

Rare Diseases Clinical Research Network Contact Registry

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You are invited to join a contact registry hosted and managed by the Rare Diseases Clinical Research Network (RDCRN). The RDCRN is a National Institutes of Health-funded research network of 20 consortia, which are teams of researchers, patients and clinicians focused on a group of rare diseases. The network fosters collaboration among researchers to better understand rare diseases and to develop improved approaches for diagnosis and treatment.

Please read this information carefully to decide if you want to take part.

What is a contact registry?

A registry is a collection of information about individuals, usually focused on a specific diagnosis or condition. We are looking to gather and maintain information about:

- Individuals with a rare disease
- Individuals without a rare disease
- Individuals interested in learning about rare diseases
- Individuals willing to be contacted about opportunities to participate in research and about other RDCRN activities

What is involved?

If you choose to provide contact information to the registry, you will fill in the information on the following pages. Once your information is in the registry, you may be contacted and given the opportunity to participate in optional research opportunities and surveys.

You may provide information for yourself, or, if you are the parent/legal guardian of a minor, about your child who lives with a rare disease. If you are a caregiver of an adult that is unable to complete this information on their own, you may provide information on his/her behalf.

Information about you/your child may also be transferred from the previous RDCRN contact registry into this new contact registry, or from RDCRN consortia contact registries that have your permission to share your data with this contact registry.

Who will see my information?

The contact information you share, and responses to surveys, may be shared with RDCRN consortia and patient advocacy groups (non-profit organizations that provide information and services to those with rare diseases and their families).

How will I learn about new information/new research studies?

You may be contacted in various ways, including telephone, mail, text, social media, email, and other web tools that may become available. These various methods may be used to notify you and others in the registry that there is a study you/they may be interested in learning about. You may also be contacted to update your information.

What information will be collected from me?

The information we will collect and store about you will include your protected health information (PHI), including but not limited to:

- Your name, email address, postal address, and phone number;
- Diagnoses,
- Demographic information
- Medical history

You are not required to fill out every item and may choose to fill out what you want to complete.

What information will be collected about my child with a rare disease?

If you have a child with a rare disease, we may also gather information about your child if you are willing to provide that information. Information that we will collect includes, but is not limited to:

- Diagnoses,
- Demographic information, and
- Medical history.

You are not required to fill out every item and may choose to fill out what you want to complete. Contact information will only be collected for adults and/or parents of a child with a rare disease.

What are the benefits of joining a registry?

This registry will provide opportunities for future research about rare diseases. Future research will use information you provide to us. Future research may produce helpful information for those with a rare disease.

There may be direct benefits to participation, such as learning about potential research opportunities. If you choose to participate in this contact registry, you will not receive payment. You will not be charged for participating in this registry.

What are the risks?

The risk of participating in the registry is a loss of confidentiality, meaning that the information you provide could identify you.

Entering your contact information and other information into this registry means that you consent to be contacted, and for your data and/or the data of your child to be used and shared for future, unspecified research. You will not be able to be identified in research publications. No medical advice will be offered based on the information collected from the registry.

GDPR statement for Members in the European Economic Area:

By registering, you are providing consent for the NIH-designated RDCRN Data Management and Coordination Center (DMCC) in the United States to process your personal data, such as your name and contact information, for the purpose of facilitating rare disease research for the duration of the rare disease registry project. With your permission, your personal data may be shared with researchers. You may be contacted and asked if you would like to consent to participate in future research studies. You can contact the current DMCC at <<insert contact registry email>> with questions, to request to view or edit your personal data, to withdraw your consent, or to request that your data be removed. You may contact the data supervisory authority in your country if you have a complaint about the processing of your personal data.