

Research Opportunity for Patients and Caregivers

A new research study is inviting children with heart failure related to Danon disease or another heart condition and/or their caregivers to take part in one 75-minute interview.

The purpose of the study is to:

- Learn about the experiences of children with heart failure related to Danon disease or another heart condition, and
- Gather feedback on a health questionnaire for patients and caregivers of patients with heart failure related to Danon disease or another condition

What is involved?

Being in this study means taking part in one 75-minute interview (by telephone or computer). During the interview, a researcher will first ask questions about what it is like to have heart failure (or for caregivers, what you see in your child with heart failure). Then, you will be asked to provide feedback on a health questionnaire. All study participants will be paid for their time. This study does not include any treatments.

Who is eligible to participate?

You may be able to participate in this study if you:

- Are 8-17 years old and have been diagnosed with heart failure related to Danon disease or another heart condition
- Are a caregiver of a child 8-17 years old who has been diagnosed with heart failure related to Danon disease or another heart condition
- Can provide confirmation of diagnosis of heart failure and the related condition (this could be a screenshot from a patient portal that shows the diagnosis, or a letter from a doctor)
- Currently living in the United States
- Are able to read (if age 13 or older) and speak English fluently
- Are willing and able to participate in an interview for approximately 75 minutes

How do I participate?

If you are interested in this study, please send an email to:

eirini.kamperou@iqvia.com

A member of the study team will contact you at a later date to determine if you are eligible.