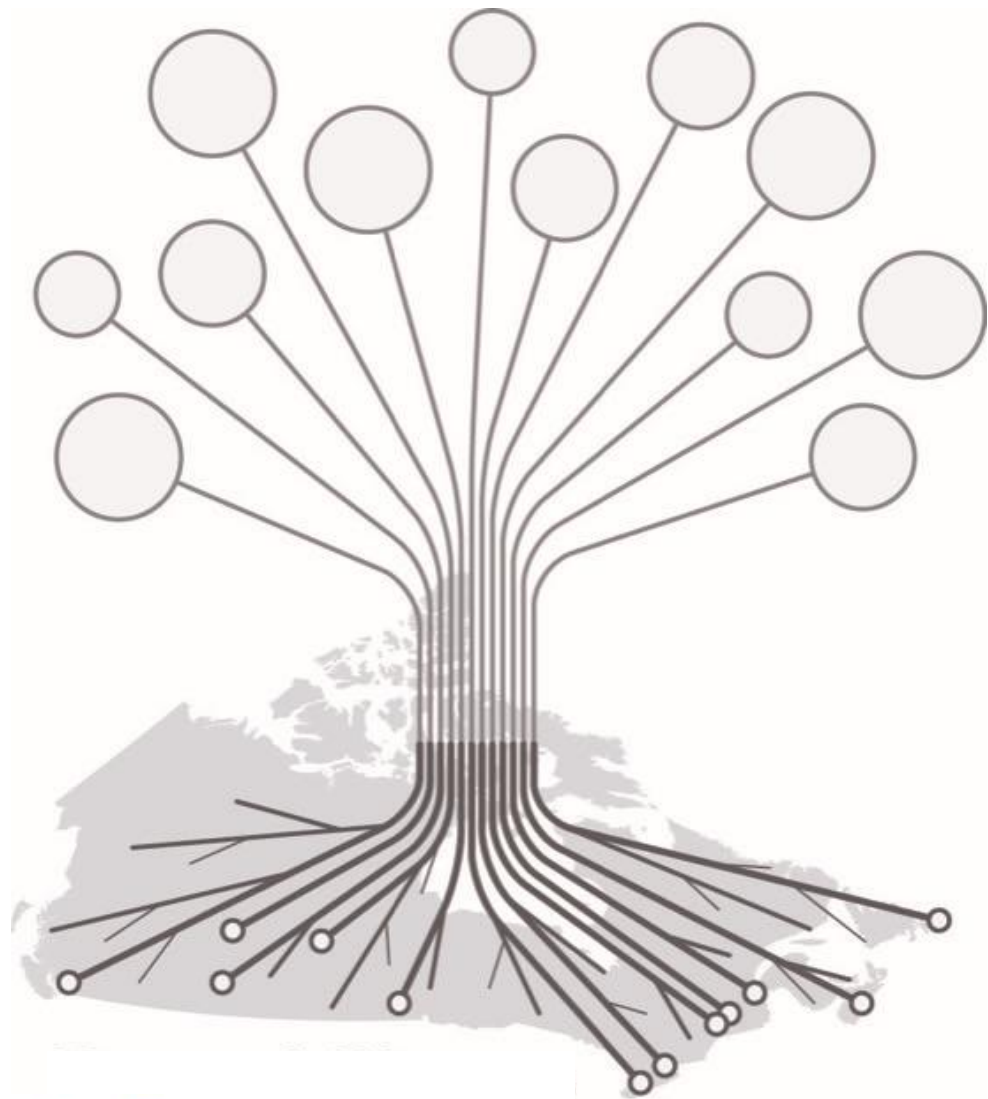


Canadian networks linking research to care



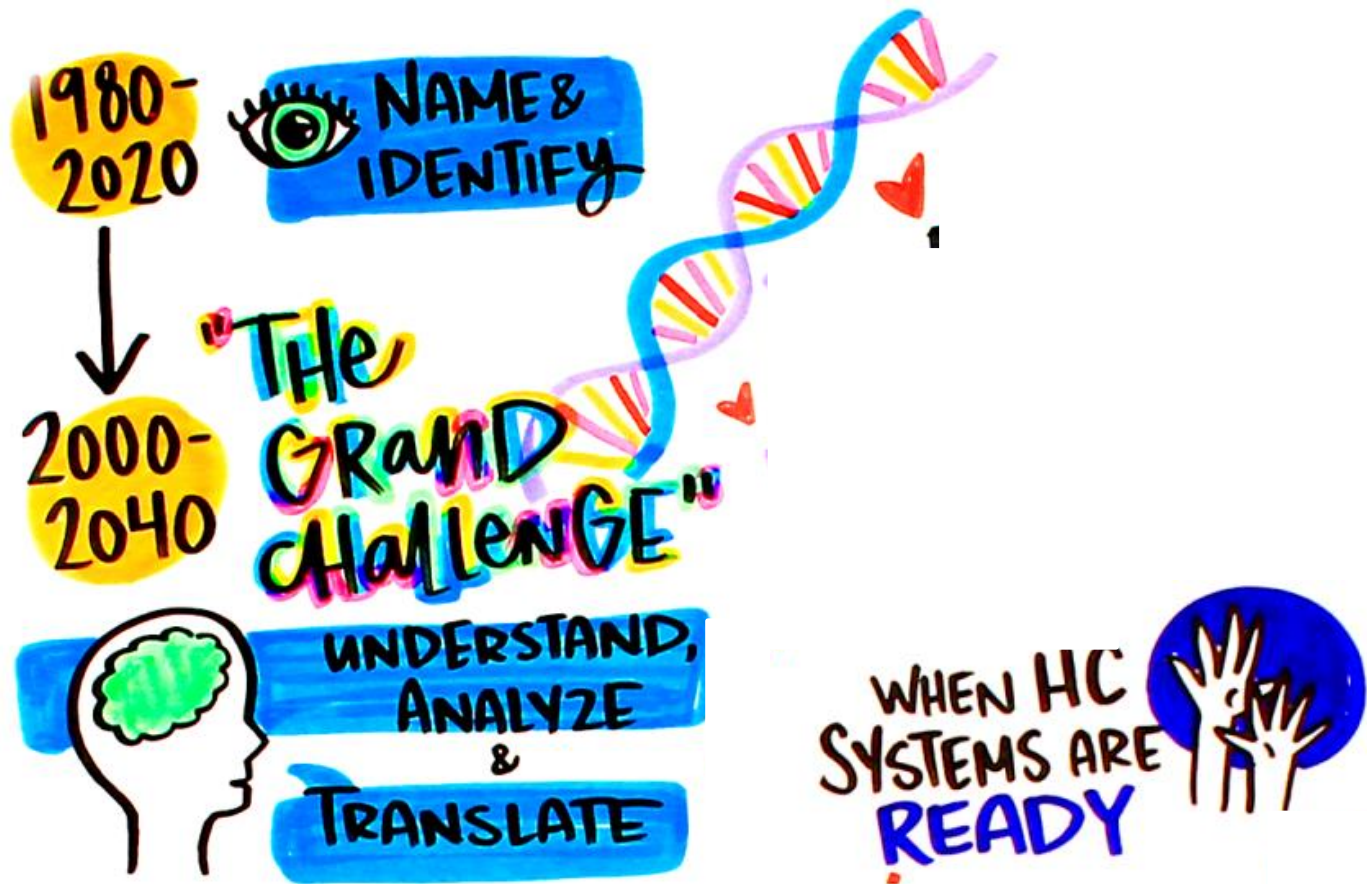
Kym Boycott
Professor of Pediatrics,
CHEO, University of Ottawa



CARE
forRARE



RareConnect.org



CARE
forRARE

Identify the causes of rare diseases
Facilitate access to testing



Quinlan



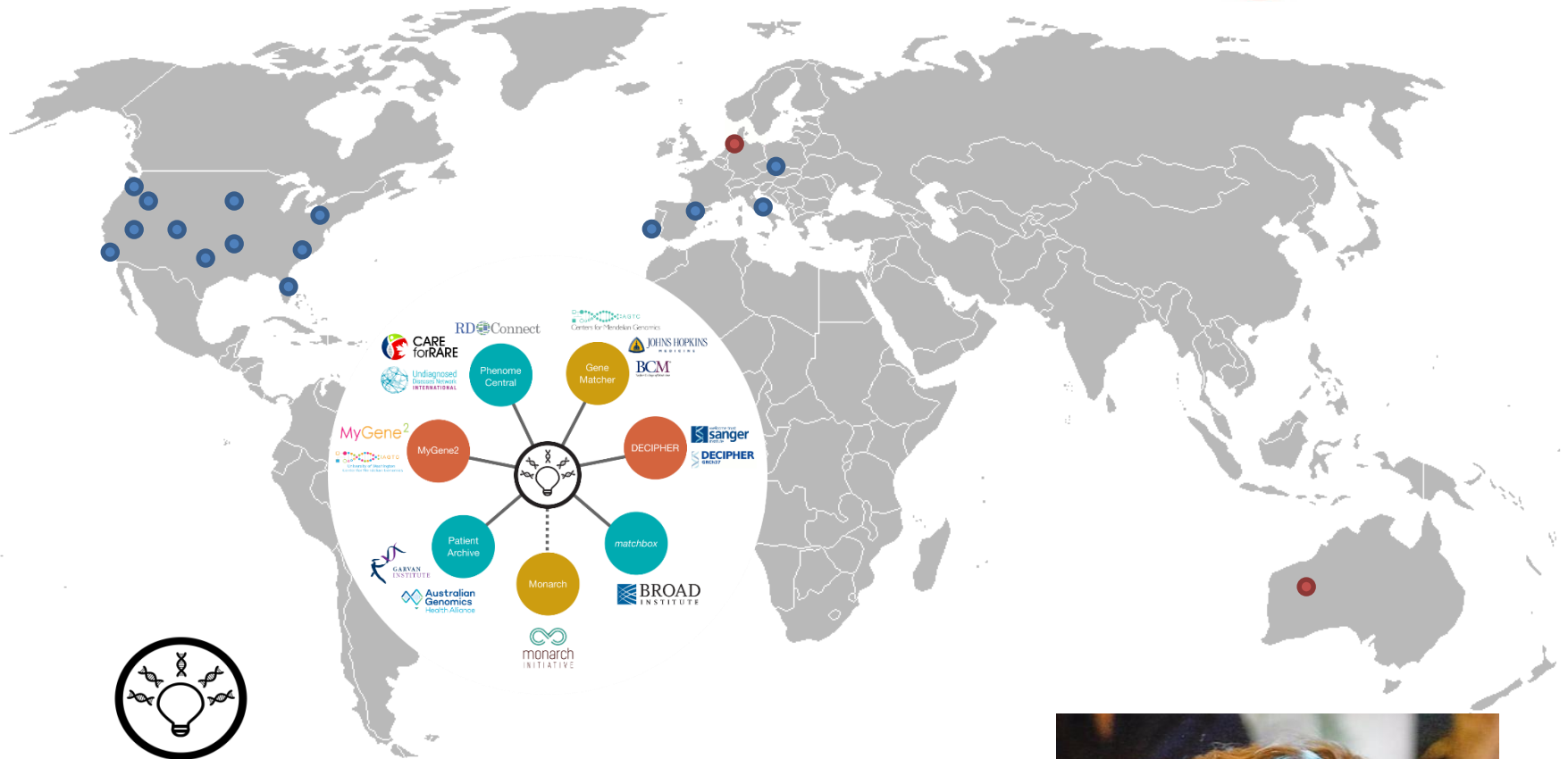
Abby



Justin

>1500 rare diseases studied
>5000 families recruited
50% of families diagnosed
100s of novel discoveries

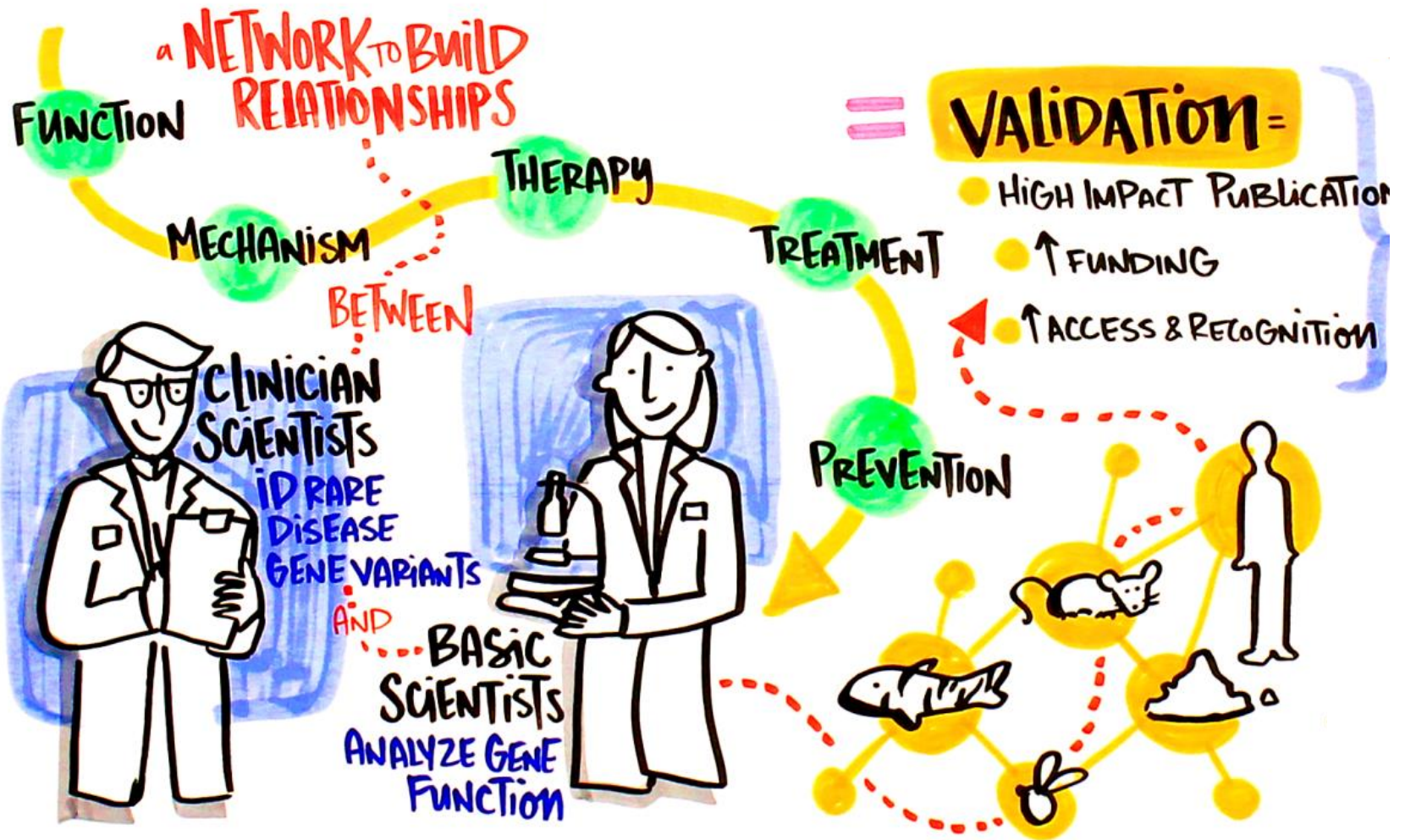
- *USP7*
- *TMEM106B*



Matchmaker
Exchange

Matchmaker Exchange
International data sharing for discovery
Connecting 50,000 undiagnosed patients
From 67 countries





Partner every new rare disease gene we discover with a scientist to study its function

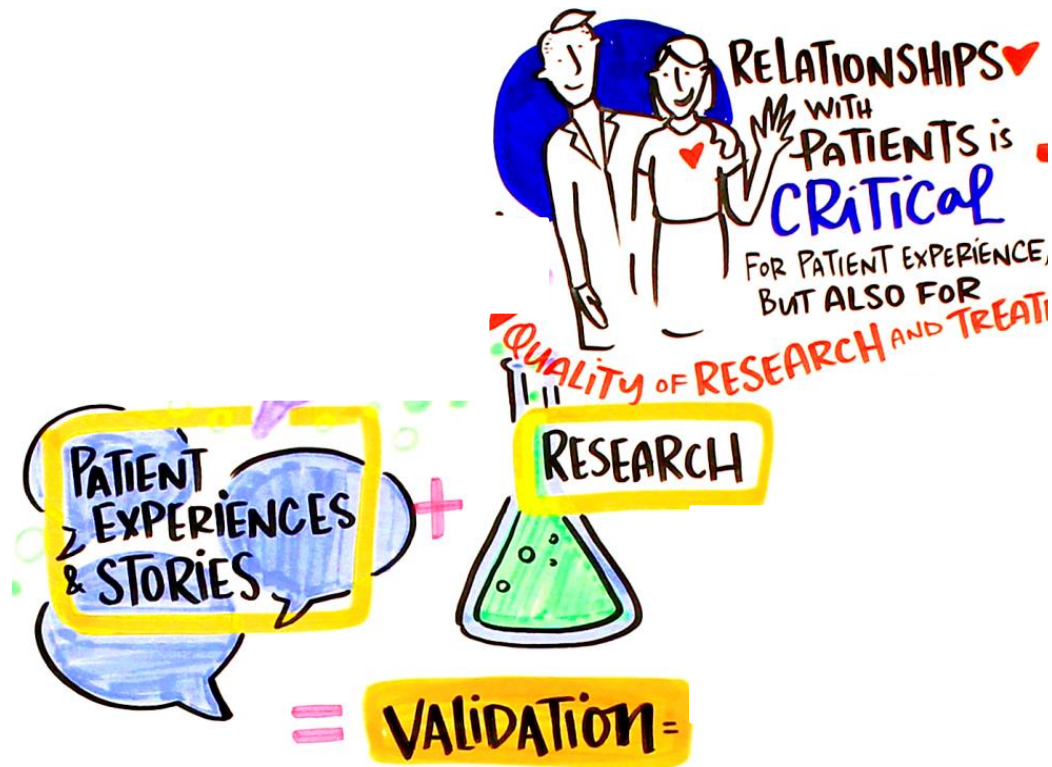


81 partnerships and counting

514 scientists registered

Connecting now to Europe, Japan and Australia

Partnering with patient organizations



RareConnect.org

Research
RareConnect.org

Connecting patients and families globally

Enabling patients and families as research partners

“We have found a community”
-Quinlan’s dad



40,000 users



RareConnect.org

12 languages

179 patient communities

30 new users a day

950 patient organizations

2 studies

Research
RareConnect.org

[illegible]

Graphic Record of the Canadian Networks: by Corrina Keeling