

# HI Global Registry

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# 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?

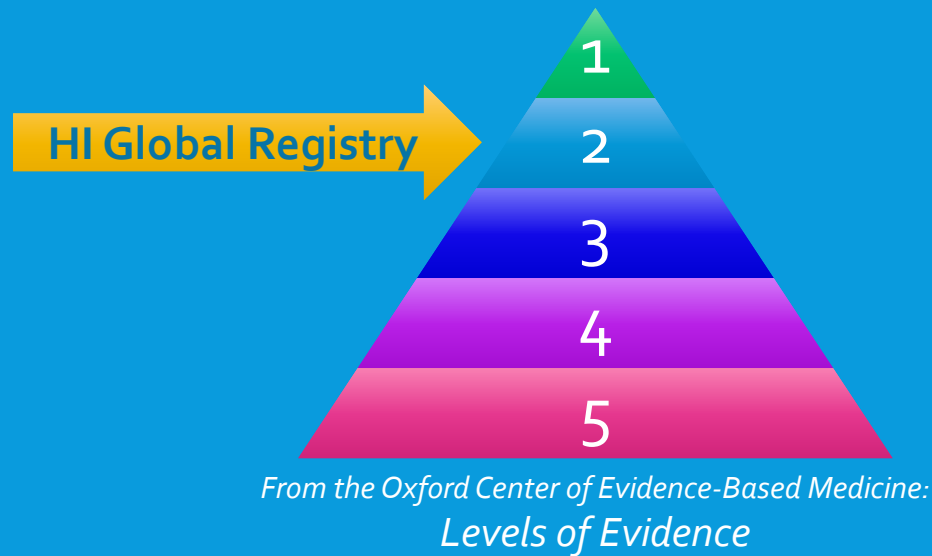


# WHAT DO WE HOPE TO LEARN?

**\*\*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 SLS Registry Home About News Contact Register Log in

## 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

[Learn more »](#)

### Getting started

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

[Register now »](#)

### How will my information be used?

View our about page to learn more about what we'll do with your information and how we'll protect your privacy.


[Learn more »](#)

### Researchers

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

[Find out more »](#)

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

  Sjögren-Larsson Syndrome Network

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## Register

[Home](#) / [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 Sjogren-Larsson Syndrome Patient Registry ("SLS Registry") is a project of the The Sjogren-Larsson Syndrome Network Community to collect patient information and medical information concerning Sjogren-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

**a. General.** Use of the SLS Registry website (the "Website") and the services 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. All

First name \*

Middle name

Last name \*

User name (e-mail address) \*

Password \*

Confirm password

☒ I have read and agreed to the terms and conditions.

### Contact preferences

Yes, I would like to be contacted about...

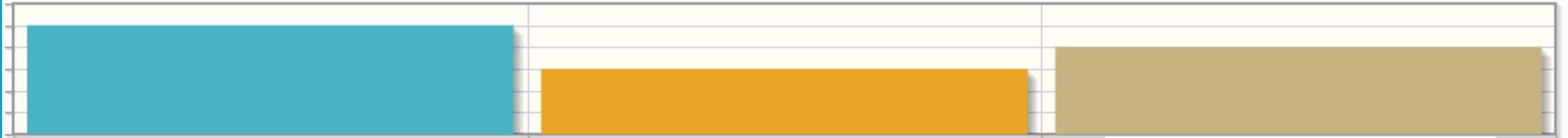
☒ Clinical trials I may be eligible for †

\*Example from Sjogren-Larsson Syndrome Registry



# FLASH POLLS\*

Why are you joining the Global PWS Registry (check all that apply) (Responses: 6)



To help advance and  
direct PWS research

To learn about potential  
clinical trial opportunities

To help understand and  
characterize the full  
spectrum of PWS

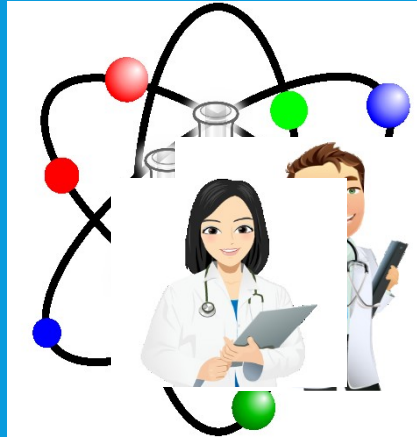


\*Example from the Prader-Willi Syndrome Registry Demo

# WHAT'S IN IT FOR...



Patients/Families



Researchers



CHI & HI Groups  
Around the World

# QUESTIONS???

