



## CoRDS Rare Diseases Registry: Latin America

### FREQUENTLY ASKED QUESTIONS

#### **Why CoRDS was established?**

The CoRDS registry was established in 2010 by Dr. David Pearce after determining the benefits of patient registries on research. As very few rare diseases have dedicated patient registries, thus the goal of the CoRDS registry is to serve as a central resource for data on rare diseases with the aim of accelerating research into those diseases.

#### **How does CoRDS work?**

CoRDS provides a secure way for participants to share their de-identified information with researchers if they have been diagnosed with a rare disease, a disease with unknown prevalence, or don't yet have a diagnosis.

The goal of the CoRDS registry is to connect those affected by rare diseases with researchers who study those rare diseases. The CoRDS Registry is made up of information securely submitted by individuals with rare diseases or their caretakers. That information, when de-identified, can be accessed by researchers who have appropriate approval in order to find participants that are eligible for their studies. CoRDS personnel will contact eligible participants to inform them of research opportunities.

#### **Why enroll in the CoRDS registry?**

The CoRDS registry provides opportunities to be informed of research studies or clinical trials for which one may be eligible. It also creates a central resource for researchers for more rapid recruitment of research participants. The CoRDS registry has the potential to accelerate research into rare diseases. It is also free to enroll and takes little time!

#### **Who is eligible to enroll in CoRDS?**

The CoRDS registry is open to any individual, of any age, who has been diagnosed with a rare disease, a disease of unknown prevalence or is still awaiting a diagnosis.

#### **How does one enroll in CoRDS?**

There are three steps to enrollment in the CoRDS registry:

- Complete the CoRDS Registry Form to enter screening, where CoRDS personnel will review your eligibility and send you the materials to enroll via your preferred enrollment method.

- Complete the CoRDS Informed Consent Form which describes how your information is kept and used in order to be considered enrolled in the registry.
- Finally, complete the CoRDS Questionnaire, which is a short questionnaire with contact, clinical, and demographic information to be stored in the CoRDS registry.

### **Is my information secure?**

Yes, we take your privacy and security very seriously. Your identifiable information can only be accessed by CoRDS personnel and any patient advocacy group with whom you consent to share your information. All electronic information is stored in the secure Patient Enrollment. All hard copy information, such as consent forms and questionnaires, is stored in a locked fireproof cabinet. Every possible effort will be made to maintain confidentiality- and if a breach ever occurs, CoRDS personnel will contact you.

### **Who can access my data?**

There are three different ways data may be shared:

- **Researchers:** The de-identified information in CoRDS will be made available to researchers studying rare, uncommon, or undiagnosed disorders if they have obtained approval for their research project from (1) the Institutional Review Board (IRB) at the researcher's institution and (2) the CoRDS Scientific Advisory Board led by Dr. David A. Pearce. (An IRB is a group of scientists and laypersons from the community (i.e. lawyers, clergy, professors) who review proposed research using human subjects. The IRB will review the research to ensure that CoRDS participants' rights are upheld.)
- **Other Patient Registries:** A subset of de-identified information collected from each profile can be shared with certain other databases. CoRDS shares data with other databases in order to help improve understanding of rare diseases, to avoid the duplication of efforts, and to collaborate with existing research efforts and organizations dedicated to rare diseases.
- **Patient Advocacy Groups:** Patient advocacy groups (PAGs) representing individuals with rare or uncommon diseases who have partnered with CoRDS may also request access to information in CoRDS that may or may not include participants' names. The PAG will sign an agreement stating that they will not use the information for research purposes. If a participant indicates that they would like their information shared this way, Dr. David A. Pearce and CoRDS personnel will not be held responsible for the use of information by the PAG.

You will have the option to choose which ways you would like your data shared.

### **What kind of questions will CoRDS ask me?**

The CoRDS questionnaire will ask you for basic contact, demographic, and clinical information as well as your interest in future research participation. The questionnaire is designed to be relevant to all rare diseases as outlined by the NIH Office of Rare Disease Research (ORDR) in their Common Data Elements.