

Resources to Support Oncology Nurses in the Care of Patients With NF1

RESOURCE	BEST FOR	NOTES
 2021 Revised Diagnostic Criteria for NF1 and Legius Syndrome nature.com/articles/s41436-021-01170-5	Diagnosis, differential diagnosis, genetics	Essential for clinicians evaluating children with pigmentary findings, mosaic NF1, Legius syndrome, or incomplete clinical criteria. The consensus update incorporates advances in genetics, ophthalmology, dermatology, and neuroimaging.
 AAP/American College of Medical Genetics and Genomics (ACMG): Health Supervision for Children With NF1 publications.aap.org/pediatrics/article/143/5/e20190660/37168/Health-Supervision-for-Children-With	Pediatric primary care and subspecialty coordination	Still the key U.S. pediatric surveillance framework. It emphasizes NF1 as a multisystem, age-dependent disorder and provides anticipatory guidance for development, vision, skeletal issues, blood pressure, neurologic signs, and family counseling.
 ACMG: Care of Adults With NF1 nature.com/articles/gim201828	Current treatment landscape	Useful for updating clinicians on evolving NF1-plexiform neurofibroma (PN) care, mitogen-activated protein kinase kinase (MEK) inhibitor use, surveillance, natural history, multidisciplinary care, and remaining evidence gaps.
 European Reference Network on Genetic Tumour Risk Syndromes (ERN GENTURIS) NF1 Tumor Surveillance Guideline thelancet.com/journals/eclinm/article/PIIS2589-5370(22)00547-8/fulltext	Tumor surveillance across children and adults	One of the most useful current NF1 clinician resources. It integrates surveillance for plexiform neurofibromas, malignant peripheral nerve sheath tumors (MPNSTs), optic pathway gliomas, breast cancer, pheochromocytomas/paragangliomas, gastrointestinal stromal tumors (GISTs), glomus tumors, and other NF1-associated tumors. The guideline was developed by a multidisciplinary European expert group with patient representatives and is published in <i>EClinicalMedicine</i>.

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 Neuro-Oncology consensus/review resources on NF1-PN management academic.oup.com/neuro-oncology/article/28/4/847/8466018	Plexiform neurofibroma management	The 2022 <i>Neuro-Oncology</i> consensus-style review on NF1-associated plexiform neurofibromas is a strong practical resource for multidisciplinary decision-making, surgery, imaging, morbidity assessment, and MEK inhibitor-era management.
 GeneReviews: Neurofibromatosis 1 ncbi.nlm.nih.gov/books/NBK1109	Genetics, inheritance, phenotype spectrum	Detailed, regularly maintained clinical genetics review. Strong for diagnostic workup, genotype-phenotype considerations, counseling, and family testing. Orphanet also links clinicians to GeneReviews and related rare-disease resources.
 ClinicalTrials.gov clinicaltrials.gov	Trials and natural history studies	Best source for identifying active, recruiting, and completed NF1 studies; useful for referral, clinical trial matching, and understanding evolving endpoints.
 Children's Tumor Foundation clinician/research resources ctf.org/research-tools-resources	NF clinic network, registry, research updates	Useful for identifying NF specialty clinics, connecting patients with registries, and tracking translational/research developments.