Sanfilippo Syndrome Behavior Rating Scale

Sanfilippo Syndrome

The Sanfilippo Behavior Rating Scale questionnaire can define Sanfilippo syndrome behavior along a specific pattern and progression of behavioral symptoms. Currently, there is no scale specifically for the disease. Sanfilippo syndrome (also known as Mucopolysaccharidosis type III) is a genetic neurological disease which manifests early in life, generally ending in death in adolescence with dementia. Symptoms of the disease include increasingly impaired cognitive ability, seizures, language loss and other behavioral problems. Without a rating scale, physicians track behavior clinically, often referring to psychiatrists without any systematic method of organizing data.

Understanding Effects of Sanfilippo Treatment

A rating scale allows physicians to better understand and monitor the progression of behaviors in Sanfilippo syndrome and facilitates monitoring of the effects of new treatments. The Sanfilippo Behavior Rating Scale (SBRS) was developed with the use of a questionnaire, completed by parents, along 68 specific behaviors grouped into 15 functional categories.

Benefits of Sanfilippo Syndrome (Mucopolysaccharidosis type III) Rating Scale:

- Facilitates understanding of the progression of behaviors in Sanfilippo syndrome
- Allows physicians to monitor the effects of new treatments on Sanfilippo syndrome behaviors
- Only behavior rating scale specifically designed for Sanfilippo Syndrome

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Licenses for the Sanfilippo Behavior Rating Scale

The Sanfilippo Behavior Rating Scale licenses allow the Scale to be used in either clinics or research. The license fee is based on the number of patients that the Scale will be used with during the life of the study or the length of time the Scale is in use at a clinic. The term of the license is perpetual.

- the Large Clinic or Research license is for licensees who will use the Scale with more than ten patients for the term of the license.
- the Medium Clinic or Research license is for licensees who will use the Scale for research with ten or fewer patients OR in a clinic with three to ten patients. The number of patients is for the term of the license.
- the Small Clinic license is for licensees who will use the Scale for one or two patients in a clinic.
- the Academic license is for licensees who are teachers or students in an academic institution and will use the Scale for teaching and student projects.

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