

Annual
Meeting
2024 DEC
11-12
NASHVILLE TENNESSEE

Patients in the Driver Seat

10:20 AM | Dec. 11



Anna McCollister
Panel Moderator &
CESWG Co-Chair



Holly Miller
MedAllies



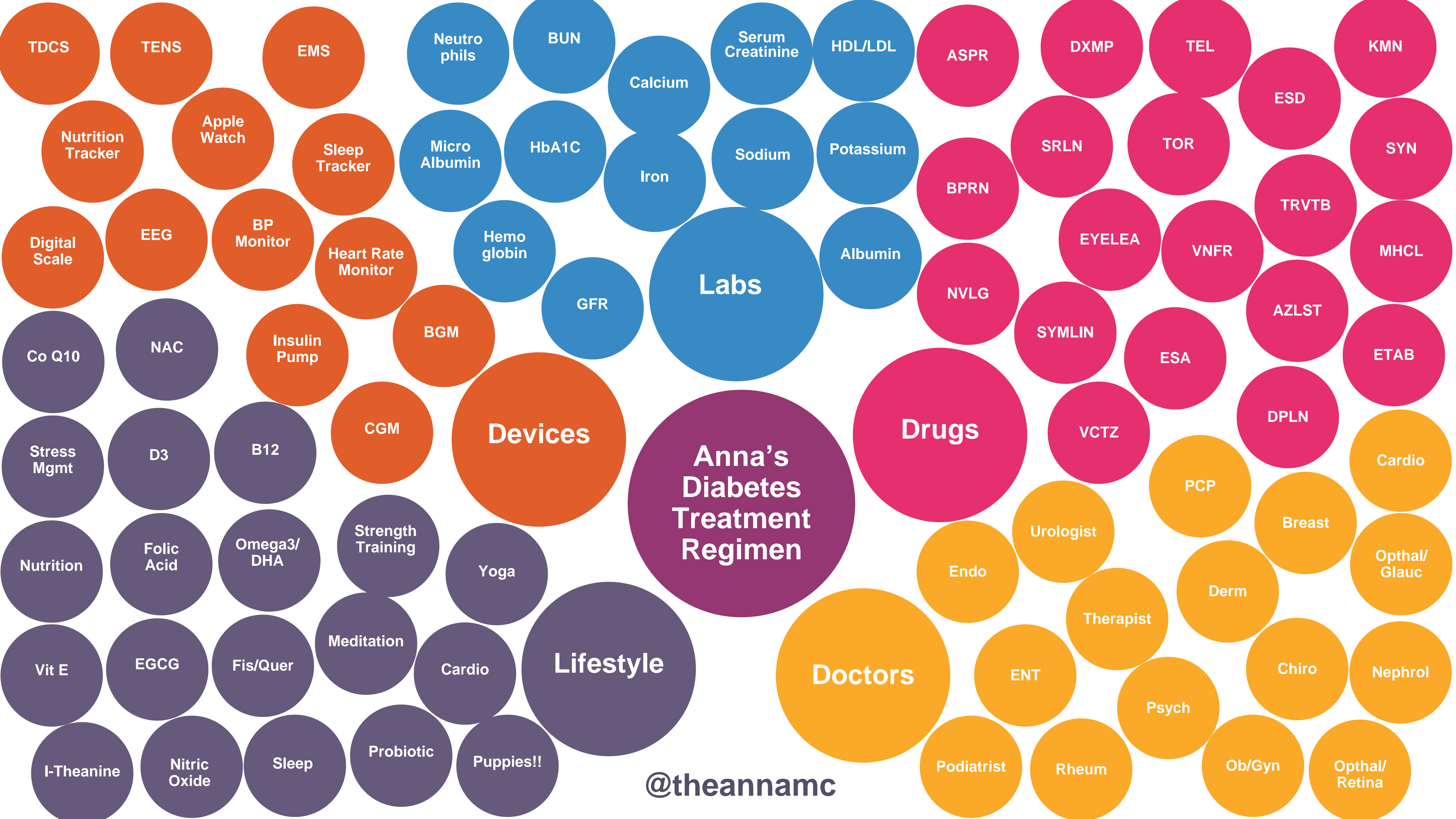
Josh Mast
Oracle Health



**Cathriona
Dolphin-Dempsey**
Stanford Health Care

The curious case of the super engaged,
highly knowledgeable, empowered, well
connected patient and information
blocking

Seriously... how is this still a thing?



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It's me! Hi!



2 X health tech startup founder

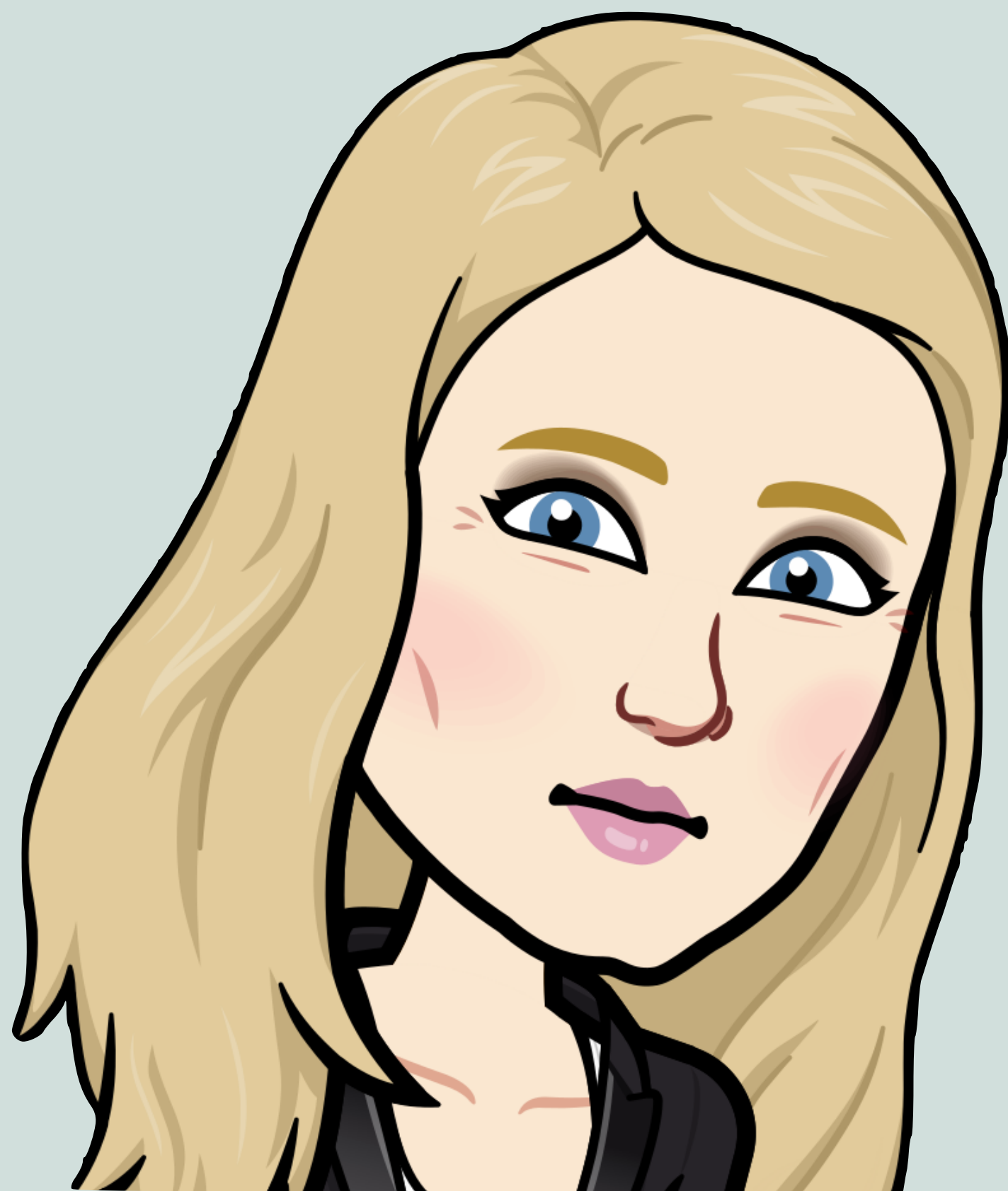
Co-Founder patient hacker
#WeAreNotWaiting mvmt

HITAC Member

Sequoia Board Member

CESWG Workgroup lead and co-
chair

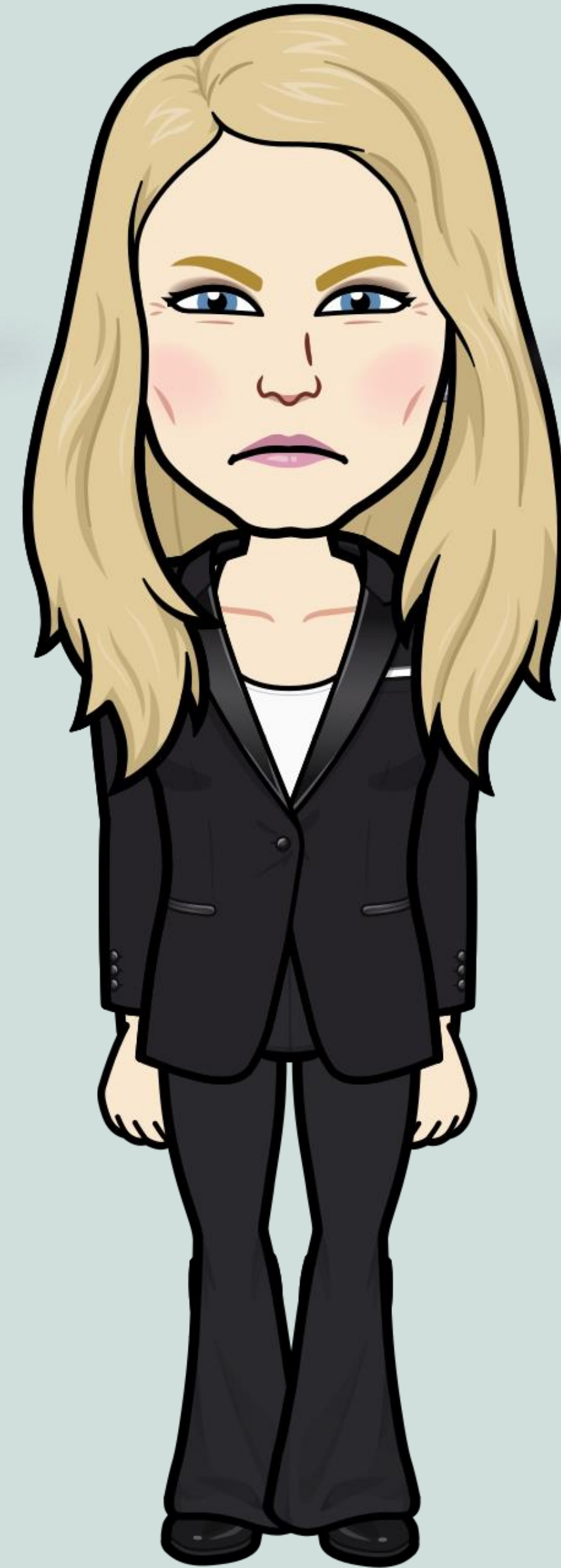
...But I'm NOT the problem



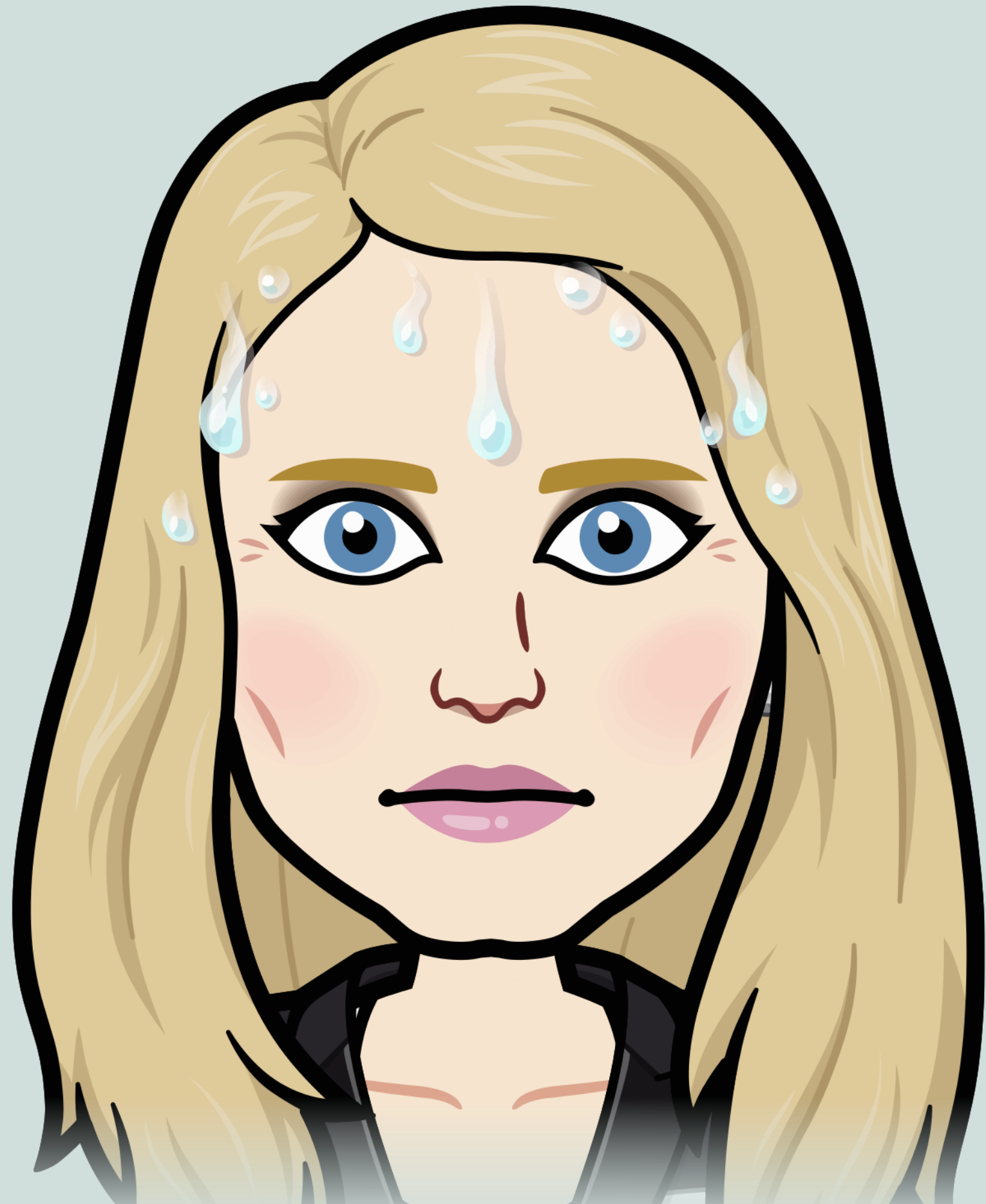
- Urgent, evolving and frightening health issue
- Time sensitive need for access to data
- Difficult family issue
- Busy professional demands
- Other complex health issues
- Desperate need to get a second opinion
- Hesitation about implications of informing doctor about interest in second opinion

THIS is the problem

- My appointment with the new specialist was in less than a week – historical data was critical to proper assessment
- No access to data on portal
- REQUIRED to go through medical records, BUT...
 - Medical records didn't have the data
 - Actual data location – doctor's office (15 minutes away)
- Unnecessary complex medical record access “process”
 - Complete a form requesting data access
 - Mail a check for the fees (or drive an hour to hand deliver)
 - After the check had cleared, they would have 30 days to provide me with the data



What did it take for me to get my data?



- In-person HITAC
- Personal cell number for former lead for HIPAA at HHS/OCR
 - Reminded me to check info blocking rule
- So... I took action
 - Used ChatGPT4 to quickly find specific section of Info Blocking rule
 - Emailed office manager and medical records office
 - Informed them of intent to file complaint for information blocking if images not received in a timely manner
 - They responded...
- The next day...
 - I purchased a new USB drive
 - Ubered to doctor's office to guide staff on image downloads
 - Uploaded the data to a secure dropbox folder
 - Sent images via email to new physician – who was willing to click on a dropbox link

**WE can make
this work
better!!**

