



# Congenital Heart INITIATIVE



## JOIN THE CONGENITAL HEART INITIATIVE!

Stand with the ACHD patients, providers, and researchers who are fighting for a better future for those living with congenital heart defects.

### WHO IS BEHIND THE CONGENITAL HEART INITIATIVE?

We're just like you. We are patients, providers and researchers who are passionate about improving the lives of adults living with congenital heart defects. We believe that better data will ultimately lead to a better understanding of the condition – contributing to improved outcomes and providing hope to all those living with ACHD.

### THE POWER OF COMMUNITY

We all have the power to fundamentally reshape the way both patients and clinicians understand ACHD if we all stand together. It's time for our community to come together to improve access to care and identify research needs moving forward.

The Congenital Heart Initiative will:

- Improve our understanding of the ACHD population for patients, providers, and researchers
- Inform future research projects of the needs within the community
- Spur innovation within congenital heart disease treatment

This isn't about any one patient or any one research project. We're working to develop a platform for everyone in our community to come together and learn more about congenital heart disease

### ADD YOUR VOICE TO THE INITIATIVE TODAY

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

You and your experience can hold the key for unlocking a better future for ACHD patients! After signing up today, here's how we may ask you to contribute to this collaborative:

- Tell us about your medical history
- Answer a few surveys about your quality of life
- Check back in every 6 months to let us know how you are feeling

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

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