



# Congenital Heart INITIATIVE



## LET'S WORK TOGETHER!

### Help Promote the Congenital Heart Initiative Registry

#### THE POWER OF COMMUNITY

We have the power to fundamentally reshape the way both patients and clinicians understand ACHD. It's time for our community to come together to improve access to care and identify research needs moving forward through connecting providers and researchers to a foundation of critical patient-reported outcomes data from ACHD patients.

#### THE CONGENITAL HEART INITIATIVE REGISTRY FEATURES:

User-friendly data collection

- Demographics and health status updates
- Patient reported outcomes
  - Quality of Life with Life Scale (SF-20)
  - Mental Health (HADS)
  - Physical Activity (IPAQ)
- Routine follow-up surveys every 6 months
- Linkage to other datasets
- Center specific data available

Informing your patients about this registry will help us create a platform for everyone in our community to come together and learn more about congenital heart disease.

Together, we will:

- Improve our understanding of the ACHD population for patients, providers, and researchers.
- Build a research platform to connect physicians and researchers to the broad ACHD patient population

#### WE NEED YOUR TO HELP US PROMOTE THE CONGENITAL HEART INITIATIVE REGISTRY!

Provider involvement is key to this registry's success and there are multiple ways for you to engage:

- Inform your ACHD patients about the registry and encourage them to participate in this on-going research opportunity
- Champion the Congenital Heart Initiative to your fellow providers
- Share the registry's promotion materials in your clinics and across your clinic's social media channels

Brought to you by Children's National Medical Center in collaboration with UCSF, the Adult Congenital Heart Association, and the Heart Research Alliance.

Adult  
Congenital  
Heart   
Association



Heart Research Alliance

UCSF  
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