

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

GENERAL NEUROFIBROMATOSIS TYPE 1 (NF1) RESOURCES

RESOURCE	BEST USE	WHY IT IS USEFUL
 Children's Tumor Foundation (CTF) ctf.org	Excellent all-around NF/NF1 hub	CTF has NF1 education, downloadable patient brochures, clinic-finder resources, an NF Registry, clinical-trial information, and materials in multiple languages. Its "Diagnosed with NF1" brochure is specifically written for people living with NF1 and caregivers.
 CTF Find a Doctor/NF Clinic Network ctf.org/find-a-doctor	Finding NF-experienced care	CTF's clinic designation system identifies NF clinics and centers with NF expertise, patient education, research activity, and comprehensive or specialty NF care.
 Neurofibromatosis Network nfnetwork.org	Advocacy, community support, doctor-finding	A U.S.-based NF advocacy organization focused on federal research funding, NF community-building, support groups, education, and "Find a Doctor" resources.
 National Institutes of Health (NIH)/ National Institute of Neurological Disorders and Stroke (NINDS) Neurofibromatosis ninds.nih.gov/health-information/ disorders/neurofibromatosis	Government-vetted overview	Clear NIH overview of NF diagnosis, clinical features, genetics, and treatment concepts. Good for families who want a noncommercial medical summary.

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 MedlinePlus / MedlinePlus Genetics medlineplus.gov/neurofibromatosis.html	Plain-language medical and genetics education	Patient-facing NIH/National Library of Medicine (NLM) material covering NF and NF1, with links to medical encyclopedia pages, Spanish-language resources, and genetics/inheritance information.
 NF Registry / CTF Registry ctf.org/nfregistry	Research participation and natural-history contribution	A patient-powered NF registry where people with NF can securely share health information and lived experience to support natural-history research, drug development, clinical-trial planning, and care improvement.
 ClinicalTrials.gov clinicaltrials.gov	Finding active or completed NF1 studies	Best government source for clinical trial listings. It includes NF1 natural-history and interventional studies, but families should review any study with their NF specialist before acting.

PEDIATRIC AND FAMILY-SPECIFIC RESOURCES

RESOURCE	BEST USE	WHY IT IS USEFUL
 Children's Hospital of Philadelphia (CHOP) NF1 resources chop.edu/centers-programs/neurofibromatosis-program	Pediatric NF1 care and family support	CHOP provides NF1 resources created by NF1 experts, including caregiver-facing materials and links to support resources.
 Littlest Tumor Foundation littlesttumor.org	Family support and educational resources	A nonprofit NF-focused resource center for families seeking support, education, and practical resources.
 Childhood Tumour Trust childhoodtumourtrust.org.uk	Child/family NF1 support, especially United Kingdom (UK)-facing	Provides practical NF1 information for children and families, including guidance on pain, plexiform neurofibromas, and when to seek specialist input.

CARE TRANSITION AND ADULT NF1 RESOURCES

RESOURCE	BEST USE	WHY IT IS USEFUL
 CTF “Living with NF1: A Guide for Adults” ctf.org/wp-content/uploads/2023/11/CTF-Adults-with-NF-Brochure.pdf	Adult NF1 education	Adult-specific guide covering common manifestations, complications, and the importance of ongoing NF-specialist care.
 Neurofibromatosis Northeast nfnortheast.org	Support programs and transition resources	Offers patient and family programs and participates in NF Collective projects, including resources for transition from pediatric to adult care.
 Nerve Tumours UK nervetumours.org.uk	Adult/family NF1 education and practical documents	UK charity with NF1 support materials, helplines, and downloadable patient information documents. Useful even outside the UK for general education, though local care pathways differ.
 Got Transition gottransition.org	Advice about transitioning children to adult care	While not exclusively NF1 focused, it provides evidence-driven strategies for health care professionals, youth, young adults, and their families on moving children with chronic medical conditions from childhood care models into adult care models that are applicable to children with NF1.

MORE MEDICALLY DETAILED BUT STILL USEFUL FOR EDUCATED PATIENTS/CAREGIVERS

RESOURCE	BEST USE	WHY IT IS USEFUL
 NIH Genetic and Rare Diseases Information Center (GARD) rarediseases.info.nih.gov/diseases/10420/neurofibromatosis	Rare-disease navigation and help finding information	GARD is designed to provide current, reliable, plain-language rare-disease information and access to information specialists.
 American Academy of Pediatrics (AAP) clinical report: Health Supervision for Children With NF1 publications.aap.org/pediatrics/article/143/5/e20190660/37168/Health-Supervision-for-Children-With	Pediatric surveillance framework	Written for clinicians rather than families, but very helpful for understanding recommended monitoring and transition issues in children with NF1.
 Johns Hopkins NF1 page hopkinsmedicine.org/neurology-neurosurgery/specialty-areas/neurofibromatosis	Academic medical-center overview	Clear overview of NF1 genetics, symptoms, variability, and monitoring/treatment concepts from a major NF center.