



INFORMATION

Livestream

Living with Neurofibromatosis Patient and Family Symposium will be live-streamed via Zoom. Instructions will be emailed to registrants the week of May 12.

About Cleveland Clinic

Cleveland Clinic Neurological Institute and Cleveland Clinic Children's Neurofibromatosis (NF) Program is a member of the Children's Tumor Foundation's NF Clinic Network (NFCN). Overseen by the Foundation's Clinical Care Advisory Board and Medical Affairs Committee, the NFCN recognizes clinics that provide appropriate NF care through implementation of current consensus clinical care guidelines for NF.

Cleveland Clinic and Cleveland Clinic Children's offer a comprehensive neurofibromatosis program to treat patients and families with NF1, NF2, and schwannomatosis. Using a tailored and holistic approach, we provide care for children and adults throughout the entire spectrum and lifetime of their disorder.

Our program offers a full array of medical and surgical services, including diagnostic testing, genetic counseling, medication management, surgical interventions, rehabilitation, and neuropsychological services. Our goals are to optimize the health and quality of life for patients and families with these complex conditions, taking into account the unique needs and challenges of each individual.

For more information on Cleveland Clinic's Neurofibromatosis Clinic, please email NFSymposium@ccf.org

About The Children's Tumor Foundation

The Children's Tumor Foundation is a non-profit 501(c)(3) medical foundation, dedicated to improving the health and well being of individuals and families affected by the neurofibromatoses (NF).

The Children's Tumor Foundation is a founding member of the International Foundation, please visit www.ctf.org or call 800.323.7938.

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Living with Neurofibromatosis

2025 Patient and Family Symposium

Saturday, May 17, 2025

Livestreamed via Zoom



9500 Euclid Ave, R20
Cleveland, Oh 44195



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A free program hosted by Cleveland Clinic and Cleveland Clinic Children's

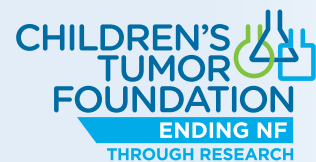


This program is funded in part through grants from





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AGENDA

This symposium offers patients and family members an opportunity to gain a better understanding of the management of neurofibromatosis type 1 and 2.

9:00 am	Welcome and Introductions Gary Hsich, MD	10:40 am	Panel Discussion with Faculty
9:10 am	Natural History and Medical Management of Tumors in Neurofibromatosis Type 1 (NF1) Neha Patel, MD	10:55 am	Break
9:25 am	Living with NF 1: A Patient's Story Patient and Gary Hsich, MD	11:05 am	Improving Hearing with Assessments and Aids Sarah Sydlowski, AuD, PhD
9:40 am	Question & Answer Session	11:20 am	Surgery in Tumors of Peripheral Nerve: When, Why, What Kind? Megan Jack, MD
9:55 am	Natural History and Medical Management of Tumors in Neurofibromatosis Type 2 (NF2)/ Schwannomatosis Mina Lobbous, MD, MSPH	11:35 am	Management of Pain Associated with Neurofibromatosis Pavan Tankha, DO
10:10 am	Surgery in NF2 / Schwannomatosis – When, Why, What Kind? Pranay Soni, MD	11:50 am	Tweaking the Gene: Gene Editing in Genetic Disorders Andrew Dhawan, MD, PhD
10:25 am	Living with NF 2: A Patient's Story Patient and Pranay Soni, MD	12:05 pm	How to Prevent Passing on the Neurofibromatosis Disease to Future Generations Mindy Christianson, MD
		12:20 pm	Panel Discussion with Faculty
		12:50 pm	Closing
		1:00 pm	Adjourn

PROGRAM DIRECTORS



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