Note: The data in this report is not a substitute for medical advice. Please discuss any medical treatment and care choices with your health care practitioner or cardiology care team.
Since its launch in December 2020, the Congenital Heart Initiative (CHI) has come a long way, perhaps further than some of us had imagined! As of April 2023, more than 3,700 adults with congenital heart disease (ACHD) from around the world have joined the registry in the largest one-year growth thus far. The CHI gathers information directly from patients, cultivating a shared understanding of the needs of the ACHD population while also shedding light on what people can expect in the future.

In May 2022, we expanded our ability to illuminate the effects of gaps in care with the recruitment launch of the Congenital Heart Initiative: Redefining Outcomes and Navigation to Adult-Centered Care study (CHI-RON), which has recruited more than 2,000 patients so far. Led by Children’s National and the Louisiana Public Health Institute, the CHI-RON study is the first sub-study within the CHI. The goal of the study is to understand the impact of current recommended care guidelines while also better understanding the barriers to receiving adequate healthcare.

Most importantly, this registry highlights the strength, commitment, and collaboration of our ACHD community. The CHI would not be possible without the individuals who contribute countless time and energy, united by a model of servant leadership and a commitment to placing the betterment of others ahead of their own interests. As always, we continue to strive to better understand the research priorities of the ACHD community.

We thank all participants of the CHI for their time, effort, and willingness to share key aspects of their lives. We hope this report and the entire CHI effort create a path forward to a more innovative future that changes our collective understanding of and care for adults with congenital heart disease.

— DR. ANITHA JOHN
ACHD Specialist and Researcher
The CHI registry has seen substantial growth, with 3x more participants than last year, but there is plenty more work to be done to increase representation. Registry participants provide baseline patient-reported outcomes (PROs) and four-month follow-up PROs, which drive patient-informed clinical care, research, and patient and provider education.

**CHI REGISTRY FRAMEWORK**

- **BASELINE PROS**
  - N=3,330
  - ALL 50 STATES
  - 32 COUNTRIES PLUS USA

- **4-MONTH FOLLOW-UP PROS**

- **DATA ANALYSIS**

- **PATIENT AND PROVIDER ADVOCACY AND EDUCATION**
  - Demographic
  - Health Services Use
  - Satisfaction with Life Scale and Short Form-20
  - International Physical Activity Questionnaire
  - Hospital Anxiety Depression Scale

- **PATIENT-INFORMED CLINICAL CARE AND RESEARCH**
  - Health Services Use
  - Satisfaction with Life Scale and Short Form-20
  - International Physical Activity Questionnaire
  - Hospital Anxiety Depression Scale

*PROs - Patient-Reported Outcomes*
## KEY STATISTICS

### PARTICIPANT SEX ASSIGNED AT BIRTH

- **Female**: 1,721 (64.3%)
- **Male**: 955 (35.7%)
- **Other**: 2 (0.1%)

*Total: 2,678

### PARTICIPANT CHD* TYPE BY SEX ASSIGNED AT BIRTH

- **Tetralogy of Fallot (TOF)**: 688 (23%) - Male: 247, Female: 200
- **Transposition of great arteries (TGA)**: 344 (12%) - Male: 144, Female: 203
- **Coarctation of aorta (CoA)**: 329 (11%) - Male: 126, Female: 203
- **Anomalies of aortic valves (AV)**: 294 (10%) - Male: 154, Female: 140
- **Univentricular**: 251 (8%) - Male: 98, Female: 153
- **Other anomalies**: 189 (6%) - Male: 62, Female: 127
- **Anomalies of Pulmonary atresia (PA) or pulmonary valve stenosis (PV)**: 169 (6%) - Male: 64, Female: 105
- **Atrial septal defect (ASD)**: 164 (5%) - Male: 31, Female: 133
- **Hypoplastic left heart syndrome (HLHS)**: 93 (3%) - Male: 39, Female: 54
- **Ventricular septal defect (VSD)**: 85 (3%) - Male: 15, Female: 70
- **Don't Know**: 78 (3%) - Male: 34, Female: 44
- **Ebstein anomaly**: 71 (2%) - Male: 17, Female: 54
- **Anomalies of veins**: 66 (2%) - Male: 17, Female: 49
- **Endocardial cushion**: 61 (2%) - Male: 10, Female: 51
- **Double outlet right ventricle (DORV)**: 46 (2%) - Male: 23, Female: 23
- **Truncus arteriosus**: 25 (1%) - Male: 8, Female: 17
- **Patent ductus arteriosus (PDA)**: 18 (1%) - Male: 1, Female: 17
- **Eisenmenger syndrome/cyanotic heart disease**: 17 (1%) - Male: 4, Female: 13

*CHD - Congenital Heart Disease
KEY STATISTICS

PARTICIPANT RACE AND ETHNICITY

n = 2,987

PATIENT PERSPECTIVE

“It’s very important to me that a person of color, like myself, is able to participate... The CHI allows us to share our health stories, be a support system, and let the younger generation who have congenital heart disease (CHD) know that you can grow up and be an adult and live what we know as normal lives.”

— Alison Gill, CHD patient and CHI registry participant who has embraced her newfound congenital heart community
KEY STATISTICS

PARTICIPANT AGE RANGE

Number of Participants

<table>
<thead>
<tr>
<th>Age Range</th>
<th>Number of Participants</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>18-25</td>
<td>468</td>
<td>18%</td>
</tr>
<tr>
<td>26-35</td>
<td>818</td>
<td>31%</td>
</tr>
<tr>
<td>36-45</td>
<td>636</td>
<td>24%</td>
</tr>
<tr>
<td>46-55</td>
<td>352</td>
<td>13%</td>
</tr>
<tr>
<td>56-65</td>
<td>243</td>
<td>9%</td>
</tr>
<tr>
<td>Over 65</td>
<td>153</td>
<td>6%</td>
</tr>
</tbody>
</table>

n = 2,682

PARTICIPANT EDUCATION ATTAINMENT

Number of Participants

<table>
<thead>
<tr>
<th>Education Level</th>
<th>Number of Participants</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Graduate or Professional Degree</td>
<td>902</td>
<td>34%</td>
</tr>
<tr>
<td>Bachelor Degree</td>
<td>861</td>
<td>32%</td>
</tr>
<tr>
<td>Associate Degree</td>
<td>211</td>
<td>8%</td>
</tr>
<tr>
<td>Some college, no degree</td>
<td>436</td>
<td>16%</td>
</tr>
<tr>
<td>High School, GED, or Equivalent</td>
<td>225</td>
<td>8%</td>
</tr>
<tr>
<td>9th to 12th grade</td>
<td>42</td>
<td>2%</td>
</tr>
<tr>
<td>Don't know</td>
<td>1</td>
<td>0%</td>
</tr>
</tbody>
</table>

n = 2,678

PARTICIPANT MARITAL STATUS

n = 2,680

- Married: 1349 (50%)
- Other: 77 (3%)
- Divorced: 149 (6%)
- Unknown: 2 (0.1%)
- Single: 1103 (41%)

- Married: 1349 (50%)
- Other: 77 (3%)
- Divorced: 149 (6%)
- Unknown: 2 (0.1%)
- Single: 1103 (41%)
Key Statistics

Participants with a 3+ Year Gap in Cardiology Care

Note: Studies have shown that CHD patients with lapses in care for two years had a three-fold increase in required medical interventions.

“The CHI is one of the most important actions ever undertaken in the field of ACHD.”

— Dr. Rich Krasuski, ACHD Specialist

Graph showing:
- Yes: 973 (36%)
- No: 1589 (59%)
- Not Sure: 78 (3%)

Total participants: n = 2,640
PARTICIPANTS’ MOST RECENT VISIT TO CARDIOLOGY PROVIDER

n = 2,680

“The CHI is a new and wonderful way to facilitate the CHD journey; serving many purposes: networking, learning, and giving.”

— Dr. Ron Kanter, ACHD Specialist
**KEY STATISTICS**

**ALL PARTICIPANTS WITH/WITHOUT CHILDREN**

Note: No two patients are the same, even if they share the same CHD. Please talk to your cardiologist about family planning and advice relating to your CHD and specific health condition(s).

**Number of Participants**

<table>
<thead>
<tr>
<th>Group</th>
<th>Participants</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>No Children</td>
<td>1703</td>
<td>51%</td>
</tr>
<tr>
<td>Biological</td>
<td>1150</td>
<td>34%</td>
</tr>
<tr>
<td>Adopted</td>
<td>71</td>
<td>2%</td>
</tr>
<tr>
<td>Other</td>
<td>66</td>
<td>2%</td>
</tr>
</tbody>
</table>

**FEMALE PARTICIPANTS WITH/WITHOUT CHILDREN**

**Number of Participants**

<table>
<thead>
<tr>
<th>Group</th>
<th>Participants</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>No Children</td>
<td>1074</td>
<td>56%</td>
</tr>
<tr>
<td>Yes, Biological</td>
<td>730</td>
<td>38%</td>
</tr>
<tr>
<td>Yes, Adopted</td>
<td>57</td>
<td>3%</td>
</tr>
<tr>
<td>Other</td>
<td>50</td>
<td>3%</td>
</tr>
<tr>
<td>No Children</td>
<td>1074</td>
<td>56%</td>
</tr>
</tbody>
</table>

n = 3,339

n = 1,911
KEY STATISTICS

FEMALE PARTICIPANT BIRTHS

Note: No two patients are the same, even if they share the same CHD. Please talk to your cardiologist about family planning and advice relating to your CHD and specific health condition(s).

NUMBER OF CHILDREN REPORTED BY FEMALE PARTICIPANTS, BY CHD COMPLEXITY

Note: CHD complexity classification is categorized as simple (I), moderate (II), or “great complexity” (III) as defined by the American College of Cardiology and the American Heart Association (Stout, 2019). For this report, tetralogy of Fallot was included in CHD Complexity III.
## KEY STATISTICS

### MOST COMMON ADDITIONAL MEDICAL CONDITIONS

<table>
<thead>
<tr>
<th>Non-Cardiac Conditions</th>
<th>Proportion of Participants Reporting</th>
</tr>
</thead>
<tbody>
<tr>
<td>PTSD, Anxiety, or Depression</td>
<td>981 (30%)</td>
</tr>
<tr>
<td>Asthma</td>
<td>463 (13%)</td>
</tr>
<tr>
<td>Anemia</td>
<td>354 (11%)</td>
</tr>
<tr>
<td>Obstructive Sleep Apnea</td>
<td>225 (7%)</td>
</tr>
<tr>
<td>Arthritis</td>
<td>229 (7%)</td>
</tr>
<tr>
<td>Liver Disease</td>
<td>194 (6%)</td>
</tr>
<tr>
<td>Diabetes or Pre-Diabetes</td>
<td>188 (6%)</td>
</tr>
<tr>
<td>Cancer</td>
<td>130 (4%)</td>
</tr>
<tr>
<td>Peptic Ulcer</td>
<td>97 (3%)</td>
</tr>
<tr>
<td>Lung Disease</td>
<td>93 (3%)</td>
</tr>
<tr>
<td>Kidney Failure</td>
<td>40 (1%)</td>
</tr>
<tr>
<td>Other Chronic Health Problems</td>
<td>439 (13%)</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Cardiac Conditions</th>
<th>Proportion of Participants Reporting</th>
</tr>
</thead>
<tbody>
<tr>
<td>Arrhythmias</td>
<td>999 (30%)</td>
</tr>
<tr>
<td>High Blood Pressure [Hypertension]</td>
<td>563 (17%)</td>
</tr>
<tr>
<td>Congestive Heart Failure</td>
<td>435 (13%)</td>
</tr>
<tr>
<td>High Cholesterol [Hyperlipidemia]</td>
<td>302 (9%)</td>
</tr>
<tr>
<td>Stroke</td>
<td>191 (6%)</td>
</tr>
<tr>
<td>Clotting Disorder</td>
<td>99 (3%)</td>
</tr>
<tr>
<td>Bleeding Disorder</td>
<td>72 (2%)</td>
</tr>
<tr>
<td>Heart Attack</td>
<td>52 (2%)</td>
</tr>
</tbody>
</table>

### NUMBER OF ADDITIONAL MEDICAL CONDITIONS PER PARTICIPANT

![Bar chart showing the distribution of the number of additional medical conditions per participant.](chart)
PARTICIPANT-REPORTED QUALITY OF LIFE BY CHD COMPLEXITY

Question: In general, would you say your health is excellent, very good, good, fair, or poor?

Note: Most CHD patients reported that their overall health was good, very good, or excellent regardless of sex or CHD anatomy.

PARTICIPANT-REPORTED QUALITY OF LIFE BY SEX

Question: In general, would you say your health is excellent, very good, good, fair, or poor?
KEY STATISTICS

HOW CHD PATIENTS FEEL 3 YEARS INTO THE PANDEMIC

Question: Compared to pre-pandemic (before March 2020), how much have things gotten back to normal in your life?

Note: Most patients report that their life has returned to normalcy three years after the start of the COVID-19 pandemic.

POST-TRAUMATIC STRESS DISORDER, ANXIETY, AND DEPRESSION BY AGE AND SEX

Note: More women than men report a diagnosis of PTSD, anxiety, or depression.

n = 657
**KEY STATISTICS**

**PROVIDER PERSPECTIVE**

“The CHI registry will provide us with information that will allow us to advocate so that we can build in mental health professionals as part of the cardiology care team. The Congenital Heart Initiative is truly one of a kind. The ACHD community has been involved at every step, and the information that we will learn undoubtedly will have a positive impact on ACHD care moving forward.”

— *Dr. Jamie Jackson, Clinical Health Psychologist*

**PHYSICAL ACTIVITY BY SEX**

*Note: Physical activity goals are considered met if the participant achieves 75 minutes of vigorous activity per week or a combination of vigorous and moderate activity totaling 150 minutes per week. A higher proportion of men reported meeting recommended physical activity guidelines than women.*

<table>
<thead>
<tr>
<th>Percent of Sex</th>
<th>Met physical activity guidelines?*</th>
</tr>
</thead>
<tbody>
<tr>
<td>Female</td>
<td>[Bar chart showing 795 (51%) Yes, 763 (49%) No]</td>
</tr>
<tr>
<td>Male</td>
<td>[Bar chart showing 286 (33%) No, 569 (67%) Yes]</td>
</tr>
</tbody>
</table>

n = 2,413
ABOUT CHI-RON

CHI-RON
Congenital Heart Initiative: Redefining Outcomes and Navigation to Adult-Centered Care

The CHI-RON study is a sub-study of the CHI and the first nationwide CHD patient-powered research study linking parts of your medical history at your care center with your patient-reported outcomes surveys.

The story of CHI-RON, and inspiration for the study name, revolves around that of the wounded healer, someone who cannot heal himself but uses the wound as a source of healing for others. That is part of the hope of the CHI, and the CHI-RON study—that CHD patients will share their stories to promote the healing for generations to come.

Patients seen at one of 12 participating sites* can enroll in the CHI-RON study and allow researchers to gain a fuller picture of life with CHD by sharing their care journeys.

CHI vs. CHI-RON

<table>
<thead>
<tr>
<th>CHI vs. CHI-RON</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>What is it?</td>
<td>A registry that collects info through short surveys directly from you about how your heart health impacts your life</td>
</tr>
<tr>
<td>Who can participate?</td>
<td>Anyone age 18 years or older with congenital heart disease (CHD) across the globe can participate</td>
</tr>
<tr>
<td>How do I join?</td>
<td>You can join the registry by visiting <a href="http://www.chi.eurekaplatform.org">www.chi.eurekaplatform.org</a></td>
</tr>
</tbody>
</table>

Wounded Healers
“They are not born and they are not made... They create themselves through conquering adversity, trial and error and extreme pain and suffering. They conquer fear and find a way to speak their truth even when they are afraid. In doing so they shine light for others who are lost and feeling alone, and in return their inner light ignites with renewed purpose. A purpose greater than they ever could have imagined.”

* CHI-RON Recruiting Sites: Children’s Hospital Colorado, Children’s Hospital of Philadelphia, Cincinnati Children’s Hospital, Columbia/NY Presbyterian, Mount Sinai Hospital, Nationwide Children’s Hospital, Nicklaus Children’s Hospital, NYU-Langone Health, Ochsner Medical Center, University of Florida, University of Miami, Weill-Cornell Medical Center
VOICES OF THE CHI COMMUNITY

OFFERING SPACE FOR UNDERSERVED COMMUNITIES

“I've been able to see firsthand the role CHI-RON plays in providing space for the voices of our patients. One participant, who identifies as Black and has autism, substantiated this mission when noting, ‘It’s refreshing to be able to have my voice counted when I usually am left out.’

— Victoria Grant, CHI-RON Research Coordinator

BUILDING CONNECTION AT THE ACHA CAFE

“I learned how fortunate I am from the faces in the small zoom boxes on the ACHA Café, a casual, virtual monthly gathering going into its 3rd year. Sure, we discuss life with CHD, but we also discuss … life. Making new friends as you get older, can be a challenge to anyone. I’m lucky — CHD weaves a thread around this community and gives us an instant connection. Many times, I hear my story repeated, ‘I can’t believe there are other people out there like me.’

We’re a unique, vibrant, and fierce gang of the best people I know focused on supporting the best people I know. Sharing our experiences helps the 22-year-old in the Rocky Mountains find their way from pediatric to adult care. Casual conversations empower a Midwesterner to ask the cardiologist tough questions. Coffee talk over zoom evolves into lunch in midtown over the Thanksgiving holiday, and one comment can turn an ER visit from chaos to calm.”

— Aliza Marlin, adult with CHD and ACHA Café Organizer

DRIVING MEANINGFUL IMPACT

“(Our) work is directly impacting adults with CHD already. We’ve heard from providers that they are seeing patients who had fallen out of consistent care suddenly appear in their clinics. The CHI newsletter promotes the monthly ACHA Café, which a number of the CHI participants have attended, finding a community that they didn’t know existed.

On a recent call, one participant remarked that they had always felt forgotten, like a lost child, until they got plugged into the CHI and became aware of this community. Many participants noted how encouraging and exciting it is to know that there is a group of passionate, dedicated researchers and providers who care about them and their future enough to start a registry and conduct multisite studies.”

— Ruth Phillippi, adult with CHD
SPECIAL THANKS

CHI-RON PARTICIPATING ORGANIZATIONS
SPECIAL THANKS

ADDITIONAL ADVISORY ORGANIZATIONS

Alliance for Adult Research in Congenital Cardiology, inc.  National Heart, Lung, and Blood Institute (NHLBI)
Centers for Disease Control and Prevention (CDC)

ACKNOWLEDGMENTS

Abigail Khan, MD, MSCE
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Mt Sinai Hospital

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Daniel Halpern, MD
NYU Langone Health

Emily Ruckdeschel, MD
Children’s Hospital of Philadelphia

Jamie Jackson, PhD
Nationwide Children’s Hospital

Karen Uzark, PhD, NP
Mott Children's Hospital

Leigh Reardon, MD
University of California, Los Angeles

Mark Weiner, MD
Weill Cornell Medicine

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Richard Krasuski, MD
Duke University

Ronald Kanter, MD
Nicklaus Children’s Hospital

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Lena Morsch
Marissa Mendoza
Michael Katchman
Misty Sharpe
Ry Rivard
Ryan O’Connor
Stephanie Alexander
Susan Timmins
Thank you for powering the Congenital Heart Initiative to help improve the lives of adults living with congenital heart defects. We are continuously recruiting patients to join the CHI — if you know someone with ACHD would be interested in joining the registry, please direct them to chi.eurekaplatform.org.

This year, we’re looking ahead to more engagement with researchers and patients to answer key questions needed to improve care for adults with ACHD. Improving mental health, healthcare transition, and overall quality of life are some of the key priorities for patients and researchers engaging with the CHI. We are also engaging ACHD centers to determine how the CHI or CHI-RON can benefit your patients — please contact us at chdinitiative@eurekaplatform.org for more information!

Connect with us! We are on Facebook (@CongenitalHeartInitiative), Twitter (@ACHD_CHI), and Instagram (@achdchi). Follow us for the latest updates and CHD educational information.

If you have any questions, comments or concerns about the CHI or CHI-RON, please reach out to chdinitiative@eurekaplatform.org.

Special thanks to Savion Mercedes, Mindi Messmer, and Diana Pressey for report creation.