

# Empower Patients. Improve Care.

## 🎯 Our Goal:

*To help you*

- ◆ **confidently navigate your healthcare** with knowledge and support.
- ◆ make **informed decisions**.
- ◆ **feel valued and respected** in the healthcare system.

## 📝 Why:

*Because we believe*

- ◆ empowering patients leads to a **better quality of life** and **improved health outcomes**.
- ◆ the **health system is complex** making it difficult to access and utilize care effectively.
- ◆ you deserve the **knowledge** to be a partner in your health.

# Empower Patients. Improve Care.

## How:

*Together, we can achieve this*

- ◆ through **resources** built by those who understand your challenges.
- ◆ by transforming uncertainty into confidence through **guidance and support**.
- ◆ offering **tools** to manage visits, understand care, and connect with peers.

## What:

*Providing tools & support through*

- ◆ a **mobile** and **web app** to manage your care and find support.
- ◆ **peer-powered guidance** for navigating CHD and healthcare.
- ◆ continuous **feedback from you** to shape the resources and tools.

# What EmpowerMyCH Patients Have Shared



## Procedures

“How are others coping with the prospect of having to undergo heart surgery within the next few years? I feel terribly afraid and while I can accept the fact and commit to preparing for the procedure, I still struggle with the anxiety.”



## Symptom Management

“How do you know symptoms are related to CHD and not some other condition?”



## Aging with CHD

“I’m curious to know what other people’s experiences have been as they get older with my condition.”

# What EmpowerMyCH Patients Have Shared

## Knowledge About my CHD

“I had open heart surgery to repair a fenestrated ostium secundum type atrial septal defect when I was two and a half years old, and I just had my 35th bday! What are any possible late onset long term complications?”

## Effect of CHD on Other Conditions

“How to manage comorbidities with your CHD, especially with overlapping symptoms.”

## Transplants

“How long did it take to be put on the heart transplant list after all the testing was done?”

# What EmpowerMyCH Patients Have Shared



## Family Planning

“ I know that it would be difficult to have my own children but I am curious as to what paths people have taken to have children.”



## Maternal Health

“ I'm curious to hear about other women's experience with pregnancy. I'm considering having a 2nd child.”



## Mental Health

“ How do others manage PTSD and stress related to having experienced ICD therapy in the midst of working and caring for a family? ”

# What EmpowerMyCH Patients Have Shared

## Finding CHD Care

“Have you had difficulty finding a non-pediatric cardiologist who specializes in CHD?”

## Advocacy

### **Donna from Montreal, Canada**

*Transposition of the Great Arteries Patient*

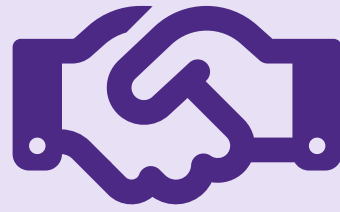
“What are some of the ways you have had to advocate for yourself with doctors/ in and outside of the heart institutions?”

## Building Community

### **Kenny from Kentucky**


*Transposition of the Great Arteries Patient*

“I [would] like to meet other[s] who have CHD in person.”



**Since many of you are looking for ways to meet other patients, we compiled a list of community events.**

*The events are listed in alphabetical order by state.*

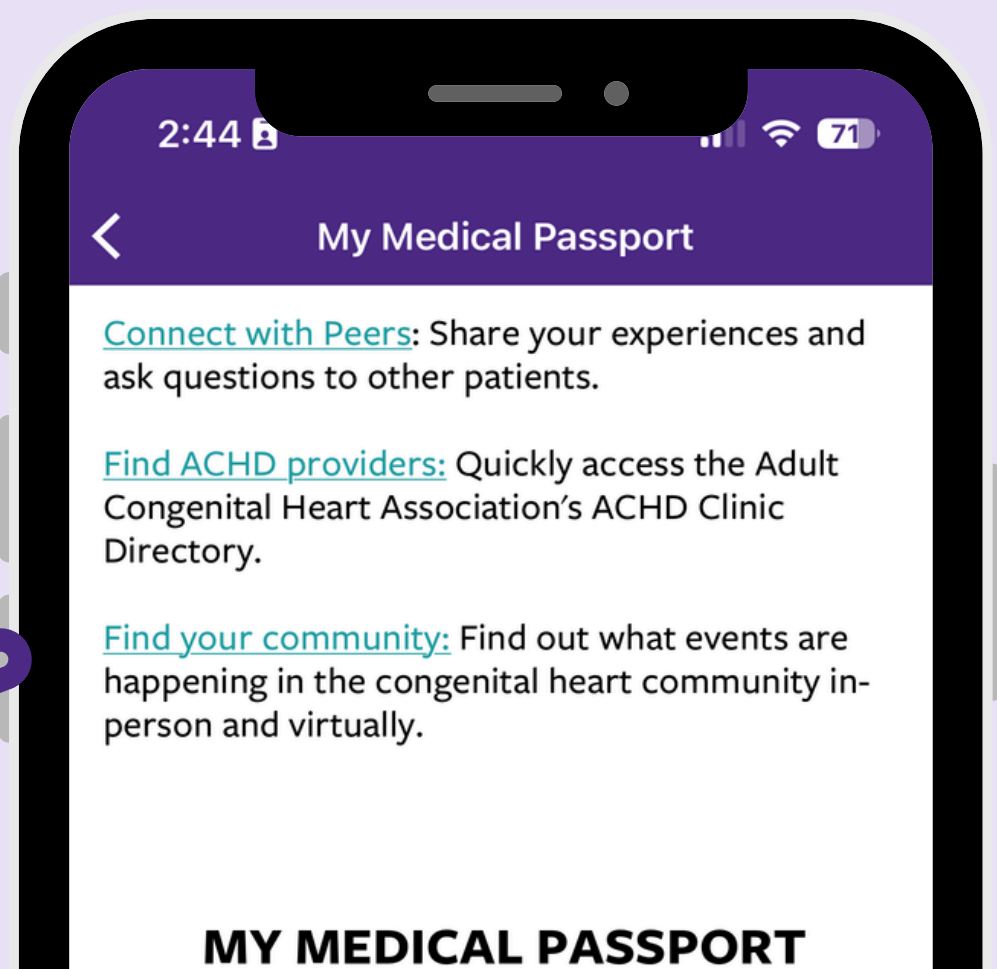
To learn more about each event, type the case sensitive URL next to the  into your browser.

**Example** - [bit.ly/EmpowerMyCH](https://bit.ly/EmpowerMyCH) 

**Please share other events we missed!**

Stay updated with events at  
**[bit.ly/EmpowerMyCHEvents](https://bit.ly/EmpowerMyCHEvents)** 

On the mobile app, you can find events linked on the medical passport page!



## **PEER-EMPOWERMENT**

### *EmpowerMyCH Participant*

“ I went to Camp Del Corazon as a child and now volunteer as a nurse. I encourage adults with CHD to get involved and donate to help children with CHD.”



## **On-Going Event**

### **Adult Congenital Heart Association's Wellness Wednesdays Series**

[bit.ly/WebinarsACHA](https://bit.ly/WebinarsACHA) 

**Free Virtual Event:**  
**Every Wednesday**  
*7-8pm EDT*



Educational topics, quality of life issues, and healthy lifestyle presentations.

Live Q&As with peer mentors and others in the CHD community.



# EmpowerMyCH Features

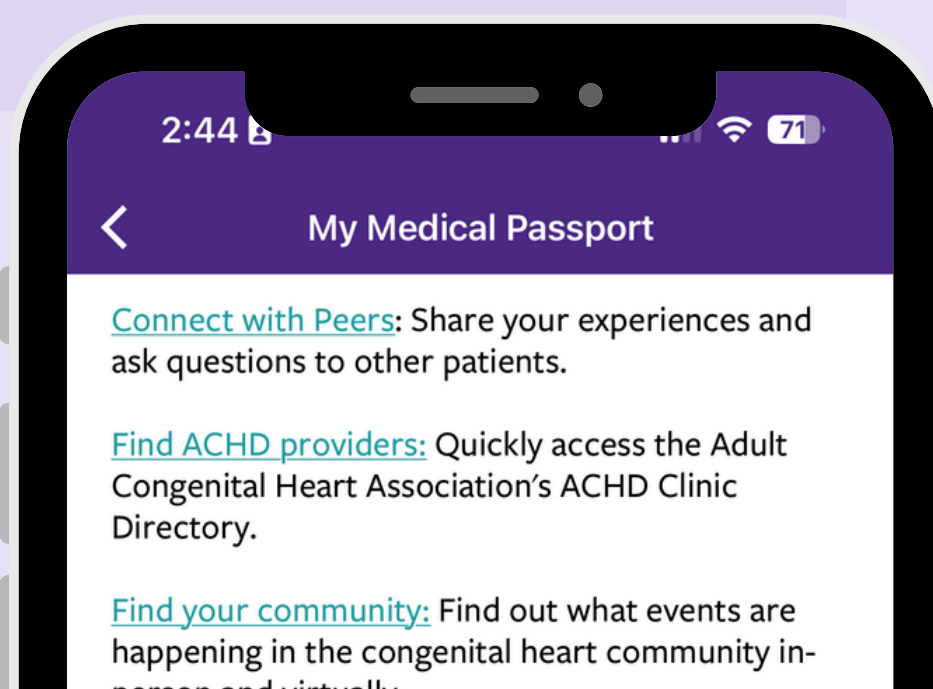
## On the Mobile App

### Connect With Peers

This is an entire community of other **patients like you** with whom you can engage. You will have opportunities to **share your experiences and ask questions** to other patients while hearing from others and building a support network.

### Find ACHD Providers

Quickly access the **Adult Congenital Heart Association's** provider directory in the mobile app. The **ACHD Clinic Directory** provides information on ACHD Board Certified cardiologists, ensuring you have access to the specialized care you need.



# Last Months Feedback

***Thank you for your feedback on “Finding my ACHD Team”. Please keep it coming —it helps us do better!***

 Helpful? **Yes - 76% Maybe - 17%**

**“**I like seeing the frequency that certain tests should be performed. My doctor probably knows this but didn't share it.**”**

**“**I never knew of Heartpedia and it seems like a really good resource.**”**

**“**This gives a lot of information not only for those of us with CHD, but also for our family to understand better.**”**

 Helpful? **No - 7%**

**“**I have been fortunate enough to receive care my whole life including transitionary care into adulthood. This is repetitive information for me.**”**

**“**I have been told all this lots of times. I see my Doc every year at least once a year from time I was born till now.**”**

# Topics to Expect in the Near future

*We are currently creating materials on topics you have prioritized:*

- ◆ Navigating your cardiologist appointment
- ◆ Managing your symptoms
- ◆ Understanding your test results
- ◆ Preparing for procedures and surgeries

We will provide **small insights** on various topics every few months, allowing you to absorb the information at your **own pace**. While not all information may be helpful, we hope you find valuable resources.

Based on your feedback, we will share **insights from leading CHD experts and fellow patients**. Stay connected with the CHD community by receiving updates on events and ACHD research. Keep notifications on!

# Digital Medical Passport

You can access EmpowerMyCH activities through the **mobile app** or a **web browser** on your favorite device. While the activities for building the passport can be accessed through a web browser on a computer or tablet, the '**My Medical Passport**' for viewing your entered health information is only available on the mobile app. Tap the "My Medical Passport" bar at the top of your app screen.



## Things to Have Ready

- ◆ Congenital Heart Diagnosis
- ◆ Heart Surgeries  
*(name and year of the surgery, hospital, surgeon)*
- ◆ Cardiologist & Primary Care Doctor  
*(doctor name and clinic or hospital name)*
- ◆ Pacemaker or Defibrillator  
*(company name)*
- ◆ Other Medical Conditions
- ◆ Any health information you want to easily access  
*(Procedures, Medications, etc.)*

