

**Aortic Dissection Collaborative**  
**Community Report**  
**May 15, 2021**  
**Discussion Summary**



**Gaps/Unanswered Questions Identified During Discussion:**

- Of those who did undergo genetic testing, how many had the testing before they dissected vs after?
- Most educational materials are developed in English, and only ~15% of the global population speak English, so most of the world's population do not have educational materials about aortic dissection developed for them.
- Education of physicians – doctors need basic education on what dissections are (i.e., not aneurysms), how to talk about them, and how to talk with their patients about them. Physicians need best practices for what are the best educational materials, when to give those materials, and how to structure conversations.
- What kind of exercise/activity can someone safely do after an aortic dissection?
- Optical migraines – what are treatments? Why do people with aortic dissection experience these?
  - **Action item: If you are interested in working on this topic, contact us at [aorticdissection@uw.edu](mailto:aorticdissection@uw.edu).**
- Medical bureaucracy – how can patients collect their medical records when different records don't talk to each other, and personal systems to store records don't stick around (e.g., Backpack, etc.)

**Action Items:**

- If you are interested in working on the optical migraine topic, contact us at [aorticdissection@uw.edu](mailto:aorticdissection@uw.edu).
- If you are interested in taking part in a topic working group, contact us at [aorticdissection@uw.edu](mailto:aorticdissection@uw.edu).