

Visit 5: Neuropsychological Assessment

Objective: At this visit you will have neuropsychological testing.

In this section:

- Neuropsychological testing at the PKU Clinic: Frequently Asked Questions
- This might be a good place to keep the report once your assessment is complete.

At this visit:

- Nutrition assessment- bring your 3 day food record to clinic
- Physical assessment-a brief visit with PKU doctor
- Neuropsychological assessment
- Confirm next visit

Who is involved:

- **You**
- Your support team:
 - Your parents
 - PKU clinic physician
 - PKU clinic psychologist
 - PKU clinic nutritionist



Cristine M. Trahms Program for Phenylketonuria
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Neuropsychological Testing at the PKU Clinic Frequently Asked Questions

What is neuropsychological testing?

Neuropsychological testing is the term used to describe the series of tasks performed to evaluate brain function. The testing is done in a specific manner so that the scores of the person being tested can be compared to the performance of other people of the same age.

Examples of the types of activities at a neuropsychological testing session include reading comprehension tests (similar to standardized tests you may take at school), problem solving tests, tests of memory, and intelligence ("IQ") tests.

What is does neuropsychological mean?

Neuropsychological is a term that describes a way to look at brain function by summarizing the results of a series of organized mental tasks. For example, the mental tasks of memory and problem solving are important skills for successful learning.

Who is tested?

In the PKU Clinic everyone with PKU is tested at specific ages from age three to adulthood. You have probably completed one or more of the neuropsychological testing sessions when you were 10, 12 or 15 years old.

Why is it important to repeat the tests at specific ages?

There are two reasons. 1) It is important to know that people with PKU are continuing to learn more each year and they are able to use this new information in more complex ways. Information about how you learn can also be used to help you develop strategies for doing your best during high school, vocational training, and college. 2) If a person with PKU has high blood phe levels for a long time, intellectual skills may begin to decrease. This information can be compared to previous performance scores to help the person motivate him or herself to re-double his or her efforts at maintaining low phe blood levels.

What are the tests like?

Different tests are given to a person depending on his or her age and previous testing results. The tests are all given in a 'standardized manner' which means that everyone who takes the test has the same amount of time and the same prompts. This is so that the person's scores can be compared to his or her previous scores and also to the whole group of people of the same age. The tests measure overall intelligence as well as specific skills that help with efficient learning. The tasks that are generally measured are memory, processing speed and skill, and executive function. The role of memory is well understood by everyone. Processing speed and skill and executive function tasks measure the ability to make a plan for using the information that is presented in the problem, to use one's memory of similar problems, and to come up with a solution to the problem.



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What do the test results mean?

A person's scores are compared to 'national norms' obtained from a large group of people of the same age. This is called 'norm referencing'. Scores are also compared to a person's previous scores to look at increased intellectual skills over time or at the effect of changes in blood levels since the previous testing.

How do I know what the scores mean?

Standardized test scores are reported in a variety of ways. They may be called 'T-scores', 'scaled scores' or 'standard scores'. Scores used to measure intelligence are called standard scores. Standard scores have an average of 100, with most people's scores falling between 85-115 (the average range).

An example of how test scores will be presented to you:

Area	Standard Score*	Percentile Rank
Verbal	107	68

* Standard scores have an average of 100, with most people's scores falling between 85 and 115.

Judy's score (107) was in the range that most people score (85-115) and her score was better than 68% of the people her age.

What if I have questions about my scores?

Interpreting testing scores is a complex task. You will have an opportunity to meet with the psychologist after you have finished your testing. The scores will be explained to you and your parents so that we are sure that you understand the scores. The meeting with the psychologist to talk about your scores will be at the visit following your testing. It takes quite a bit of time to score your hard work on the tests, compare your scores with the norms, and then organize the scores so they will be understandable to you.

How can I prepare myself for testing?

The most important thing you can do for yourself is to get a good night's sleep before your appointment. If you are ill, tired, or hungry you will perform less well than if you are well, rested, and comfortable.

After I am 18 and transition to the adult PKU Clinic will I ever have to take these tests again?

Generally a person has developed his or her full intellectual ability by age 18 even though we all keep on learning throughout our lives. You will not be requested to take this set of tests again unless you are having difficulties with learning in college or keeping a job. Tests that are given to a person who is having difficulties are meant to look at specific problems rather than assess capabilities so they are different from these tests.



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Assessment of the PKU Adolescent Transition Curriculum

Session 5.

Objective: At this visit you will have neuropsychological testing

Post Session Objective: Each participant will be able to explain why neuropsychological testing is important.

I. Please tell us three things that you have learned during this visit

1)

2)

3)



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