ECD Global Alliance
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ECD and the Brain

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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-life drugs in trials
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
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