

What did we learn from this journey?

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1. Get second (or third) opinions early, especially for unexplained symptoms. These are rare diseases and not all neurologists are aware of how to evaluate the symptoms.
2. Don't accept an unconfirmed or non-specific diagnosis. Push to get a referral to a top neurologist (Movement Disorder Specialist).
3. Make the significant care decisions early while it can be a fully conscious and in-depth discussion with the caregiver and the patient together on several subjects:
 - a. Feeding tubes
 - b. Do Not Resuscitate orders
 - c. Hospitalization or die at home
 - d. Brain donation - Arrange well in advance. Brain Support Network can help:
www.brainsupportnetwork.org/brain-donation
4. Start exercise early and continue exercise as long and as much as possible (it does extend life). The more the better.
5. Work with doctors, hospice or whatever caregivers you have to try to make life as normal as possible.
6. Check out available clinical trials.
7. As either the caregiver or patient, be proactive, participate in support groups. Brain Support Network leads the caregiver support group here in San Mateo.
8. Keep a "Binder" or file with notes on each medical visit and copies of all test results from the various doctors / hospitals. You (the caregiver) are responsible for making sure that each doctor knows what the others are doing and coordinating all of the care. This is invaluable.