

Phenotype

Research Subject ID Research ID

Sleep apnea (Adult Protocol)

Height (m)

(PX091501)

Weight (kg)

(PX091501)

Age

(PX091501)

Gender

Male
 Female
(PX091501)

CATEGORY 1 Do you snore?

Yes
 No
 Don't know
(PX091501)

CATEGORY 1 Your snoring is

Slightly louder than breathing
 As loud as talking
 Louder than talking
 Very loud can be heard in adjacent rooms
(PX091501)

CATEGORY 1 How often do you snore?

Nearly every day
 3-4 times a week
 1-2 times a week
 1-2 times a month
 Never or nearly never
(PX091501)

CATEGORY 1 Has your snoring ever bothered other people?

Yes
 No
 Don't know
(PX091501)

CATEGORY 1 Has anyone noticed that you quit breathing during your sleep?

Nearly every day
 3-4 times a week
 1-2 times a week
 1-2 times a month
 Never or nearly never
(PX091501)

CATEGORY 2 How often do you feel tired or fatigued after your sleep?

- Nearly every day
 3-4 times a week
 1-2 times a week
 1-2 times a month
 Never or nearly never
 (PX091501)

CATEGORY 2 During your waking time, do you feel tired, fatigued, or not up to par?

- Nearly every day
 3-4 times a week
 1-2 times a week
 1-2 times a month
 Never or nearly never
 (PX091501)

CATEGORY 2 Have you ever nodded off or fallen asleep while driving a vehicle?

- Yes
 No
 (PX091501)

CATEGORY 2 How often does this occur?

- Nearly every day
 3-4 times a week
 1-2 times a week
 1-2 times a month
 Never or nearly never
 (PX091501)

CATEGORY 3 Do you have high blood pressure?

- Yes
 No
 Don't know
 (PX091501)

Sleep apnea (Child Protocol)

Today's date

(PX091502)

Where are you completing this questionnaire?

(PX091502)

Sex

- Male
 Female
 (PX091502)

Nighttime and sleep behavior: WHILE SLEEPING, DOES YOUR CHILD ever snore?

- Yes
 No
 Don't know
 (PX091502)

Nighttime and sleep behavior: WHILE SLEEPING, DOES YOUR CHILD snore more than half the time?

- Yes
 No
 Don't know
 (PX091502)

Nighttime and sleep behavior: WHILE SLEEPING, DOES YOUR CHILD always snore?

- Yes
 No
 Don't know
 (PX091502)

Nighttime and sleep behavior: WHILE SLEEPING, DOES YOUR CHILD snore loudly?

- Yes
 No
 Don't know
(PX091502)

Nighttime and sleep behavior: WHILE SLEEPING, DOES YOUR CHILD have "heavy" or loud breathing"?

- Yes
 No
 Don't know
(PX091502)

Nighttime and sleep behavior: WHILE SLEEPING, DOES YOUR CHILD have trouble breathing, or struggle to breathe?

- Yes
 No
 Don't know
(PX091502)

Nighttime and sleep behavior HAVE YOU EVER seen your child stop breathing during the night?

- Yes
 No
 Don't know
(PX091502)

If so, please describe what has happened:

(PX091502)

Nighttime and sleep behavior HAVE YOU EVER been concerned about your child's breathing during sleep?

- Yes
 No
 Don't know
(PX091502)

Nighttime and sleep behavior: HAVE YOU EVER had to shake your sleeping child to get him or her to breathe, or wake up and breathe?

- Yes
 No
 Don't know
(PX091502)

Nighttime and sleep behavior HAVE YOU EVER seen your child wake up with a snorting sound?

- Yes
 No
 Don't know
(PX091502)

Nighttime and sleep behavior DOES YOUR CHILD have restless sleep?

- Yes
 No
 Don't know
(PX091502)

Nighttime and sleep behavior DOES YOUR CHILD describe restlessness of the legs when in bed?

- Yes
 No
 Don't know
(PX091502)

Nighttime and sleep behavior: DOES YOUR CHILD have "growing pains" (unexplained leg pains)?

- Yes
 No
 Don't know
(PX091502)

Nighttime and sleep behavior: DOES YOUR CHILD have "growing pains" that are worst in bed?

- Yes
 No
 Don't know
(PX091502)

Nighttime and sleep behavior: WHILE YOUR CHILD SLEEPS, HAVE YOU SEEN brief kicks of one leg or both legs?

- Yes
 No
 Don't know
(PX091502)

Nighttime and sleep behavior: WHILE YOUR CHILD SLEEPS, HAVE YOU SEEN repeated kicks or jerks of the legs at regular intervals (i.e., about every 20 to 40 seconds)?

- Yes
 No
 Don't know
(PX091502)

Nighttime and sleep behavior: AT NIGHT, DOES YOUR CHILD USUALLY become sweaty, or do the pajamas usually become wet with perspiration?

- Yes
 No
 Don't know
(PX091502)

Nighttime and sleep behavior: AT NIGHT, DOES YOUR CHILD USUALLY get out of bed (for any reason)?

- Yes
 No
 Don't know
(PX091502)

Nighttime and sleep behavior: AT NIGHT, DOES YOUR CHILD USUALLY get out of bed to urinate?

- Yes
 No
 Don't know
(PX091502)

If YOUR CHILD USUALLY gets out of bed to urinate, how many times each night, on average?

(PX091502)

Does your child usually sleep with the mouth open?

- Yes
 No
 Don't know
(PX091502)

Is your child's nose usually congested or "stuffed" at night?

- Yes
 No
 Don't know
(PX091502)

Do any allergies affect your child's ability to breathe through the nose?

- Yes
 No
 Don't know
(PX091502)

DOES YOUR CHILD tend to breathe through the mouth during the day?

- Yes
 No
 Don't know
(PX091502)

DOES YOUR CHILD have a dry mouth on waking up in the morning?

- Yes
 No
 Don't know
(PX091502)

DOES YOUR CHILD complain of an upset stomach at night?

- Yes
 No
 Don't know
(PX091502)

DOES YOUR CHILD get a burning feeling in the throat at night?

- Yes
 No
 Don't know
(PX091502)
-

DOES YOUR CHILD grind his or her teeth at night?

- Yes
 No
 Don't know
(PX091502)
-

DOES YOUR CHILD occasionally wet the bed?

- Yes
 No
 Don't know
(PX091502)
-

Has your child ever walked during sleep ("sleep walking")?

- Yes
 No
 Don't know
(PX091502)
-

Have you ever heard your child talk during sleep ("sleep talking")?

- Yes
 No
 Don't know
(PX091502)
-

Does your child have nightmares once a week or more on average?

- Yes
 No
 Don't know
(PX091502)
-

Has your child ever woken up screaming during the night?

- Yes
 No
 Don't know
(PX091502)
-

Has your child ever been moving or behaving, at night, in a way that made you think your child was neither completely awake nor asleep?

- Yes
 No
 Don't know
(PX091502)
-

If so, please describe what has happened:

(PX091502)

Does your child have difficulty falling asleep at night?

- Yes
 No
 Don't know
(PX091502)
-

How long does it take your child to fall asleep at night? (a guess is O.K.)

(PX091502)

At bedtime does your child usually have difficult "routines" or "rituals" argue a lot, or otherwise behave badly?

- Yes
 No
 Don't know
(PX091502)

DOES YOUR CHILD bang his or her head or rock his or her body when going to sleep?

- Yes
 No
 Don't know
(PX091502)

DOES YOUR CHILD wake up more than twice a night on average?

- Yes
 No
 Don't know
(PX091502)

DOES YOUR CHILD have trouble falling back asleep if he or she wakes up at night?

- Yes
 No
 Don't know
(PX091502)

DOES YOUR CHILD wake up early in the morning and have difficulty going back to sleep?

- Yes
 No
 Don't know
(PX091502)

Does the time at which your child goes to bed change a lot from day to day?

- Yes
 No
 Don't know
(PX091502)

Does the time at which your child gets up from bed change a lot from day to day?

- Yes
 No
 Don't know
(PX091502)

WHAT TIME DOES YOUR CHILD USUALLY go to bed during the week?

(PX091502)

WHAT TIME DOES YOUR CHILD USUALLY go to bed on the weekend or vacation?

(PX091502)

WHAT TIME DOES YOUR CHILD USUALLY get out of bed on weekday mornings?

(PX091502)

WHAT TIME DOES YOUR CHILD USUALLY get out of bed on weekend or vacation mornings?

(PX091502)

DOES YOUR CHILD wake up feeling unrefreshed in the morning?

- Yes
 No
 Don't know
(PX091502)

DOES YOUR CHILD have a problem with sleepiness during the day?

- Yes
 No
 Don't know
(PX091502)

DOES YOUR CHILD complain that he or she feels sleepy during the day?

- Yes
 No
 Don't know
(PX091502)

Has a teacher or other supervisor commented that your child appears sleepy during the day?

- Yes
 No
 Don't know
(PX091502)

Does your child usually take a nap during the day?

- Yes
 No
 Don't know
(PX091502)

Is it hard to wake your child up in the morning?

- Yes
 No
 Don't know
(PX091502)

Does your child wake up with headaches in the morning?

- Yes
 No
 Don't know
(PX091502)

Does your child get a headache at least once a month, on average?

- Yes
 No
 Don't know
(PX091502)

Did your child stop growing at a normal rate at any time since birth?

- Yes
 No
 Don't know
(PX091502)

If so, please describe what happened:

(PX091502)

Does your child still have tonsils?

- Yes
 No
 Don't know
(PX091502)

When were they removed?

(PX091502)

Why were they removed?

(PX091502)

HAS YOUR CHILD EVER had a condition causing difficulty with breathing?

- Yes
 No
 Don't know
(PX091502)

If so, please describe:

(PX091502)

HAS YOUR CHILD EVER had surgery?

- Yes
 No
 Don't know
(PX091502)

Did any difficulties with breathing occur before, during, or after surgery?

- Yes
 No
 Don't know
(PX091502)

HAS YOUR CHILD EVER become suddenly weak in the legs, or anywhere else, after laughing or being surprised by something?

- Yes
 No
 Don't know
(PX091502)

HAS YOUR CHILD EVER felt unable to move for a short period, in bed, though awake and able to look around?

- Yes
 No
 Don't know
(PX091502)

Has your child felt an irresistible urge to take a nap at times, forcing him or her to stop what he or she is doing in order to sleep?

- Yes
 No
 Don't know
(PX091502)

Has your child ever sensed that he or she was dreaming (seeing images or hearing sounds) while still awake?

- Yes
 No
 Don't know
(PX091502)

Does your child drink caffeinated beverages on a typical day (cola, tea, coffee)?

- Yes
 No
 Don't know
(PX091502)

How many cups or cans per day?

(PX091502)

Does your child use any recreational drugs?

- Yes
 No
 Don't know
(PX091502)

Which recreational drugs does your child use?

(PX091502)

How often does your child use recreational drugs?

(PX091502)

Does your child use cigarettes, smokeless tobacco, snuff, or other tobacco products?

- Yes
 No
 Don't know
(PX091502)

Which tobacco products does your child use?

(PX091502)

How often does your child use cigarettes, smokeless tobacco, snuff, or other tobacco products?

(PX091502)

Is your child overweight?

- Yes
 No
 Don't know
(PX091502)

At what age did this first develop?

(PX091502)

Has a doctor ever told you that your child has a high-arched palate (roof of the mouth)?

- Yes
 No
 Don't know
(PX091502)

Has your child ever taken Ritalin (methylphenidate) for behavioral problems?

- Yes
 No
 Don't know
(PX091502)

Has a health professional ever said that your child has attention-deficit disorder (ADD) or attention-deficit/hyperactivity disorder (ADHD)?

- Yes
 No
 Don't know
(PX091502)

If you are currently at a clinic with your child to see a physician, what is the problem that brought you?

(PX091502)

If your child has long-term medical problems, please list the three you think are most significant.

(PX091502)

If your child has long-term medical problems, please list the three you think are most significant.

(PX091502)

If your child has long-term medical problems, please list the three you think are most significant.

(PX091502)

Sleep apnea (Child Protocol) Current Medication

Please list any medications your child currently takes

Medicine 1.

(PX091502)

Medicine 1 Size (mg) or amount per dose.

(PX091502)

Medicine 1 Taken how often?

(PX091502)

Medicine 1 Dates Taken.

(PX091502)

Medicine 1 Effect.

(PX091502)

Medicine 2

(PX091502)

Medicine 2 Size (mg) or amount per dose.

(PX091502)

Medicine 2 Taken how often?

(PX091502)

Medicine 2 Dates Taken.

(PX091502)

Medicine 2 Effect.

(PX091502)

Medicine 3

(PX091502)

Medicine 3 Size (mg) or amount per dose.

(PX091502)

Medicine 3 Taken how often?

(PX091502)

Medicine 3 Dates Taken.

(PX091502)

Medicine 3 Effect.

(PX091502)

Medicine 4

(PX091502)

Medicine 4 Size (mg) or amount per dose.

(PX091502)

Medicine 4 Taken how often?

(PX091502)

Medicine 4 Dates Taken.

(PX091502)

Medicine 4 Effect.

(PX091502)

Sleep apnea (Child Protocol)Past Medications

Please list any medication your child has taken in the past if the purpose of the medication was to improve his or her behavior, attention, or sleep:

Medicine 1.

(PX091502)

Medicine 1 Size (mg) or amount per dose.

(PX091502)

Medicine 1Taken how often?

(PX091502)

Medicine 1 Dates Taken.

(PX091502)

Medicine 1 Effect.

(PX091502)

Medicine 2

(PX091502)

Medicine 2 Size (mg) or amount per dose.

(PX091502)

Medicine 2 Taken how often?

(PX091502)

Medicine 2 Dates Taken.

(PX091502)

Medicine 2 Effect.

(PX091502)

Medicine 3

(PX091502)

Medicine 3 Size (mg) or amount per dose.

(PX091502)

Medicine 3 Taken how often?

(PX091502)

Medicine 3 Dates Taken.

(PX091502)

Medicine 3 Effect.

(PX091502)

Medicine 4

(PX091502)

Medicine 4 Size (mg) or amount per dose.

(PX091502)

Medicine 4 Taken how often?

(PX091502)

Medicine 4 Dates Taken.

(PX091502)

Medicine 4 Effect.

(PX091502)

Please list any sleep disorders diagnosed or suspected by a physician in your child.

(PX091502)

The date the sleep disorder started?

(PX091502)

Is the sleep disorder still present?

Yes
 No
(PX091502)

Please list any sleep disorders diagnosed or suspected by a physician in your child.

(PX091502)

The date the sleep disorder started?

(PX091502)

Is the sleep disorder still present?

Yes
 No
(PX091502)

Please list any sleep disorders diagnosed or suspected by a physician in your child.

(PX091502)

The date the sleep disorder started?

(PX091502)

Is the sleep disorder still present?

Yes
 No
(PX091502)

Please list any sleep disorders diagnosed or suspected by a physician in your child.

(PX091502)

The date the sleep disorder started?

(PX091502)

Is the sleep disorder still present?

Yes
 No
(PX091502)

Please list any psychological, psychiatric, emotional, or behavioral problems diagnosed or suspected by a physician in your child.

(PX091502)

The date the psychological, psychiatric, emotional, or behavioral problem started?

(PX091502)

Is the psychological, psychiatric, emotional, or behavioral problem still present?

Yes
 No
(PX091502)

Please list any psychological, psychiatric, emotional, or behavioral problems diagnosed or suspected by a physician in your child.

(PX091502)

The date the psychological, psychiatric, emotional, or behavioral problem started?

(PX091502)

Is the psychological, psychiatric, emotional, or behavioral problem still present?

Yes
 No
(PX091502)

Please list any psychological, psychiatric, emotional, or behavioral problems diagnosed or suspected by a physician in your child.

(PX091502)

The date the psychological, psychiatric, emotional, or behavioral problem started?

(PX091502)

Is the psychological, psychiatric, emotional, or behavioral problem still present?

Yes
 No
(PX091502)

Please list any psychological, psychiatric, emotional, or behavioral problems diagnosed or suspected by a physician in your child.

(PX091502)

The date the psychological, psychiatric, emotional, or behavioral problem started?

(PX091502)

Is the psychological, psychiatric, emotional, or behavioral problem still present?

Yes
 No
(PX091502)

Please list any sleep or behavior disorders diagnosed or suspected in your child's brothers, sisters, or parents:

Relative 1

(PX091502)

Condition 1

(PX091502)

Relative 2

(PX091502)

Condition 2

(PX091502)

Relative 3

(PX091502)

Condition 3

(PX091502)

Please print any additional comments you feel are important. Please also describe details regarding any of the above questions.

(PX091502)

This child often does not seem to listen when spoken to directly.

- Does not apply
 - Applies just a little
 - Applies quite a bit
 - Definitely applies most of the time
- (PX091502)
-

This child often has difficulty organizing tasks and activities.

- Does not apply
 - Applies just a little
 - Applies quite a bit
 - Definitely applies most of the time
- (PX091502)
-

This child often is easily distracted by extraneous stimuli.

- Does not apply
 - Applies just a little
 - Applies quite a bit
 - Definitely applies most of the time
- (PX091502)
-

This child often fidgets with hands or feet or squirms in seat.

- Does not apply
 - Applies just a little
 - Applies quite a bit
 - Definitely applies most of the time
- (PX091502)
-

This child often is "on the go" or often acts as if "driven by a motor".

- Does not apply
 - Applies just a little
 - Applies quite a bit
 - Definitely applies most of the time
- (PX091502)
-

This child often interrupts or intrudes on others (e.g., butts into conversations or games.)

- Does not apply
 - Applies just a little
 - Applies quite a bit
 - Definitely applies most of the time
- (PX091502)
-

Pediatric migraine disability assessment (pedmidas)

How many full school days of school were missed in the last 3 months due to headaches?

_____ (PX130502)

How many partial days of school were missed in the last 3 months due to headaches (do not include full days counted in the first question)?

_____ (PX130502)

How many days in the last 3 months did you function at less than half your ability in school because of a headache (do not include days counted in the first two questions)?

_____ (PX130502)

How many days were you not able to do things at home (i.e., chores, homework, etc.) due to a headache?

_____ (PX130502)

How many days did you not participate in other activities due to headaches (i.e., play, go out, sports, etc.)?

_____ (PX130502)

How many days did you participate in these activities, but functioned at less than half your ability (do not include days counted in the 5th question)?

_____ (PX130502)

Headache Frequency

_____ (PX130502)

Headache Severity

_____ (PX130502)

Pediatric NIH stroke scale (pednihss)

1a. Level of Consciousness: the investigator must choose a response, even if a full evaluation is prevented by such obstacles as an endotracheal tube, language barrier, orotracheal trauma/bandages. A 3 is scored only if the patient makes no movement (other than reflexive posturing) in response to noxious stimulation.

- 0 - Alert; keenly responsive.
 - 1 - Not alert, but arousable by minor stimulation to obey, answer, or respond.
 - 2 - Not alert, requires repeated stimulation to attend, or is obtunded and requires strong or painful stimulation to make movements (not stereotyped).
 - 3 - Responds only with reflex motor or autonomic effects or totally unresponsive, flaccid, areflexic.
- (PX0820802)

1b. LOC Questions: The patient is asked the month and his/her age. The answer must be correct - there is no partial credit for being close. Aphasic and stuporous patients who do not comprehend the questions will score 2. Patients unable to speak because of endotracheal intubation, orotracheal trauma, severe dysarthria from any cause, language barrier, or any other problem not secondary to aphasia are given a 1. It is important that only the initial answer be graded and that the examiner not "help" the patient with verbal or non-verbal cues. Modified for children age 2 years and up. A familiar Family Member must be present for this item: Ask the child 'how old are you' Or 'How many years old are you?' for question number one. Give credit if the child states the correct age.

- 0 - Answers both questions correctly.
 - 1 - Answers one question correctly.
 - 2 - Answers neither question correctly.
- (PX0820802)

1c. LOC Commands: The patient is asked to open and close the eyes and then to grip and release the non-paretic hand. For children one may substitute the command to grip the hand with the command 'show me your nose' or 'touch your nose'. Substitute another one step command if the hands cannot be used. Credit is given if an unequivocal attempt is made but not completed due to weakness. If the patient does not respond to command, the task should be demonstrated to them (pantomime) and score the result (i.e., follows none, one or two commands). Patients with trauma, amputation, or other physical impediments should be given suitable one-step commands. Only the first attempt is scored.

- 0 - Performs both tasks correctly
 - 1 - Performs one task correctly
 - 2 - Performs neither task correctly
- (PX0820802)

2. Best Gaze: Only horizontal eye movements will be tested. Voluntary or reflexive (oculocephalic) eye movements will be scored but caloric testing is not done. If the patient has a conjugate deviation of the eyes that can be overcome by voluntary or reflexive activity, the score will be 1. If a patient has an isolated peripheral nerve paresis (CN III, IV or VI) score a 1. Gaze is testable in all aphasic patients. Patients with ocular trauma, bandages, pre-existing blindness or other disorder of visual acuity or fields should be tested with reflexive movements and a choice made by the investigator. Establishing eye contact and then moving about the patient from side to side will occasionally clarify the presence of a partial gaze palsy.

- 0 - Normal
 - 1 - Partial gaze palsy. This score is given when gaze is abnormal in one or both eyes, but where forced deviation or total gaze paresis are not present.
 - 2 - Forced deviation, or total gaze paresis not overcome by the oculocephalic maneuver.
- (PX0820802)

3. Visual: Visual fields (upper and lower quadrants) are tested by confrontation, using finger counting (for children > 6 years) or visual threat (for children age 2 to 6 years) as appropriate. Patient must be encouraged, but if they look at the side of the moving fingers appropriately, this can be scored as normal. If there is unilateral blindness or enucleation, visual fields in the remaining eye are scored. Score 1 only if a clear-cut asymmetry, including quadrantanopia is found. If patient is blind from any cause score 3. Double simultaneous stimulation is performed at this point. If there is extinction patient receives a 1 and the results are used to answer question 11.

- 0 - No visual loss
 - 1 - Partial hemianopia
 - 2 - Complete hemianopia
 - 3 - Bilateral hemianopia (blind including cortical blindness)
- (PX0820802)

4. Facial Palsy: Ask, or use pantomime to encourage the patient to show teeth or raise eyebrows and close eyes. Score symmetry of grimace in response to noxious stimuli in the poorly responsive or non-comprehending patient. If facial trauma/bandages, orotracheal tube, tape or other physical barrier obscures the face, these should be removed to the extent possible.

- Normal symmetrical movement
 - Minor paralysis (flattened nasolabial fold, asymmetry on smiling)
 - Partial paralysis (total or near total paralysis of lower face)
 - Complete paralysis of one or both sides (absence of facial movement in the upper and lower face)
- (PX0820802)

5a. Motor Arm and Leg: LEFT ARM - The limb is placed in the appropriate position: extend the arms (palms down) 90 degrees (if sitting) or 45 degrees (if supine) and the leg 30 degrees (always tested supine). Drift is scored if the arm falls before 10 seconds or the leg before 5 seconds. For children too immature to follow precise directions or uncooperative for any reason, power in each limb should be graded by observation of spontaneous or elicited movement according to the same grading scheme, excluding the time limits. The aphasic patient is encouraged using urgency in the voice and pantomime but not noxious stimulation. Each limb is tested in turn, beginning with the non-paretic arm. Only in the case of amputation or joint fusion at the shoulder or hip, or immobilization by an IV board, may the score be 9 and the examiner must clearly write the explanation for scoring as a 9. Score each limb separately.

- 0 - No drift, limb holds 90 (or 45) degrees for full 10 seconds.
 - 1 - Drift, Limb holds 90 (or 45) degrees, but drifts down before full 10 seconds; does not hit bed or other support.
 - 2 - Some effort against gravity, limb cannot get to or maintain (if cued) 90 (or 45) degrees, drifts down to bed, but has some effort against gravity.
 - 3 - No effort against gravity, limb falls.
 - 4 - No movement
 - 9 - Amputation, joint fusion explain below:
- (PX0820802)

5b. Motor Arm and Leg: LEFT ARM - Only in the case of amputation or joint fusion at the shoulder or hip, or immobilization by an IV board, may the score be "9" and the examiner must clearly write the explanation for scoring as a "9". Score each limb separately. Explain:

(PX0820802)

5c. Motor Arm and Leg: RIGHT ARM - The limb is placed in the appropriate position: extend the arms (palms down) 90 degrees (if sitting) or 45 degrees (if supine) and the leg 30 degrees (always tested supine). Drift is scored if the arm falls before 10 seconds or the leg before 5 seconds. For children too immature to follow precise directions or uncooperative for any reason, power in each limb should be graded by observation of spontaneous or elicited movement according to the same grading scheme, excluding the time limits. The aphasic patient is encouraged using urgency in the voice and pantomime but not noxious stimulation. Each limb is tested in turn, beginning with the non-paretic arm. Only in the case of amputation or joint fusion at the shoulder or hip, or immobilization by an IV board, may the score be 9 and the examiner must clearly write the explanation for scoring as a 9. Score each limb separately.

- 0 - No drift, limb holds 90 (or 45) degrees for full 10 seconds.
- 1 - Drift, Limb holds 90 (or 45) degrees, but drifts down before full 10 seconds; does not hit bed or other support.
- 2 - Some effort against gravity, limb cannot get to or maintain (if cued) 90 (or 45) degrees, drifts down to bed, but has some effort against gravity.
- 3 - No effort against gravity, limb falls.
- 4 - No movement
- 9 - Amputation, joint fusion explain below: (PX0820802)

5d. Motor Arm and Leg: RIGHT ARM - Only in the case of amputation or joint fusion at the shoulder or hip, or immobilization by an IV board, may the score be 9 and the examiner must clearly write the explanation for scoring as a 9. Score each limb separately. Explain:

(PX0820802)

6a. Motor Arm and Leg: LEFT LEG - The limb is placed in the appropriate position: extend the arms (palms down) 90 degrees (if sitting) or 45 degrees (if supine) and the leg 30 degrees (always tested supine). Drift is scored if the arm falls before 10 seconds or the leg before 5 seconds. For children too immature to follow precise directions or uncooperative for any reason, power in each limb should be graded by observation of spontaneous or elicited movement according to the same grading scheme, excluding the time limits. The aphasic patient is encouraged using urgency in the voice and pantomime but not noxious stimulation. Each limb is tested in turn, beginning with the non-paretic arm. Only in the case of amputation or joint fusion at the shoulder or hip, or immobilization by an IV board, may the score be 9 and the examiner must clearly write the explanation for scoring as a 9. Score each limb separately.

- 0 - No drift, leg holds 30 degrees position for full 5 seconds.
- 1 - Drift, leg falls by the end of the 5 second period but does not hit bed.
- 2 - Some effort against gravity; leg falls to bed by 5 seconds, but has some effort against gravity.
- 3 - No effort against gravity, leg falls to bed immediately.
- 4 - No movement
- 9 - Amputation, joint fusion explain below: (PX0820802)

6b. Motor Arm and Leg: LEFT LEG - Only in the case of amputation or joint fusion at the shoulder or hip, or immobilization by an IV board, may the score be 9 and the examiner must clearly write the explanation for scoring as a 9. Score each limb separately. Explain:

(PX0820802)

6c. Motor Arm and Leg: RIGHT LEG - The limb is placed in the appropriate position: extend the arms (palms down) 90 degrees (if sitting) or 45 degrees (if supine) and the leg 30 degrees (always tested supine). Drift is scored if the arm falls before 10 seconds or the leg before 5 seconds. For children too immature to follow precise directions or uncooperative for any reason, power in each limb should be graded by observation of spontaneous or elicited movement according to the same grading scheme, excluding the time limits. The aphasic patient is encouraged using urgency in the voice and pantomime but not noxious stimulation. Each limb is tested in turn, beginning with the non-paretic arm. Only in the case of amputation or joint fusion at the shoulder or hip, or immobilization by an IV board, may the score be 9 and the examiner must clearly write the explanation for scoring as a 9. Score each limb separately.

- 0 - No drift, leg holds 30 degrees position for full 5 seconds.
- 1 - Drift, leg falls by the end of the 5 second period but does not hit bed.
- 2 - Some effort against gravity; leg falls to bed by 5 seconds, but has some effort against gravity.
- 3 - No effort against gravity, leg falls to bed immediately.
- 4 - No movement
- 9 - Amputation, joint fusion explain below: (PX0820802)

6d. Motor Arm and Leg: RIGHT LEG - Only in the case of amputation or joint fusion at the shoulder or hip, or immobilization by an IV board, may the score be 9 and the examiner must clearly write the explanation for scoring as a 9. Score each limb separately. Explain:

(PX0820802)

7. Limb Ataxia: This item is aimed at finding evidence of a unilateral cerebellar lesion. Test with eyes open. In case of visual defect, insure testing is done in intact visual field. The finger-nose-finger and heel-shin tests are performed on both sides, and ataxia is scored only if present out of proportion to weakness. In children, substitute this task with reaching for a toy for the upper extremity, and kicking a toy or the examiner's hand, in children too young (< 5 years) or otherwise uncooperative for the standard exam item. Ataxia is absent in the patient who cannot understand or is paralyzed. Only in the case of amputation or joint fusion may the item be scored 9 and the examiner must clearly write the explanation for not scoring. In case of blindness test by touching nose from extended arm position.

- 0 - Absent
 - 1 - Present in one limb
 - 2 - Present in two limbs
- (PX0820802)

8. Sensory: Sensation or grimace to pin prick when tested, or withdrawal from noxious stimulus in the obtunded or aphasic patient. For children too young or otherwise uncooperative for reporting gradations of sensory loss, observe for any behavioral response to pin prick, and score it according to the same scoring scheme as a 'normal' response, 'mildly diminished' or 'severely diminished' response. Only sensory loss attributed to stroke is scored as abnormal and the examiner should test as many body areas [arms (not hands), legs, trunk, face] as needed to accurately check for hemisensory loss. A score of 2, severe or total should only be given when a severe or total loss of sensation can be clearly demonstrated. Stuporous and aphasic patients will therefore probably score 1 or 0.

- 1 - Normal; no sensory loss.
- 2 - Mild to moderate sensory loss; patient feels pinprick is less sharp or is dull on the affected side; or there is a loss of superficial pain with pinprick but patient is aware he/she is being touched.
- 3 - Severe to total sensory loss; patient is not aware of being touched in the face, arm, and leg. (PX0820802)

9. Best Language: A great deal of information about comprehension will be obtained during the preceding sections of the examination. For children age 6 years and up with normal language development before onset of stroke: The patient is asked to describe what is happening in the attached picture, to name the items on the attached naming sheet, to repeat words from the attached list, and to read from the attached list of sentences (Table S1; Fig S1, S2, S3). Comprehension is judged from responses here as well as to all of the commands in the preceding general neurological exam. If visual loss interferes with the tests, ask the patient to identify objects placed in the hand, repeat, and produce speech. The intubated patient should be asked to write. The patient in coma (question 1a=3) will arbitrarily score 3 on this item. The examiner must choose a score in the patient with stupor or limited cooperation but a score of 3 should be used only if the patient is mute and follows no one step commands. For children age 2 yrs to 6 yrs (or older children with premorbid language skills < 6 yr level), score this item based on observations of language comprehension and speech during the examination. The patient with brain stem stroke who has bilateral loss of sensation is scored 2. If the patient does not respond and is quadriplegic score 2. Patients in coma (item 1a=3) are arbitrarily given a 2 on this item.

- 0 - No aphasia, normal
- 1 - Mild to moderate aphasia; some obvious loss of fluency or facility of comprehension, without significant limitation on ideas expressed or form of expression. Reduction of speech and/or comprehension, however, makes conversation about provided material difficult or impossible. For example in conversation about provided materials examiner can identify picture or naming card from patient's response.
- 2 - Severe aphasia; all communication is through fragmentary expression; great need for inference, questioning, and guessing by the listener. Range of information that can be exchanged is limited; listener carries burden of communication. Examiner cannot identify materials provided from patient response.
- 3 - Mute, global aphasia; no usable speech or auditory comprehension.
(PX0820802)

Fluency and word finding:

The picture (IMAGE 1) is presented and the child is asked to describe what he/she sees.

IMAGE - image_1_820802

Language testing items for PedNIHSS:

Repetition:

Each of 4 word-repetition tasks is presented:

- a. Stop
- b. Stop and go
- c. If it rains we play inside
- d. The President lives in Washington

Reading:

Each of 3 items is presented for the child to read in IMAGE 3. Adjust expectations according to child's age/school level

Naming:

Pictures are presented and of a clock, pencil, skateboard, shirt, baseball, bicycle (IMAGE 2).

IMAGE - image_2_820802

IMAGE - image_3_820802

10. Dysarthria: If patient is thought to be normal an adequate sample of speech must be obtained by asking patient to read or repeat words from the attached list. If the patient has severe aphasia, the clarity of articulation of spontaneous speech can be rated. Only if the patient is intubated or has other physical barrier to producing speech, may the item be scored '9' and the examiner must clearly write an explanation for not scoring. Do not tell the patient why he/she is being tested.

- 0 - Normal
 1 - Mild to moderate; patient slurs at least some words and, at worst, can be understood with some difficulty.
 2 - Severe; patient's speech is so slurred as to be unintelligible in the absence of or out of proportion to any dysphasia, or is mute/anarthric.
 9 - Intubated or other physical barrier, explain below:
 (PX0820802)

10a. Dysarthria: Only if the patient is intubated or has other physical barrier to producing speech, may the item be scored '9' and the examiner must clearly write an explanation for not scoring. Do not tell the patient why he/she is being tested.

(PX0820802)

11. Extinction and Inattention (formerly Neglect): Sufficient information to identify neglect may be obtained during the prior testing. If the patient has a severe visual loss preventing visual double simultaneous stimulation, and the cutaneous stimuli are normal, the score is normal. If the patient has aphasia but does appear to attend to both sides, the score is normal. The presence of visual spatial neglect or anosagnosia may also be taken as evidence of abnormality. Since the abnormality is scored only if present, the item is never untestable.

- 0 - No abnormality.
 1 - Visual, tactile, auditory, spatial, or personal inattention or extinction to bilateral simultaneous stimulation in one of the sensory modalities.
 2 - Profound hemi-inattention or hemi-inattention to more than one modality. Does not recognize own hand or orients to only one side of space.
 (PX0820802)

Migraine

1. Over the past year, have you suffered from severe headaches?

- Yes
 No
 (PX0130501)

2. Age

(year | | PX0130501)

4. When you have a severe headache, do you experience any of the following? (check all that apply)

- Nausea
 Vomiting
 One side of head only
 Pulsating/throbbing headaches
 Pain-free intervals of days or weeks between severe headache attacks
 Sensitivity to light
 Sensitivity to noise
 Blurring of vision
 Seeing shimmering lights, circles, other shapes, or colors before the eyes, before the headache starts
 Numbness of lips, tongue, fingers, or legs before the headache starts
 (PX0130501)

4a. About how often do your severe headaches occur? (Write In Number Of Headache Days You Have Per Week, Month or Year - please specify which in answer)

(week, month, year | | PX0130501)

5. Which statement best describes the pain of your severe headaches? (Check ONE)

- Extremely severe pain
 Severe pain
 Moderately severe pain
 Mild pain
(PX0130501)

6. Which best describes how you are usually affected by severe headaches? (Check ONE)

- Able to work/function normally
 Working ability or activity impaired to some degree
 Working ability or activity severely impaired
 Bed rest required
(PX0130501)

7. Each time you have a severe headache, how long are you unable to work or undertake normal activities? (Check ONE)

- 0 days (no activity restriction)
 Less than 1 day
 1-2 days
 3-5 days
 6 or more days
(PX0130501)

8. On how many days in the last 3 months did you have a headache (if headache lasted more than 1 day, count each day)?

_____ (day | | PX0130501)

9a. Because of your headaches on how many days in the last 3 months... ? did you miss work or school

_____ (day | | PX0130501)

9b. Because of your headaches on how many days in the last 3 months... ? was your productivity at work/school reduced by half or more (not including days missed in qu. 9a above)

_____ (day | | PX0130501)

9c. Because of your headaches on how many days in the last 3 months... ? did you not do household work

_____ (day | | PX0130501)

9d. Because of your headaches on how many days in the last 3 months... ? was your productivity in house-hold work reduced by half or more (not including days counted in qu. 9c above)

_____ (day | | PX0130501)

9e. Because of your headaches on how many days in the last 3 months... ? did you miss family, social, or leisure activities

_____ (day | | PX0130501)

10. At what age did you BEGIN having severe headaches?

_____ (year | | PX0130501)

11. Have you ever gone to the hospital emergency room or to an urgent care clinic because of your severe headaches?

- Yes
 No
(PX0130501)

12. Which best describes the way you usually treat severe headaches? (Check ONE)

- Take non-prescription medications
 Take prescription medications
 Take both prescription and non-prescription medications
 Take no medications
(PX0130501)

13. Have you ever taken prescription medication for headache on a DAILY basis, whether or not you have a headache, to help prevent a severe headache from happening in the first place?

- Yes
 No
(PX0130501)

14. Are you currently taking any other medication on a DAILY basis? (Check all that apply)

- Water pill or prescription diuretic for high blood pressure
 Prescription medicine (other than water pill) for high blood pressure
 Prescription medicine for seizures, epilepsy, or fits
 Prescription medicine for diabetes
 Prescription medicine for cholesterol
 Prescription medicine for depression or anxiety
(PX0130501)

15. When did you last take prescription medication for headache on a DAILY basis to help prevent a severe headache from happening in the first place? (Check ONE)

- Currently taking
 Last took within the past 3 months
 Last took 3 to 12 months ago
 Last took more than 12 months ago
 Never took
(PX0130501)

16. Do you consider your severe headaches to be migraines?

- Yes
 No
(PX0130501)

17. Have you ever been diagnosed by a physician or other health professional as suffering from... (Check all that apply)

- Tension headaches
 Sinus headaches
 Cluster headaches
 Stress headaches
 Sick headaches
 Migraine headaches
(PX0130501)

18. If diagnosed with migraines, at what age were you FIRST DIAGNOSED with migraines?

_____ (year | | PX0130501)

19a. Height - in feet?

_____ (foot | | PX0130501)

19b. Height - in inches?

_____ (inch | | PX0130501)

Scoring Instructions

In Lipton et al. (2001), respondents were classified as suffering from migraine if they fulfill the criteria for migraine with aura and migraine without aura established in 1998 by the International Headache Society (IHS) (Headache Classification Committee of the International Headache Society, 1998). This included one or more severe headache in the last year with "unilateral or pulsatile pain, and either nausea, vomiting, or phonophobia with photophobia; or visual or sensory aura before the headache" (Lipton et al., 2001). These criteria were updated by the International Headache Society in 2004 (Headache Classification Subcommittee of the International Headache Society, 2004).