

Surveillance Protocol for schwannomatosis

	Exam or surveillance	Interval	Age to Start	Strength*
Schwannomatosis	Clinical examination and assessment for pain and neurological examination	Annual	12-14 years	Moderate
Schwannomas	Brain and spine MRI	According to specific gene / age recommendations	Diagnosis or 12-14 years	Strong
	Whole-Body MRI	Baseline or soon after. Consider alternating with Craniospinal-	Diagnosis or 12-14 years	Moderate
	Ultrasound	Consider for problem solving in limbs or intercostal-	As appropriate	Moderate

*This grading is based on published articles and expert consensus: strong - expert consensus AND consistent evidence, moderate - expert consensus WITH inconsistent evidence AND/OR new evidence likely to support the recommendation, weak - expert majority decision WITHOUT consistent evidence

Surveillance Protocol

Schwannomatosis

This guideline has been drawn from the best available evidence and the consensus of experts in this area and it is regularly updated to reflect changes in evidence.

The expectation is that clinicians will follow this guideline, unless there is a compelling clinical reason specific to an individual patient not to.



**European
Reference
Network**

for rare or low prevalence
complex diseases

 **Network**
Genetic Tumour Risk
Syndromes (ERN GENTURIS)



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