rettX database

Patient registry

Pedro Rocha Asociación Española del Síndrome de Rett

Patient registry



- A registry is a collection of standardized information about a group of individuals, such as those living with the same disease
- With a rare disease registry, you bring together the entire community, which includes patients, caregivers, clinicians, researchers, and industry
- One of the main difficulties of learning more about rare diseases is the challenge of finding enough people eligible to participate in research studies. The more participants in a study, the more powerful the results.

Source https://registries.ncats.nih.gov

- Develop an open-source patient registry, with multi-language support that can be used by any rare disease community
 - Envisioning / Design Thinking
 - Web front-end / back-end developer
 - Azure infra setup / automation
 - GitHub CI/CD
 - DBA

Why?

What?

How can

I help?



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Groundbreaking initiative aimed at creating a **comprehensive and accessible database** for individuals affected by rare diseases.

This registry seeks to **bridge that gap** by bringing together patients, healthcare professionals, researchers, and advocates to collaborate and make a lasting impact on the lives of those living with rare diseases.

Rare diseases: a global challenge



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+ 300 million

People worldwide live with a rare disease

+ 7.000

Unique rare diseases identified

Together we can change puzzles into life changing solutions

Impact

rettX database



Accelerating the pace of rare disease research by providing researchers with a comprehensive and diverse data pool

Facilitating collaboration among patients, healthcare professionals, researchers, and advocacy groups to drive innovation in rare disease research and care

Features and functionality

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Data Visualization

Display anonymized and aggregated data in visually appealing formats such as graphs and charts, making trends and patterns easier to comprehend

Secured data collection

Gather data on disease demographics, symptoms, treatments, and outcomes to contribute to a better understanding of the rare disease landscape Anonymized and protected data fuels research without compromising patient confidentiality

Discussion forums

Create discussion boards for patients and caregivers to share insights, advice, and emotional support

User profile

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Patients, caregivers, and healthcare professionals can create profiles to share relevant medical information, personal stories, and experiences

Research collaboration



Researchers can request access to specific data sets, facilitating collaborative research efforts across geographical and institutional boundaries

Educational resources

Provide a repository of educational materials, including information about various rare diseases, treatment options, and clinical trials.

Benefits





Patient-centric registry with structured data stored using industry standards Security and privacy in the core using state of art technologies

Foster the patient community (forums, discussion, messaging)



Data sharing policies

Raise rare disease awareness

Longitudinal data for Natural History studies



Unlock research potential with rich patient data

Enable patients to manage their medical history

Attract pharmaceutical partnerships, enhancing patient access to clinical trials and therapies

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Take the database survey now



Rett Syndrome Europe Database Survey

