LIVESTREAM

MEK Inhibitors in Neurofibromatosis Type 1

Nursing Contributions to NF1-PN Management

SYLLABUS & COURSE GUIDE

A free, 60-minute live activity

Premiere date: Saturday, September 27, 2025

12:00 PM–1:00 PM ET

LOGIN

https://ceconcepts.com/MEKSTREAM

PRESENTING FACULTY

Amy Armstrong, MD
Aerang Kim, MD, PhD
Sanita Burgic, MSN, APRN, AGNP-C

Take advantage of our LIVE Q&A segment during this webcast!

- Click on the Ask Question tab to type and submit a question.
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- Call Creative Educational Concepts at 859.260.1717.

Information for Participants

TARGET AUDIENCE

Pediatric hematology/oncology nurses

OVERVIEW

Neurofibromatosis type 1 (NF1) treatment options and management strategies are evolving, and the multiplicity of clinical manifestations, both near- and long-term, makes diagnosis and management of the disease complex. The development of plexiform neurofibromas (PNs) further negatively impacts patients' clinical outcomes and quality of life. These challenges necessitate an integrated, longitudinal management approach that encompasses the totality of the interprofessional, multidisciplinary team of clinicians in pediatric and adult care settings.

In this CEC Oncology livestream, case-based symposium, expert faculty will discuss key characteristics of clinical presentation and disease advancement over a lifespan; review patient and caregiver education needs on the integration of MEK inhibitors in the management of NF1-associated PNs; and explore the role of nurses in comprehensive care plans, including disease monitoring, treatment personalization, toxicity management, and transitioning care of patients with NF1 across their lifespan

LEARNING OBJECTIVES

At the conclusion of this activity, learners will be able to better:

- Distinguish key characteristics of NF1 clinical presentation and disease progression across patient's lifespan, including genetic etiology and multisystem pathophysiology of NF1, that impact early and accurate diagnosis
- Provide patient and caregiver education on MEK inhibitors in the management of NF1-associated PNs in pediatric patients
- Examine the role of oncology nurses in comprehensive care plans, including disease monitoring, treatment personalization, toxicity management, and transitioning the care of patients with NF1 across their lifespan

FINANCIAL SUPPORT

Supported by independent educational grants from Alexion Pharmaceuticals and SpringWorks Therapeutics Inc.

Faculty

AMY ARMSTRONG, MD
Associate Professor of Pediatrics
Director, Solid Tumor Program
Co-Director, Adolescent and Young Adult Sarcoma Program
Washington University School of Medicine
St. Louis Children's Hospital
Division of Pediatric Hematology/Oncology
St. Louis, Missouri

Amy Armstrong, MD, is a pediatric oncologist who directs the Solid Tumor Program at Siteman Kids, affiliated with St. Louis Children's Hospital, as well as co-directs the Adolescent and Young Adult Sarcoma Program in collaboration with Siteman Kids and Siteman Cancer Center. She is an associate professor of pediatrics at Washington University–St. Louis and has research interests in neurofibromatosis type 1 (NF1)–related plexiform neurofibromas (PNs), renal tumors, and sarcomas found most in the adolescent and young adult population. Dr. Armstrong serves as the site principal investigator for the Children's Oncology Group, Neurofibromatosis Clinical Trials Consortium, and National Pediatric Cancer Foundation, and is invested in conducting and developing clinical trials to serve a diverse range of solid tumors in both the upfront and relapsed setting.

AERANG KIM, MD, PHD
Director of Clinical Research, Division of Oncology
The Lexi Speight Professor of Pediatric Oncology
Children's National Hospital
Washington, DC

AeRang Kim, MD, PhD, is a professor of pediatrics with tenure, director of clinical research in the Division of Oncology, and solid tumors attending at Children's National Hospital in Washington, DC. Her research has focused on the clinical development of novel therapeutics for pediatric solid tumors, sarcomas, and neurofibromatosis type 1 (NF1)–associated tumors, in particular malignant peripheral nerve sheath tumors (MPNST). She serves as the MPNST disease committee chair for the Department of Defense Clinical Trials Consortium and the co-director for the Focused Ultrasound Foundation Center of Excellence at Children's National. With collaborators and federal funding support, Dr. Kim has developed and led early phase trials of novel combination therapeutics for pediatric patients with solid tumors including sarcoma.

SANITA BURGIC, MSN, APRN, AGNP-C
Nurse Practitioner
Division of Medical Oncology
Washington University School of Medicine
St. Louis, Missouri

Sanita Burgic, MSN, APRN, AGNP-C, works as an oncology nurse practitioner at WashU Siteman Cancer Center in St. Louis, Missouri, specializing in the care of patients with breast cancer and cancer predisposition syndromes. Her role involves not only managing complex treatment plans but also providing education and emotional support to patients and their families. She is passionate about advocacy, research, and improving healthcare outcomes for individuals facing rare and hereditary cancers. Outside of work, Ms. Burgic enjoys traveling, volunteering, and organizing community fundraisers for humanitarian causes. She has a deep interest in cultural history, cooking traditional dishes, and staying active outdoors. These personal passions help her stay grounded and bring balance to the emotionally demanding nature of oncology care.

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- Treatment

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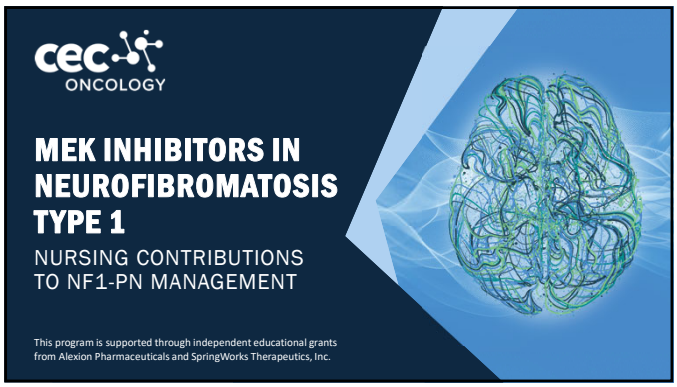
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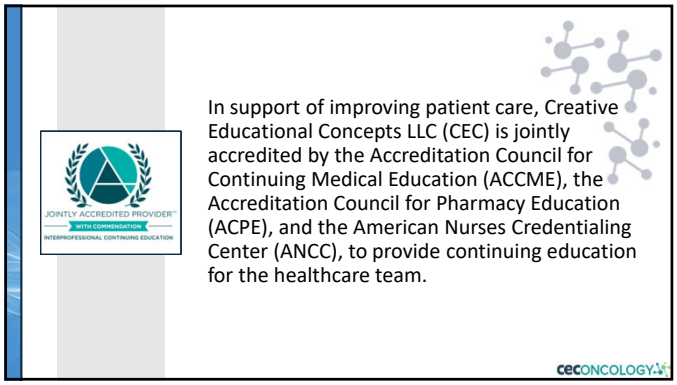
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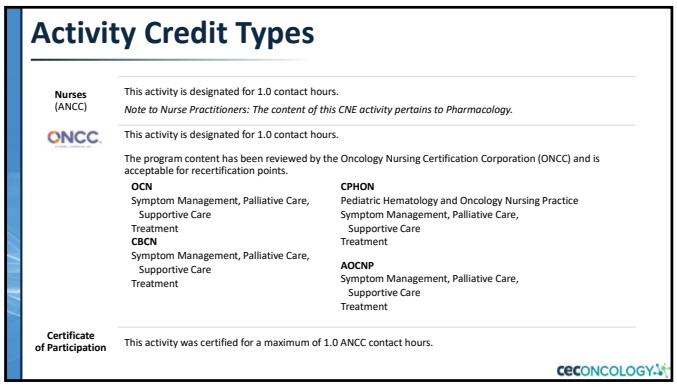
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Treatment
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Symptom Management, Palliative Care, Supportive Care
Treatment
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7

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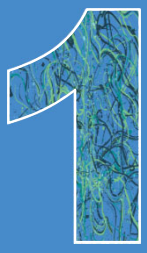
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- Nichole Lainhart (planning committee)
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- Sandra Caballero, PharmD (planning committee)
- Sharon Tordoff (planning committee)

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LEARNING OBJECTIVE



Distinguish key characteristics of NF1 clinical presentation and disease progression across patient's lifespan, including genetic etiology and multisystem pathophysiology of NF1, that impact early and accurate diagnosis

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LEARNING OBJECTIVE 2

Provide patient and caregiver education on MEK inhibitors in the management of NF1-associated PNs in pediatric patients

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LEARNING OBJECTIVE 3

Examine the role of oncology nurses in comprehensive care plans, including disease monitoring, treatment personalization, toxicity management, and transitioning the care of patients with NF1 across their lifespan

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To Ask a Question

To submit a question, please go to the ***Ask Question*** tab at the bottom of the screen.

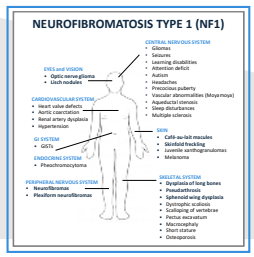
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Neurofibromatosis Type 1

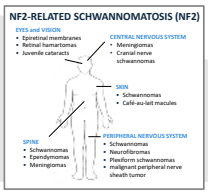
Clinical Features and Diagnostic Criteria

13

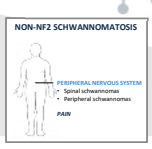
Neurofibromatosis



1 in 2,800 people worldwide



1 in 67,700 people worldwide



1 in 158,000 people worldwide

GIST, gastrointestinal stromal tumors.

Friedman JM. Neurofibromatosis 1. In: *GeneReviews*. Updated April 3, 2025. https://www.ncbi.nlm.nih.gov/books/NBK1109/.
Moodley M, et al. *Semin Pediatr Neurol*. 2024;52:101172. Lee TJ, et al. *Orphanet J Rare Dis*. 2023;18(1):292.

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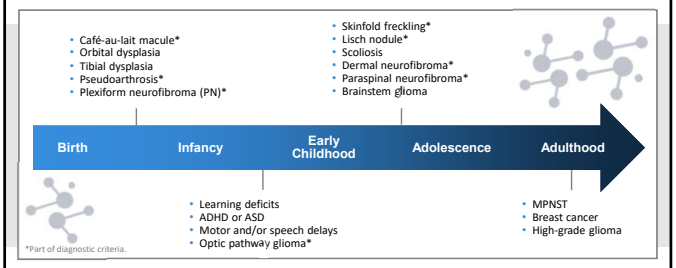
Genetic Considerations in NF1

- Autosomal dominant tumor predisposition syndrome
  - Heterozygous mutation in NF1 gene on chromosome 17q11.2
  - 100% penetrance (every patient with pathogenic mutation will show signs of NF1)
- Newly diagnosed patients with a family history (50%)
- Clinical issues and problems
  - Wide variation among patients, even within families and those with same genetic defect

Lalvani S, et al. *J Multidiscip Healthc*. 2024;17:1803–1817. Armstrong AE, et al. *BMC Cancer*. 2023;23(1):553.
Gutmann DH, et al. *Nat Rev Dis Primers*. 2017;3:17004. Kerashvili N, et al. *Expert Rev Neurother*. 2024;24:409–420.

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Development of Clinical Features of NF1
Timing and Severity Varies



ADHD, attention-deficit hyperactivity disorder; ASD, autism spectrum disorder; MPNST, malignant peripheral nerve sheath tumors.
Kerashvili N, et al. *Expert Rev Neurother*. 2024;24:409–420. Botero V, et al. *J Neurodev Disord*. 2024;16:49.

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NF1
Abnormalities in Skin Pigmentation

Café-au-lait Macules



- Often first sign of NF1
  - May be present at birth and can continue to develop and/or darken over time
  - By 1 year of age, 80% have ≥6 macules
- Not markers of severity
- Present in ~90% of patients with NF1

Skinfold Freckling



- Present in ~75% of patients
- Usually detected by 5–8 years of age

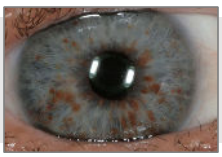
Lalvani S, et al. *J Multidiscip Healthc*. 2024;17:1803–1817.
Kerashvili N, et al. *Expert Rev Neurother*. 2024;24:409–420. Botero V, et al. *J Neurodev Disord*. 2024;16:49.

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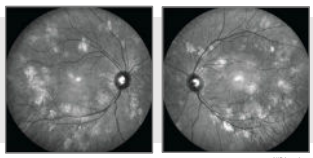
NF1
Ocular Abnormalities

Lisch Nodules



- Present in nearly all patients with NF1
  - Rarely in infants
  - No effect on vision
- Identification requires slit-lamp examination

Choroidal Abnormalities



- Present in >64% of patients
  - May be found at earlier ages
  - Asymptomatic
  - Appearance and dimensions can increase with age
- Identification requires spectral domain optical coherence tomography in near-infrared reflectance modality

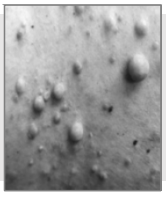
Lalvani S, et al. *J Multidiscip Healthc*. 2024;17:1803–1817. Kerashvili N, et al. *Expert Rev Neurother*. 2024;24:409–420.
Cosmo E, et al. *Cancers*. 2022;14:1423. Mallone F, et al. *Orphanet J Rare Dis*. 2022;17:223.

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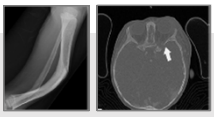
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NF1
Additional Manifestations

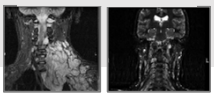
Dermal Neurofibromas



Dysplasia of Tibia and Sphenoid Bone



Cervical and Brachial PN



Optic Pathway Glioma



Korf BR. *Handb Clin Neurol*. 2013;111:333–340.
Gaillard F. Radiopaedia website. Updated August 29, 2025. https://radiopaedia.org/articles/optic-pathway-glioma.

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Periodic Reevaluation of Needs in Children with NF1

- Early intervention improves outcomes and quality of life (QoL)
- Timely detection of treatable complications may reduce permanent disability or life-threatening outcomes
- Ongoing education and support for families as new challenges or questions arise at different child development stages

Domain	What to Monitor	Typical Frequency
Skin	New or changing neurofibromas	Annually
Eyes	Signs of optic pathway glioma	Annually
Cardiovascular	Blood pressure (especially for hypertension risk)	Annually
Skeletal	Scoliosis, tibial dysplasia	Annually
Neurodevelopmental	Cognitive, academic, and behavioral issues	Annually, or as needed
Growth/endocrine	Growth patterns, puberty abnormalities	Annually

Peduto C, et al. *Cancers (Basel)*. 2023;15(4):1217. Miller DT, et al. *Pediatrics*. 2019;143(5):e20190660.

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NF1
Diagnostic Criteria

1988

Diagnostic criteria for NF1 are met if **two or more** of the following are found:

1. Six or more café-au-lait spots (in the greatest diameter)
   - 1.5 cm or larger after puberty
   - 0.5 cm or larger before puberty
2. Freckling in the axilla or groin
3. Two or more Lisch nodules
4. Two or more neurofibromas OR one plexiform neurofibroma
5. Optic pathway glioma
6. A distinctive osseous lesion, such as sphenoid dysplasia or thinning of long bone cortex with or without pseudoarthrosis
7. First-degree relative with NF1

2021

Diagnostic criteria for NF1 are met in an individual who **does not have a parent diagnosed with NF1** if **two or more** of the following are found:

1. Six or more café-au-lait spots (in the greatest diameter)
   - 1.5 cm or larger after puberty
   - 0.5 cm or larger before puberty
2. Freckling in the axilla or groin
3. Two or more neurofibromas OR one plexiform neurofibroma
4. Optic pathway glioma
5. Two or more iris Lisch nodules OR **two or more choroid abnormalities**
6. A distinctive osseous lesion, such as sphenoid dysplasia, anterolateral bowing of tibia or pseudoarthrosis of a long bone
7. **Heterozygous pathogenic *NF1* variant with a variant allele fraction of 50% in apparently normal tissue**

If a **parent meets the above diagnostic criteria**, the individual only requires one or more of the above criteria to merit an NF1 diagnosis

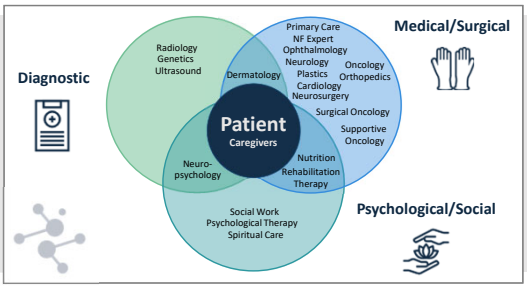
NIH Consensus Development Conference. *Neurofibromatosis*. 1988;1(3):172–178. Legius E, et al. *Genet Med*. 2021;23:1506–1513.

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NURSING CONTRIBUTIONS TO NF1-PN MANAGEMENT

Multidisciplinary Care for Patients with NF1



Lalvani S, et al. *J Multidiscip Healthc*. 2024;17:1803–1817. Armstrong AE, et al. *BMC Cancer*. 2023;23(1):553.

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Irene (Renie) Moss



Renie Moss
Patient Advocate and Caregiver

Renie Moss lives in Alabama with her husband of 24 years, Philip Sr., and two children, Philip Jr. (age 20) and Helen (age 17), all three of whom have been diagnosed with NF1. Ms. Moss is an avid advocate for the neurofibromatosis patient and research communities.

- Former chair of the Children's Tumor Foundation (CTF) Volunteer Leadership Council
- Former patient liaison to the Synodos NF1 Research Consortium
- Patient representative for Response Evaluation in Neurofibromatosis and Schwannomatosis International Collaboration (REiNS)
- Member of the University of Alabama–Birmingham (UAB) NF Clinic Patient Advisory Board
- Member of the UAB Genetic Counseling Program's advisory board

Renie Moss. Interview with CE Concepts. August 2025.

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Challenges of Accessing NF1 Care



Renie Moss
Patient Advocate and Caregiver



Renie Moss. Interview with CE Concepts. August 2025.

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Case: Jonathon J.



Jonathon J. is a 7-year-old male, who has experienced some mild learning difficulties and clumsiness in school, which has been attributed to behavioral issues and not formally evaluated. He has a younger brother (4 years) and sister (2 years).

At his annual physical examination, his pediatrician notes axillary freckling and small, soft cutaneous nodules. Ophthalmologic exam finds Lisch nodules. NF1 is diagnosed based on clinical criteria. Parents do not have clinical characteristics of NF1.

Examination reveals:

- 9 café-au-lait spots >0.5 cm (largest 1.5 cm, multiple smaller spots), initially referred to as "birth marks" without follow up investigation
- Bilateral axillary freckling, no neurofibromas palpable
- Mild hypotonia, coordination difficulty noted
- No scoliosis on Adam's Forward Bend Test; no long bone abnormalities
- Visual-spatial and processing deficits, attention and executive function concerns

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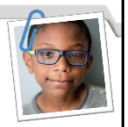
What do you recommend for this patient?

1. Genetic evaluation
2. Neuropsychological testing
3. Occupational therapy
4. Speech-language pathology testing
5. Behavioral therapy
6. MRI scans of brain/orbits
7. Normal monitoring of growth and development
8. Recommend school support (Individualized Education Plan [IEP] or 504 plan)
9. Regular monitoring by primary care

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Jonathon J. (…cont'd)



Recommendations

- Genetic testing for NF1 confirmation, at parents' request (concern for their other children)
- Comprehensive ophthalmologic exam
- Baseline neurological evaluation and developmental monitoring
- Refer to developmental-behavioral pediatrics for ADHD and behavioral support
- Genetic counseling to discuss inheritance, family testing, reproductive planning
- Continue occupational therapy and speech therapy per IEP
- Initiate parent support via Children's Tumor Foundation and/or local NF1 support networks
- Annual follow-up appointments for NF1 surveillance: neurological exam, skin, ophthalmology, growth and development

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When Is Genetic Testing Advisable?

- Diagnostic clinical criteria sufficient for majority of cases
- Potential use of genetic testing
  - For unusual cases or those >10 years of age without a clear diagnosis
  - To help inform therapy decisions
  - When the differential includes non-NF1 condition(s)
  - When there is concern for siblings or family planning
  - Inform prenatal testing and family planning
- Limited genotype/phenotype correlation
  - Wide variation
  - Not completely predictive of risks
  - Cost-benefit considerations

Lalvani S, et al. *J Multidiscip Healthc*. 2024;17:1803–1817. Armstrong AE, et al. *BMC Cancer*. 2023;23(1):553. Gutmann DH, et al. *Nat Rev Dis Primers*. 2017;3:17004. Kerashvili N, et al. *Expert Rev Neurother*. 2024;24:409–420.

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Common Missed Opportunities

- Failure to recognize diagnostic criteria for NF1
- Underestimating the impact of mild developmental delays
- Delayed referral to specialists
- Inadequate family history taking
- Lack of coordination with schools
- Overlooking emotional and behavioral health
- Early diagnosis NF1 complications
- Not referring to NF1 specialty clinics

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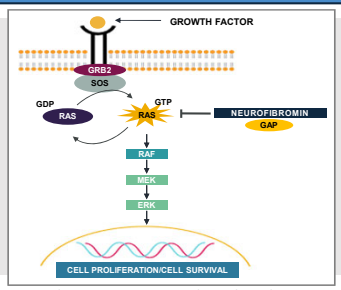
Neurofibromatosis Type 1

MEK Inhibitors for the Treatment of Symptomatic, Inoperable Plexiform Neurofibromas

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Tumors Associated with NF1

- Dermal neurofibromas
- Plexiform neurofibromas (PNs)
- Optic pathway gliomas and other low-grade tumors
- Malignant peripheral nerve sheath tumors (MPNSTs)
- High-grade glioma
- Breast cancer
- Gastrointestinal stromal tumors (GISTs)
- Pheochromocytoma and/or paragangliomas
- Rhabdomyosarcomas



ERK, extracellular signal-regulated kinase; GAP, GTPase-activating proteins; GDP, guanosine diphosphate; GRB2, growth factor receptor-bound protein 2; GTP, guanosine triphosphate; MEK, mitogen-activated kinase; RAF, rapidly accelerated fibrosarcoma; RAS, rat sarcoma; SOS, Son of Sevenless.

Lalvani S, et al. *J Multidiscip Healthc*. 2024;17:1803–1817. Kerashvili N, et al. *Expert Rev Neurother*. 2024;24:409–420. Botero V, et al. *J Neurodev Disord*. 2024;16:49.

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NF1-Plexiform Neurofibromas (PNs)

- Develop in up to 50% of patients with NF1
  - Typically, congenital or manifest in early childhood
  - Grow most rapidly in children <5 years of age
- Matrix of tumorigenic NF1-deficient Schwann cells, fibroblasts, endothelial cells, and mast cells
- Highly infiltrative, most frequently located in trunk or extremities
  - Multinodular enlargement
  - Can obstruct major organs, potentially life-threatening
    - Airway dysfunction, visual impairment, and bladder or bowel dysfunction
  - Pain, disfigurement, and motor dysfunction

Lalvani S, et al. *J Multidiscip Healthc*. 2024;17:1803–1817.
Acar S, er al. *Expert Opin Investig Drugs*. 2022;31:31–40. Kerashvili N, et al. *Expert Rev Neurother*. 2024;24:409–420.

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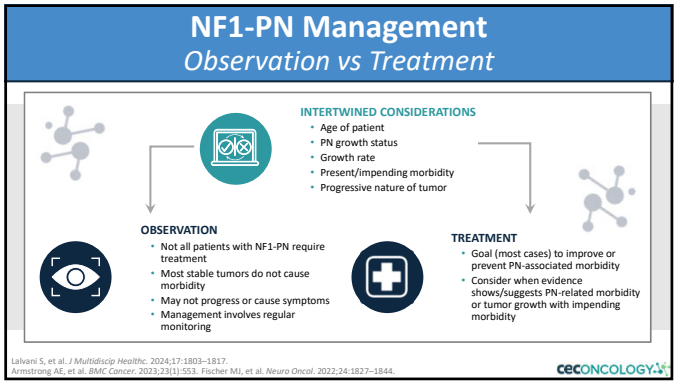
NF1-PNs

- Most patients have ≥1 PN-associated morbidity
  - Most common: pain, disfigurement, and motor dysfunction
  - Other comorbidities of note: defects in vision, airway, and bowel/bladder function
  - Morbidities tend to worsen over time without treatment
- Symptomatic PNs tend to be larger than asymptomatic PNs
  - Asymptomatic and symptomatic often coexist
- Benign, but may progress to atypical neurofibromas and then undergo transformation to MPNST
  - Estimated lifetime risk of MPNST in patients with NF1 is 8%–13%
  - Risk of transformation to MPNST is higher in patients with NF1

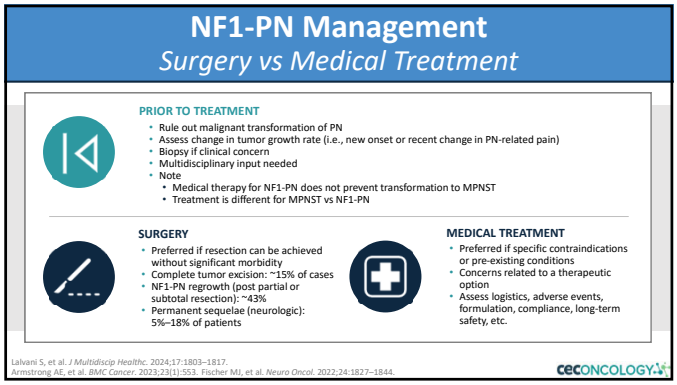
Lalvani S, et al. *J Multidiscip Healthc*. 2024;17:1803–1817. Armstrong AE, et al. *BMC Cancer*. 2023;23(1):553.
Acar S, er al. *Expert Opin Investig Drugs*. 2022;31:31–40. Kerashvili N, et al. *Expert Rev Neurother*. 2024;24:409–420.

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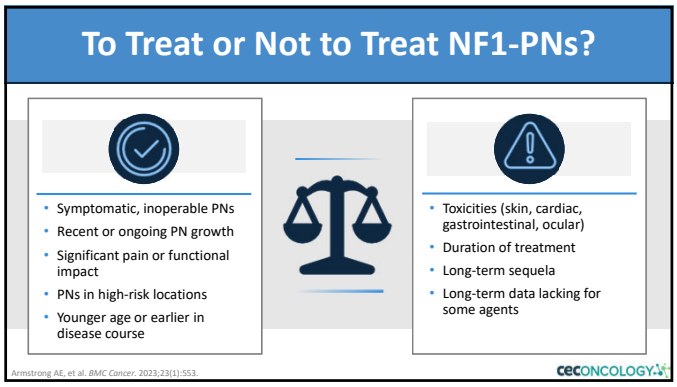
NURSING CONTRIBUTIONS TO NF1-PN MANAGEMENT



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Jonathon J. (… cont'd)

At 10 years of age, Jonathon develops a slowly enlarging area of diffuse swelling along the lower left jaw and neck. This area feels rubbery, is sometimes tender, and grows steadily but unpredictably. The mass is non-resectable due to its size and location and causes cosmetic deformity and periodic discomfort. MRI confirms a plexiform neurofibroma.

Over several years, the lesion causes noticeable facial asymmetry and mild difficulty with chewing and speech. He begins to experience neuropathic pain and occasional airway discomfort by age 13–14. Function and QoL decline, and the mass becomes increasingly prominent.

At 15 years of age, progressive pain, continued functional decline, and disfigurement are negatively impacting his QoL.

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Jonathon J. (… cont'd)

Recommendations

- Complete resection is not possible due to location
- In consultation with his parents, it is decided that he should receive systemic therapy

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Targeted Medical Therapy for NF1-PN

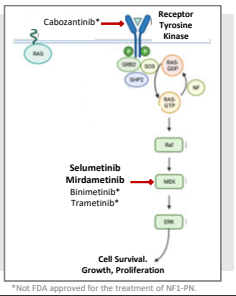
Several MEK inhibitors and tyrosine kinase inhibitors (TKIs) have demonstrated activity against NF1-PN.

Outcomes of note in clinical trials:

- Assessed PN growth and response via 3D volumetric analysis
- Patient-reported and functional outcome assessments

SELUMETINIB
FDA-approved in *pediatric* patients ***1 year of age and older*** with NF1 who have symptomatic, inoperable PN

MIRDAMETINIB
FDA-approved in *adult and pediatric* patients 2 years of age and older with NF1 who have symptomatic PN not amenable to complete resection



*Not FDA approved for the treatment of NF1-PN.

NF, neurofibromin; SHP2, Src homology-2 protein tyrosine phosphatase.
Na B, et al. *Curr Oncol Rep*. 2024;26:706–713. Armstrong AE, et al. *BMC Cancer*. 2023;23(1):553.
Fischer MJ, et al. *Neuro Oncol*. 2022;24:1827–1844. de Blank PM, et al. *Neuro Oncol*. 2022;24:1845–1856.
Mirdametinib (package insert). Revised February 2025. https://www.accessdata.fda.gov/drugsatfda_docs/label/2025/219379Orig1s000lbl.pdf.
Selumetinib (package insert). Revised September 2025. https://www.accessdata.fda.gov/drugsatfda_docs/label/2025/219943Orig1s000lbl.pdf.

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NURSING CONTRIBUTIONS TO NF1-PN MANAGEMENT

SPRINT Trial Selumetinib in Children with Inoperable PN		ReNeu Trial* Mirdametinib in Children with Inoperable PN	
Phase 2, open label			
• Children (2–18 years; median 10 years)		• Pediatric (2–17 years; median 10 years) • Adult cohort (≥18 years)	
Selumetinib 25 mg/m² BID Treatment cycle: 28 days (no rest between cycles)		**Mirdametinib 2 mg/m² BID (max 4 mg/m²)** Treatment cycle: 28 days (3 weeks on, 1 week off)	

Primary Endpoint
• Partial response (≥20% volume reduction in target PN by 3D analysis of MRI)
  • Confirmed (2 consecutive)
  • Durable (lasting ≥12 cycles)
	Secondary Endpoints
	• Duration of response
	• Safety
	• Patient-observer reported outcomes
		Primary Endpoint
		• Partial response (≥20% volume reduction in target PN by volumetric MRI)
			Secondary Endpoints
			• Duration of response
			• Safety
			• QoL and physical functioning

*Data for adult patients is not included.
BID, twice daily; MRI, magnetic resonance imaging.
Gross AM, et al. *N Engl J Med*. 2020;382:1430–1442. Moertel CL, et al. *J Clin Oncol*. 2025;43(6):716–729.

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MEKi Trial Efficacy

SPRINT Trial Selumetinib in Children with Inoperable PN	ReNeu Trial* Mirdametinib in Children with Inoperable PN

• Combined cohort (n=74)
  • Median duration of treatment: 57.5 cycles
  • Remaining on treatment at data cutoff (n=31)
• Partial response
  • Confirmed and durable: 70% and 59%
• Median time to response
  • Initial: 8 cycles (range 4–40)
  • Best response: 18 cycles (range 4–94)
• Median progression-free survival (PFS)
  • 88 cycles (7.3 years)
• 1-year probability of being progression-free after 60 cycles
  • 61% (95% CI, 46%–73%)
• Self-reported Numeric Rating Scale-11 (NRS-11) Scores improved throughout treatment
	• Combined cohort (n=56)
	  • Median duration of treatment: 22 months)
	• Partial response
	  • Confirmed and durable: 52% and 39%
	• Median time to response
	  • Initial: 8 cycles (range 4–19)
	  • Best response: 13.4 months (range, 4–33)
	• Median PFS not reached
	• Participants had a clinically meaningful improvement from baseline in chronic pain intensity scores

*Data for adult patients is not included.
BID, twice daily; MRI, magnetic resonance imaging.
Gross AM, et al. *N Engl J Med*. 2020;382:1430–1442. Moertel CL, et al. *J Clin Oncol*. 2025;43(6):716–729.

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MEKi Safety

All grade	Selumetinib (Grade 3–4)		Mirdametinib* (Grade 3–4)	
≥80%	Vomiting (6%)	All rashes† (6%)		
50%–79%	Abdominal pain Diarrhea (16%) Nausea (2%) Stomatitis Dry skin	Rash acneiform (4%) Increased CPK (7%) Musculoskeletal pain Fatigue Pyrexia (8%)	Rash (4%) Diarrhea (5%)	Increased CPK (5%)
20%–49%	Constipation Paronychia (6%) Pruritus Dermatitis (4%) Hair changes Headache (2%) Epistaxis Hematuria (2%)	Proteinuria Decreased appetite Decreased ejection fraction Sinus tachycardia Skin infection (2%) Edema	Nausea Vomiting Stomatitis Headache (2%) Paronychia Cough Pyrexia	Left ventricular dysfunction (2%) Abdominal pain (4%) Musculoskeletal pain (2%) Upper respiratory tract infection COVID-19

Data on AEs occurring in ≥20% of pediatric patients
*Data for adult patients is not included.
†Rash includes dermatitis acneiform, eczema, maculopapular rash, pustular rash, dermatitis, erythematous rash, palmar-plantar erythrodysesthesia syndrome, exfoliative rash, skin exfoliation, pruritic rash, papule, papular rash, and macular rash.
CPK, creatine phosphokinase.
Selumetinib (package insert). Revised September 2025. https://www.accessdata.fda.gov/drugsatfda_docs/label/2025/219943Orig1s000lbl.pdf.
Mirdametinib (package insert). Revised February 2025. https://www.accessdata.fda.gov/drugsatfda_docs/label/2025/219379Orig1s000lbl.pdf.

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Selumetinib* *Warnings and Precautions*

- Ocular toxicity: blurred vision, photophobia, cataracts, and ocular hypertension
  - 15% of pediatric population (resolved in 82%)
- Cardiomyopathy
  - Decreased LVEF of ≥10% occurred in 23% of pediatric patients (all were identified during routine echocardiography); decreased LVEF resolved in 71% of these patients
- Skin toxicity
  - Rash occurred in 91% of pediatric patients (8% Grade 3); the most frequent rashes included dermatitis acneiform (54%), maculopapular rash (39%), and eczema (28%)
- Gastrointestinal toxicity
  - Diarrhea in 77% of pediatric population (15% Grade 3)
- Increased creatine phosphokinase
  - Occurred in 76% of pediatric population (9% Grade 3 or 4)
- Risk of bleeding
  - Vitamin E is excipient and can inhibit platelet aggregation and antagonize vitamin K-dependent clotting factors
- Embryo-fetal toxicity

Toxicities seen in an unapproved adult population* with multiple tumor types who received selumetinib as a single agent or in combination with other anti-cancer agents:

- Retinal vein occlusion (RVO) and retinal pigment epithelial detachment (RPED)
- Intestinal perforation, colitis, ileus, and obstruction
- Cardiomyopathy (decreased LVEF)
- Severe palmar-plantar erythrodysesthesia syndrome
- Rhabdomyolysis

*Selumetinib is not FDA approved in adult patients who have a PN.

LVEF, left ventricular ejection fraction.
Selumetinib (package insert). Revised September 2025. https://www.accessdata.fda.gov/drugsatfda_docs/label/2025/219943Orig1s000lbl.pdf.

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Mirdametinib *Warnings and Precautions*

- Ocular toxicity: retinal vein occlusion (RVO), retinal pigment epithelium detachment (RPED), and blurred vision
  - 19% of pediatric patients (20% Grade 1, 3.8% Grade 2, and 0.8% Grade 3)
- Left ventricular dysfunction
  - Decreased LVEF of 10% to <20% occurred in 25%, and decreased LVEF of ≥20% occurred in 1.8% of patients (all were identified during routine echocardiography; decreased LVEF resolved in 75% of adult and pediatric patients)
- Dermatological AEs
  - Rash occurred in 72% of pediatric patients (3.4% Grade 3); higher frequency in patients aged 12 to 17 years (77%) than those aged 2 to 11 years (16%); non-acneiform rashes occurred with a higher frequency in patients aged 2 to 11 years (53%) than those aged 12 to 17 years (15%)
- Embryo-fetal toxicity

Toxicities seen in the approved adult population:

- Ocular toxicity: retinal vein occlusion (RVO), retinal pigment epithelium detachment (RPED), and blurred vision
  - 28% of adult patients (21% Grade 1, 5% Grade 2, and 1.3% Grade 3)
- Left ventricular dysfunction
  - Decreased LVEF of 10% to <20% occurred in 16%, (all were identified during routine echocardiography; decreased LVEF resolved in 75% of patients)
- Dermatological AEs
  - Rash occurred in 92% of pediatric patients (8% Grade 3)
- Embryo-fetal toxicity

Mirdametinib (package insert). Revised February 2025. https://www.accessdata.fda.gov/drugsatfda_docs/label/2025/219379Orig1s000lbl.pdf.

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General MEKi Safety Experience in Clinical Trials

Pediatric/Children

- Rash (eczema, dry skin)
- Paronychia
- Hypotonia or muscle weakness
- Impact on developmental changes are unknown

Adolescents/Adults

- Rash (acne)
- Paronychia
- Weight gain
- Fatigue
- GI problems

GI, gastrointestinal.
Gross AM, et al. *Nat Med*. 2025;31(1):105–115. Solares I, et al. *ESMO Open*. 2021;6(4):100223.
Gross AM, et al. *Neuro Oncol*. 2023;25:1883–1894. Moertel CL, et al. *J Clin Oncol*. 2025;43(6):716–729.

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General Dermatological Care While Receiving MEK Inhibitor Therapy

- Daily baths, mild cleansers, high-quality moisturizer over entire body twice daily within 5 mins after bath
- Bleach baths 3–4 times weekly (1 tsp/gal = ¼ cup/full bathtub)
- Avoid products with fragrances (e.g., soaps, laundry detergents, creams)
- Use clothing for sun cover up, mineral-based sunscreens; use sunscreen on face daily regardless of anticipated sun exposure

Klesse LJ, et al. *Oncologist*. 2020;25(7):e1109–e1116.

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Management of MEK Inhibitor Dermatological Toxicities

Skin Care Recommendations for ALL PATIENTS

- Counseling to adopt gentle skin care practices, daily baths, and the use of mild cleansers
- Use of cream or ointment-based hypoallergenic skin moisturizers at least twice a day

Patient Group	Prepubescent Patients		Postpubescent Patients
All patients upon MEK inhibitor initiation	Directions for bleach baths should be provided to patients and can begin with MEKi treatment or in reaction to the development of rash • Add ¼ to ½ cup of regular strength bleach to a full bathtub (or approximately 1 teaspoon per gallon) and soak 5–10 minutes • Recommended frequency is 3× per week • Follow immediately by a high0quality hypoallergenic skin moisturizer		Prophylactic treatment with topical clindamycin and an oral tetracycline at an antiOinflammatory dose is recommended • Topical clindamycin lotion 1.0% BID should be applied to the face • Begin treatment with a tetracycline (e.g., doxycycline or minocycline) 50 mg/day for 3 months
Mild rash reactive treatment	DERMATITIS Use hydrocortisone cream 2.5% BID for face and skinfold areas, and triamcinolone ointment 0.1% BID on trunk and extremities	ACNEIFORM RASH Topical clindamycin lotion 1.0% BID should be used until rash is clear, and as needed thereafter; hydrocortisone cream 2.5% BID can be added	
Moderate to severe rash reactive treatment		ACNEIFORM RASH Cephalexin 20 mg/kg/day divided BID (with max dose of 500 mg) for up to 6 weeks **or** Amoxicillin 25 mg/kg/day divided BID (with max dose of 875 mg) for up to 6 weeks	If acneiform rash still develops **and** bothers patient, add hydrocortisone cream 2.5% BID or triamcinolone ointment 0.1% BID
Referral to dermatology	Dermatitis uncontrolled with recommended supportive care	For moderate/severe acneiform rash concurrent with initiation of cephalexin/amoxicillin, or suspected infection	If acneiform rash continues to worsen or if an infection is suspected, refer to dermatology; stronger topical steroids or oral retinoids may be added
Agents and strategies to avoid	Agents with the potential to dry skin, such as benzoyl peroxide, salicylic acid, acne skin washes, scrubs, exfoliants, anti-aging creams, alcohol (cleansers, wipes), or other agents that can dry skin; avoid topical retinoids		

Adapted from: Hirbe A, et al. 29th Annual Meeting of the Society for NeuroOncology. 2024. Poster CTNI-20. https://www.ajmc.com/formulary/nf1pn/Hirbe%20SNO%202024%20Derm%20AE%20Poster.pdf.

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Management of MEK Inhibitor Diarrhea

DIARRHEA RECOMMENDATIONS FOR ALL PATIENTS

First onset of diarrhea is typically reported during the first 2 cycles of MEKi treatment, typically grade 1 or 2.

- For diarrhea, all patients should be counseled at treatment initiation to manage their diet

Initial interventions for grade 1–2 diarrhea should include avoidance of greasy foods and possible adoption of the BRAT diet.

- Probiotics can also be added
- If this is insufficient, loperamide or similar anti-diarrheal agents can be used per institutional practice

Consider if other newly prescribed medications may be contributing to diarrhea.

Adapted from: Hirbe A, et al. 29th Annual Meeting of the Society for NeuroOncology. 2024. Poster CTNI-20. https://www.ajmc.com/formulary/nf1pn/Hirbe%20SNO%202024%20Derm%20AE%20Poster.pdf.

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Management of MEK Inhibitor Cardiac Toxicities

- Baseline
  - Cardiovascular assessment, including echocardiogram to assess LVEF
  - Blood pressure, including hypertension correction
  - Review medications
- Routine monitoring
  - Repeat echocardiogram at 4 weeks, then every 3 months
  - Routine clinical assessment for cardiotoxicity (dyspnea, edema, palpitations)
- LVEF reduction
  - Asymptomatic: withhold selumetinib/mirdametinib until resolution; resume at reduced dose
  - Symptomatic or severe: permanently discontinue
- Hypertension
  - Mild-moderate: initiate or adjust antihypertensive medication
  - Stage 2 hypertension: hold until controlled; resume at reduced dose
  - Grade 4: discontinue
- QTc prolongation
  - ≥500 ms or increases by >60 ms from baseline, hold therapy until normalization, resume at reduced dose or permanently discontinue on recurrent events

Azizi AA, et al. *Neuroancol Pract.* 2024;11(5):515–531. Glen C, et al. *JACC CardioOncol.* 2022;4(1):1–18.
Mirdametinib (package insert). Revised February 2025. https://www.accessdata.fda.gov/drugsatfda_docs/label/2025/219379Orig1s000lbl.pdf.
Selumetinib (package insert). Revised September 2025. https://www.accessdata.fda.gov/drugsatfda_docs/label/2025/219943Orig1s000lbl.pdf.

Management of MEK Inhibitor Ocular Toxicities

- Baseline ophthalmic examination
- Routine monitoring
  - Ophthalmic exams ever 3–6 months
  - Prompt assessment of visual changes (blurred vision, floaters, photophobia, visual field changes)

Selumetinib	
Retinal pigment epithelial detachment (RPED)	• Withhold until resolution • Resume at reduced dose
Retinal vein occlusion (RVO)	• Permanently discontinue

Mirdametinib	
Grade ≤2	• Continue mirdametinib at current dose level • Consider ophthalmologic examinations every 2–4 weeks until resolution to grade ≤1 or baseline
Grade ≥3	• Withhold mirdametinib until grade ≤1 or baseline • If recovery occurs ≤14 days, resume mirdametinib at the next lower dose • If recovery occurs in >14 days, consider permanent mirdametinib discontinuation
RPED	• Withhold mirdametinib until grade ≤1 or baseline • Resume mirdametinib at the same dose
RVO	• Permanently discontinue mirdametinib

Azizi AA, et al. *Neuroancol Pract.* 2024;11(5):515–531. Han J, et al. *Oncalogy (Williston Park).* 2023;37(3):130–141. Jeng-Miller KW, et al. *Oncologist.* 2024;29(5):e616–e621.
Mirdametinib (package insert). Revised February 2025. https://www.accessdata.fda.gov/drugsatfda_docs/label/2025/219379Orig1s000lbl.pdf.
Selumetinib (package insert). Revised September 2025. https://www.accessdata.fda.gov/drugsatfda_docs/label/2025/219943Orig1s000lbl.pdf

MEK Inhibitor Options

SELUMETINIB*
- Pediatric patients
- Pill and granular (sprinkle) dosing
- Continuous therapy
- 6.2-hour serum half life
- Avoid CYP3A4 inhibitors



MIRDAMETINIB
- Pediatric and adult patients
- Pill and liquid dosing
- 3 weeks on, 1 week off
- 28-hour serum half life

No head-to-head comparisons
No data on MEKi switching

*Selumetinib is not FDA approved in adult patients who have a PN.

Selumetinib (package insert). Revised September 2025. https://www.accessdata.fda.gov/drugsatfda_docs/label/2025/219943Orig1s000lbl.pdf.
Mirdametinib (package insert). Revised February 2025. https://www.accessdata.fda.gov/drugsatfda_docs/label/2025/219379Orig1s000lbl.pdf.

NF1-PN and MEKi Therapy Monitoring

Exam	Monitoring
Review of systems and physical examination (including GI, vision, skin, oral mucosa, and nails)	• Every visit (generally monthly)
Ophthalmologic examination	• Baseline, then every 6–12 months • Consider increased frequency with new symptoms
Echocardiogram/ejection fraction	• Baseline, every 3–6 months
Electrocardiogram	• Baseline, then as clinically indicated
Pregnancy status	• Baseline, then per institutional standards
Laboratory examinations	• Baseline, then every 3–6 months: creatine kinase, metabolic panel, liver function tests, CBC • Baseline, then as clinically indicated: amylase, lipase

CBC, complete blood count; GI, gastrointestinal.
Friedman JM. Neurofibromatosis 1. In: Adam MP, et al., eds. *GeneReviews*. Seattle (WA): University of Washington, Seattle; 1993 (updated 2025).
Moodley M, et al. *Semin Pediatr Neurol*. 2024;52:101172. Na B, et al. *Curr Oncol Rep*. 2024;26:706–713. Lee TJ, et al. *Orphanet J Rare Dis*. 2023;18(1):292.

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Neurofibromatosis Type 1

Nurse's Role in Transitioning Patients from Pediatric Care to Adult Care

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The Role of Peers in the Transition from Pediatric to Adult Care



Renie Moss
Patient Advocate and Caregiver



Renie Moss. Interview with CE Concepts. August 2025.

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NURSING CONTRIBUTIONS TO NF1-PN MANAGEMENT

Transition from Pediatric to Adult Care
Differences in Delivery of Care

	Pediatric Care Model	Adult Care Model
Practice approach	• Family-centered • Shared decision-making with parents	• Patient-centered • Shared decision-making with patient
Multidisciplinary staffing	• Multiple subspecialists are often available for an MDT approach to care—"one-stop shop"	• Few or no "one-stop shop" multidisciplinary clinics • Separate referrals/appointments for each specialist needed
Coordination of care and access to support services	• Coordination of care often provided by clinic coordinator or nurse navigator • Social work and case management support is often available	• Care coordination services are not often provided; few public care coordination programs are available for adults with NF1 • Less social work, case management staffing, and support available
Length of appointment	• Long	• Short
Adherence to care	• Frequent reminders and support from healthcare system • Healthcare provider has the duty to report non-adherence that may reach a level that looks like medical negligence	• Expectation of self-adherence; often no appointment reminders or follow-up from missed appointments • Healthcare provider has no reporting duty of non-adherence, unless patient has a court-appointed guardian and is being neglected per provider opinion

MDT, multidisciplinary team.
White PH, et al. *Pediatrics*. 2018;142:e20182587. Radtke HB, et al. *Pediatric Health Med Ther*. 2023;14:19–32.

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Core Elements of Health Care Transition

Key Elements for Transition to Adulthood Program
- Annual assessments to plan transition
- Establishment of yearly personal goals
- Bi-monthly adolescent and young adult transition planning meetings
- Dedicated collaborative specialists across the lifespan

1 TRANSITION POLICY	2 TRANSITION TRACKING AND MONITORING	3 TRANSITION READINESS	4 TRANSITION PLANNING	5 TRANSFER/ INTEGRATE INTO ADULT-CENTERED CARE	6 TRANSITION COMPLETION AND ONGOING CARE WITH ADULT CLINICIAN
Ages 12–14	Ages 14–18			Ages 18–21	Ages 18–26
• Discuss transition policy with patient and family	• Track progress	• Assess skills	• Develop healthcare transition plan, including medical summary	• Transfer to adult-centered care • Integration into adult practice	• Confirm transfer completion • Elicit feedback

White PH, et al. *Pediatrics*. 2018;142:e20182587.

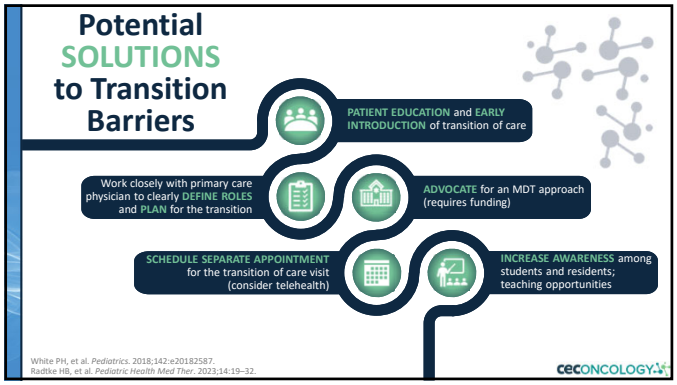
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BARRIERS to Successful NF1 Health Care Transitions

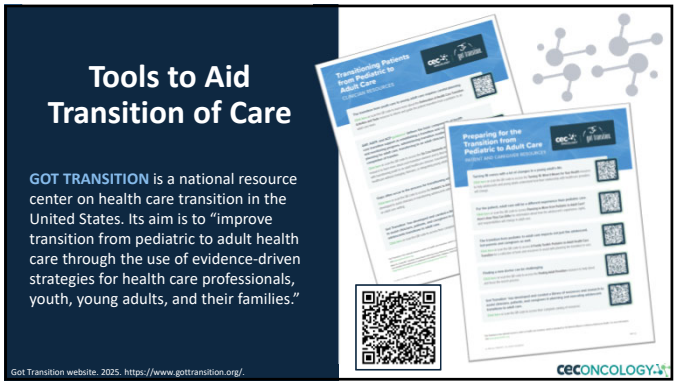
- **LIMITED STAFF AVAILABILITY** — SW, communication and coordination, OT, GC, nursing, and case management
- **LACK OF ADULT PROVIDERS** — Fewer providers willing to take over care
- **LESS SUPPORTIVE APPROACH** — Less support in adult vs pediatric healthcare
- **INSURANCE** — Limited or lack of insurance
- **LEGAL SUPPORT** — Lack of timely legal support

GC, genetic counselling; SW, social work.
White PH, et al. *Pediatrics*. 2018;142:e20182587.
Radtke HB, et al. *Pediatric Health Med Ther*. 2023;14:19–32.

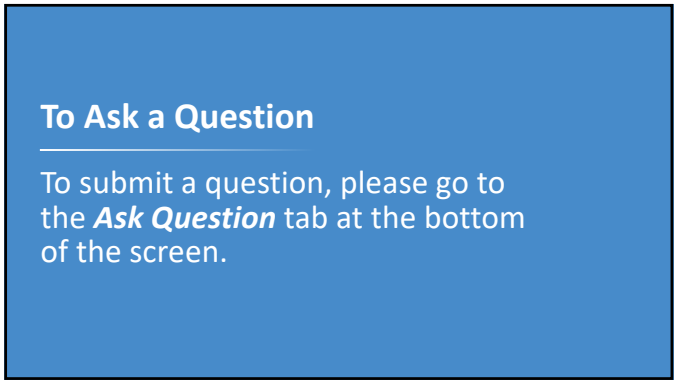
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Potential SOLUTIONS to Transition Barriers
PATIENT EDUCATION and EARLY INTRODUCTION of transition of care
Work closely with primary care physician to clearly DEFINE ROLES and PLAN for the transition
ADVOCATE for an MDT approach (requires funding)
SCHEDULE SEPARATE APPOINTMENT for the transition of care visit (consider telehealth)
INCREASE AWARENESS among students and residents; teaching opportunities
White PH, et al. Pediatrics. 2018;142:e20182587.
Radtke HB, et al. Pediatric Health Med Ther. 2023;14:19–32.
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Tools to Aid Transition of Care
GOT TRANSITION is a national resource center on health care transition in the United States. Its aim is to "improve transition from pediatric to adult health care through the use of evidence-driven strategies for health care professionals, youth, young adults, and their families."
Got Transition website. 2025. https://www.gottransition.org/.
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To Ask a Question
To submit a question, please go to the Ask Question tab at the bottom of the screen.

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Put information into action!

Takeaways from this program can be implemented into your practice to improve patient care.

- *Develop a robust multidisciplinary team for NF1 patient care.* NF1 is a complex disease, and clinicians should have a low threshold for calling in support from specialists in neurology, cardiology, nephrology, pulmonology, genetics, and other specialties.
- *Monitor patients receiving MEK inhibitors.* Some toxicities are common (e.g., rash, diarrhea) while others are less common but may be serious (e.g., ocular, cardiac). Young patients may not be able to express what they are feeling.
- *Implement strategies to improve transitions from pediatric care and integration into adult care.* Because patients with NF1 will need long-term care, clinicians and caregivers need to prepare adolescents to actively manage their disease, which may be challenging for a young person. Remember, it is not too early to plan for the future.

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Renie's Message to Nurses



Renie Moss
Patient Advocate and Caregiver



Renie Moss. Interview with CE Concepts. August 2025.

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Additional Resources

Visit **www.ceconcepts.com** for clinical information and certified educational activities

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In-Person

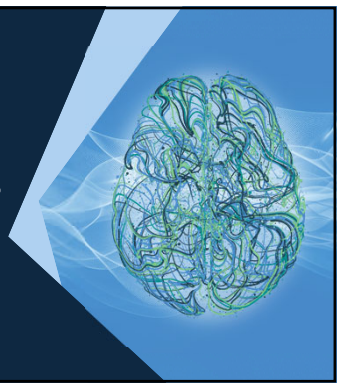
Livestream

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MEK INHIBITORS IN NEUROFIBROMATOSIS TYPE 1

NURSING CONTRIBUTIONS TO NF1-PN MANAGEMENT



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