



Neurocognitive Enrollment Criteria Form

GENERAL INSTRUCTIONS

The Neurocognitive Enrollment Criteria (NE) form is completed for all patients two years of age or older and enrolled in the PALF Cohort study at the 6 month and the 12 month follow-up visit. This form is to be completed by the coordinator prior to completion of any neurocognitive battery assessments.

The Neurocognitive Enrollment Criteria form captures inclusion and exclusion criteria for determining patient eligibility to complete the Neurocognitive Comprehensive Battery.

Patients who do not complete the Neurocognitive comprehensive battery at the 6 month follow-up visit are eligible to participate in the neurocognitive battery at the 12 month follow-up visit.

SPECIFIC INSTRUCTIONS

Patient ID: Record the Patient ID.

Date of Determination: Record the date (month/day/year) that eligibility was determined.

Timepoint: Check the follow-up timepoint corresponding to the follow-up visit.

Section I: Inclusion Criteria

Inclusion Criteria: For each criterion, check "Yes" or "No" to indicate whether or not the patient meets the criterion. The response to all inclusion criteria must be YES for a patient to be eligible for the Neurocognitive Comprehensive Battery. If a criterion is unknown or not assessed leave the response blank.

PALF enrollment: The patient must be enrolled in the PALF Cohort study.

Age: To meet this criterion, the patient must be between

- a) 2 years, 0 months, 0 days and 16 years, 0 months, 0 days at the time of PALF Cohort enrollment, and
- b) 3 years, 0 months, 0 days and 16 years, 11 months, 29 days at the 12 month time point

Patient language: The patient must speak fluent English.

Parent/guardian language: The parent/guardian must speak fluent English.

Section II: Exclusion Criteria

Exclusion Criteria: Check "Yes" or "No" to indicate if the patient meets any of the following exclusion criteria. The response to all exclusion criteria must be NO for a patient to be eligible for the Neurocognitive Comprehensive Battery. If a criterion is unknown or not assessed leave the response blank.

Awaiting liver transplantation: If the patient is not on the transplant list or if the patient is on the transplant list, but has no evidence of cirrhosis with portal hypertension, check "No." If the patient is on the transplant list and has evidence of cirrhosis with portal hypertension, check "Yes."

Cancer diagnosis: The patient is not eligible if there was a past cancer diagnosis.

Hospitalization: The patient is not eligible if there has been any in-patient hospitalization in the four weeks prior to the neurocognitive testing date.



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Uncontrolled seizures: If the patient has no history of seizures, check “No.”

If a patient has a history of seizures and meets at least two of the following, check “No.”

- a) Patient must be seizure free for at least one month
- b) Patients with refractory seizures, must have had no recent increase in seizure frequency above their established baseline during the previous month
- c) Patients should not have had a change in anti-epileptic regimen in the last month

If a patient has had a history of seizures and does not meet at least two of the above criteria, check “Yes.”

No speech: The patient is not eligible if he/she does not speak any intelligible words or is not able to follow simple commands.

If the patient does not have speech or cannot follow simple commands, check “Before the ALF episode” or “After the ALF episode” to indicate when this began.

Weakness: If the patient has weakness or abnormality of muscle tone or coordination due to disease, such as cerebral palsy, and this is sufficiently severe that it impairs his/her ability to perform physical tasks required for testing, check “Yes.”

To assess the level of coordination and strength, use the subset of the NIH stroke scale. The child is asked to hold up each arm, extended with the palm pronated for 10 seconds while the examiner counts the time. If the patient cannot raise their dominant arm for the 10 seconds, check “Yes.” If the patient’s arm drifts from the elevated position, but they can sustain 10 seconds with their arm raised, check “No.”

If a patient is excluded due to weakness, then indicate the level of severity and when this began using the following table:

Table 1. Severity of Cerebral Palsy⁽¹⁻³⁾

	Gross Motor	Fine Motor	Cognitive	Speech	Overall
Mild	Independent walker	Unlimited function	IQ > 70	More than 2 words	Independent life
Moderate	Supported walk or creep	Limited function	IQ 50-70	Single words	Needs assistance
Severe	No locomotion	No function	IQ < 50	Indistinct	Total Care

References:

- 1) Russman BS, Disorders of motor execution I Cerebral Palsy. In Child and Adolescent Neurology. Editor David RB. 1998: 453-68.
- 2) Minear WL: A classification of cerebral palsy, *Pediatrics* 1956 18;841
- 3) Veelken N et al Diplegia cerebral palsy in Swedish term and preterm children. *Neuropediatrics* 1983 14;20.

Section III: Enrollment

Eligibility: All inclusion criteria must be met and none of the exclusion criteria met for the patient to be eligible for the Neurocognitive Comprehensive Battery.

Check “Yes” or “No” to indicate whether or not the patient meets all eligibility criteria for the PALF Neurocognitive Comprehensive Battery.



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- Enrollment:** Check “Yes” or “No” to indicate whether or not the patient is enrolled in the PALF Neurocognitive Comprehensive Battery.
- Not enrolled:** Indicate the reason the patient was not enrolled.
- Enrolled:** Current medications: review the current medications taken by the child, and update the Medication Log.
- BRIEF teacher form:** Indicate if a BRIEF-teacher form was sent to the child’s primary teacher (the teacher with whom the child spends the most time) for elementary students or the child’s English/Language Arts teacher for middle and high school students. If yes, record the date (month/day/year) the form was sent. If no, indicate the reason the letter was not sent. If the reason the BRIEF-teacher was not sent is because the patient is cyber/home schooled, check “Yes” or “No” to indicate whether the patient was being cyber/home schooled prior to their episode of PALF.
- If testing is to occur during the summer months, the examiner should prepare the teacher packet with the prior year teacher’s contact information to send when school restarts. Leave this question missing and update when the letter is sent.
- Psychologist appointment scheduled:** For the 12 month timepoint, indicate the date the psychologist appointment is scheduled. Update the date as necessary if the appointment is rescheduled. If the participant does not attend the psychologist appointment (and the appointment will not be rescheduled), indicate the reason the participant did not attend.