ECD and the Brain: Overview

- ECD lesions in the brain and spine

- Neurologic problems without lesions?

- Thinking and memory problems

- Other issues and what you can do
ECD and the Brain

• ~one third of ECD patients have problems in the brain
• Most common symptoms are balance problems, speech problems, coordination of arms and legs
• More severe symptoms include trouble swallowing
• Unusual or inappropriate emotions (laughing/crying)
ECD in the brain
ECD in the brain
Other ECD brain symptoms

- “dementia”
- Incontinence
- Hormonal problems including diabetes insipidus
- Mood and behavior problems
- Depression
- Fatigue
ECD in the brain
ECD in the brain: treatment

• Probably most difficult form of ECD to treat
• Especially if BRAF “negative”
• But there are options
  • Interferon
  • Chemotherapies
  • Immune system drugs
  • New BRAF-like drugs in trials
Successful Treatment of BRAF-negative brain ECD
ECD and the spine

- Not very common, rare in the spinal cord itself
- But can affect bones of the spine, nerves in front of the spine
- Back pain
- Rarely, spinal cord problems if tumors grow and press on spinal cord
Balance problems without tumors?

- Many ECD patients have balance problems without a good explanation
- Unsteadiness, falls
- We don’t really understand this
Cognitive Problems in ECD

• Very common and unrecognized problem

• Trouble paying attention, trouble remembering things, multi-tasking

• Ability to work normally can be affected

• Even patients “without ECD in the brain”

• We don’t really know why but we have ideas
Brain changes in ECD without tumors
Cortical thickness: ECD versus normal
Other neurologic problems

- Neuropathy (numbness, burning, tingling in the feet) is VERY common
- Can also affect balance
- Pain can affect quality of life severely
- May be related to vitamin or nutritional problems
- Pain CAN be treated
What can you do

- **BE GREEDY** with your quality of life!
- All ECD patients should have a brain MRI
- Be evaluated for neuropathy
- Treat fatigue! There are many good medications. And exercise helps.
- Treat depression
- Get your vitamins and hormones checked
- See an ECD specialist if you have unexplained symptoms
Thanks