

Day of INFormation Schedule
May 6, 2023
Central Time Zone

- 8:00 - 8:30 Check-in and breakfast
- 8:30 - 8:45 Introductions: Kim Bischoff, Executive Director of the Neurofibromatosis Network; Bonnie Fainman, Alexion Patient Education Manager
- 8:50 - 9:30 Dr. Kevin Bielamowicz, Arkansas Children’s Hospital — *NF1 overview and navigating treatment options for pediatric NF1-associated tumors*
- 9:35 - 10:10 Kara Anstett, MS, CGC, NYU Langone Health Comprehensive Neurofibromatosis Center — *Preparing for the Next Generation: family planning when you have NF*
- 10:15 - 10:45 Dr. Robert Listernick, Feinberg School of Medicine, Northwestern University; Dr. Karin Walsh, Children’s National Medical Center; Dr. Kristi Canty, Children’s Mercy Hospital, Kansas City; Kaymee Phillips, parent — *How to talk to your kids about NF, a panel discussion*
- 10:45 - 10:55 BREAK
- 11:00 - 11:40 Dr. Karin Walsh, Children’s National Medical Center — *Navigating your child’s learning disabilities and social challenges*
- 11:45 - 12:15 Dr. Gary Brenner, Massachusetts General Hospital — *Bacteriotherapy for NF2 and its broader implications*
- 12:20 - 12:35 Judy Waechter, RN, CRRN, BCPA — *Is there any room for humor when coping with a chronic illness?*
- 12:35-1:05 LUNCH

- 1:05 - 1:35 Dr. Robert Listernick, Feinberg School of Medicine,
Northwestern University — *An update on the diagnosis and
management of optic gliomas*
- 1:40 - 2:30 Dr. Kaleb Yohay, NYU Langone Health Comprehensive
Neurofibromatosis Center — *Food for Thought: What we
Know About Diet and Supplements for NF*
- Dr. Nicole Brossier, Washington University — *Obesogenic diet
as modulator of tumor penetrance in NF1 optic pathway glioma*
- 2:35 - 3:10 Dr. Sanjay Bidichandani, University of Oklahoma Health
Sciences Center — *Who Gets the Research Funds: the process,
the people, the progress*
- 3:15 - 3:30 Jenni Bischoff and Jenina Sorenson — *Living with NF:
personal stories to inspire us*
- WRAP-UP