



MASSACHUSETTS GENERAL HOSPITAL



Boston Children's Hospital

EVENT ENDED



2023 Neurofibromatosis Patient and Family Symposium

By MGH and Boston Children's NF Clinics

Follow

Richard B. Simches Research Center · Boston, MA

Saturday, Apr 29, 2023 from 8:30 am to 2 pm

Sales ended
Sat, Apr 29, 2023
• 8:30 am

Explore similar events

Overview

2023 NF Symposium

Massachusetts General Hospital, in collaboration with Boston Children's Hospital's Neurofibromatosis Program, invites you to the in person 2023 Patient & Family Neurofibromatosis Symposium. Learn about the latest research and clinical trials, connect with other families, ask questions, and meet the experts.

The agenda will include (see below for detailed agenda)

- Updates on medications to help shrink tumors in NF and Schwannomatosis
- Genetic counseling and family planning
- Tours of NF science laboratories
- Highlights from Neurofibromatosis Northeast and Children's Tumor Foundation
- "Ask the Experts" sessions

Parking, breakfast, and lunch are included with the \$15 registration fee PER FAMILY

Please park at Charles River Plaza Garage and enter at 209 Cambridge Street, Boston, MA 02114.

We believe everyone should be able to participate, regardless of financial barriers. If you are unable to pay or register through our website, please reach out to the contacts below.

Contact:

Leah Hesse lhesse@mgh.harvard.edu

Dani Silverman dsilverman2@mgh.harvard.edu

This event is made possible with sponsorship from the Children's Tumor Foundation and NF Northeast.

DETAILED AGENDA:

9am - Welcome, Dr. Justin Jordan

9:10am - Updates in Gene Therapy, Dr. Scott Plotkin

9:35am - How Reading a Tumor's DNA Can Help Patients, Dr. David Miller

10am - Genetic Counseling and Prenatal Testing, Steph Hicks

10:25am - Patient Advocacy Resources, CTF and NF Northeast

Breakout session #1 - Neurofibromatosis 1 (Moderator: Dr. Nicole Ullrich)

11am - Using artificial intelligence to improve care in NF1, Dr. Ina Ly

11:20am - Cognitive considerations in school, Dr. Nicole Ullrich

11:40am- Cutaneous neurofibroma therapy considerations, Dr. Rox Anderson

noon - Panel Discussion / General Q+A, Drs. Nicole Ullrich, Ina Ly, David Miller

Breakout session #2 - Schwannomatosis (Moderator: Dr. Justin Jordan)

11am - Targeted therapy for NF2-SWN, Dr. Leia Nghiemphu

11:20am - Doxycycline for cutaneous schwannomas, Dr. Brad Welling

11:40am- Clinical Trials for Schwannomatosis-Related Pain, Dr. Vanessa Merker

noon - Panel Discussion / General Q+A, Drs. Justin Jordan, Leia Nghiemphu, Brad Welling, Scott Plotkin

12:30pm-2pm - LUNCH AND LAB TOURS

This event is sponsored by the Children’s Tumor Foundation (CTF), a nonprofit organization dedicated to finding effective treatments and supporting the millions of people worldwide living with neurofibromatosis. For more information, please visit www.ctf.org.

[Read less](#)

Good to know

Highlights

🕒 5 hours 30 minutes

📍 In person

Location

Richard B. Simches Research Center

185 Cambridge Street
3rd Floor Boston, MA 02114

How do you want to get there?

🚗 Driving

🚏 Public transport

🚲 Biking

