



The RESONANCE Patient Registry

REgiStry Of the NATural history of recurrenceNt periCarditis in pEdiatric and adult patients

Advancing Research in Recurrent Pericarditis Together

WHAT TO EXPECT

- 1 ENROLLMENT.**
The registry is due to open in early 2021. You will receive a notification once the registry is ready for participants.
- 2 DOWNLOAD THE APP.**
Once enrolled, you will receive instructions from your registry site to download the RESONANCE Registry App and complete your registration.
- 3 COMPLETE SURVEYS.**
You'll start by answering an initial questionnaire about your experience living with recurrent pericarditis. You will then receive notifications to complete short surveys about your recurrences, symptoms, and level of pain about four times per year. After your initial enrollment questionnaire, you will receive a \$25 gift card for each subsequent survey completed.

What is the RESONANCE Patient Registry?

RESONANCE is a voluntary, patient-powered registry and network of physicians and researchers dedicated to advancing research efforts in recurrent pericarditis. The registry will collect data on your diagnosis, recurrences, symptoms, treatment, and impact on your daily life. The registry is an observational research study, meaning that physicians and participants living with recurrent pericarditis will report data over time to understand how the disease and severity of symptoms may change over time.

Discovering New Insights for the Community

As recurrent pericarditis is a rare disease, the information available to patients and healthcare providers is limited. To help fill this gap in knowledge, Kiniksa Pharmaceuticals developed the RESONANCE patient registry with input from people living with recurrent pericarditis, patient advocacy group leaders, and experts in the field.

You have an Important Role in Advancing Research

As a participant in the RESONANCE patient registry, you will contribute your personal experiences of living with recurrent pericarditis to help researchers understand the impact it has on your life. Your participation in the registry will help to create a better understanding of the disease and support physicians and researchers to better diagnose, manage, and potentially develop or improve treatments for recurrent pericarditis.



RESONANCE PATIENT REGISTRY

Giving a Voice to People Living with Recurrent Pericarditis

The RESONANCE Patient Registry

Frequently Asked Questions

Who can enroll in the registry?

Anyone who lives in the United States who has been diagnosed with recurrent pericarditis can contribute important information and are encouraged to participate. For minors under the age of 18 or those needing assistance, parents, legal guardians, or caregivers may submit information on their behalf. You can also ask your doctor if your center is participating in the registry. If not, email Kiniksa at Resonance@kiniksa.com for more information.

What's the difference between a registry and a clinical trial?

A registry is "observational" in nature, which means it collects data on a voluntary basis in the regular course of a doctor's or patient's actual experience. Your enrollment in the registry does not set any particular obligation to participate, schedule, or undergo treatment or specific medical tests.

What am I expected to do in the registry?

There are two ways that we gather information for the registry. We will gather information about your treatment through access to your medical records which are reviewed by a registry healthcare professional. You will also complete surveys in the Registry App on a regular basis to help us understand how the condition is affecting you over time. There is no cost to enroll in the registry.

What is involved in the surveys?

Once logged into the Registry App, the surveys will ask you about your recurrent pericarditis episodes, the pain, your other symptoms, your ability to work/go to school, and your mental health. The surveys will take about 30 minutes to complete and you will receive a notification to complete them every 3 months.

Are the surveys available in different languages?

Currently we are offering the surveys in English or Spanish. You will be able to select your language in the Registry App.

Will my information be kept private/secure?

Yes, we take your privacy and security seriously. The information provided is kept strictly confidential. Any surveys that you complete will never be associated with your name. An anonymous ID number will be assigned instead of using your name. All records related to registry data will be kept in a secure area, and access to this information will be restricted to registry personnel only. All electronic information will be stored in the secure registry database.

How long will you collect data for?

The registry will collect data for a minimum of 5 years. This is to understand more about recurrent pericarditis, including how medications affect the condition over time and how treatment practices affect recurrent episodes. You can decide to leave the registry at any time; you are not committing to stay in the registry for any duration.



Where can I find out more information about the RESONANCE patient registry?

If you have additional questions, please email us at Resonance@kiniksa.com