



Sanfilippo Syndrome Behavior Rating Scale (SBRS) (20130141, Dr. Elsa Shapiro)

Technology ID
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Category

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Questionnaires
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Sanfilippo Syndrome

The Sanfilippo Behavior Rating Scale questionnaire can define Sanfilippo syndrome behavior along a specific pattern and progression of behavioral symptoms. This is the only known scale specifically for the syndrome. 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

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.

- Large Clinic or Research license -- for licensees who will use the Scale with more than ten patients for the term of the license.
- Medium Clinic or Research license -- 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.
- Small Clinic license -- for licensees who will use the Scale for one or two patients in a clinic.
- Academic license -- for licensees who are teachers or students in an academic institution and will use the Scale for teaching and student projects.
- Translation license -- to use the Scale in a language other than in English (see list below).
- License to Create Translations -- for licensees interested in translating the scale to languages other than the ones listed below.

Available Translations

The Sanfilippo Behavior Rating Scale is available in the following languages:

- English - US
- English - Australia
- English - UK
- Spanish - US
- Spanish - Colombia
- Spanish - Spain
- Chinese - Taiwan
- Dutch - Netherlands
- German - Germany
- Japanese - Japan
- Portuguese – Brazil
- Turkish - Turkey

Licensees interested in translating the scale to other languages must purchase 1) an appropriate license to use the scale (\$100-\$2,000), 2) a license to create translation (\$0), and agree to share the new translated work with the University.

Researchers

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[External Link](http://shapironeuropsych.com) (shapironeuropsych.com)

Publications

[*Quantifying behaviors of children with Sanfilippo syndrome: The Sanfilippo Behavior Rating Scale*](#)

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