Speaking Genetics

Co-Chairs: Suzanne Belinson and Carla Easter
To build a meta-language that takes complex concepts in genetic medicine and distills them into a fluid, accessible and comprehensible vocabulary and system of expression that will work across the communication landscape of genetic medicine.
Membership of Working Group:

Ann Karty
Heather Brown
Bob Wildin
Colleen McBride
Highlights of progress made since last meeting:

The Genetic and Rare Diseases Information Center has provided contact data that is currently being analyzed by Madarka, Inc.
Methodology:

1. Data-driven and quantitative
2. In line with best practices
3. User centric
Best practices to share:

1. Don't reinvent the wheel
2. Ensure that everyone is on board
3. Promote common understanding of what’s next
4. Find out what will be most helpful to those who consume the outputs
Barriers encountered:

1. Getting access to data can be a challenge

2. Working on a large project in small pieces takes a lot of work
Next steps:

1. Continued analysis of the data

2. Possible expansion and inclusion of additional data