

Agenda

Located outside Farkus Auditorium

8:00 am Registration

Located in Smilow Conference room

9:00am Breakfast with the Experts

Advocacy: Traceann Rose CTF

Audiology/ENT : J. Thomas Roland, MD / William Shapiro, AuD

Genetics : John Pappas, MD / Kara Anstett, MS, GCG

Neurology/ Neuro Oncology : Kaleb Yohay, MD / Jeffrey Allen, MD

Neuropsychology /Education : Preeti Saigal PhD / Julia Gomez MA Ed

Physical Therapy : Nashwa Kalil PT, DPT, NCS, PCS /
Danielle Long PT, DPT, NCS, PCS

Farkus Auditorium

10:00am Welcome & Introductions

Carole Mitchell, MS, RN

Patient Advocacy

Traceann Rose Children's Tumor Foundation

10:20am Parent / Patient Panel

Kim Hansen - Lara Lipof - Stacey Decillis - Anita Gribben -

Laura Perfetti – Christine Spotto

10:50-11:00am Break and Room Change

11:00- 1PM Concurrent Sessions

Moderated by Coordinators Carole Mitchell MS, RN

and Celia Engelson MS, RN, FNP-BC

NF 1 Sessions: Located in Alumni Hall B

11:00 am Key Note Speaker

Marisa McGrody

11:20 am Ophthalmic Findings in NF 1

Zachary Elkin, MD

11:40 am NF 1 Guidelines

Kaleb Yohay, MD

12:00 pm Clinical Trials and Research Update NF1

Jeffrey C. Allen, MD

NF2 Sessions: Located in Farkus Auditorium

11:00 am Key Note Speaker

Christine Panza

11:20 am Controversies in Radiation

Benjamin Cooper, MD

11:40 am Hearing Options

J. Thomas Roland, MD & William Shapiro, AuD

12:00 pm Clinical Trials and Research Update NF2

Matthias Karajannis, MD

Parent / Patient panel:

Kim Hanson : Kimhans02@yahoo.com

Stacey Decillis : staceydecillis@gmail.com

Anita Gribben : anitagrib84@gmail.com

Lara Lipof : Llevinelipof@gmail.com

Laura Perfetti : ajmom721@aol.com

Christine Spotto : mrs.spoto@gmail.com

CART Services provided by Lauren Schechter, CCR, CRC. from Total Caption.

Lauren@totalcaptions.com

ASL Services provided by Language Cultural & Disability Services at NYU Langone Health

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

This event is sponsored in part by NF Northeast, a nonprofit organization whose mission is to find treatments and the cure for neurofibromatosis by promoting scientific research, creating awareness, and providing hope and support to those who are affected by NF. For more information, please visit www.nfnortheast.org