



# Speaking Genetics

Co-Chairs: Suzanne Belinson  
and Carla Easter

# Working Group Task:

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