ECD Studies at MSKCC

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Phase 2 Trial of Cobimetinib for Adults with Histiocytic Disorders

- Clinical Trial for ECD patients WITHOUT \textit{BRAF} mutation
- Or for BRAF+ who cannot obtain or cannot take BRAF inhibitors
- 7 out of 7 patients treated thus far with improvement
- 11 spots remaining
- Medication is provided by company
Pilot Study of 18F-Fluorocholine PET to Improve Accuracy of Diagnostic Biopsy in Histiocytic Disorders

- Testing new kind of PET scan performed when biopsy is done to diagnose ECD or to obtain tissue for genetic testing
- PET scan uses choline which is used by cells that are dividing
- Hopefully this PET will identify ECD cells more specifically than “regular” FDG PET alone
- Participants get both PET scans and biopsy of two ECD sites and results are compared
- Three patients enrolled, two spots remaining
A Prospective Study of the Natural History and Genetic Landscape of Histiocytic Disorders

• Biospecimen protocol

• ECD patients give blood, urine, CSF to be stored for research

• Analyzed for gene mutations, markers of inflammation

• 54 ECD patients enrolled, >200 samples
A Clinical, Structural, and Functional Neuroimaging Study of Cognition in Adults with Histiocytosis

- Detailed study of brain function in patients with ECD (funded by ECDGA)

- Participants undergo MRI of the brain, cognitive testing, quality of life and symptom questions

- Trying to detect early brain changes in ECD and patterns of thinking and memory problems

- 30 spots available
ECD Global Registry

- MSKCC and Newcastle (UK)

- ECDGA-funded

- Collects clinical information, scans about ECD patients over time

- All ECD patients encouraged to participate

- Can enroll by telephone

- Answer surveys online about symptoms, quality of life, ways ECD affects your lives

- Optional collection of blood and urine

- Open January 2017
Thank You!