



NF Midwest 2024 iNFo Fair Schedule

Auditorium	
8:55	Prize Drawing
9:00-9:10	Welcome & Introduction
9:10-9:35 <i>VIRTUAL</i>	Journey to FDA Approved Drugs in NF Andrea Gross, MD
9:35-10:05	Interventional Research Miriam Bornhorst, MD
10:05-10:35	Observational Research Vanessa Merker, PhD
10:35-10:50	Break
10:50	Prize Drawing
10:50-11:10	How NF Research is Funded Sarah Lees, MS, MEd, MHA
11:10-12:00	Participating in Research: Personal Experiences Panel Discussion
LUNCH STARTS IN ATRIUM	
12:00-1:00	Kids will have pizza in room 250. You may have them join you or they can remain in 250. Please, do not have pizza as we ordered only enough for the kids.
1:00	Prize Drawing
1:00-1:45	Gene Therapy in NF/SWN Miranda McManus, MS
1:45-2:00	We will now split out into separate topic groups NF1 will remain in the Auditorium NF2-SWN and Schwannomatosis will go to room #105

Thank you so much for being here today!

We encourage everyone to listen to each presentation. Even if a topic doesn't feel directly relevant now, it might be in the future, and it's a great way to stay informed and become a stronger advocate for NF. That said, we understand that sometimes you need a moment to recharge. Please feel free to step out, relax, or chat with others in the lobby—we also encourage you to meet new people and connect! Our presenters are happy to meet with you there if you have more questions or would prefer a more private conversation.

Just a small favor—we kindly ask that you move away from the auditorium doors so your conversation doesn't sneak back inside.

Thanks again for joining us today!

Thank you to our co-chairs, Dr. Bornhorst and Dr. Merker and to our volunteers. Thank you to our sponsors Alexion and SpringWorks.

Continues on Back...



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Break Out Sessions

NF1 Breakout - Auditorium RESEARCH UPDATES	
2:00-2:15	What is a Patient Education Manager? Mike Sager, Alexion
2:15-2:30 <i>VIRTUAL</i>	NF Genetics Cohort: the Clinical, Genomic and Photographic Registry for Neurofibromas in NF1 Kavita Sarin, MD, PhD
2:30-3:15	NF1 Clinical Trials Miriam Bornhorst, MD
3:15-3:30	Break - Treats in Atrium
3:30-4:15	The Use of Biomarkers in NF1 Jenny Garzon, MD
Approx. 4:15	End of NF1 Session

NF2/SWN - Breakout Room #105 RESEARCH UPDATES	
2:00-2:25	NF2-SWN Clinical Trials Vanessa Merker, PhD
2:25-2:50	NF2-SWN Updates and Current Non-Interventional Research Vanessa Merker, PhD
2:50-3:15	SWN Updates and Current Research Vanessa Merker, MD
3:15-3:30	Break - Treats in Atrium
3:30-4:15 <i>VIRTUAL</i>	Laboratory Models of NF2-SWN Related Tumors and How They Inform Clinical Trials Matthias Karajannis, MD, MS
Approx. 4:15	End of NF2-SWN and SWN Session