EXPLORING THE HI GLOBAL REGISTRY

• What is it?
• How does it work?
• What can we learn?
• What does it mean to have “data”?
• When can we sign into the registry?
• Why is the registry important?
HOW DOES THE HI GLOBAL REGISTRY WORK?
WHAT DO WE HOPE TO LEARN?

**Convenient, secure, online database for HI families to self-report their HI experience**

- How does HI affect people throughout their whole life?
- Where does HI occur in the world?
- What are common health problems among people with HI?
- What developmental problems occur in HI?
- Are problems due to HI type, timing of diagnosis, treatments, diet?
- Do different treatments affect the health, well-being and quality of life of people with HI?
- How hard is it for people around the world get care, supplies, and medications for HI?
HOW DOES DATA HELP DOCTORS?

1. Systematic Reviews & Randomized Control Trials
2. Cohort Studies
3. Case-Controlled Studies
4. Case Series
5. Case Report & Expert Opinion

Scientific knowledge about best care is not applied systematically or expeditiously to clinical practice. It now takes an average of 17 years for new knowledge generated by randomized controlled trials to be incorporated into practice, and even then application is highly uneven.  

IOM, “Crossing the Quality Chasm” 2001
TIMELINE & MILESTONES

Set up committees
Create registry protocol
Get IRB approval
Develop survey questions
Launch registry

December 2016
PEEK AT NORD REGISTRY SYSTEM*

The Sjögren-Larsson Syndrome (SLS) Network Community Registry

This is a registry for patients with Sjögren-Larsson Syndrome (SLS), which is different from Sjogren’s Syndrome.

Getting started
To get started, all you need to do is register an account and begin responding to surveys. It’s free to participate.

How will my information be used?
View our about page to learn more about what we do with your information and how we’ll protect your privacy.

Researchers
This is a unique rare disease patient registry. Are you interested in using our data to further your rare disease research?

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Join the SLS Network Community on Facebook | Sign up for NORD newsletters

Register

 Please read the following information carefully. In utilizing this service, you represent that you are at least eighteen (18) years of age, and you acknowledge that you understand and accept the following terms and conditions. In compliance with the Children’s Online Privacy Protection Act, you must be eighteen (18) years of age or older to submit personal medical data and information. If you do not accept these terms and conditions, you may not access this site or utilize any of the services provided on or through this site.

The Sjögren-Larsson Syndrome Patient Registry ("SLS Registry") is a project of the Sjögren-Larsson Syndrome Network Community to collect patient information and medical information concerning Sjögren-Larsson Syndrome (SLS) in order to accelerate research and find better treatments and ultimately a cure for these conditions.

1. General; Purpose and Acceptance of Terms and Conditions

General. Use of the SLS Registry website (the "Website") and the websites associated with the SLS Registry website (the "Services") is governed by the following terms and conditions herein (the "Terms and Conditions") and a privacy policy (the "Privacy Policy"), both of which you must read before using the Registry Website and the Services.

First name
Middle name
Last name
User name (e-mail address)
Password
Confirm password

I have read and agree to the terms and conditions.

Contact preferences
Yes, I would like to be contacted about...
Clinical trials I may be eligible for

*Example from Sjogren-Larsson Syndrome Registry
**FLASH POLLS**

- To help advance and direct PWS research
- To learn about potential clinical trial opportunities
- To help understand and characterize the full spectrum of PWS

*Example from the Prader-Willi Syndrome Registry Demo*
WHAT’S IN IT FOR...

Patients/Families

Researchers

CHI & HI Groups
Around the World
QUESTIONS???