**End of year Rare Disease Scholar’s Survey and Needs Assessment**

Please return your survey to Debra Regier. You are welcome to send via email or for anonymity, you can fax your survey to 202-476-2390 (attention Debra Regier). Please rank each activity from 0 (not at all helpful or good) to 10 (most helpful and amazing)

**PCORI Funding Options**  
*Helpful to your work*: (0-10)\_\_\_\_ \_\_\_  
*Quality of Presentation*: (0-10)\_\_\_ 0\_\_\_\_  
*Recommendation (i.e. keep, do more, do less, etc*):

**The politics of rare disease: How to talk with YOUR politician***Helpful to your work*: (0-10)\_\_\_ \_\_\_  
*Quality of Presentation*: (0-10)\_\_\_ \_\_\_\_  
*Recommendation (i.e. keep, do more, do less, etc*):

**Biosketch 101: update, write, create!***Helpful to your work*: (0-10)\_\_\_ \_\_\_\_  
*Quality of Presentation*: (0-10)\_\_\_ \_\_\_\_  
*Recommendation (i.e. keep, do more, do less, etc*):

**How to Run a Meeting**  
*Helpful to your work*: (0-10)\_\_\_ \_\_\_\_  
*Quality of Presentation*: (0-10)\_\_\_\_\_\_  
*Recommendation (i.e. keep, do more, do less, etc*):

**You have more time than you think**  
*Helpful to your work*: (0-10)\_\_\_ \_\_\_\_  
*Quality of Presentation*: (0-10)\_\_\_ \_\_\_\_  
*Recommendation (i.e. keep, do more, do less, etc*):

**Optional Modules:**

**Which module did YOU choose? \_\_\_\_\_\_\_\_\_\_\_\_\_\_**  
*Helpful to your work*: (0-10)\_\_\_\_\_\_\_  
*Quality of Presentation*: (0-10)\_\_\_\_\_\_\_  
*Recommendation (i.e. keep, do more, do less, etc*):

**Update Phone Call with other participants**  
*Helpful to your work*: (0-10)\_\_\_ \_\_\_\_  
*Quality of Presentation*: (0-10)\_\_ \_\_\_\_\_  
*Recommendation (i.e. keep, do more, do less, etc*):

**What Percent of activities have you watched in real time ?\_\_   
What Percent of activities have you watched at a later time?\_\_\_\_\_\_\_\_  
What Percent of activities have occurred, and you plan to watch in the future?\_\_\_\_\_\_**

**Research Update:**

1. **What exciting progress have you made this year?**
2. **Where have you identified hurdles and what have you done to overcome these hurdles?**
3. **What resources could we offer to help you with your research hurdles?**
4. **What topics do you need in the second half of the year to further YOUR research?**

GRADUATION REQUIREMENTS :

-I have completed the 3 quizzes on-line

-I have “interacted” with 80% of the material this year

-I will share my ORCID ID with the group so that I don’t have to send Deb my CV yearly (OPTIONAL!): \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_ (not sure what I’m talking about?? https://orcid.org/)

-I don’t have an ORCID ID, so I am OK with Deb asking for my CV yearly (OPTIONAL TO PROVIDE)

-I will share my rare disease research at the NORD meeting (or if an alternate location, please list the meeting you will be attending: \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_)