



# The Ehlers-Danlos Society

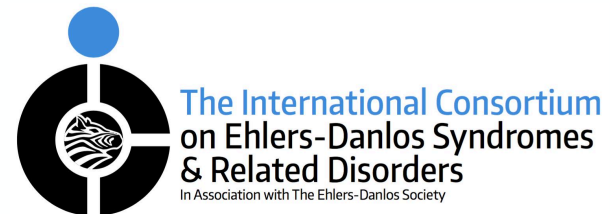
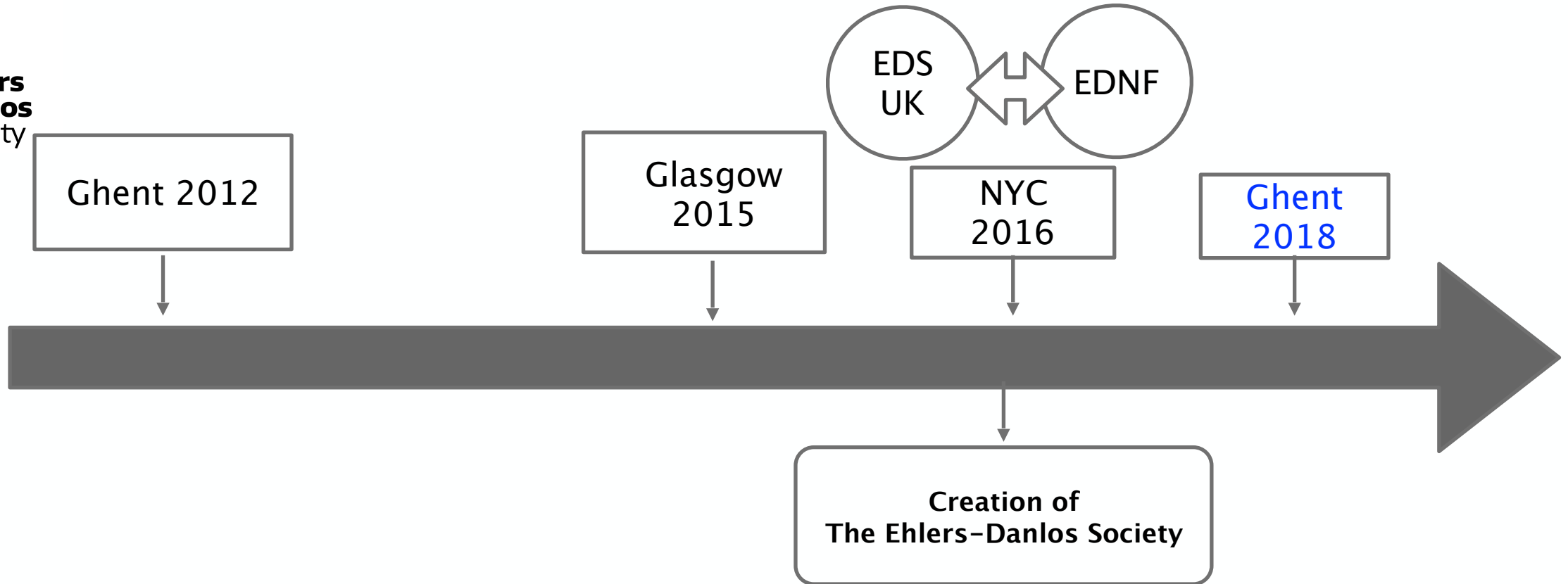
**The need for an EDS Registry:**

**But how do we make it a reality?**

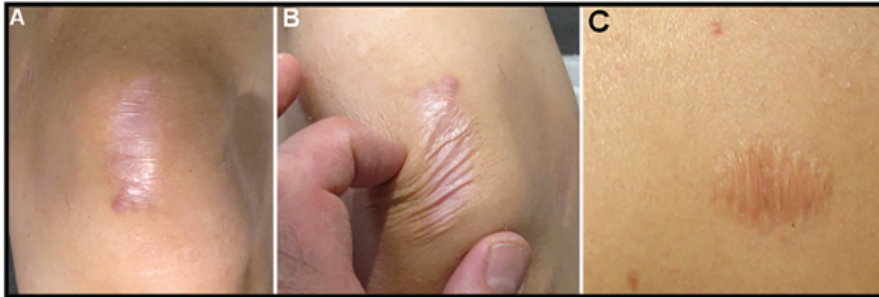
**Feb 2018**



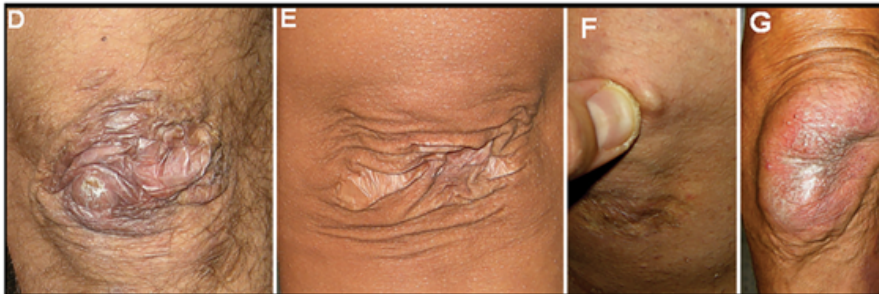
# TIMELINE



### Hypermobile EDS



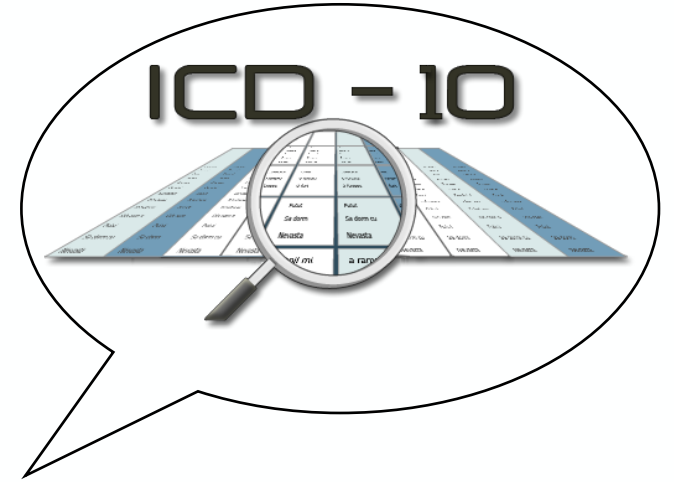
### Classical EDS



- **18 papers**
- **96 medical professionals**
- **20 year wait**
- **From 6 to 13 types**
- **HSD introduced**
- **EDS rare - HSD common**
- **Management & care guidelines**

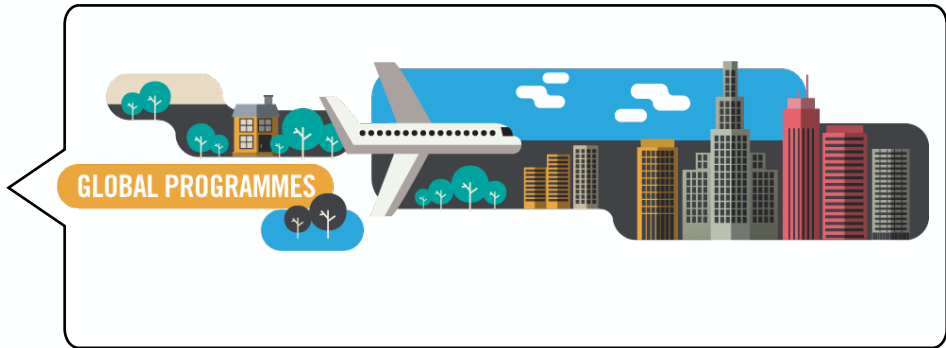


**NICE**  
National Institute for  
Health and Care Excellence



**World Health  
Organization**

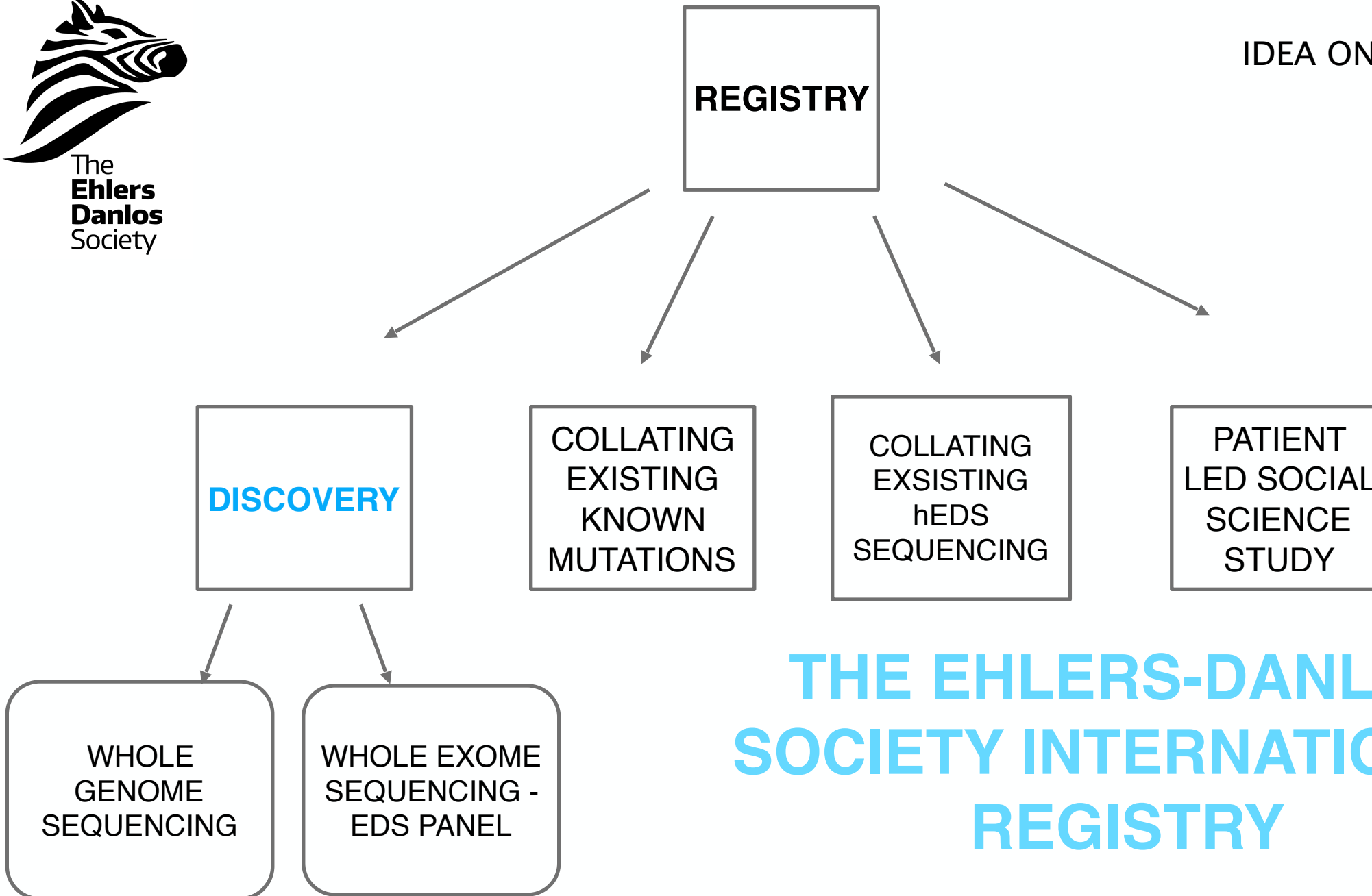
**RHEUMATOLOGY 2017**  
25-27 April 2017 | ICC Birmingham, UK



**RARE  
DISEASES  
INTERNATIONAL**  
A EURORDIS INITIATIVE



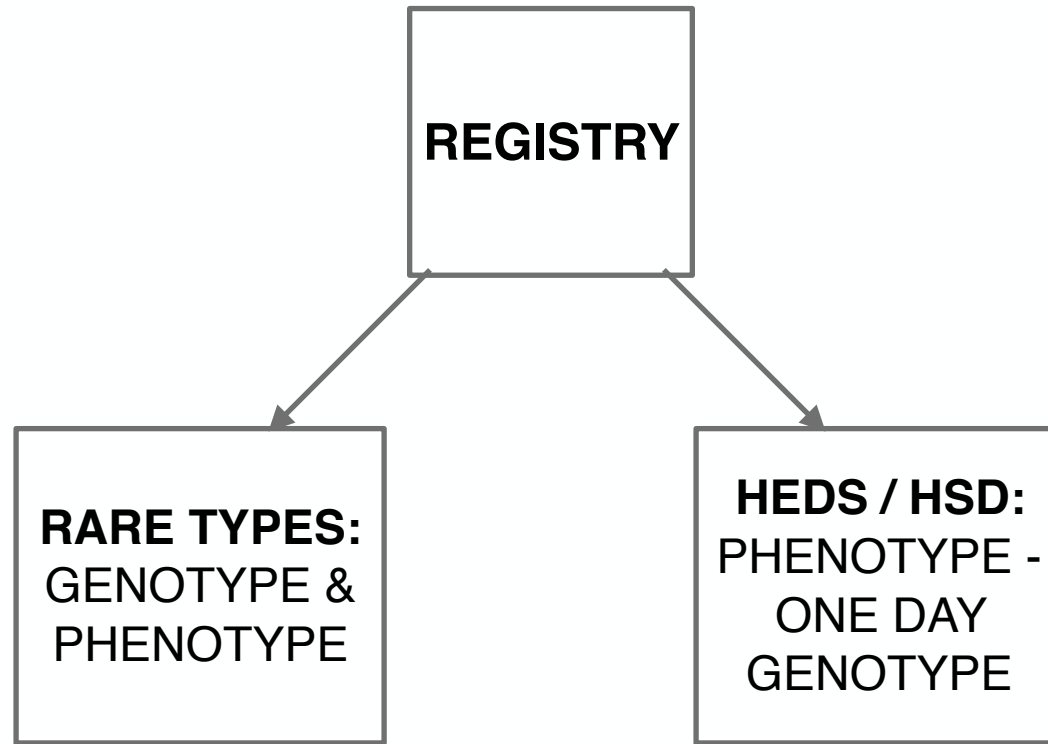
IDEA ONE - 2017



# THE EHLERS-DANLOS SOCIETY INTERNATIONAL REGISTRY



IDEA TWO - 2018

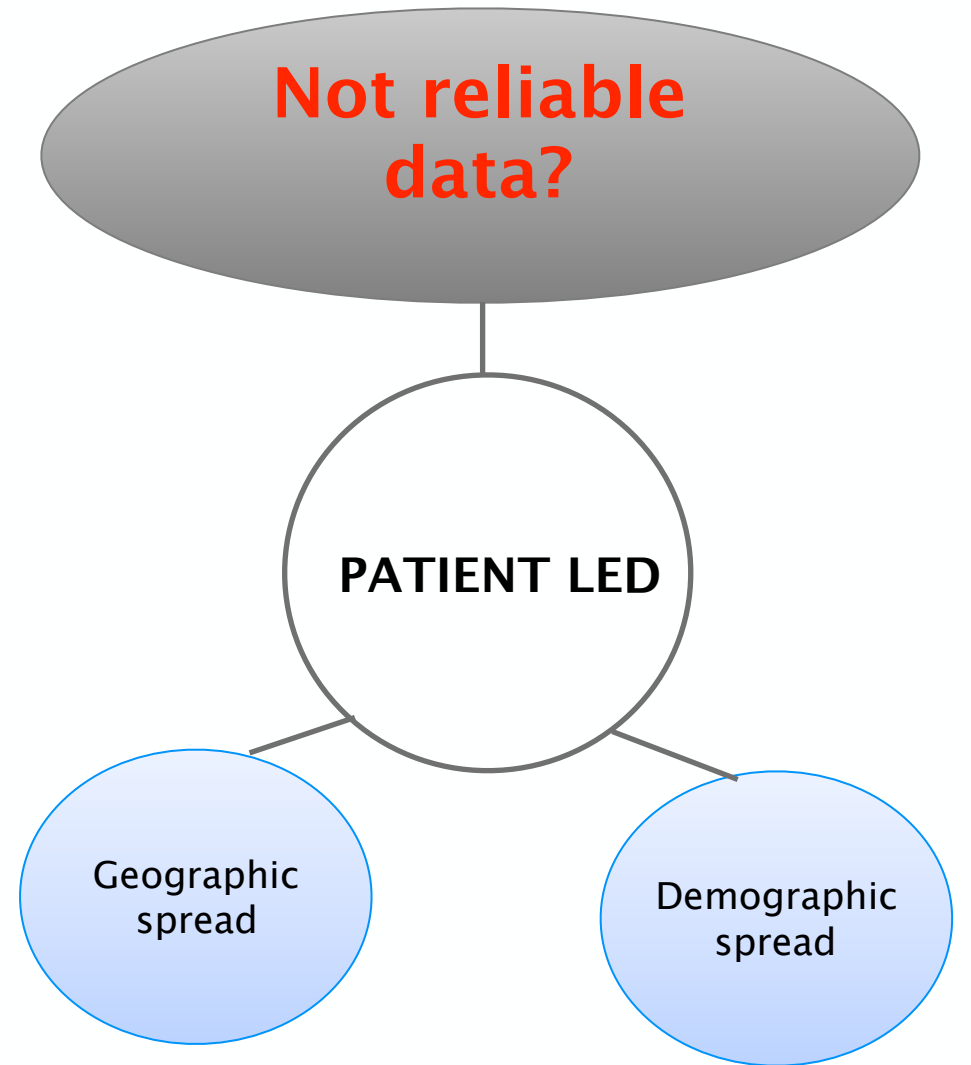
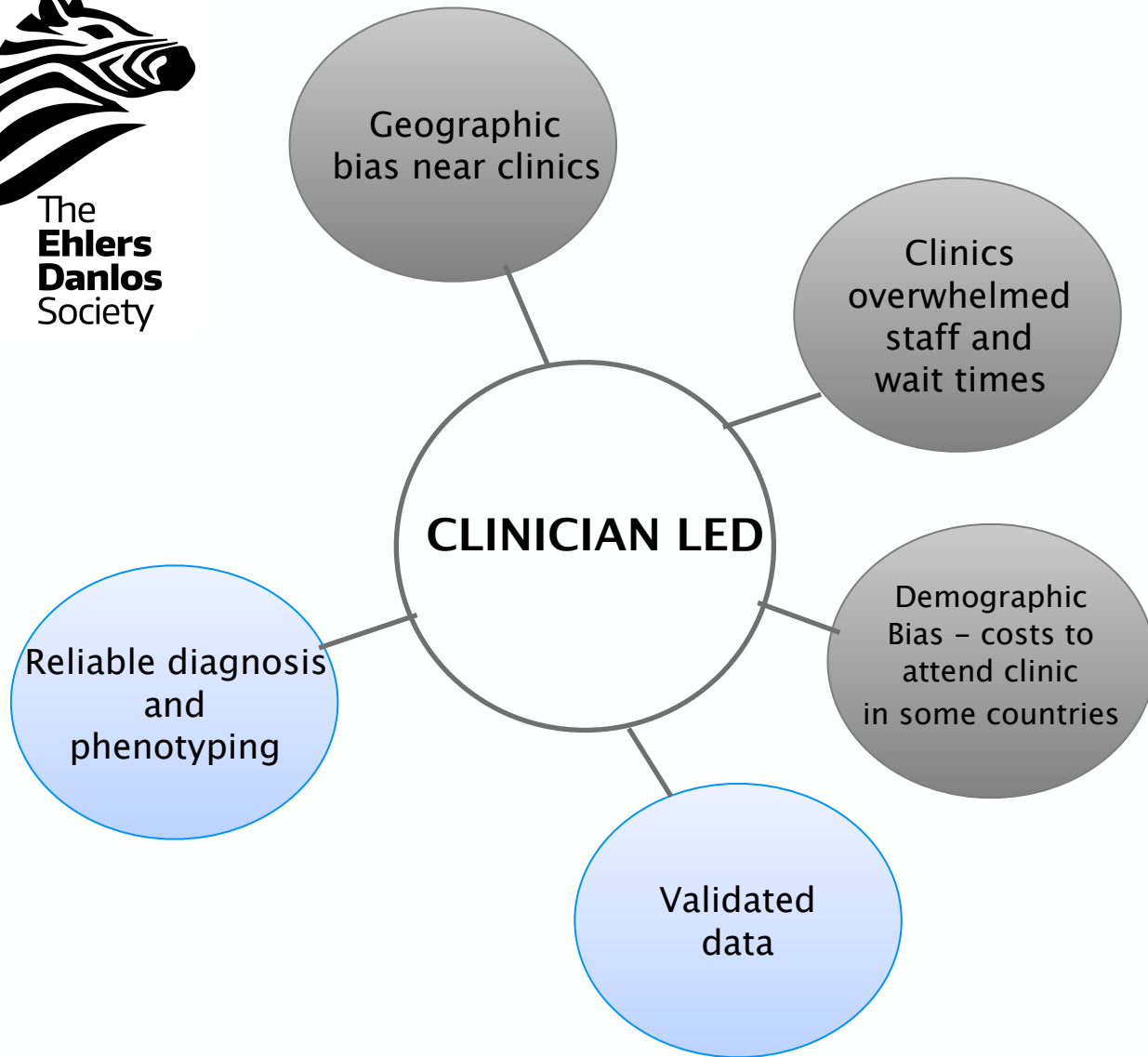


# THE EHLERS-DANLOS SOCIETY INTERNATIONAL REGISTRY



**BUT HOW DO WE  
INPUT THE DATA???**

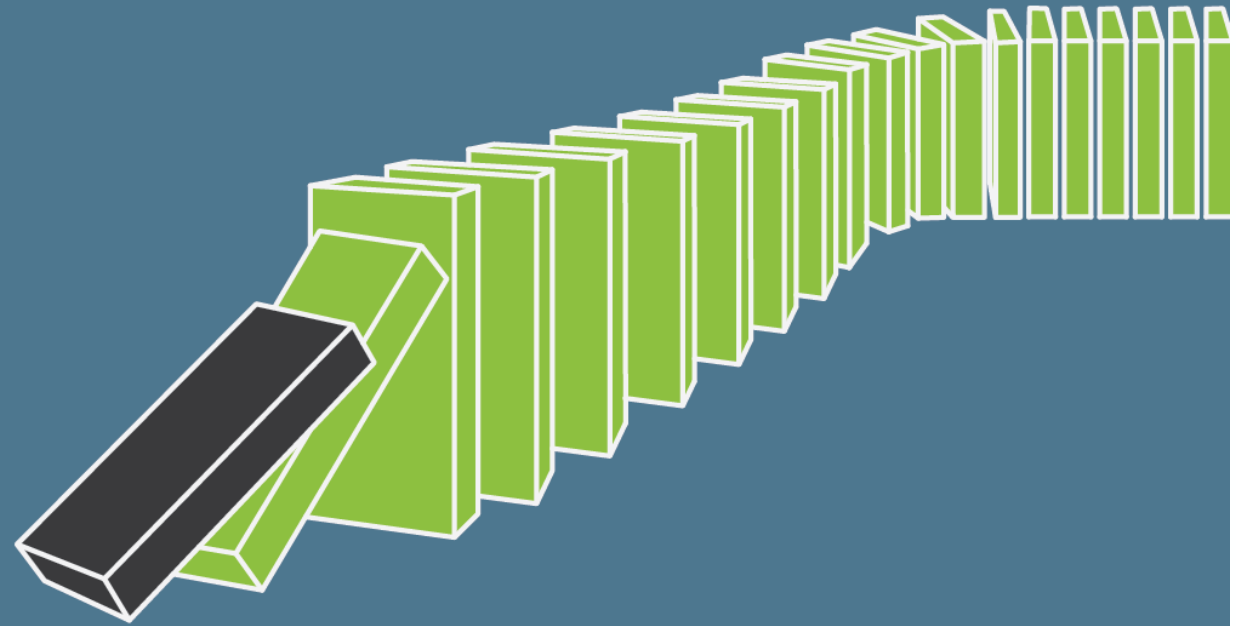








**BAD DATA = BAD EVERYTHING**





# COMMON DATA ELEMENTS (CDEs)

- The **Common Data Element (CDE)** movement aims to address this problem by providing standardized data elements that can be re-used across medical datasets
- CDEs are
  - owned, managed, & curated by single authority (NINDS, NCI)
  - stored and managed in large repositories called CDE registries
  - available for diverse areas of clinical practice and research, and at very fine granularity
    - larger repositories hold up to 50,000 elements available
- CDEs serving as a foundation for interoperability across data systems



Platform?

Staff?

CDE Process?



The  
**Ehlers  
Danlos**  
Society

## Contact:

**[www.ehlers-danlos.com](http://www.ehlers-danlos.com)**

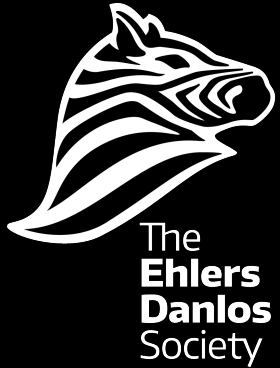
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