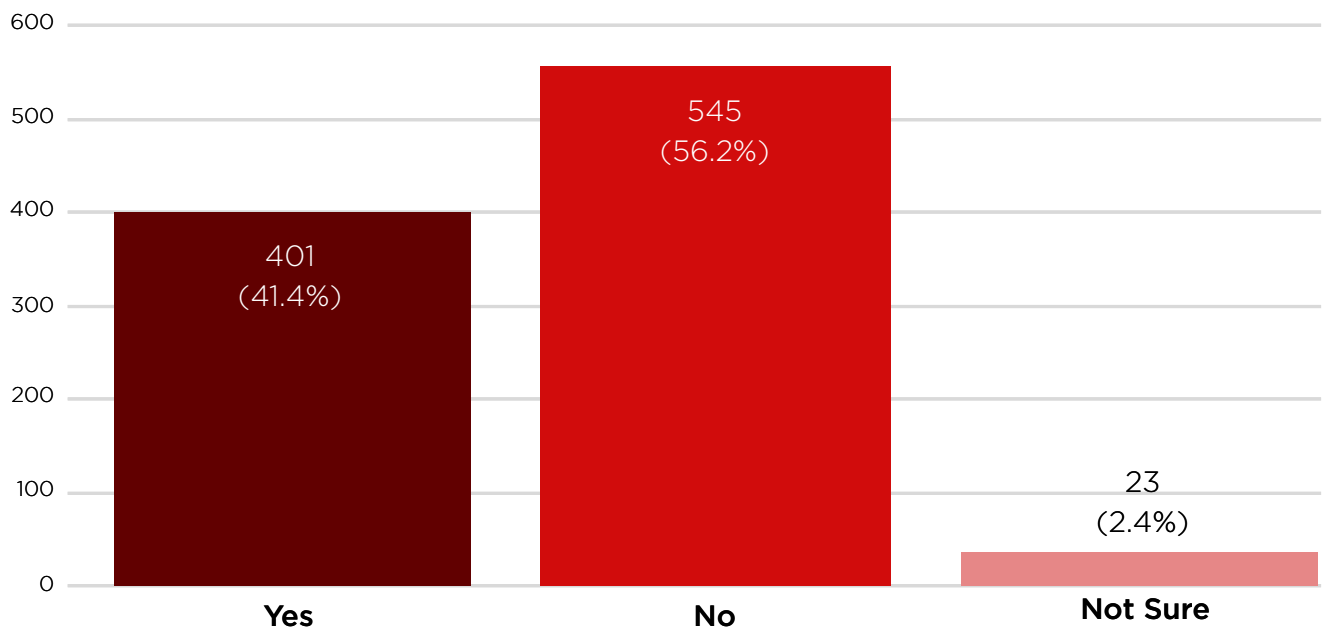


KEY STATISTICS

PARTICIPANT'S MOST RECENT VISIT TO CARDIOLOGY PROVIDER

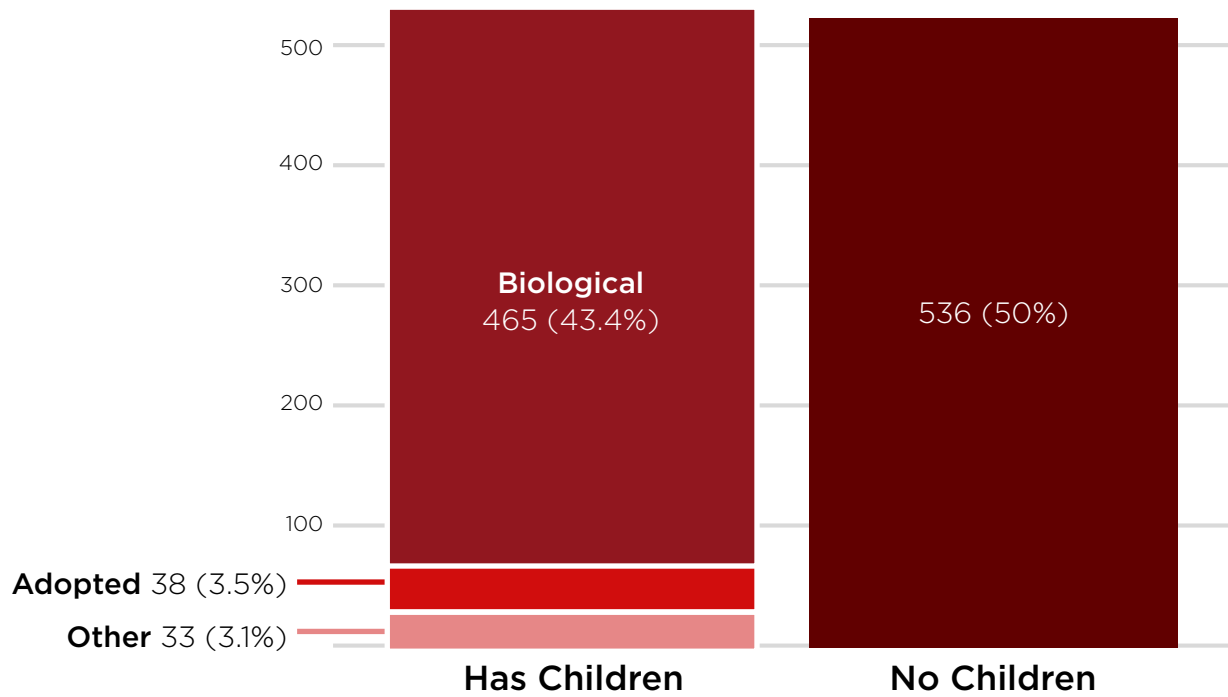


PARTICIPANTS WHO HAD A 3+ YEAR GAP IN CARE

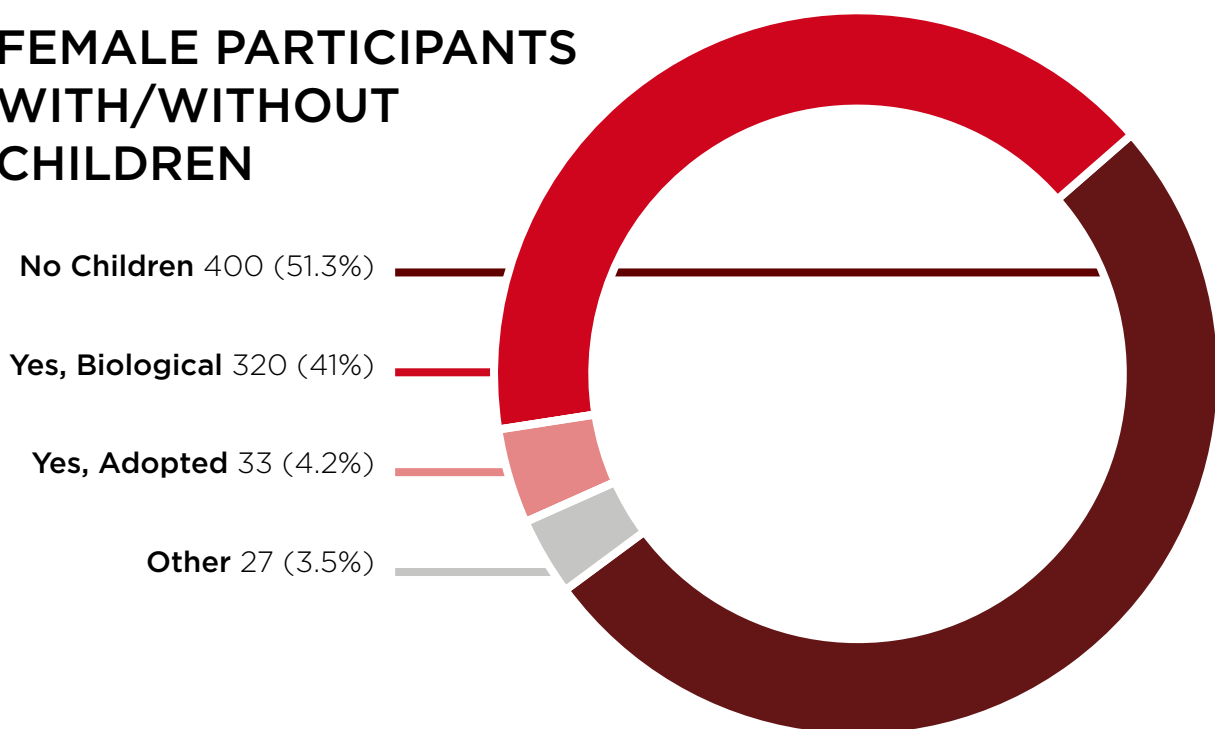


KEY STATISTICS

PARTICIPANTS WITH/WITHOUT CHILDREN

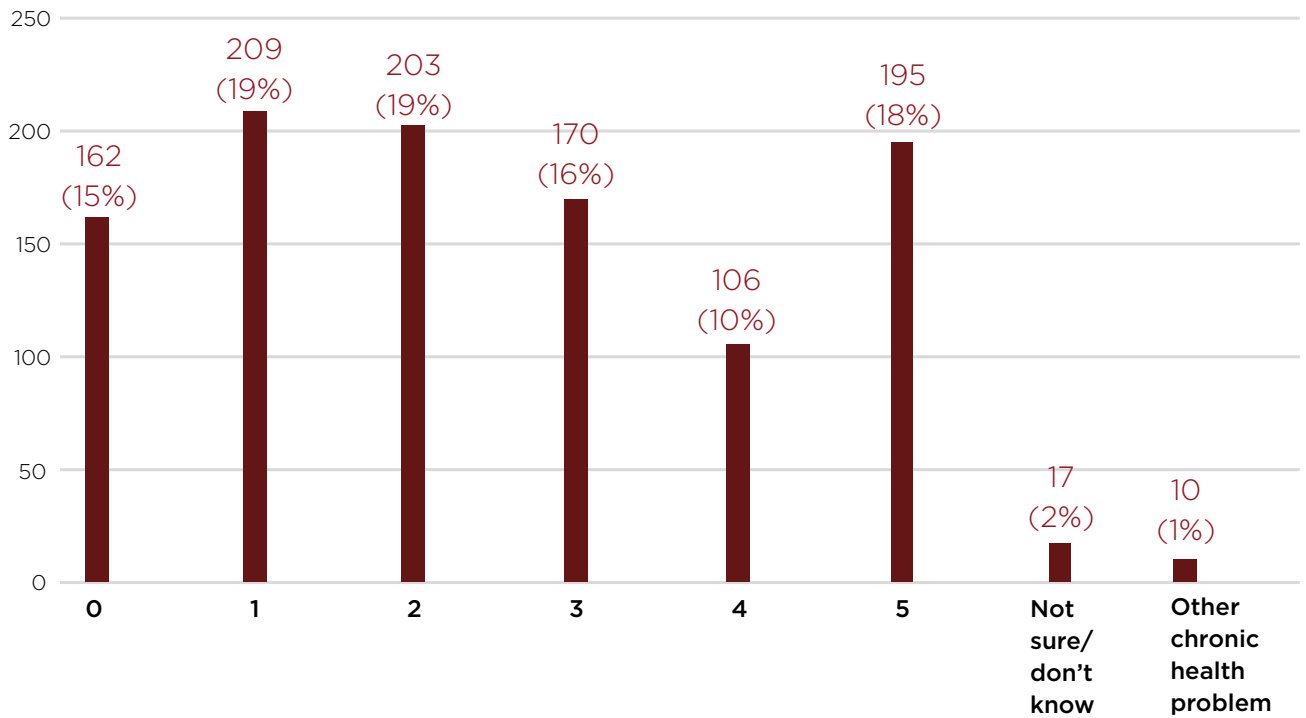


FEMALE PARTICIPANTS WITH/WITHOUT CHILDREN



KEY STATISTICS

NUMBER OF COMORBIDITIES PER PATIENT



MOST COMMON COMORBIDITIES

Cardiac Comorbidities	Frequency
Arrhythmia or heart rhythm problem	44%
High blood pressure (hypertension)	21%
Congestive heart failure	19%
High cholesterol (hyperlipidemia)	14%
A stroke	8%
Heart Attack	3%
Clotting disorder (form clots easily or had a prior blood clot)	4%
Bleeding disorder (when blood is too thin/bleed for a long time)	3%

Non-Cardiac Comorbidities	Frequency
Mood disorder (like anxiety or depression)	35%
Asthma	17%
Anemia, low hemoglobin	15%
Obstructive sleep apnea	10%
Arthritis (gout, lupus, fibromyalgia)	12%
Liver disease	9%
Diabetes (pre-diabetes, or sugar related problems)	8%
Cancer or malignancy of any kind	6%
Lung disease	5%
An ulcer in the stomach, intestine or peptic ulcer	4%
Kidney failure	1.5%
Other chronic health problem	19%



SPECIAL THANKS

ADDITIONAL ADVISORY ORGANIZATIONS

American College of Cardiology,
Adult Congenital & Pediatric
Cardiology (ACPC) Section

Centers for Disease Control and
Prevention (CDC)

National Heart, Lung, and Blood
Institute (NHLBI)

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SPECIAL THANKS

PARTICIPATING ORGANIZATIONS

Adult Congenital Heart Association
(ACHA)

Adult Congenital Heart Disease
Cause Group

Alliance for Adult Research in
Congenital Heart Disease, Inc.
(AARCC)

Children's National Hospital

Heart Research Alliance (formerly the
Health eHeart Alliance)

University of California -
San Francisco/Eureka

WHAT'S NEXT?

We thank you for powering the Congenital Heart Initiative, and uniting with us to improve the lives of adults living with congenital heart defects everywhere. We're continuing to recruit patients to join the Congenital Heart Initiative! If someone you know would be interested in joining the registry, please send them to chi.eurekaplatform.org.

For ACHD centers interested in learning how the CHI registry might be useful, there are plenty of opportunities to get involved. We are actively engaging centers to determine how the CHI can benefit your patients. Please contact us at chdinitiative@eurekaplatform.org for more information!

Exciting news! Children's National Hospital and Louisiana Public Health Institute were awarded \$4.9 million by the Patient Centered Outcomes Research Institute (PCORI) to study the effects of gaps in care on CHD patients' health and well-being. The Congenital Heart Initiative: Redefining Outcomes and Navigation to Adult-Centered Care (CHI-RON) study will begin recruiting in May 2022 at the 12 participating centers.



Get social with us! We are on Facebook ([@CongenitalHeartInitiative](https://www.facebook.com/CongenitalHeartInitiative)) and Twitter ([@ACHD_CHI](https://twitter.com/ACHD_CHI)). Follow along for the latest registry updates, and CHD educational information.

If you have any questions, comments or concerns about this study, please reach out to chdinitiative@eurekaplatform.org.