A Patient Registry for all Rare Diseases

CoRDS Registry
Coordination of Rare Diseases at Sanford

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Mission & Purpose
The Coordination of Rare Diseases at Sanford (CoRDS) is an international registry and centralized data resource designed to accelerate research with rare diseases. The registry:
- Provides researchers, who have IRB approval, access to de-identified data.
- Collects information to create an opportunity for conducting a comparative analysis, thereby improving the understanding and treatment for each rare disease.
- Notifies participants if research opportunities become available.
- Offers a secure online portal to collect and store participant data providing:
  - Feature to allow comparison of participants’ metrics
  - Automated email notifications
  - Populated fields from previous questionnaire, providing user-friendly interface
  - Capability to see questionnaires and complete at participant’s convenience
  - Secure control of participants’ data through withdrawal or de-identification at any time

Features future systematic surveys and phenotyping.

Automated PAGs are able to regulate their data

Feature to allow comparison of participants’ metrics

23%
Ability to consent participants in multiple languages through use of short form

92%

PAGs are able to regulate their data

50%

PAGs are able to regulate their data

Dimensions, Metrics and Participant Profiling
As of January 31, 2018, CoRDS represents:
- 2164 fully enrolled participants
- 286 rare diseases
- 50 U.S. states
- 47 countries

- 26% of enrolled participants with biospecimen records
- 95% of participants willing to be contacted for clinical trials
- 15% of participants are actively and/or were previously engaged in a clinical trial
- 69% of participants completed all 7 required CDEs for a Global Unique Identifier (GUID)
- 23% of participants completed 67 required CDEs

PAGs are able to regulate their data

Findings
These figures and diagrams are only offered to illustrate the potential power of the CoRDS Registry’s database.

Parents and Legally Authorized Representatives (LARs) complete more common data elements than those enrolling themselves.

Our Patient Enrollment System (PES), launched in June 2015, has drastically improved our ability to partner with new disease-specific PAGs and maintain a steady growth within the registry.

A comparison between the age of diagnosis and age of first symptoms may reveal trends between cohorts of symptoms and the probability of being diagnosed. These illustrations are aggregated with the CoRDS general questionnaire. These trends are likely a result of a multitude of factors, such as physical abnormalities vs. hidden genetic markers.

In this example, we have compared the disability scale rating (measured in conjunction with the National Ataxia Foundation) between two ataxias along with age of participant at the time of the disability rating. We have found that Friedreich Ataxia participants trend to rate their disability as more severe than Machado-Joseph Disease and that both seem to get progressively worse with age.

Another example of how the CoRDS registry can benefit the public health field is by comparing the symptoms between diseases to identify overlapping conditions. Rare diseases exhibit a spectrum of phenotypes. If an overlapping relationship can be identified, this may warrant future research studies and even could support the increasing popularity of drug repurposing. This is just one potential method that may help our rare disease communities accelerate research.

A large part of our growth has been due to social media efforts. Connecting rare disease patients to create new communities focused around fostering understanding and awareness of their disease is the short-term goal. Long-term goals for each disease-specific registry include collecting enough participant data and/or contact information to support researchers efforts to initiate clinical trials.

Resemblance Between Disease Symptoms
Friedreich Ataxia
Behcet’s Disease
Klippel-Feil Syndrome

- Headache
- Loss of sensation to the perineum
- Restricted movement of head/neck
- Scared speech

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For more information, contact:
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