

Schwannomatosis (SCWN) CLINICAL PATHWAY

The Patient Clinical Pathway is “the whole care pathway from identification, diagnostics, and multidisciplinary case discussions to surveillance and preventive surgery”, so indeed a pathway in time, focusing on HOW

Annual Review Recommended

At time of diagnosis, or possible diagnosis, ALL patients should be seen in a genetics department.

Care can be co-ordinated through the schwannomatosis MDT team by an appropriate specialist

Annual review should be undertaken by a recognised specialist.

Patients, other local specialists and GPs have telephone access to the NF Reference Centre for NF-related concerns.


AGE	DIAGNOSTIC APPOINTMENT	REVIEWS CARRIED OUT BY	MRI head and spine
<12 50% risk or child of sporadic schwannomatosis patient or tested positive for family pathogenic variant (PV)	Based on symptoms	Care can be coordinated through the schwannomatosis MDT team by an appropriate specialist.	Not required unless symptomatic
12-15 50% risk	Confirmation of diagnosis & assessment. Genetic testing & counselling for family. Discharge if negative for family PV or on linkage	Care can be coordinated through the schwannomatosis MDT team by an appropriate specialist.	Symptom check at SCWN review and Baseline MRI and MRI 3-yearly if no tumours
<16 affected already with schwannomas	Confirmation of diagnosis & assessment. Genetic counselling for family.	Care can be coordinated through the schwannomatosis MDT team by an appropriate specialist. At least annual with paediatric neurologist.	6-month MRI after diagnosis and then 2-3 yearly MRI* unless symptomatic
12-15 offspring of a schwannomatosis patient and tested positive for PV	Confirmation of diagnosis & assessment. Genetic counselling for family.	Care can be coordinated through the schwannomatosis MDT team by an appropriate specialist. Annual with paediatric neurologist.	2-3 yearly MRI* until tumours identified
≥16 Affected with schwannomas	Confirmation of diagnosis & assessment. Genetic counselling for family.	Care can be coordinated through the schwannomatosis MDT team by an appropriate specialist. At least annual with team.	6-month MRI after diagnosis and then 2-3 yearly MRI* unless symptomatic
≥16 50% risk	Confirmation of diagnosis & assessment. Genetic testing & counselling for family Discharge if negative for family PV or on linkage	Care can be coordinated through the schwannomatosis MDT team by an appropriate specialist. Symptom check.	Baseline MRI and MRI 3-5 -yearly if no tumours. Stop screening aged 40-50.
≥16 offspring of a schwannomatosis patient and tested positive for PV	Confirmation of diagnosis & assessment. Genetic counselling for family.	Care can be coordinated through the schwannomatosis MDT team by an appropriate specialist. Symptom check.	Annual symptom check. Baseline MRI and MRI 2-3 -yearly* if no tumours. Stop screening age 70 if no tumours.

*Whole Body MRI can be alternated

Schwannomatosis Review Checklist—Children (0–16)		
	WHAT TO LOOK FOR	WHEN TO REFER
SKIN	Subcutaneous nodules that move beneath skin and can often feel on thickened nerve	If symptomatic or needed for genetic diagnosis
NEUROLOGICAL	Neurological symptom review, particularly loss of neurological function	If loss of function
Schwannomatosis Review Checklist—Adults (16+)		
	WHAT TO LOOK FOR	WHEN TO REFER
SKIN	Check for symptomatic lesions	If symptomatic or needed for genetic diagnosis
PSYCHOLOGICAL BURDEN	Effects are underestimated. Psychological problems are common but patients, may be reluctant to talk about these issues and need encouragement.	
NEUROLOGICAL	Neurological symptom review, particularly headaches, nerve pain, and visual and gait disturbances and loss of muscle function including mononeuropathy	If loss of function
PAIN	It's important review quality, intensity and location of pain.	Uncontrolled pain



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 <p>Schwannomatosis (SCWN) Clinical Pathway</p> <p>Faculty:</p>	<p>Family name:</p> <p>Given name(s):</p> <p>Address:</p> <p>Date of Birth: Sex: <input type="checkbox"/> M <input type="checkbox"/> F <input type="checkbox"/> I</p>
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Annual Review Recommended

At time of diagnosis, or possible diagnosis, ALL patients should be seen in a genetics department. **Care can be co-ordinated through the schwannomatosis MDT team by an appropriate specialist.** Annual review of symptoms should be undertaken by a recognised specialist. Patients, other local specialists and GPs have telephone access to the NF Reference Centre for NF-related concerns.

AGE	DIAGNOSTIC APPOINTMENT	ANNUAL SCWN REVIEWS OF SYMPTOMS CARRIED OUT BY	MRI head and spine
<12 50% risk or child of sporadic schwannomatosis patient or tested positive for family PV	Based on symptoms	Care can be co-ordinated through the schwannomatosis MDT team by an appropriate specialist.	Not required unless symptomatic
12-15 50% risk	Confirmation of diagnosis & assessment. Genetic testing & counselling for family. Discharge if negative for family PV or on linkage		Baseline MRI and MRI 3-yearly if no tumours
≥16 50% risk			Baseline MRI and MRI 3-5 -yearly if no tumours. Stop screening aged 40-50
12-15 offspring of a schwannomatosis patient and tested positive for PV	Confirmation of diagnosis & assessment. Genetic counselling for family.		2-3 yearly MRI* until tumours identified
≥16 offspring of a schwannomatosis patient and tested positive for PV			Baseline MRI and MRI 2-3 -yearly* if no tumours. Stop screening age 70 if no tumours
<16 affected already with schwannomas			6-month MRI after diagnosis and then 2-3 yearly MRI* unless symptomatic
≥16 Affected with schwannomas			6-month MRI after diagnosis and then 2-3 yearly MRI* unless symptomatic

* Whole Body MRI can be alternated

Review Checklist – Adults (16+)

<p>Clinical Presentation:</p> <p>..... <input type="checkbox"/></p> <p>..... <input type="checkbox"/></p> <p>..... <input type="checkbox"/></p> <p>Other symptoms:</p> <p>.....</p> <p>Genetic counselling completed <input type="checkbox"/></p> <p>Date Completed:</p> <p>Clinical diagnosis</p> <p>.....</p> <p>Genetic Test '+ve <input type="checkbox"/></p> <p>Diagnosis Date:</p>	<p>General Health Check:</p> <p>Please record the follow as soon as possible and then annually:</p> <p>Height</p> <p>Weight</p> <p>Blood Pressure</p> <p>.....</p>	<p style="text-align: center;">WHAT TO LOOK FOR</p> <p>SKIN: check for symptomatic lesions.</p> <p>Psychological burden: Effects are underestimated. Psychological problems are common but patients, may be reluctant to talk about these issues and need encouragement.</p> <p>Neurological symptom review, particularly headaches, nerve pain, visual and gait disturbances and loss of muscle function including mononeuropathy.</p> <p>Pain: It is important to review quality, intensity and location of pain.</p>	<p style="text-align: center;">WHEN TO REFER</p> <p>If symptomatic or needed for genetic diagnosis.</p> <p><input type="checkbox"/> Date Referred:</p> <p>Consider REFERRAL to an appropriate counselling service.</p> <p><input type="checkbox"/> Date Referred:</p> <p>REFER to Complex National Reference Centre or neurologist if loss of function.</p> <p><input type="checkbox"/> Date Referred:</p> <p>REFER to pain specialist if uncontrolled pain.</p> <p><input type="checkbox"/> Date Referred:</p>
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Notes:


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Doctor:

Review date:

Faculty:



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Care Pathway schwannomatosis version 1.3 – accepted 26-09-2021

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