Appendix 1: Seizure Screen Part 1 & 2

Part 1. Seizure Screen

Read script to each participant

Children can have a variety of events that resemble seizures. We will begin with a list of behaviors that may relate to seizures or seizure-like events. Did any of the following happen to your child? Please answer each item with yes, no, or I don't know.

Ouestions

- 1) Has your child ever unexpectedly stared and not responded when you attempted to alert him/her? [SEP]
- 2) Has your child ever unexpectedly lost consciousness or awareness? [SEP]
- 3) Has your child ever unexpectedly lost her/his ability to talk or respond? [5]
- 4) Has your child ever unexpectedly lost the ability to move?
- 5) Has your child ever unexpectedly had abnormal twitches, jerks, trembles, or shakes of the arms, legs, head, face, or body?
- 6) Has your child ever unexpectedly stiffened or tightened the arms, legs, face, or body?
- 7) Has your child ever unexpectedly slumped over, collapsed, or become limp? [5]
- 8) Has your child ever unexpectedly had a period of confusion lasting minutes to an hour or two?
- 9) Has your child ever unexpectedly lost the ability to hold his/her head up when not appearing to be tired?
- 10) Has your child ever seen a doctor who diagnosed your child with one of the following: [SEP] a. epilepsy?[SEP] b. seizure or seizure disorder?[SEP] c. febrile seizures or seizures with fever? d. fits?[SEP] e. attacks? [SEP] f. spells?[SEP] convulsions? [SEP]
- 11) Has your child ever had an EEG (also called a brain wave test) during which wires were pasted to the scalp to record brain waves?

Part 2 Seizure Screen

The term episode refers to any event which is sudden and unexpected and lasted seconds to minutes. Not all episodes are seizures. An episode may cause different symptoms, such as a change in your child's consciousness, ability to respond, unusual movements of his arms or legs, or altered your child's ability to move normally.

Has your child ever had an episode? (Participant may answer yes or no.)

Do you think your child has had more than one type of episode? (Participant answers yes or no.) If so we will discuss these one at a time.

Questions 1-30 are asked for each episode type:

- 1. Does he/she lose awareness, become unresponsive, or lose consciousness?
- 2. Does he/she stare or get a glazed look? [SEP]
- 3 Does he/she suddenly become still or unresponsive?
- 4. Does he/she suddenly stop what he/she is doing?
- 5. During an episode, does your child have a change in his/ her ability to communicate? [5]
- 6. During an episode, does your child have a change in his/ her ability to follow commands?
- 7. During an episode, does your child have a change in his/ her ability to walk? [SEP]
- 8. During an episode, does your child have a change in his/ her ability to follow people purposefully with his/her eyes?
- 9. During an episode did you ever notice that his/her head and/or eyes are stuck to the left or right side?
- 10. During an episode did you ever notice that he/she has rhythmic or jerking eye movements to one side?
- 11. During an episode did you ever notice that he/she arches his/her back, arches his/her neck, or bends backward?
- 12. During an episode did you ever notice that he/she suddenly bends at the waist?
- 13. During an episode did you ever notice that he/she suddenly stiffens, jerks, twitches, or shakes only one side of the body?
- 14. During or after this type of episode did you ever notice that he/she stiffens, jerks, twitches, or shakes on both sides of the body?
- 15. During an episode, does he/she suddenly slump over, collapse, or go limp?
- 16. During an episode, does he/she ever gurgle or froth at the mouth?
- 17. During or after an episode, does he/she drool more than usual? [5]
- 18. During or after an episode, does he/she ever look dusky or blue in the face and/or lips?
- 19. During or after an episode, does he/she ever have trouble breathing or stop breathing?
- 20. During or after an episode, does he/she wet or soil himself/herself?
- 21. After an episode, does he/she become more sleepy than usual?[SEP]
- 22. After an episode, does he/she become more tired or slower to respond?
- 23. After an episode, does he/she have less energy or seem less active than usual?
- 24. After an episode, does he/she appear confused? LEP
- 25. After an episode, does he/she have difficulties talking or communicating?[5]
- 26. After an episode, does he/she have trouble understanding what is said? SEP!
- 27. After an episode, does he/she become weak or have more trouble than usual moving only one side of the body?[5]
- 28. Does this type of episode occur only when he/she is upset, mad, or in pain?
- 29. Does this type of episode occur only with fever?
- 30. Does this type of episode occur without fever?