

## EAIN 2419-Meeting#3 PPT Presentation Evaluation-Survey Results

**32/33 members responded =97%**

For the following statements, please indicate to what extent you disagree or agree with “0” indicating “strongly disagree” and “10” indicating “strongly agree”. There are no right or wrong answers, it is important that the responses reflect your individual experience and opinions.

1. The information in the <b>PPT#3 presentation</b> was provided in an easy to understand manner	Rating Average	Response Count
	<b>8.97</b>	32
	<i>answered question</i>	
2. Additional <b>patient/parent personal stories</b> were informative and provided in an easy to understand manner	Rating Average	Response Count
	<b>9.47</b>	32
	<i>answered question</i>	
3. Examples of <b>published epidemiological/patient outcomes studies</b> were informative and provided in an easy to understand manner	Rating Average	Response Count
	<b>8.91</b>	32
	<i>answered question</i>	
4. Examples of <b>genetic research done by our CAB members (Scientists)</b> were informative and provided in an easy to understand manner	Rating Average	Response Count
	<b>9</b>	32
	<i>answered question</i>	
5. Would you like to schedule a <b>personal meeting and/or call</b> with the PI for further clarification of materials discussed in the PPT #3 presentation?	Response Percent	Response Count
	Yes, I would like to schedule a meeting	<b>3.1%</b> 1
	No, not at this point	<b>96.9%</b> 31
	<i>answered question</i>	
	32	

## Additional Comments

### Meeting#3 presentation (PPT#3)

- 1) I wanted to tell you personally what a great job you did on the PPT#3 presentation. It was so professionally organized and all the stories were very compelling.
- 2) It was a little more challenging than previous presentations due to the more technical research study descriptions.
- 3) I felt it was quite over my head.
- 4) Some of the research details get dense.
- 5) Very comprehensive summaries

### PPT#3-Patient stories

- 1) Really enjoyed Kelly Ranallo's video.
- 2) I appreciated the links for the videos.
- 3) These stories were very interesting. However, if our group had more non-health professionals, I think some of the information would have been fairly difficult to understand.
- 4) I was unsuccessful after multiple attempts to open Kelly's YouTube video.
- 5) Stories really helped frame the information.

### PPT#3-Examples of published epidemiological/patient outcomes studies

- 1) I'm not sure how you could improve this area. It's complex.
- 2) Again, very informative, but not as easy to understand. (Hard to evaluate this question effectively and question #2 since you are asking two (more than one) evaluations.
- 3) Again, as a non-medical person, I felt they were a little technical.
- 4) A better way to convey the messages might be to use visuals instead of text.
- 5) Not clear the strength of correlation.
- 6) Very informative
- 7) Attempted to click the links to access references, but was unable.
- 8) Tables were very clear and concise.

### **PPT#3-Examples of genetic research done by our CAB members (Scientists)**

- 1) I really like the CAB profiles!!
- 2) Fascinated by the sleep/synapse connection.
- 3) Since I do not work daily with genetic data, it took me some time to understand it.
- 4) Some of the genetics research is hard to understand.
- 5) Studies are very exciting.

### **PPT#3-Project website**

- 1) Website looks great.
- 2) Great job in putting together a very informative presentation on person experiences involving personalized medicine.
- 3) Keep adding stuff. It's great.
- 4) Enjoyed clicking here and there, nice job!
- 5) Separate "informative" and "easy to understand" in evaluation question.
- 6) The researchers may provide clearer description of what their research means to patients.
- 7) I like the collaborative nature of this.
- 8) I would present data so that non-scientific or individual from other science clearly understand.
- 9) I would consider using easier to understand language when describing the genetics research. The researchers are clearly very bright and it is great data, but dense to get through.
- 10) Further interactive sessions with the CAB scientist members would form a great addition to ask additional questions about each others' work and to see whether cross-collaborations between different fields are possible. Perhaps these types of interactions will be scheduled later on in the trajectory? I found the work presented very interesting and would love to hear more about it.
- 11) The presentations were informative and easier to understand.
- 12) Awesome presentation!

### **PPT#3-Overall suggestions/comments**

- 1) Both of my kids are adopted. My younger son was adopted from Thailand. We don't know any details about his birth family. When I read your study I think of him and how important this is going to be to adoptees who have little data on their birth family.
- 2) It would be good to understand the sources of information used for the studies. Are they all primary sources? Or were there secondary data sources that were utilized?
- 3) Overall the 3rd PPT was very good. Sharing parent/child stories and related research is nice. Thank you!!!
- 4) I found the genetic research tied to autism of great interest to me both as a parent as well as a provider. We have often discussed the implication of Autism like symptoms that exist in our girls with Turner Syndrome (close to 100%) and varied based on level of mosaicism. Sleep disturbances are common in our TS population. The discussions make me wonder if we are seeing the same subset of problems due to the lack of estrogen which we know is present or is there something on the second X chromosome that protects typical girls (XX) from the incidence of autism which is why our XO girls and boys are more likely affected. Good conversation on why genetic information even that which crosses over disease states may be relevant to understanding clinical symptoms.
- 5) I found the information very interesting - especially in ways that genetic information can be used to improve care, teaching and patient/family knowledge and adherence.
- 6) The YouTube video of Dr. from George Washington U. was helpful to understand her part/her research.
- 7) I like what Dr. Hu and Dr. Veatch are doing. Is there something we can do to help them make progress on their research?
- 8) I have enjoyed the patient experience formats. It is great to hear a perspective from a fellow scientist who has had a family member affected by genotypic variations.