

Invitation to take part in a patient insights project: understanding the experiences of people living with Cold Agglutinin Disease (CAD)

For patient insights purposes only
Project 5496 | Version 4

Why have I been given this leaflet?

You have been given this leaflet because your patient organization thinks you may be interested in taking part in a patient insights project.

The project is being conducted by Origins, an independent patient agency, on behalf of a sponsoring pharmaceutical company, Recordati Rare Diseases.

The purpose of the project is to better understand what it is like to live with Cold Agglutinin Disease (CAD), including the impact of the disease on your daily life, your experiences of diagnosis and receiving treatment, and practical aspects of disease and treatment management.

This is an advisory group meeting and is not a clinical trial. Taking part will not affect your medical care or your relationship with your healthcare team.

What is the purpose of the project?

We would like to learn about:

- Your experience of living with CAD
- How CAD affects your daily activities and quality of life
- Your journey from early symptoms through to diagnosis and management
- Your experiences of receiving and managing the treatment including how the treatment has impacted your disease and any ongoing challenges

Your experiences will help improve understanding of the needs of people living with CAD and help inform and shape the sponsor's future medical plans, disease awareness initiatives and patient support activities.

The advisory board is not intended to assess treatment safety and efficacy, clinical outcomes or the value of any specific medicine. Discussions will focus on participants' experiences of living with CAD and managing the condition.

What would I need to do?

If you choose to take part, you will be invited to join one virtual patient advisory board meeting with a small group of other people living with CAD.

The discussion will last approximately 2-hours and will be led by an experienced moderator from Origins. Representatives from the sponsoring pharmaceutical company, Recordati Rare Diseases, may be in attendance during the meeting as observers, without leading the meeting or participating in the discussions.

Who can take part?

You may be eligible if you:

- are aged 18 years or over;
- have been diagnosed with Cold Agglutinin Disease (CAD) by a healthcare professional; and
- are currently receiving an approved treatment for CAD

If you are interested in taking part and contact Origins, you will be asked a few questions to confirm whether you are eligible.

Will I receive anything for taking part?

Where permitted by applicable local laws and industry requirements, which will vary on a country by country basis, participants may receive compensation in recognition of their time and contribution. Details will be explained during the recruitment process.

Will my information be kept confidential?

Origins will manage all participant communications, eligibility screening and consent. Representatives from the sponsoring pharmaceutical company may observe the advisory group meeting and, as a result, will be aware of the identity of participants who attend. However, any personal information collected as part of organizing and conducting the advisory board will be handled in accordance with applicable data protection legislation. Recordati Rare Diseases will otherwise receive only anonymised or aggregated findings unless disclosure is required by law, for pharmacovigilance purposes, or with your additional consent.

The discussion will be audio and video recorded to support analysis. The sponsoring pharmaceutical company will receive anonymized and aggregated findings, which may include anonymised quotations from participants. No information that could identify you will be shared. Data processed through these tools will not be used to train publicly available artificial intelligence models and will be used solely to facilitate transcription, translation and analysis of this project.

Do I have to take part?

Taking part is entirely voluntary. If you decide not to participate, or if you change your mind at any time, this will not affect your medical care in any way.

Interested?

If you would like to find out more or see if you are eligible, please contact Origins directly by sending an email to research@origins-patients.com with CAD in the subject line.

When you contact us, we will explain the project in more detail, answer any questions you may have and, if you wish, complete a short eligibility questionnaire with you.

About Origins

Origins is an independent patient agency specialising in healthcare research. We conduct research with patients to help improve understanding of the experiences, needs and priorities of people living with different health conditions.

For more information about how your personal information will be used, please visit:

www.origins-patients.com/privacy-policy