

## **Appendix e-1: Electronic survey with complete cases and questions**

*Introduction: while recognizing each case is different and the patient's desire of continuing or stopping medications is often the most important factor, please choose the answer that best reflects your common practice and limit free text to strategies that are not included.*

### **CASE 1: Focal epilepsy of unknown etiology**

A right-handed 14-year-old boy presents with a 7-year history of seizures. They usually last less than 5 minutes and are described as “butterflies in the stomach” sensation, followed by unresponsiveness with blank stare, sometimes accompanied by chewing and lip smacking, and stiffening of both arms. He was started on oxcarbazepine at age 8 and has had several seizures despite increasing the dose until maximized at age 13. He has been seizure- and aura-free for the past 6 months. High resolution 3T MRI and PET at age 12 were normal. Recent EEG revealed rare sharp waves in the left temporal region, similar to prior EEGs. For the past 2 years, he has been bullied at school and his parents request that medication be stopped while minimizing the risk of seizure recurrence. He is otherwise healthy with normal development, takes no other medications, and has no history of febrile seizures or family history of seizures.

**Question #1: Assuming that the patient remains seizure- and aura-free, when would you consider tapering the oxcarbazepine?**

- 1) After a total of 1 year of seizure freedom
- 2) After a total of 2 years of seizure freedom
- 3) After a total of 3 years of seizure freedom
- 4) After a total of 3-5 years of seizure freedom
- 5) I would not consider tapering the medication
- 6) Other – write in

**Question #2: Prior to starting the AED taper, what further tests would you recommend to guide your decision?**

- 1) Repeat EEG and wait longer if not normalized
- 2) Repeat a high-resolution brain MRI to look for a possible structural etiology
- 3) Repeat both EEG and MRI
- 4) No further tests
- 5) Other – write in

### **CASE 2: Temporal lobe epilepsy after lobectomy**

A right-handed 35-year-old man diagnosed with epilepsy at age 18 is initially treated with carbamazepine. Despite optimization of treatment, he continued to have 1-2 generalized tonic-clonic seizures every 6 months; levetiracetam was added with no benefit. EEGs revealed mild right temporal slowing. A recent MRI showed blurring of the

gray-white junction in the right temporal pole. He underwent a right temporal lobectomy with no perioperative complications. Pathology revealed an area of focal cortical dysplasia. He has continued to take carbamazepine and levetiracetam with excellent compliance since surgery. He has been seizure-free, but continues to have mild AED-induced sedation. Postoperative EEG shows no seizure activity and MRI reveals changes related to epilepsy surgery without any definite residual lesion. He works as an accountant, operates a motor vehicle and lives alone. He enjoys bicycling and jogging. He does not have other major co-morbidities.

**Question #3: What would you recommend for this patient's medically refractory epilepsy at the 6-month follow-up after surgery?**

- 1) Taper one of the two AEDs now, with the goal of lifelong monotherapy
- 2) Wait for another 6 months then taper one of the two AEDs, with the goal of lifelong monotherapy
- 3) Wait for a total of 2 years then taper one of the two AEDs, with the goal of lifelong monotherapy
- 4) Taper one of the two AEDs now, with the goal of withdrawing all AEDs
- 5) Wait for another 6 months then taper one of the two AEDs, with the goal of withdrawing all AEDs
- 6) Wait for a total of 2 years then taper one of the two AEDs, with the goal of withdrawing all AEDs
- 7) Other – write in

**CASE 3: Juvenile myoclonic epilepsy**

An otherwise healthy 19-year-old man is diagnosed at age 18 with juvenile myoclonic epilepsy (JME) and started on valproic acid. He has had no seizure recurrence, is not experiencing side effects from the medication, and has no atypical features on EEG.

**Question #4: How many years of seizure freedom would you recommend before considering AED withdrawal in this patient?**

- 1) 2 years of seizure freedom
- 2) 3 years of seizure freedom
- 3) 5 years of seizure freedom
- 4) More than 5 years of seizure freedom
- 5) I do not generally recommend AED withdrawal for patients with JME
- 6) Other – write in

**Question #5: What patient population do you treat?**

- 1) Adults (18 years and older)
- 2) Children (0-18 years)
- 3) Both (adults and children)

**Question #6: Are you a neurophysiologist/epileptologist?**

- 1) Yes
- 2) No

**Question #7: How many years have you been in practice?**

- 1) 1-4
- 2) 5
- 3) 5-10
- 4) Over 10

**Question #8: What is your primary work setting?**

- 1) Academic based
- 2) Hospital based
- 3) Government based
- 4) Multispecialty group
- 5) Neurology group
- 6) Other private or public hospital or clinic
- 7) Solo practice

**Question #9: What is your current level of training?**

- 1) Faculty/Board certified physician
- 2) Resident/Fellow
- 3) Advanced practice provider

**Question #10: Do you practice in the United States?**

- 1) Yes
- 2) No

**Question #11a (if response to #10 = yes): In what state is your practice located?**

Dropdown menu with list of the 50 states

**Question #11b (if response to #10 = no): In what country is your practice located?**

Dropdown menu with list of countries