

## **Standardized video protocol for affected individuals**

**Have the participant roll up sleeves to elbow, remove sock and shoes, roll pant legs up half-way to the knee, and put long hair up.**

**On a piece of paper write: research ID and date of videotaping.**

**If the child is not able to do all these tasks, try to videotape them in different positions, or modify these steps according to what they are able to do.**

### **Sitting position**

1. Film the piece of paper for 10 seconds.
2. Film the entire body of the participant sitting at rest, feet flat on the floor, arms relaxed, and one hand on each thigh.
  - a. If child is able to stay seated on the floor but not on a chair, film the entire body while the participant is seated;
  - b. If child is unable to remain seated, film the entire body while the participant is lying down on his/her back.

### **Head and Face**

Zoom in on the participant's head. If participant has motor control and understands commands, ask the participant to: (if not, skip to step 9)

3. Slowly turn head to the left, to the right, up, straight ahead, and downward.
4. Looking straight ahead, slowly tilt head to the right, touching ear to shoulder. Repeat to the left.
5. Close the eyes for 10 seconds. Then open the eyes for 10 seconds. Blink the eyes 10 times.
6. Open and close the mouth 5 times. Protrude the tongue for 5 seconds.

If participant is verbal proceed to 7-8, if not skip to step 9

7. Say any sentence (or any words in the case of younger children) in any language.
8. Count from 1 to 10 in any language or say the days of the week in any language.

### **Upper Body**

If participant has motor control and can understand commands proceed with steps 9-20.

If not skip to line 18.

9. Zoom in on the upper part of the body.
10. Have the arms outstretched straight in front of the participant, with fingers spread out, and palms down then open and close hands 2-5 times.
11. Slowly turn hands over so that the palms face the ceiling.
12. Slowly turn palms down again.
13. Make a "wing" position: (both elbows straight out to the side, each elbow bent with palms of hands facing the floor, and both hands facing toward each other; close but not touching)
14. Have someone hold their finger out in front of the participant, about an arm's length away from their face. Using index finger, touch the nose, then slowly

- extend arm to touch the other person's finger, extending the arm FULLY (if participant is unable to perform this task, hold out an object for the participant to reach and grab with each hand). Do this 2-5 times with each hand.
15. Write "it's a beautiful day" (or the equivalent in the language of the participant) on a piece of paper. If participant cannot write, simply film how they grasp the pen and try to write.
  16. Draw a spiral without the hand resting on the paper. Draw one with the right hand, then the left hand. Hold up the spiral. If participant cannot draw a spiral, simply film how they grasp the pen and try to draw.

### **Lower Body**

17. Do heel to toe taps 5 times with each foot. If unable to do heel to toe taps, ask participant to tap with their foot onto the floor while keeping the heel down.

### **Whole body/gait**

18. Zoom out to view the entire body. If participant was unable to perform the majority of tasks, film entire body movements for 1-2 minutes. If participant is ambulant, proceed with steps 19 and 20, If not end video.
19. Have the participant stand up. Film the front view for 10 seconds, side view for 5 seconds, and back view for 5 seconds.
20. Walk up and down a long hallway, going back and forth 2 times. Film the whole body; zoom into different body parts, especially the feet.