PROGRAM BOOK

2025 NF CONFERENCE

JUNE 21-24, 2025

OMNI SHOREHAM HOTEL
WASHINGTON, DC

CHILDREN'S TUMOR FOUNDATION
ENDING NF THROUGH RESEARCH

Network: makeNFvisible

Password: endNF2025

Welcome to the 2025 Global NF Summit and Conference in Washington, DC

On behalf of the Children's Tumor Foundation (CTF) and CTF Europe, welcome to the **2025 Global NF Summit and NF Conference** in Washington, DC!

This event is far more than a scientific or patient meeting—it is a truly global gathering of everyone working to end neurofibromatosis and schwannomatosis: researchers, clinicians, industry leaders, regulators, and most importantly, patients and families. We are thrilled to host this year's conference in the heart of the U.S. capital. It's a powerful demonstration of international collaboration and deep personal connections, setting the stage for a week of bold thinking and meaningful momentum.

I want to extend special thanks to our NF Conference planning committee: **Drs. Dusica Babovic-Vuksanovic (Mayo Clinic)**, **Elisabeth Castellanos Perez (Fundació Institut d'Investigació en Ciències de la Salut Germans Trias i Pujol, Spain)**, and **Rebecca Dodd (University of Iowa)**. They worked in close partnership across borders, institutions and with a highly committed CTF team to deliver an exceptional program. Their efforts were a masterclass in teamwork, scholarship, and community spirit.

This year's meeting will introduce two timely, high-impact sessions:

- A panel on the **Regulatory Landscape in Rare Diseases**, featuring top experts **Amy Comstock Rick, JD (FDA)** and **Steffen Thirstrup, MD, PhD (EMA)**, moderated by the incomparable **Julie Tibbets** of Goodwin Procter LLP.
- A dynamic discussion on the **Future of Healthcare and Research Funding**, organized by our excellent partners at **Capstone**.

As is tradition every other year, the patient-focused **NF Summit** and the scientific **NF Conference** are held back-to-back. This year, they are more integrated than ever.

Our 2025 NF Summit is co-chaired by a powerful group of dedicated NF clinicians **Dr. Miriam Bornhorst (Lurie Children's Hospital)** and **Dr. Carlos Romo (Johns Hopkins University)**, in close collaboration with three patient representatives **Christine Panza**, **Jason Gonzales**, and **Eunice Lee**. The summit program is a powerful combination of information, education and engagement.

Moreover, the summit and conference excels in building powerful bridges between the research and patient communities. The research **poster sessions** will include guided tours for Summit attendees, and **Dr. Mark Hutchinson (University of Adelaide)**, a leading expert in pain research, will moderate a unique panel on pain management—open to both researchers and patients.

Our Conference keynote speakers stand out for their work across diverse and innovative areas:

Next-Generation Treatments: *"What Doesn't Kill the Tumor Cell Makes It…Senesce"*
—*David Gewirtz, PhD* (Virginia Commonwealth University)

Microenvironments & Immune Response: *"What drives Plexiform neurofibroma formation? Progress and future prospects"*
—*Nancy Ratner, PhD* (Cincinnati Children's Hospital)

Translational Models & Novel Research Approach: *"Unlocking the Future of Oncology: Human-Centric Advanced Cell Models in Preclinical Drug Development"*
—*Pelin Candarlioglu Deacon, PhD* (Vivodyne)

Clinical Manifestation Management: *"The NIH Undiagnosed Diseases Program: Discovery, Diagnosis, Community, Sharing"*
—*William Gahl, MD, PhD* (NIH, National Human Genome Research Institute)

We are also proud to present the **second annual Young Investigator Day**, and we encourage you not to miss the **many satellite meetings** focused on specific high-priority topics—organized by our long-standing partners and collaborators.

Finally, we will open this year's meeting with a heartfelt tribute. Together with **Dr. Miriam Bornhorst**, I will honor the memory of two extraordinary individuals who left an indelible mark on our community:
Dr. Vincent Riccardi, a pioneering figure and compassionate clinician often called the "father of NF," and
Dr. Verena Staedtke, a brilliant physician-scientist whose work in gene therapy broke new ground and whose kindness touched so many lives.

Please take a moment to reflect on their immense contributions—and to let their legacy inspire us as we continue the work they helped set in motion.

Thank you for being here. I hope this week fills you with renewed purpose, collaboration, and resolve. This conference is one of the CTF team's proudest achievements. Each year, I leave more certain that this connected unique community will achieve our mission: **to end NF globally**.

Warmly,

Annette Bakker, PhD

CEO, Children's Tumor Foundation

Chair (ad interim) CTF Europe

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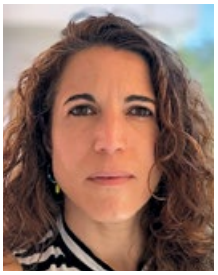
2025 NF Conference Co-Chairs

Dusica Babovic-Vuksanovic, MD, *Mayo Clinic*

Dusica Babovic-Vuksanovic was born in Sarajevo, Yugoslavia, where she completed her undergraduate and medical education. After her training in Pediatrics and Pediatric Endocrinology at the Children's Hospital in Sarajevo she worked there as a staff physician and Assistant Professor until 1992. Thanks to the Fulbright fellowship granted to her husband, her family came to the US, where she completed additional training at Mayo Clinic and became certified in Pediatrics, Clinical Genetics and Molecular Genetics. She has been a staff of Mayo Clinic in Rochester, MN since 1999. She carried on multiple leadership positions including a role of Chair of the Department of Medical Genetics Mayo Clinic and a Chair of the Enterprise Department of Clinical Genomics- Rochester, MN, Jacksonville, FL and Scottsdale, AZ, member of the IRB Board, Departmental Chair of Research and member of the Executive Committee of the Center for Individualized Medicine, leading the development of Individualized Medicine Clinic at Mayo. She was Director of Clinical Genetics Residency and Laboratory Genetics Fellowships in Clinical Molecular Genetics, Clinical Biochemical Genetics and Clinical Cytogenetics. Currently, she is serving as a Director of the Mayo Clinic Center of Excellence for Rare Disease (NORD). In addition to Mayo leadership roles, Dr. Babovic-Vuksanovic has been active at the national organizations such as the ACGME Review Committee for Medical Genetics and Genomics (including a role of vice-chair), and a member of the USMLE Pathology and Genetics Test Material Development. She is an active participant in international organizations, including member of Organizational Conference Committee for Royal Board of Princess Katherine of Serbia, and Bosnian-Herzegovinian-American Academy of Arts and Science, where she served as a President and a Vice-president.

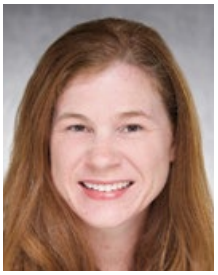
Dr. Babovic-Vuksanovic has 24 years of experience in Clinical Genetics and Genomics, and most of her work is related to rare disease. Her special clinical and research interest is in neurofibromatosis type 1, neurofibromatosis type 2, schwannomatosis and other RAS-pathway disorders. Dr. Babovic-Vuksanovic has been a director of Neurofibromatosis Program at Mayo Clinic since 1999 and has clinical experience in diagnosis and management of children and adults with neurofibromatoses. As a PI and Co-PI on several intramural and federally funded studies, she carried out preclinical studies and conducted 4 clinical trials for patients with neurofibromatosis type 1. She described a new syndrome characterized by bilateral orbital neurofibromas, Marfanoid body built and hypertrophic neuropathy, and published a first case series showing that paraspinal neurofibromas and peripheral neuropathy are features of Noonan syndrome. She led multiple collaborative studies which resulted in description of new phenotypes, and participated in the discovery of new genes.



Elisabeth Castellanos Perez, PhD, *Fundació Institut d'Investigació en Ciències de la Salut Germans Trias, Spain*

Dr. Castellanos has been leading the Clinical Genomics Unit of the Genetics Service of the German Trias & Pujol Hospital since 2010. Her laboratory is responsible for diagnosing genetic diseases such as Neurofibromatosis (NFs) and Schwannomatosis among other genetic diseases. Since 2015, the Genetics Service of the Germans Trias & Pujol Hospital has been one of the two Spanish Reference Centers (CSUR) for Phakomatosis. In recent years, the group joined GENTURIS, the European Reference Network for rare genetic syndromes with tumor risk.

In addition to caring for NF patients, Dr. Castellanos is developing a translational research program focused on Neurofibromatosis and Schwannomatosis patients. This research has led to several publications improving genetic testing for these diseases, developing new cellular models to study the role of neurofibromatosis and Schwannomatosis (NF-SWN) genes in tumorigenesis, and testing new RNA-based therapies for *NF2*-related Schwannomatosis. Dr. Castellanos is leading the EURONET-NF consortium to develop new genetic tests for Neurofibromatosis and Schwannomatosis. Together with Dr. Plotkin, she co-leads the expert panel responsible for defining the international guidelines for the classification of NF-SWN genes (NF-SWN Variant Classification Expert Panel (VCEP)).

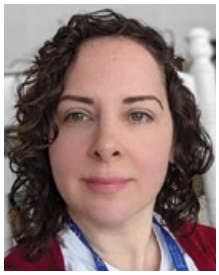


Rebecca Dodd, PhD, *University of Iowa*

Rebecca Dodd, PhD, is an Associate Professor of Medicine at the University of Iowa and serves as the Leader of the Cancer Genes and Pathways program at the Holden Comprehensive Cancer Center. She earned her PhD and completed her post-doctoral fellowship at Duke University where she trained in development of preclinical cancer models. Dr. Dodd's translational oncology lab focuses on MPNST biology and metastasis, with specific interest in tumor evolution, *in vivo* CRISPR/Cas9 tools, and therapeutic targeting of the tumor microenvironment.

BIOS

2025 NF Conference Keynote Speakers



Pelin Candarlioglu Deacon, PhD, *3D and 3Rs Ltd.*

Dr. Pelin Candarlioglu is a seasoned scientist and leader in advanced cell models, with over 15 years of experience spanning tissue engineering, oncology, and immunotherapy. She has developed complex in vitro models (CIVMs) such as organ-on-chip, 3D spheroids, and microphysiological systems (MPS), integrating them into drug discovery workflows for enhanced translational accuracy. Dr. Candarlioglu's work has directly impacted the pharmaceutical industry's ability to model human disease and evaluate therapeutic efficacy, supporting innovative drug safety and efficacy testing approaches.

As the founder and director of **3D and 3Rs Ltd.**, she champions the integration of complex in vitro models (CIVMs) in drug discovery, emphasising the principles of "3D" (three-dimensional, human-relevant models) and "3Rs" (Replacement, Reduction, Refinement of animal use). This mission captures both the scientific focus and purpose-driven ethos that have guided her career from her early work in tissue engineering to her current leadership in regulatory science. She has been providing independent consultancy services to SMEs in selecting and applying Advanced Cell Models for pharmaceutical applications to various clients, such as Vivodyne, where she has been leading the strategic development of next-generation MPS models, including adaptive immune system platforms. Previously, she led the MPS strategy at GlaxoSmithKline, where she initiated high-impact collaborations and championed the use of immune organ models to improve oncology drug testing.

Dr. Candarlioglu has held influential roles within global scientific networks, including Chair of the EUROoCS Industry Advisory Board and lead of the regulatory subgroup for the NA3RsC MPS Initiative, where she has driven industry-wide efforts to standardize and validate MPS technologies. She is a recognized thought leader, having contributed to strategic roadmaps, regulatory guidance, and numerous high-impact publications in the field.

Her work continues to shape the future of precision medicine by bridging the gap between innovative in vitro models and clinical relevance, driving the adoption of next-generation technologies across the pharmaceutical industry.

William A. Gahl, MD, PhD, *NIH, National Human Genome Research Institute*

Dr. William A. Gahl graduated from the Massachusetts Institute of Technology and earned his M.D. and Ph.D. from the University of Wisconsin. He served as pediatric resident and chief resident at the University of Wisconsin hospitals and completed clinical genetics and clinical biochemical genetics fellowships at the NIH. Dr. Gahl elucidated the basic defects in cystinosis and Salla disease and helped bring cysteamine to new drug approval by the Food and Drug Administration as the treatment for cystinosis. He has published over 650 papers, reviews, book chapters, and editorials, trained 42 biochemical geneticists and cultivated international experts in Hermansky-Pudlak syndrome, alkaptonuria, Oculocerebrorenal Syndrome of Lowe, Menkes disease, Congenital Disorders of Glycosylation, Griscelli Syndrome, Gray Platelet Syndrome, Joubert Syndrome, polycystic kidney disease and other ciliopathies, Hutchinson-Gilford Progeria, GNE myopathy, oculocutaneous albinism, sialuria, and free sialic acid storage disorders. His group identified the genes responsible for Hartnup disease, Gray Platelet Syndrome, two types of renal Fanconi syndrome, 3-methylglutaconic aciduria type III, a new neutrophil defect, and many other disorders. In 2008, he established the NIH Undiagnosed Diseases Program (UDP), which has made more than 350 rare disease diagnoses and discovered 30 new genetic diseases. Dr. Gahl expanded the UDP to a national Undiagnosed Diseases Network and a worldwide Undiagnosed Diseases Network International. He established American Board of Medical Specialties certification for medical biochemical genetics. Dr. Gahl received the Dr. Nathan Davis Award for Outstanding Government Service from the AMA, the Service to America Medal in Science and the Environment, the EURORDIS Lifetime Achievement Award, and numerous other awards. In 2019, he was elected to the National Academy of Medicine.

BIOS

2025 NF Conference Keynote Speakers

David A. Gewirtz, PhD, *Virginia Commonwealth University*

Dr. David Gewirtz is a Professor of Pharmacology and Toxicology and member of the Massey Comprehensive Cancer Center at Virginia Commonwealth University. His research for the past four decades has been focused on the nature of the response of solid tumors to chemotherapy and radiation. In particular, he has worked on identifying the role(s) of both autophagy and senescence in limiting the effectiveness of therapeutic strategies. Some of the scientific contributions of his laboratory include the finding that autophagy has multiple functional forms in addition to its cytoprotective function; the existence of an autophagic switch that allows autophagy to change its functional form; that therapy-induced senescence is not irreversible (i.e. that tumor cells that enter into senescence can escape and recover proliferative capacity); that therapy-induced senescence is distinct from replicative senescence in not being a consequence of telomere shortening; studies of senolytic action that can suppress senescence and improve the response to various forms of therapy in preclinical experimental models. His group was one of the first to suggest that senescence might be one form of tumor cell dormancy that is permissive for disease recurrence. He and his colleagues have recently published an article in Cancer Research that evaluates the potential utility of senolytic strategies and the likelihood that these strategies will have clinical ramifications. In previous publications, he has argued that clinical trials of autophagy inhibition have been premature in the absence of more effective and reliable drugs for autophagy inhibition. He and colleagues are currently writing an article that identifies significant issues in the preclinical scientific literature (studies in cell culture and tumor-bearing animals) that are thought to account for the limited applicability of drug-related findings to the clinic. His laboratory has recently initiated studies of the autophagic and senescence responses of solid tumor models to antibody drug conjugates, one of the most promising recently developed class of targeted antitumor drugs.

Nancy Ratner, PhD, *Cincinnati Children's Hospital*

Dr. Ratner is interested in the brain in Neurofibromatosis type 1 and Rasopathies, and in peripheral nerve tumors that occur in the Neurofibromatoses, NF1 and NF2. She uses genomics, animal, and cell culture models to study neurofibroma formation and neurofibroma therapeutics. Ratner received her bachelor's degree from Brown University, her doctorate from Indiana University, Bloomington (during which time she was a student in the Neurobiology Course at MBL), and was a postdoctoral fellow at Washington University in St. Louis. A member of the faculty at the University of Cincinnati from 1987 – 2004, she is currently a Professor in the Department of Pediatrics, Cincinnati Children's Hospital, University of Cincinnati, and the Program Leader for Cancer Biology and Neural Tumors Program in the Cancer and Blood Disorders Institute where she also co-Leads the Rasopathy Program and holds the Beatrice C. Lampkin Endowed Chair in Cancer Biology. She has served on numerous national and international review panels and authored over 100 peer-reviewed manuscripts and 30 reviews. She was awarded the von Recklinghausen Award in 2010, and received a Jacob K. Javits NIH Neuroscience Investigator Award in 2014.

Special Session Presenters - Pain

Johnny Crupi, *Chief Technology Officer, Ryght*

Prior to co-founding Synthetica Bio, Johnny Crupi was CTO at Predixion and JackBe. Mr. Crupi brings three decades of experience building enterprise scale applications for real-time systems. He has been awarded as a Sun Microsystems Distinguished Engineer and is a three-time Washingtonian Tech Titan. Mr. Crupi has a M.S. in Engineering Administration with a sub-focus in AI from the George Washington University and a B.S. in Mechanical Engineering for the University of Maryland.

John Forsayeth, PhD, *University of California San Francisco*

John Forsayeth is Professor Emeritus of Neurological Surgery at the University of California San Francisco (UCSF). He received his Ph.D. in Biochemistry from Monash University, Australia, in 1984 and subsequently did two post-doctoral fellowships at UCSF in the Department of Physiology. In 1989, he moved to the UCSF Department of Anesthesia to start his own laboratory where he was promoted to Assistant Professor. In 1997, he was appointed Director of Molecular Biology at Neurex Corporation in Menlo Park, CA. The Company was subsequently acquired by Elan Inc. At Elan, he was promoted to Principal Scientist and asked to establish a Parkinson's disease research team. In 2001, he moved to Avigen Inc., Alameda, CA, to become Director of Neurobiology. In 2004, he returned to UCSF to join the laboratory of Dr. Krystof Bankiewicz and, in 2009, was promoted to Adjunct Professor. He is the founder of three biotechnology Companies, Xalud Therapeutics, Rio Pharmaceuticals and Immunologic. He serves as Executive Chairman at Rio Pharmaceuticals and CEO at Immunologic.

Mark Hutchinson, PhD, *University of Adelaide*

Professor Mark Hutchinson is a pioneering researcher and academic leader who serves as the Director of the Institute for Photonics and Advanced Sensing (IPAS) at the University of Adelaide. His groundbreaking work in neuroimmunopharmacology has revolutionised our understanding of the "other brain"—the 90% of brain cells known as glia—and their crucial role in pain, addiction, and various neurological conditions. As head of the Neuroimmunopharmacology Laboratory, he has developed innovative approaches to biomarker identification and complex data analytics, successfully bridging the gap between laboratory discoveries and clinical applications.

In recognition of his exceptional contributions to science and leadership, Professor Hutchinson holds several prestigious appointments, including membership on the Prime Minister's National Science and Technology Council and Australia's Economic Accelerator board member. He chairs the Safeguarding Australia through Biotechnology Response and Engagement (SABRE) Alliance and the Australian Pain Solutions Research Alliance board, while his previous roles as President of Science and Technology Australia, review of the ARC Legislation and as Director of the ARC Centre of Excellence for Nanoscale BioPhotonics have strengthened Australia's scientific landscape. His research has pioneered novel drug activity at innate immune receptors, leading to transformative clinical applications that have advanced from laboratory concepts to bedside treatments.

Professor Hutchinson's impact extends beyond academic achievements, with his work fostering strong industry partnerships and commercial translations. His leadership has been celebrated through numerous accolades, including being named a 2024 Finalist for the Eureka Prize for Leadership in Science and receiving the Vice-Chancellor's Award for Outstanding Achievement in creating a Culture of Impact. Through his research and leadership, he continues to drive innovation in biomedical science while advocating for greater engagement between researchers, industry, and the broader community.

Kim Sullivan, PhD, *Boston University*

Dr. Sullivan is a Research Associate Professor at the Boston University School of Public Health department of Environmental Health and the former Associate Scientific Director for the Congressionally-directed Research Advisory Committee (RAC) on Gulf War Veterans' Illnesses. She is a behavioral neuroscientist and the Principal Investigator (PI) on the large multi-site Gulf War Illness Consortium (GWIC) that includes 9 study sites and is designed to determine the pathobiology of Gulf War Illness (GWI). She is also the PI of the large, multi-site Gulf War Illness Biorepository Network (BBRAIN) designed to share biospecimens and foster collaboration with other GWI researchers. She is also site PI for multiple treatment trials including Co-enzyme Q10 and D-cycloserine to treat cognitive and fatigue problems in veterans with GWI and multiple phase I/II trials of the multi-site GWI Clinical Trials Consortium (GWICTIC). Dr. Sullivan has worked in the field of aging and behavioral neurotoxicology since 1992. She has also coordinated field studies in neurotoxicology (i.e., pesticides, methylmercury), neurobehavioral outcomes and the effects of physical stressors and genetic predisposition to disease on cognitive functioning in Alzheimer's disease, stroke and Parkinson disease.

BIOS

Special Session Presenters - Regulatory Landscape in Rare Diseases

Amy Comstock Rick, JD, *Director of Strategic Coalitions, Rare Disease Innovation Hub, CBER/CDER*

Amy Comstock Rick, J.D., is CDER's Associate Director for Rare Disease Strategy and the Director of Strategic Coalitions for FDA's Rare Disease Innovation Hub (the Hub). She serves in a cross-cutting role across FDA's Center for Drug Evaluations and Research (CDER) and Center for Biologics Evaluation and Research (CBER) to facilitate implementation of the Hub. She also works closely with both centers to develop and carry out a rare disease strategic agenda. Ms. Rick, with support from staff in CBER's and CDER's rare disease programs, is the Hub's primary point of engagement for parties external to FDA.

Most recently, Ms. Rick served as Principal Consultant at Leavitt Partners, focusing on health policy matters, with a primary focus on rare disease and medical product development. Before Leavitt Partners, she served as President and Chief Executive Officer of the Food and Drug Law Institute (FDLI), a non-profit organization dedicated to providing an innovative, open, balanced exchange of ideas and viewpoints across the field of food and drug law.

Before joining FDLI, Ms. Rick was Chief Executive Officer of the Parkinson's Action Network. Ms. Rick also served as President of the Coalition for the Advancement of Medical Research and on the Boards of Directors for Research America, the National Health Council, and the American Brain Coalition.

Ms. Rick had previous federal service as a career attorney at the U.S. Department of Education in 1988, focusing primarily on the field of government ethics. She was the Senate-confirmed Director of the U.S. Office of Government Ethics from 2000 to 2003 and Associate Counsel to the President in the White House Counsel's Office from 1998 to 2000. She received a bachelor of arts degree from Bard College and a juris doctor degree from the University of Michigan.

Steffen Thirstrup, MD, PhD, *Chief Medical Officer, European Medicines Agency*

Steffen Thirstrup is a medical doctor and board-certified specialist in clinical pharmacology and therapeutics. He holds a PhD in pharmacology and has a long background in clinical internal medicine with special emphasis on adult respiratory medicine. Additionally, Dr. Thirstrup was appointed adjunct professor in pharmacotherapy at the Faculty of Health Sciences, University of Copenhagen, in 2012.From 2004-09 Steffen Thirstrup worked at Danish Medicines Agency first as the Danish member of CHMP at the European Medicines Agency (EMA) for five years including 10 months as joint CHMP- and CAT-member, followed by a short period as head of Danish Institute for Rational Pharmacotherapy dealing with HTA and best practice guidelines for primary care. In 2011 Prof. Thirstrup rejoined the licensing division at the Danish Medicines Agency acting as Head of Division for Medicines Assessment and Clinical Trials. During this period Prof Thirstrup co-chaired the European Commission's working group on market access for biosimilars medicinal products and acted as key scientific contact for the managing entity of the IMI beneficiaries for the PROTECT collaboration (Pharmacoepidemiological Research on Outcomes of Therapeutics by a European ConsorTium).

In March 2013, Prof Thirstrup joined the pharmaceutical consultancy company NDA Group AB as a full-time medical advisor on NDA's regulatory advisory board. In April 2014 Prof Thirstrup was appointed as director for the Regulatory Advisory Board at NDA Regulatory Services Ltd. Since June 2022 Prof Thirstrup has been the Chief Medical Officer at the European Medicines Agency, Amsterdam, The Netherlands.

Prof Thirstrup is author of more than 40 scientific papers, guidelines and text-book chapters as well as co-editor of 5th edition of *Basal og Klinisk Farmakologi* (Medical school pharmacology textbook in Danish). Prof Thirstrup shares his life between Amsterdam and with his family in a small community (Værløse) just outside Copenhagen, Denmark.

Julie K. Tibbets, *Chair, Life Sciences Regulatory & Compliance, Goodwin Procter LLP*

Julie Tibbets is a partner at Goodwin Procter LLP where she chairs the Life Sciences Regulatory & Compliance practice and co-chairs Goodwin's Rare Disease Initiative, which is focused on driving education and community networking in the rare disease space in support of accelerating progress for rare disease patients. Julie has practiced over 20 years in private practice counseling clients on FDA regulatory matters. She focuses her practice on FDA-regulated product development, clinical research, product commercialization, marketing and enforcement. Her clients include industry developers, manufacturers, investors, and patient advocacy and research organizations.

The Friedrich von Recklinghausen Award: Neurofibromatosis Tradition and Progress

The Children's Tumor Foundation's Friedrich von Recklinghausen Award is given to individuals in the professional NF community who have made significant contributions to neurofibromatosis or schwannomatosis research or clinical care. It is named after Friedrich Daniel von Recklinghausen (1833–1910), the German physician who first described 'von Recklinghausen's disease'—what we now know as neurofibromatosis type 1.

2025 Friedrich von Recklinghausen Award Recipient

It is with great pleasure that the Children's Tumor Foundation announces the recipient of the 2025 Friedrich von Recklinghausen Award, **Pierre Wolkenstein, MD, PhD, Henri-Mondor Hospital, Paris East University**.

Professor Pierre Wolkenstein, MD, PhD, has dedicated nearly four decades to transforming the landscape of neurofibromatosis care and research, particularly in the field of NF1. A dermatologist by training and visionary leader by nature, he has led the French National Referral Center for Neurofibromatoses since 2004, building it into a world-class center serving over 3,000 patients. As Chair of Dermatology at Henri-Mondor Hospital and Dean of the Faculty of Medicine at Université Paris-Est Créteil, Professor Wolkenstein has harmonized clinical excellence, academic rigor, and policy advocacy. His groundbreaking research on cutaneous neurofibromas and quality of life in NF1 has yielded over 400 publications and helped define new standards of care. As an outstanding mentor, he has cultivated a vibrant community of trainees, including the next-generation leadership of the Paris NF Center.

Professor Wolkenstein is a natural convener, collaborator, and advocate whose leadership has left a lasting imprint on the global NF field. He has served as President of the European Neurofibromatoses Group, co-chaired and hosted the first joint European–CTF NF Europe meeting in Paris in 2018. He contributed at the national level as medical advisor to the French Ministry of Health. His ability to join colleagues across disciplines, foster collaboration, and envision a better future for people with NF is unmatched. With the imminent publication of the KOMET study in *The Lancet,* which he signs as senior author, 2025 marks a fitting and timely moment to recognize Professor Wolkenstein's lifelong contributions to NF science, care, and community.

The Children's Tumor Foundation, along with his colleagues and peers, is proud and thrilled to recognize Prof. Dr. Wolkenstein with the 2025 Friedrich von Recklinghausen Award, not only for his many outstanding achievements in 38 years in the field but also for his dedicated efforts in supporting the entire NF community. Please join us in congratulating Prof. Dr. Wolkenstein for this well-deserved honor.

The following are the most recent recipients of the Award:

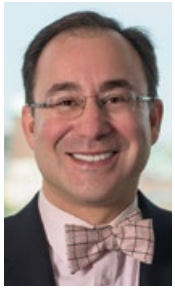
2024
Rosalie Ferner, MD
Guys and St. Thomas NHS Foundation Trust London, UK

2023
Margaret (Peggy) Wallace, PhD
University of Florida

2022
Jaishri Blakeley, MD
Johns Hopkins University

2021
Marco Giovannini, MD, PhD
UCLA

2020
D. Wade Clapp, MD
Indiana University School of Medicine



2019
Scott Plotkin, MD, PhD
Massachusetts General Hospital Harvard Medical School

2018
Ludwine Messiaen, PhD
University of Alabama at Birmingham

2017
Karen Cichowski, PhD
Harvard Medical School

2016
David Viskochil, MD, PhD
University of Utah

2015
Eric Legius, MD, PhD
University of Leuven, Belgium

2014
Gareth Evans, MD
St. Mary's Hospital, University of Manchester, UK

2013
Brigitte Widemann, MD
National Cancer Institute

2012
David Gutmann, MD, PhD
Washington University

2010
Nancy Ratner, PhD
Cincinnati Children's Hospital Medical Center

2009
Luis Parada, PhD
University of Texas Southwestern

2008
Vincent 'Vic' Riccardi, MD
The Neurofibromatosis Institute

IN MEMORIAM

We remember with deep respect and gratitude Vincent "Vic" Riccardi, MD, and Verena Staedtke, MD, PhD, whose dedication and passion enriched our community and advanced our shared mission.

VINCENT "VIC" RICCARDI, MD

VERENA STAEDTKE, MD, PHD

Schedule At-A-Glance (All times are EDT)

	TIME		EVENT	LOCATION
THU 6/19	3:00 PM	6:00 PM	REiNS Summer Meeting*	Governors Room [East Side]
	3:00 PM	7:00 PM	Registration & Check In Opens	West Registration Desk
FRI 6/20	7:00 AM	7:00 PM	Registration & Check In	West Registration Desk
	7:00 AM	6:00 PM	Young Investigator Day (Satellite Program, By Invitation Only)	Congressional
	1:00 PM	5:15 PM	**CLINICAL CARE PROGRAM: PART I [CME]**	Regency
SATURDAY JUNE 21	7:00 AM	5:00 PM	Registration & Check In	West Registration Desk
	7:00 AM	8:00 AM	Clinical Coordinators Breakfast (Closed Meeting)	Executive
	8:00 AM	11:00 AM	The NF Data Portal in Action: Analyzing Data & Accelerating Research*	Congressional
	8:00 AM	10:30 AM	**CLINICAL CARE PROGRAM: PART II [CME]**	Regency
	10:30 AM	11:00 AM	Break	Regency Gallery / Ambassador
	11:00 AM	12:00 PM	Challenges and Unmet Needs for Volumetric Analysis in NF1 Plexiform Neurofibromas*	Regency
	11:30 AM	1:30 PM	Lunch	Regency Gallery / Ambassador
	12:00 PM	5:00 PM	Exhibit Hall Open	Ambassador
	12:15 PM	1:15 PM	Special Session: The Nexus of Now: Where AI, Medicine, and Advocacy Converge on Pain	Regency
	1:30 PM	2:00 PM	**CONFERENCE OPENS**	Regency
	2:00 PM	3:00 PM	**KEYNOTE:** What Drives Plexiform Neurofibroma Formation? Progress and Future Prospects	Regency
	3:00 PM	6:00 PM	**MICROENVIRONMENTS AND THE IMMUNE RESPONSE**	Regency
	6:00 PM	7:00 PM	Special Discussion: Regulatory Landscape in Rare Diseases	Regency
	7:00 PM	9:00 PM	Combined NF Conference & NF Summit Saturday Evening Reception	Empire, Outdoor Terraces & Lawns
SUNDAY JUNE 22	7:00 AM	3:00 PM	Registration & Check In	West Registration Desk
	7:00 AM	9:00 AM	Breakfast	Regency Gallery / Ambassador
	7:00 AM	4:00 PM	Exhibit Hall Open	Ambassador
	7:30 AM	8:30 AM	Independent Satellite Symposium: Care Team Insight on the Management of Patients with NF1-PN	Empire Ballroom
	9:00 AM	9:40 AM	**KEYNOTE:** What Doesn't Kill the Tumor Cell Makes it...Senesce	Regency
	9:40 AM	12:15 PM	**NEXT GENERATION TREATMENTS**	Regency
	12:00 PM	1:30 PM	Satellite Meeting: Global NF Nurse and Allied Healthcare Professionals (AHP) Meet & Greet	Executive
	12:15 PM	1:15 PM	Lunch	Regency Gallery / Ambassador
	1:15 PM	3:20 PM	**NEXT GENERATION TREATMENTS (CONT.)**	Regency
	3:20 PM	3:35 PM	Late Breaking Platform	Regency
	3:35 PM	4:05 PM	Consortia & Collaboration Updates	Regency
	4:05 PM	4:45 PM	Friedrich von Recklinghausen Award Presentation	Regency
	4:45 PM	5:00 PM	Poster Advertisements	Regency
	5:00 PM	8:00 PM	Combined Poster Sessions & Cocktail Reception	Palladium / Diplomat
	5:15 PM	5:45 PM	Branded Product Theatre: Patient Perspectives on the NF1-PN Treatment Journey*	Empire
MONDAY JUNE 23	7:00 AM	1:00 PM	Registration & Check In	West Registration Desk
	7:00 AM	8:15 AM	Independent Satellite Symposium: Long-Term Care of Pediatric Patients with NF1-PN	Empire
	7:00 AM	8:30 AM	Breakfast	Regency Gallery / Ambassador
	7:00 AM	4:00 PM	Exhibit Hall Open	Ambassador
	8:30 AM	9:30 AM	**KEYNOTE:** The NIH Undiagnosed Diseases Program: Discovery, Diagnosis, Community, Sharing [CME]	Regency
	9:30 AM	12:30 PM	**MANAGEMENT OF DIVERSE CLINICAL MANIFESTATIONS [CME]**	Regency
	12:30 PM	1:30 PM	Lunch	Regency Gallery / Ambassador
	1:30 PM	3:30 PM	**MANAGEMENT OF DIVERSE CLINICAL MANIFESTATIONS (CONT.) [CME]**	Regency
	3:30 PM	3:45 PM	Break	Regency Gallery / Ambassador
	3:45 PM	5:45 PM	**BASIC / PRECLINICAL PLATFORMS (CONCURRENT SESSION)**	Empire
	3:45 PM	6:15 PM	**CLINICAL PLATFORMS (CONCURRENT SESSION)**	Regency
	6:30 PM	7:30 PM	Special Panel: Future of Healthcare and Research Funding	Regency
TUESDAY JUNE 24	7:00 AM	9:00 AM	Breakfast	Regency Gallery / Ambassador
	8:00 AM	9:00 AM	Poster Competition Finalists: Platform Presentations	Regency
	9:00 AM	10:00 AM	**KEYNOTE:** Unlocking the Future of Oncology: Human-Centric Advanced Cell Models	Regency
	10:00 AM	12:10 PM	**TRANSLATIONAL MODELS AND NOVEL RESEARCH APPROACHES**	Regency
	12:10 PM	1:00 PM	Lunch	Regency Gallery / Ambassador
	1:00 PM	3:00 PM	**TRANSLATIONAL MODELS AND NOVEL RESEARCH APPROACHES (CONT.)**	Regency
	3:00 PM	3:15 PM	**ADJOURNMENT**	Regency
	3:30 PM	5:30 PM	Plexiform Neurofibroma Volumetrics Workshop*	Regency

*Optional Satellite Meeting

AGENDA

Thursday · June 19, 2025 (All times are EDT)

3:00 PM	**6:00 PM**	**REiNS Summer Meeting (Optional Satellite Meeting)** Response Evaluation in Neurofibromatosis and Schwannomatosis (REiNS) 2025 Summer Meeting Open to all patient advocates and clinician researchers "New concepts: measuring how treatment affects a person's everyday life" Measuring more real-world impacts of NF in clinical trials and their long-term follow-up – things like employment, education, relationships, living independently, and more.	Governors Room [East Side]
3:00 PM	**7:00 PM**	**REGISTRATION & CHECK IN** Information & Help Desk is also open at this time.	West Registration Desk

Friday · June 20, 2025 (All times are EDT)

7:00 AM	**7:00 PM**	**REGISTRATION & CHECK IN** Information & Help Desk is also open at this time.	West Registration Desk
7:00 AM	**6:00 PM**	**YOUNG INVESTIGATOR DAY (Satellite Program, By Invitation Only)** *The Young Investigator Day is Closed Program, for invited participants only*	Congressional
7:00 AM	8:00 AM	Young Investigator Day Breakfast	
8:00 AM	8:30 AM	Hang your posters	
8:30 AM	8:35 AM	Opening Remarks by CTF	
8:35 AM	8:50 AM	Introductions by Mentors (Andi McClatchey, Edu Serra, Eric Legius, Gareth Evans, Marco Giovannini, Nancy Ratner, Vanessa Merker, Daochun Sun)	
8:50 AM	9:10 AM	Icebreaker activity	
9:10 AM	10:10 AM	**PLATFORM PRESENTATIONS, PEOPLE'S CHOICE VOTE** **Connecting Sleep and Sensory Deficits in a Drosophila Model of NF1** Jadwiga Bilchak, *University of Pennsylvania* **Secretory Mitophagy: An Adaptive Survival Mechanism in NF2 Tumors Promoting Tumor** Purva Gade, *George Mason University* **Developmental Analyses of Skeletal Manifestations in Knock-In Mouse Model of Neurofibromatosis Type I p.M992del "Mild" Patient Mutation** Alexis Stillwell, *Pennington Biomedical Research Center* **Mapping the Initiation and Evolution of Schwannoma Heterogeneity** Emily Wright, *Massachusetts General Hospital*	
10:10 AM	10:20 AM	**BREAK**	
10:20 AM	11:30 AM	Talk by Legends (Eric Legius, Marco Giovannini, Nancy Ratner, Gareth Evans)	
11:30 AM	12:10 PM	Fellowship and Grant Writing Workshop	
12:10 PM	1:25 PM	**BREAKOUT LUNCH WITH MENTORS**	
1:25 PM	1:45 PM	**BREAK** (Additional time to hang posters)	
1:45 PM	2:45 PM	Speed Networking	
2:45 PM	3:00 PM	**BREAK** (Additional time to hang posters)	
3:00 PM	3:30 PM	A Conversation with Francis Collins!	

AGENDA

Friday · June 20, 2025 (All times are EDT)

		SELECTED FLASH TALKS	
		Identification and Functional Analysis of Novel Neurofibromin-Interacting Proteins Alex Dyson, *Massachusetts General Hospital*	
		HDAC2 Activity in Schwannoma Cells and Consequences of its Inhibition Anna Nagel, *University of Central Florida*	
		Secretome Distinguishes Spectrum of NF1-associated Peripheral Nerve Sheath Tumors Chloe Sachs, *National Cancer Institute*	
		FOXM1 as a Drug Target in NF1-Associated Malignant Peripheral Nerve Sheath Tumors Ellen Voigt, *University of Iowa*	
		Proteome Analysis of Inner Ear Fluids in *NF2*-SWN Mouse Models with Hearing Loss Isam Naber, *University of California, Los Angeles*	
		Understanding and Targeting Epigenetic Vulnerabilities in Malignant Peripheral Nerve Sheath Tumors Joanna Lempiainen, *Washington University*	
		Prevalence and MRI-Based Characteristics of Distinct Nodular Lesions in Patients with NF1 on Whole-Body MRI Marie-Lena Schmalhofer, *University Medical Center Hamburg-Eppendorf*	
3:30 PM	4:00 PM	**Investigating the Cellular Heterogeneity of NF2-Altered Spinal Ependymoma with Single Cell Sequencing** Noah Burket, *Indiana University*	
		Inflammation-Driven Schwann Cell Reprogramming in Plexiform Neurofibroma: Role of the NF-κB Pathway in Neurofibroma Formation Ramya Ravindran, *Cincinnati Children's Hospital*	
		Identification of AHR and ARNT as Novel Tumor Suppressors in Schwann Cells Robert Valla, *German Cancer Research Cancer (DKFZ)*	
		Increased Myxoid Stroma in NF1-Associated Breast Cancer Roope Kallionpää, *University of Turku*	
		Characterizing the Role of ZNF423 in NF1-Related MPNST Sarah Morrow, *Indiana University*	
		Extracellular Vesicles Derived from Heterogeneous Nf2-/- Schwann Cells Present Distinct Proteomic Signatures Sara Veiga, *Massachusetts General Hospital*	
		Decision-Making Around Pre-Implantation Genetic Testing by Individuals with Neurofibromatosis Type 1: A Qualitative Study Sidney Ching, *MGH Institute of Health Professions*	
		Exploring the Role of Cutaneous Innervation in the Development of cNFs in NF1 Wanzheng Zhang, *Mondor Institute for Biomedical Research (IMRB)*	
4:00 PM	4:45 PM	Poster session A (Presenters with first names A-I)	
4:45 PM	5:30 PM	Poster session B (Presenters with first names J-W)	
5:30 PM	6:00 PM	People's Choice Vote winner announcement, Closing Remarks	
1:00 PM	**5:15 PM**	**CLINICAL CARE PROGRAM: PART I [CME]**	Regency
		Session Co-Chairs: Laura Klesse, MD, PhD, *UT Southwestern Medical Center;* Tena Rosser, MD, *Children's Hospital of Los Angeles;* Nicole Ullrich, MD, PhD, *Harvard University*	
1:00 PM	1:15 PM	**Clinical Care Program Welcome** Laura Klesse, MD, PhD, *UT Southwestern Medical Center;* Tena Rosser, MD, *Children's Hospital of Los Angeles;* Nicole Ullrich, MD, PhD, *Harvard University*	
1:15 PM	1:45 PM	**Invited Talk: Treatment of Meningiomas in *NF2*-SWN** Brian Na, MD, *University of California, San Francisco*	
1:45 PM	2:15 PM	**Invited Talk: Is it a VUS? Expanding our Knowledge of NF Variants and Classification Data** Alicia Gomes, MS, CGC - SHP, *University of Alabama at Birmingham*	

AGENDA

Friday · June 20, 2025 (All times are EDT)

2:15 PM	2:30 PM	**BREAK**	
2:30 PM	2:45 PM	**Platform: Use of Case Control Data to Classify Germline Variants in *LZTR1* Occurring in Schwannomatosis** D. Gareth Evans, MD, *University of Manchester*	
2:45 PM	3:30 PM	**Case Panel #1: Schwannomatosis Cases** **Moderator:** Nicole Ullrich, MD, PhD, *Harvard University* **Panel Presenter:** Bonnie Kaur, MD, *Columbia University* **Panel:** Leia Nghiemphu, MD, *University of California, Los Angeles;* Kaleb Yohay, MD, *NYU Langone*	
3:30 PM	4:15 PM	**Case Panel #2: NF1-Optic Glioma** **Moderator:** Nicole Ullrich, MD, PhD, *Harvard University* **Panel Presenter:** Ben Siegel, MD, *Children's National Hospital* **Panel:** Robert A. Avery, DO, MSCE, *Children's Hospital of Philadelphia;* Laura Klesse, MD, PhD, *UT Southwestern Medical Center*	
4:15 PM	5:15 PM	Clinical Care Program networking reception; light refreshments will be served.	

Saturday · June 21, 2025 (All times are EDT)

7:00 AM	**5:00 PM**	**REGISTRATION & CHECK IN** Information & Help Desk is also open at this time.	West Registration Desk
7:00 AM	**8:00 AM**	**Clinical Coordinators Breakfast (Closed Satellite Meeting)** **NFCN Clinical Coordinator Breakfast:** Discussion and networking opportunity for NFCN Clinical Coordinators and APPs supporting NF Clinics. **Co-Hosts:** Carole Mitchell, MS, RN *(NYU Langone)* and Lauren (Lo) Scheiner, RN, MSN *(UCLA)* will lead a discussion on clinic coordinator roles with CTF Clinical Program Manager, Ledare Finley, MS, LCGC.	Executive
8:00 AM	**11:00 AM**	**THE NF DATA PORTAL IN ACTION: ANALYZING DATA & ACCELERATING RESEARCH (Optional Satellite Meeting)**	Congressional
8:00 AM	9:30 AM	90-Minute Interactive Session	
9:30 AM	10:00 AM	30-Minute **BREAK**	
10:00 AM	11:00 AM	60-Minute Lightning Talks	

Seats are limited. RSVP required. Save your seat using the NF Conference attendee app

Description: During a 90 minute interactive session, attendees will receive hands-on instruction from team members from Sage Bionetworks and Pluto Bio on how to request specific datasets and send data to analysis platforms linked to the data portal. Additionally, the Sage team will present case studies demonstrating how researchers can repurpose datasets. Pluto will demonstrate how data from the portal can be explored, analyzed and visualized in order to address your unique scientific hypotheses without needing to code. Following a break, selected investigators from the NF community will highlight how they've re-used data from the NF Data Portal in their research during a 60 minute lightning talk session.

Target Audience: This session is tailored for users of all skill levels, especially those keen to discover how to locate, request, and reuse datasets from the NF Data Portal. We welcome participants from those with fundamental computer skills to experienced bioinformaticians. While the session won't cover in-depth analysis and bioinformatics, we are open to arranging subsequent sessions based on interest and feedback.

About the NF Data Portal: The NF Open Science Initiative (NF-OSI) aims to fast-track neurofibromatosis (NF) research by promoting open-science and data sharing. This initiative is a collaborative effort among various NF-oriented foundations, programs, clinicians, and researchers. NF-OSI has developed and manages the NF Data Portal, a dedicated platform for NF researchers to exchange, discover, and utilize existing research data and information about scientific tools.

Notes: Participants will be requested to bring their own laptops. Attendees with limited background on the NF Data Portal will be encouraged to view a 5 minute introductory video prior to the session to outline the key functions and features. Registered participants will be sent additional information and notes prior to the session.

Contact for Questions or Follow-Up: nf-osi@sagebionetworks.org

AGENDA

Saturday · June 21, 2025 (All times are EDT)

8:00 AM	**10:30 AM**	**CLINICAL CARE PROGRAM: PART II [CME]** Session Co-Chairs: Laura Klesse, MD, PhD, *UT Southwestern Medical Center;* Tena Rosser, MD, *Children's Hospital of Los Angeles;* Nicole Ullrich, MD, PhD, *Harvard University*	Regency
8:00 AM	8:15 AM	**CCAB Welcome & Updates** Laura Klesse, MD, PhD, *UT Southwestern Medical Center;* Amedeo Aziizi, MD, PhD, *Medical University of Vienna, Austria*	
8:15 AM	8:45 AM	**Invited Talk: Hearing Preservation in *NF2*-SWN** D. Bradley Welling, MD, PhD, FACS, *Harvard University*	
8:45 AM	9:15 AM	**Invited Talk: Dental Manifestations of NF1** Isabelle Chase, DDS, FRCDC, *Harvard School of Dental Medicine*	
9:15 AM	9:30 AM	**BREAK**	
		AI in NF1/SWN	
9:30 AM	9:50 AM	**Invited Talk: AI in NF Overview** Sanjay Aneja, MD, *Yale University*	
9:50 AM	10:10 AM	**Invited Talk: AI Use for Vestibular Schwannomas** Frank Buono, PhD, *Yale School of Medicine*	
10:10 AM	10:30 AM	**Invited Talk: AI Use for Cutaneous Neurofibromas** Kavita Sarin, MD, PhD, *Stanford University*	
10:30 AM	11:00 AM	**BREAK**	Regency Gallery / Ambassador
11:00 AM	**12:00 PM**	**Challenges and Unmet Needs for Volumetric Analysis in NF1 Plexiform Neurofibromas (Optional Satellite Meeting)** **Moderators:** Andrea Gross, MD, *National Institutes of Health;* Brigitte Widemann, MD, *National Institutes of Health* **Panelists:** Shivani Ahlawat, MD, *Johns Hopkins University;* Frank Buono, PhD, *Yale School of Medicine;* Randolph de la Rosa Rodriguez, MD, *Alexion, AstraZeneca Rare Disease;* Eva Dombi, MD, *NIH National Cancer Institute;* Gordon Harris, PhD, *Massachusetts General Hospital;* Christopher L. Moertel, MD, *Healx Ltd. and University of Minnesota;* Sébastien Perreault, MD, MSc, FRCPC, *University of Montreal;* Inka Ristow, EDiR MHBA, *UKE Hamburg*	Regency
11:30 AM	**1:30 PM**	**Lunch**	Regency Gallery / Ambassador
12:15 PM	**1:15 PM**	**Special Session: The Nexus of Now: Where AI, Medicine, and Advocacy Converge on Pain** **Moderator:** Mark Hutchinson, PhD, *University of Adelaide* **Panelists:** Kim Sullivan, PhD, *Boston University;* John Forsayeth, PhD, *University of California San Francisco;* Johnny Crupi, *Chief Technology Officer, Ryght* This unique session will address the critical intersections that shape the future of NF and SWN research, treatment, and care. Rather than simply acknowledging the complexity of the challenge, the panel will delve into proactive strategies and the practical steps necessary to foster transdisciplinary collaborations. Industry pioneers, clinical leaders, policymakers, and consumer advocates will come together to explore the convergence of life sciences, physical sciences, engineering, and beyond, emphasising that significant advancements in pain management and measurement rely on dismantling traditional silos and fostering innovative partnerships.	Regency
1:30 PM	**2:00 PM**	**CONFERENCE OPENS** **Welcome Remarks:** Annette Bakker, PhD, *Children's Tumor Foundation* **Tribute to Vincent Riccardi & Verena Staedtke:** Miriam Bornhorst, MD, *Lurie Children's Hospital of Chicago* **Opening Remarks from 2025 Conference Co-Chairs:** Dusica Babovic-Vuksanovic, MD, *Mayo Clinic;* Elisabeth Castellanos Perez, PhD, *Germans Trias & Pujol Hospital;* Rebecca Dodd, PhD, *University of Iowa*	Regency

AGENDA

Saturday · June 21, 2025 (All times are EDT)

2:00 PM	**3:00 PM**	**MICROENVIRONMENTS AND THE IMMUNE RESPONSE** **KEYNOTE: What Drives Plexiform Neurofibroma Formation? Progress and Future Prospects** Nancy Ratner, PhD, *Cincinnati Children's Hospital*	Regency
3:00 PM	**6:00 PM**	**MICROENVIRONMENTS AND THE IMMUNE RESPONSE** Session Co-Chairs: Thomas DeRaedt, PhD, *Children's Hospital of Philadelphia;* Andrea McClatchey, PhD, *Massachusetts General Hospital*	Regency
3:00 PM	3:25 PM	**Invited Talk: Mapping the Initiation, Evolution and Therapeutic Sensitivity of Heterogeneity in Schwannoma** Andrea McClatchey, PhD, *Massachusetts General Hospital*	
3:25 PM	3:40 PM	**Platform: Combined SHP2 and CDK4/6 Inhibition Depletes Intratumoral Tumor-Associated Macrophages in Malignant Peripheral Nerve Sheath Tumors** Lindy Zhang, MD. PhD, *Johns Hopkins University*	
3:40 PM	3:55 PM	**Platform: Intratumoral Plasma Cells are Required for a Durable Response to Adjuvant PD-L1 Therapy in De Novo MPNSTs** Dawn Quelle, PhD, *University of Iowa*	
3:55 PM	4:15 PM	**BREAK**	
4:15 PM	4:40 PM	**Invited Talk: Cellular Therapies for NF1 Associated Malignancies** Thomas DeRaedt, PhD, *Children's Hospital of Philadelphia*	
4:40 PM	4:55 PM	**Platform: Development of a Novel Regeneration-Driven Orthotopic Patient-Derived Xenograft (PDX) Mouse Model for *NF2*-Related Schwannomatosis (*NF2*-SWN)** Lars Riecken, PhD, *Fritz Lipmann Institute - Leibniz Institute on Aging*	
4:55 PM	5:20 PM	**Invited Talk: Decoding the Molecular Mechanisms and Immune Microenvironment in the Dynamics of Sequential Tumor Heterogeneity in Aggressive NF2 Meningiomas** Michel Kalamarides, MD, PhD, *University of California, Los Angeles*	
5:20 PM	5:35 PM	**Platform: Window of Opportunity Study of Nivolumab and Ipilimumab in People with Neurofibromatosis Type 1 and Newly Diagnosed Malignant and Pre-Malignant Peripheral Nerve Sheath Tumors** Jaishri Blakeley, MD, *Johns Hopkins University*	
5:35 PM	6:00 PM	**Invited Talk: Rewiring the Tumor Microenvironment: Unlocking How Epigenetic Plasticity Drives MPNST Metastasis** Rebecca Dodd, PhD, *University of Iowa*	
6:00 PM	**7:00 PM**	**Special Discussion: Regulatory Landscape in Rare Diseases** **Moderator:** Julie K. Tibbets, *Chair, Life Sciences Regulatory & Compliance, Goodwin Procter LLP* **Speakers:** Amy Comstock Rick, JD, *Director of Strategic Coalitions, Rare Disease Innovation Hub, CBER/CDER;* Steffen Thirstrup, *Chief Medical Officer, European Medicines Agency*	Regency
7:00 PM	**9:00 PM**	**Combined NF Conference & NF Summit Saturday Evening Reception** A cocktail and walking dinner reception hosted by Children's Tumor Foundation at the Omni Shoreham, welcoming both NF Summit and NF Conference attendees.	Empire, Outdoor Terraces & Lawns

AGENDA

Sunday · June 22, 2025 (All times are EDT)

7:00 AM	**3:00 PM**	**REGISTRATION & CHECK IN** Information & Help Desk is also open at this time.	West Registration Desk
7:00 AM	**9:00 AM**	**Breakfast**	Regency Gallery / Ambassador
7:30 AM	**8:30 AM**	**Independent Satellite Symposium: Care Team Insight on the Management of Patients with NF1-PN** Hosted by SpringWorks Therapeutics Light refreshments will be served	Empire Ballroom, Lower Level 2B
9:00 AM	**9:40 AM**	**NEXT GENERATION TREATMENTS** **KEYNOTE: What Doesn't Kill the Tumor Cell Makes it...Senesce** David A Gewirtz, PhD, *Virginia Commonwealth University*	Regency
9:40 AM	**12:15 PM**	**NEXT GENERATION TREATMENTS** Session Co-Chairs: Angela Hirbe, MD, PhD, *Washington University School of Medicine, Missouri;* Christopher L. Moertel, MD, *University of Minnesota;* Brigitte C. Widemann, MD, *NIH National Cancer Institute*	Regency
9:40 AM	9:55 AM	**Platform: Deconvoluting and Targeting Mechanism of Resistance to SHP2 Inhibition in Malignant Peripheral Nerve Sheath Tumors** Jiawan Wang, PhD, *Johns Hopkins University*	
9:55 AM	10:10 AM	**Platform: Inhibition of Focal Adhesion Kinase Impairs Tumor Formation and Preserves Hearing in a Murine Model of *NF2*-Related Schwannomatosis** Dana Mitchell, MD, *Indiana University School of Medicine*	
10:10 AM	10:35 AM	**Invited Talk: Cancer Prevention in NF1 Through Informed Surveillance and Multi-Dimensional Circulating Biomarkers** Taylor Sundby, MD, *NCI Pediatric Oncology Branch*	
10:35 AM	10:50 AM	**Platform: Proof-of-Principle of NF1 Gene Therapy in Plexiform Neurofibroma Mice Models** Jean-Philippe Brosseau, PhD, *Université de Sherbrooke*	
10:50 AM	11:05 AM	**Platform: Combined Inhibition of eIF4A and XPO1 Synergistically Enhances Anti-Tumor Effects in MPNST Models** Janet Oblinger, PhD, *Nationwide Children's Hospital*	
11:05 AM	11:20 AM	**BREAK**	
11:20 AM	11:45 AM	**Invited Talk: Redefining Pathology: How AI is Shaping the Future of Biomarker Discovery** Ali Bashashati, PhD, *University of British Columbia*	
11:45 AM	12:00 PM	**Platform: Therapeutic Targeting of PRC2-Driven MPNST Metastasis** Alexa Sheehan, BS, *University of Iowa*	
12:00 PM	12:15 PM	**Platform: Voluntary Aerobic Exercise Attenuates Tumor Growth in a Rat Model of NF1-Driven Mammary Cancer** Semira Ortiz, PhD, *Pennington Biomedical Research Center*	
12:00 PM	**1:30 PM**	**Satellite Meeting: Global NF Nurse and Allied Healthcare Professionals (AHP) Community of Practice Meet & Greet** Purpose of this meeting is to follow on from the inaugural NF Specialist Nurse meet and greet held last year at the Global NF Conference in Brussels 2024. This is an open meeting to all NF specialist nurses and allied healthcare professionals within a healthcare setting (physiotherapists, psychologists, dieticians, social workers etc) to come together and develop a Community of Practice (CoP) with the aims of sharing experience, best practice, and to encourage collaboration among NF Specialist Nurses and AHPs working in Neurofibromatosis Centres globally.	Executive
12:15 PM	**1:15 PM**	**Lunch**	Regency Gallery / Ambassador

Sunday · June 22, 2025 (All times are EDT)

1:15 PM	**3:20 PM**	**NEXT GENERATION TREATMENTS (CONT.)** Session Co-Chairs: Angela Hirbe, MD, PhD, *Washington University School of Medicine, Missouri*; Christopher L. Moertel, MD, *University of Minnesota;* Brigitte C. Widemann, MD, *NIH National Cancer Institute*	Regency
1:15 PM	1:40 PM	**Invited Talk: Exploration of Lipid Nanoparticles (LNPs) for Therapeutic Targeting of NF Tumor Cells** Lars Riecken, PhD, *Fritz Lipmann Institute - Leibniz Institute on Aging*	
1:40 PM	1:55 PM	**Platform: Dual Acting Inhibitors Target RAS/RAF/MERK/ERK, mTOR, and Autophagy to Treat MPNST** Frank Huang, PhD, *Mayo Clinic*	
1:55 PM	2:10 PM	**Platform: Merlin Restoration Prevents Schwannoma Growth in Genetically Engineered Mouse Models of *NF2*-SWN** Jeremie Vitte, PhD, *University of California, Los Angeles*	
2:10 PM	2:25 PM	**Platform: *In Vivo* Evaluation of MERTK Inhibitors UNC2025 and Clinically Tested MRX-2843 in Periostin-Cre;NF2$^{fl/fl}$ Schwannoma and Orthotopic Xenograft Meningioma Mouse Models** Sylwia Ammoun, PhD, *University of Plymouth*	
2:25 PM	2:50 PM	**BREAK**	
2:50 PM	3:05 PM	**Invited Talk: Development of Next Generation Cell Therapies to Remodel the Tumor Microenvironment** Rosie Kaplan, MD, NCI *Pediatric Oncology Branch*	
3:05 PM	3:20 PM	**Platform: Human Induced Pluripotent Stem Cell (iPSC) and Murine Immune-Proficient Preclinical Models of ANNUBP Reveal Sensitivities to MDM2 Inhibition and Low Dose Methotrexate** Garrett Draper, BS, *University of Minnesota*	
3:20 PM	3:35 PM	**Platform: Late Breaking Abstract** **Platform: Neratinib for *NF2*-Related Schwannomatosis with Progressive Tumors: Interim Analysis from the INTUITT-NF2 Platform-Basket Trial** Scott Plotkin, MD, PhD, *Massachusetts General Hospital*	Regency
3:35 PM	**4:05 PM**	**CONSORTIA & COLLABORATION UPDATES**	Regency
3:35 PM	3:50 PM	**International ClinGen NF1/SWN Variant Curation Expert Panel (VCEP)** Yunija Chen, PhD, *University of Alabama at Birmingham*	
3:50 PM	4:05 PM	**Neurofibromatosis Clinical Trials Consortium (NFCTC)** Michael Fisher, MD, *Children's Hospital of Philadelphia*	
4:05 PM	**4:45 PM**	**Friedrich von Recklinghausen Award** Presented by Annette Bakker, *Children's Tumor Foundation*	Regency
4:45 PM	**5:00 PM**	**Poster Advertisements** Twelve Semi-Finalists for the 2025 NF Conference Poster Competition will present a one-slide, one-minute pitch ('poster advertisement') to Conference attendees. Six semi-finalists from each main category (Basic/Preclinical and Clinical) were pre-selected from poster abstracts, and a panel of judges will select three finalists from each main category during the Combined Poster Session. Finalists will be announced by midday on Monday. All six finalists will have the opportunity to present their work in a 7-minute presentation, with 3 minutes of Q&A on Tuesday morning.	Regency
5:00 PM	**8:00 PM**	**Combined Poster Sessions & Cocktail Reception** Basic / Preclinical Science and Clinical Science Poster Presentations. Refreshments will be served.	Palladium / Diplomat
5:15 PM	**5:45 PM**	**Branded Product Theatre: Patient Perspectives on the NF1-PN Treatment Journey (Optional Satellite Meeting)** A sponsored presentation to showcase exciting product and treatment options Hear a patient and caregiver's experience navigating NF1-PN from diagnosis to treatment and long-term management **Speakers:** Ben Guikema, *Senior Director, U.S. Medical Affairs Alexion Pharmaceuticals* Kim and Quentin, *Patient STAR Ambassadors*	Empire

AGENDA

Monday · June 23, 2025 (All times are EDT)

7:00 AM	**1:00 PM**	**REGISTRATION & CHECK IN** Information & Help Desk is also open at this time.	West Registration Desk
7:00 AM	**8:15 AM**	**Independent Satellite Symposium: Expert Perspectives on Long-Term Care of Pediatric Patients with NF1-PN** Hosted by Alexion AstraZeneca Rare Disease **Chair:** Miriam Bornhorst, MD, *Lurie Children's Hospital of Chicago* **Speakers:** Amy Armstrong, MD, *St. Louis Children's Hospital;* Sebastien Perreault, MD, MSc, FRCPC, *University of Montreal*	Empire
7:00 AM	**8:30 AM**	**Breakfast**	Regency Gallery / Ambassador
8:30 AM	**9:30 AM**	**MANAGEMENT OF DIVERSE CLINICAL MANIFESTATIONS** **KEYNOTE: The NIH Undiagnosed Diseases Program: Discovery, Diagnosis, Community, Sharing [CME]** William Gahl, MD, PhD, *NIH, National Human Genome Research Institute*	Regency
9:30 AM	**12:30 PM**	**MANAGEMENT OF DIVERSE CLINICAL MANIFESTATIONS: OVERLAPPING NF1 AND SCHWANNOMATOSIS PHENOTYPES [CME]** Session Co-Chairs: Tena Rosser, MD, *Children's Hospital of Los Angeles;* David Stevenson, MD, *Stanford University;* Kaleb Yohay, MD, *NYU Langone* **Overlapping NF1 and Schwannomatosis Phenotypes** **Moderators:** Eric Legius, PhD, *KU Leuven;* Katharina Wimmer, PhD, *Medizinische Universität Innsbruck*	Regency
9:30 AM	9:55 AM	**Invited Talk: Constitutional Mismatch Repair Deficiency and its Connections with NF1** Katharina Wimmer, PhD, *Medizinische Universität Innsbruck*	
9:55 AM	10:20 AM	**Invited Talk: Heterozygosity for Loss-of-Function Variants in LZTR1 is Associated with Isolated Multiple Café-au-Lait Macules** Alessandro De Luca, PhD, *Istituto CSS-Mendel, Rome*	
10:20 AM	10:40 AM	**Invited Talk: Update on Intestinal Neurofibromatosis** Eric Legius, PhD, *KU Leuven*	
10:40 AM	11:00 AM	**BREAK**	
11:00 AM	11:20 AM	**Invited Talk: Hypertrophic Neuropathy in Rasopathy** Radhika Dhamija, MBBS, *Mayo Clinic*	
11:20 AM	11:40 AM	**Invited Talk: A Peripheral Nerve Sheath Tumor Syndrome Caused by Postzygotic ERBB2 Mutations** Michael Ronellenfitsch, MD, PhD, *Goethe University Frankfurt*	
11:40 AM	11:55 AM	**Platform: Deep Intronic NF1 Splice Variant Consistently Causing Spinal Neurofibromatosis in Five Patients** Kimia Hashemi, MSc, *Medizinische Universität Innsbruck*	
11:55 AM	12:10 PM	**Platform: Somatic KRASG12V-Variant as a Driver for Localized Hypertrophic Neuropathy Mimicking Plexiform Neurofibroma** Pia Vaassen, MD, *Sana Kliniken Duisburg*	
12:10 PM	12:30 PM	Panel Discussion with Q&A	
12:30 PM	**1:30 PM**	**Lunch**	Regency Gallery / Ambassador

AGENDA

Monday · June 23, 2025 (All times are EDT)

1:30 PM	**3:30 PM**	**MANAGEMENT OF DIVERSE CLINICAL MANIFESTATIONS: MUSCULOSKELETAL MANIFESTATIONS OF NF1 [CME]** Session Co-Chairs: *Tena Rosser, MD, Children's Hospital of Los Angeles;* David Stevenson, MD, *Stanford University;* Kaleb Yohay, MD, NYU Langone	Regency
		Musculoskeletal Manifestations of NF1 **Moderators:** David Stevenson, MD, *Stanford University;* and Kaleb Yohay, MD, *NYU Langone*	
1:30 PM	1:50 PM	**Invited Talk: Carnitine for Muscle Weakness and Fatigue in NF1** Yemina Berman, BScHons BMBS PhD FRACP, *University of Sydney, Australia*	
1:50 PM	2:10 PM	**Invited Talk: Targeted Therapies for Pathologic Bone Disease: Are We There Yet?** Jonathan Rios, PhD, *UT Southwestern Medical Center*	
2:10 PM	2:30 PM	**Invited Talk: Spinal Deformity in NF1** Noelle Larson, MD, *Mayo Clinic*	
2:30 PM	2:50 PM	**Invited Talk: Decoding NF1-Related Bone Dysplasia: Beyond the ERK Pathway** Florent Elefteriou, PhD, *Baylor College of Medicine*	
2:50 PM	3:30 PM	Panel Discussion with Q&A	
3:30 PM	3:45 PM	**BREAK**	Regency Gallery / Ambassador
3:45 PM	**5:45 PM**	**BASIC / PRECLINICAL PLATFORMS (CONCURRENT SESSION)** Session Co-Chairs: Elliot Robinson, MD, PhD, *Cincinnati Children's Hospital Medical Center;* Miriam Smith, PhD, *University of Manchester (UK)*	Empire
3:45 PM	4:00 PM	**Platform: Differential Expression Analysis of Schwannomas Compared to Normal Tibial Nerve Samples Identifies Potential Druggable Targets in Non-*NF2* Schwannomatosis** Sasha Scott, PhD, *Sage Bionetworks*	
4:00 PM	4:15 PM	**Platform: A New Hypomorphic *NF2* Isoform Induced by Antisense Gene Therapy is Able to Partially Recover *NF2* Deficiency on *NF2*-Related Schwannomatosis iPSC-Based Cell Model** Gemma Casals-Sendra, MS, *Germans Trias & Pujol Research Institute*	
4:15 PM	4:30 PM	**Platform: NF1 Loss Confers Susceptibility to Cell Death in Schwann Cell Tumors** Liang Hu, MD, *Cincinnati Children's Hospital Medical Center*	
4:30 PM	4:45 PM	**Platform: Using Patient-Derived Stem Cells to Model the Neurodevelopmental Phenotype of NF1** Kiymet Bozaoglu, PhD, *Murdoch Children's Research Institute*	
4:45 PM	5:00 PM	**Platform: Behavioral and Metabolic Phenotypes Exhibit Differential Requirement on Signaling Cascades Downstream of Ras** Seth Tomchik, PhD, *University of Iowa*	
5:00 PM	5:15 PM	**Platform: Mitochondrial Respiration as a Readout of NF1 Function in Mouse Models with Patient Mutations** Semira Ortiz, PhD, *Pennington Biomedical Research Center*	
5:15 PM	5:30 PM	**Platform: Aberrant Cortico-Striatal Neural Activity Underlies Impulsivity and ADHD in a Preclinical Model of Neurofibromatosis Type 1** Jodi Lukkes, PhD, *Indiana University School of Medicine*	
5:30 PM	5:45 PM	**"People's Choice" from Young Investigator Day**	

AGENDA

Monday · June 23, 2025 (All times are EDT)

3:45 PM	**6:15 PM**	**CLINICAL PLATFORMS (CONCURRENT SESSION)** Session Co-Chairs: Radhika Dhamija, MBBS, *Mayo Clinic;* Chelsea Kotch, MD, *Children's Hospital of Philadelphia*	Regency
3:45 PM	4:00 PM	**Platform: CAVS-NF1: AI-Powered Webtool for MR-T1 Volumetric Analysis of NF1 Optic Pathway Gliomas** Abhijeet Parida, MSc, *Children's National Hospital*	
4:00 PM	4:15 PM	**Platform: Treatment Heterogeneity and Survival Outcomes in an International, Multi-Institutional Cohort of Individuals with NF1-Associated High-Grade Glioma and High-Grade Astrocytoma with Piloid Features** Chelsea Kotch, MD, MSCE, *Children's Hospital of Philadelphia*	
4:15 PM	4:30 PM	**Platform: Baseline Characteristics and Cross-Sectional Analysis of a Cutaneous Neurofibroma Natural History Study in 494 People with NF1** Mandi Johnson, MBA, *Johns Hopkins University*	
4:30 PM	4:45 PM	**Platform: MRI Features and the Role of Image Guided Biopsy for Assessment of Pre-Malignant Versus Malignant Peripheral Nerve Sheath Tumors in People with Neurofibromatosis Type 1** Shivani Ahlawat, MD, *Johns Hopkins University*	
4:45 PM	5:00 PM	**Platform: Age Trends of ADHD Symptoms in Children with Neurofibromatosis Type 1: An Integrative Analysis of Data from Six Institutions** Yang Hou, PhD, *Florida State University*	
5:00 PM	5:15 PM	**Platform: Update from the Long-Term Follow-Up (LTFU) Phase of ReNeu: A Pivotal Phase 2b Trial of Mirdametinib in Children and Adults With Neurofibromatosis Type 1 (NF1)-Associated Symptomatic Plexiform Neurofibroma (PN)** Angela Hirbe, MD, PhD, *Washington University School of Medicine, Missouri*	
5:15 PM	5:30 PM	**Platform: Long-Term Efficacy and Safety of Bevacizumab for Progressive Tumors in Neurofibromatosis Type 2-Related Schwannomatosis (*NF2*-SWN)** Natalie Stec, MD, *Massachusetts General Hospital*	
5:30 PM	5:45 PM	**Platform: Updated Results on Brigatinib Treatment for Progressive Tumors in Patients with *NF2*-Related Schwannomatosis: A Sub-Study of the INTUITT-NF2 Trial** Scott Plotkin, MD, PhD, *Massachusetts General Hospital*	
5:45 PM	6:00 PM	**Platform: Development of the QUEST Patient-Reported Measure: QUality of Life Evaluation for *NF2*-Related Schwannomatosis Trials** Sophia Carias, BA, *Massachusetts General Hospital*	
6:00 PM	6:15 PM	**Platform: Clinical Evaluation of PRG-N-01 in *NF2*-Related Schwannomatosis: Interim Findings from a Phase 1/2 Study** Beom Hee Lee, MD, PhD, *Asan Medical Center, Seoul, Korea*	
6:30 PM	**7:30 PM**	**Special Panel: Future of Healthcare and Research Funding** Refreshments will be served. Agenda to follow.	Regency

AGENDA

Tuesday · June 24, 2025 (All times are EDT)

7:00 AM	**9:00 AM**	**Breakfast**	Regency Gallery / Ambassador
8:00 AM	**9:00 AM**	**Poster Competition Finalists: Platform Presentations** Finalists will give a platform presentation with time for Q&A	Regency
9:00 AM	**10:00 AM**	**TRANSLATIONAL MODELS AND NOVEL RESEARCH APPROACHES** **KEYNOTE: Unlocking the Future of Oncology: Human-Centric Advanced Cell Models in Preclinical Drug Development** Pelin Candarlioglu Deacon, PhD, *3D and 3Rs*	Regency
10:00 AM	**12:10 PM**	**TRANSLATIONAL MODELS AND NOVEL RESEARCH APPROACHES** Session Co-Chairs: Sara Gosline, PhD, *Pacific Northwest National Laboratory;* Lu Q. Le, MD, PhD, *University of Virginia School of Medicine;* Eva Trevisson, MD, PhD, *University of Padova, Italy*	Regency
10:00 AM	10:25 AM	**Invited Talk: Charting Therapeutic Vulnerabilities in NF1 Tumors with Patient-Derived Organoid Models** Alice Soragni, PhD, *University of California, Los Angeles*	
10:25 AM	10:40 AM	**Platform: Leveraging a Patient-Derived Xenograft Microtissue Platform to Identify Patient Specific Drug Combinations in NF1 Malignant Peripheral Nerve Sheath Tumors** Sara Gosline, PhD, *Pacific Northwest National Laboratory*	
10:40 AM	11:00 AM	**BREAK**	
11:00 AM	11:25 AM	**Invited Talk: Triangulating Innovation: Bridging AI, Multi-Omics, and Unmet Oncology Clinical Needs** Shannon McWeeney, PhD, *Oregon Health and Science University*	
11:25 AM	11:40 AM	**Platform: Dissecting the Role of CDKN2a Loss in Regulating Antioxidant Pathways to Promote MPNST Tumorigenesis Using *In Vivo* CRISPR/Cas9 Models** Akshaya Warrier, *University of Iowa*	
11:40 AM	11:55 AM	**Platform: Immune Competent Models for NF1-Associated Glioblastoma: Allografts Accurately Recapitulate Primary Tumors** Stephanie Brosius, MD, PhD, *Children's Hospital of Philadelphia*	
11:55 AM	12:10 PM	**Platform: A Haploinsufficiency Restoration Strategy Corrects Neurobehavioral Deficits in *Nf1*$^{+/-}$ Mice** Steven Angus, PhD, *Indiana University School of Medicine*	
12:10 PM	**1:00 PM**	**Lunch**	Regency Gallery / Ambassador
1:00 PM	**3:00 PM**	**TRANSLATIONAL MODELS AND NOVEL RESEARCH APPROACHES (CONT.)** Session Co-Chairs: Sara Gosline, PhD, *Pacific Northwest National Laboratory;* Lu Q. Le, MD, PhD, *University of Virginia School of Medicine;* Eva Trevisson, MD, PhD, *University of Padova, Italy*	Regency
1:00 PM	1:25 PM	**Invited Talk: Therapeutic Strategies to Induce Human Schwannoma Cell Death and Validation Using Functional Precision Medicine** Cristina Fernandez-Valle, PhD, *University of Central Florida*	
1:25 PM	1:40 PM	**Platform: Exploring the Interplay Between Lipid Metabolism and LZTR1 in Peripheral Nerve Pathologies** Georgia Daraki, MSc, *Fritz Lipmann Institute-Leibniz Institute on Aging*	
1:40 PM	1:55 PM	**Platform: Neurofibromatosis Type 1 is Associated with Extensive, Independent Somatic Mutation of the Wild-Type *NF1* Allele in Normal Tissues** Thomas Oliver, MD, PhD, *Wellcome Sanger Institute, Hinxton, UK*	

AGENDA

Tuesday · June 24, 2025 (All times are EDT)

1:55 PM	2:20 PM	**Invited Talk: Translational Advances in MPNST** Luis Parada, PhD, *Memorial Sloan Kettering Cancer Center*	
2:20 PM	3:00 PM	Future of Translational Models in NF: Collaboration and Innovation: Panel Discussion with Q&A	
3:00 PM	**3:15 PM**	**ADJOURNMENT** **Closing Remarks:** Annette Bakker, PhD, CEO, *Children's Tumor Foundation*	Regency
3:30 PM	**5:30 PM**	**Plexiform Neurofibroma Volumetrics Workshop (Optional Satellite Meeting)** **Workshop Goal:** To bring together various stakeholders including clinicians, imaging specialists, pharmaceutical industry representatives, clinical researchers and patient advocates to develop a framework for a centralized, standardized training and validation plexiform neurofibroma volumetric imaging dataset **Agenda:** Brief Overview of Challenges of Plexiform Neurofibroma Volumetrics • Summary of "Challenges and Unmet Needs for Volumetric Analysis in NF1 Plexiform Neurofibromas" session from Clinical Care Program • Clinical care imaging vs research imaging needs Proposed Plexiform Neurofibroma Imaging Training and Validation Set • Introduction and potential uses Interactive Feedback on Proposed Training and Validation Set including • General Feedback/alternative approaches • What to include in the dataset • How to generate the dataset • How to define the minimum standard of performance Implementation and Next Steps	Regency

CHILDREN'S TUMOR FOUNDATION
ENDING NF THROUGH RESEARCH

YOUNG INVESTIGATOR DAY

NF CONFERENCE

The Children's Tumor Foundation is thrilled to host the second annual Young Investigator Day (YI Day) on Friday, June 20, 2025, in conjunction with the 2025 Global Conference.

Developing young investigators and supporting their growth into careers as independent NF researchers is a central objective of the Children's Tumor Foundation. We are excited to share a day dedicated to supporting these up-and-coming researchers in networking, science, and mentorship, and furthering their independent research and future career plans.

Find the Young Investigator Day Program Book at ctf.org/YIDay or scan the code below.

The NF Data Portal in Action: Analyzing Data & Accelerating Research

Part of the NF Open Science Initiative (NF-OSI), the NF Data Portal is designed to fast-track neurofibromatosis research through open science and data sharing.

Join Sage Bionetworks, Pluto, and CTF for a practical session on navigating, analyzing, and reusing critical NF datasets. Learn how data from the portal can be explored and visualized to address your unique scientific hypotheses, with demonstrations to fit all levels of coding experience. The session will conclude with lightning talks from NF investigators on their data reuse successes.

Open to all skill levels. RSVP is essential as seats are limited. Please bring your laptop. Watch for pre-session preparation materials and action items.

Date: Saturday June 21, 2025, 8:00 - 11:00 AM

Location: Congressional Room, Omni Shoreham

Save your seat using the NF Conference attendee app

Contact for questions or follow-up: nf-osi@sagebionetworks.org

Plexiform Neurofibroma Volumetrics Workshop

Tuesday, June 24, 2025, 3:30 - 5:30 pm

Regency Ballroom (after NF Conference adjourns)

WORKSHOP GOAL:

To bring together various stakeholders including clinicians, imaging specialists, pharmaceutical industry representatives, clinical researchers and patient advocates to develop a framework for a centralized, standardized training and validation plexiform neurofibroma volumetric imaging dataset

AGENDA:

Brief Overview of Challenges of Plexiform Neurofibroma Volumetrics

1. Summary of ***"Challenges and Unmet Needs for Volumetric Analysis in NF1 Plexiform Neurofibromas"*** session from Clinical Care Program
2. Clinical care imaging vs research imaging needs

Proposed Plexiform Neurofibroma Imaging Training and Validation Set

1. Introduction and potential uses
2. Interactive Feedback on Proposed Training and Validation Set including
   - General Feedback/alternative approaches
   - What to include in the dataset
   - How to generate the dataset
   - How to define the minimum standard of performance

Implementation and Next Steps

REiNS Summer Meeting

Thursday June 19, 3:00 - 6:00 pm

THE REINS International Collaboration is a volunteer group of researchers, clinicians, and patients/family members who work to improve the design of NF clinical trials. Open to all patient advocates and clinician researchers.

Topic: "Practical Endpoints"

Measuring more real-world impacts of NF in clinical trials and their long-term follow-up—things like employment, education, relationships, living independently, and more.

The Children's Tumor Foundation (CTF) offers various grant programs to both academic groups and industries to advance neurofibromatosis and schwannomatosis research

ctf.org/funding-opportunities

YOUNG INVESTIGATOR AWARD (YIA)

The Young Investigator Award (YIA) provides up to three years of salary support to graduate students and postdoctoral investigators to conduct NF research under the guidance of an established mentor, with the goal of enabling these early career researchers to become established as independent NF investigators. Applications are selected not only for their scientific merit but also for the potential and commitment of the applicant to pursue a career as an independent NF researcher.

DRUG DISCOVERY INITIATIVE (DDI)

The goal of the Drug Discovery Initiative (DDI) program is to stimulate NF drug discovery by funding researchers proposing to investigate novel or repurposing therapies for NF or to validate new NF targets. Proposals are expected to be short and concentrated on obtaining key preliminary data needed to quickly advance to the next step of drug discovery.

Specifically, applications must fall into one the following two categories:

- Support early-stage testing of therapeutic compounds for the treatment of NF. Shelved compounds (compounds having successfully undergone clinical testing but not being actively developed further despite this) will be prioritized. For compounds against a specific target (where multiple compounds exist), a strong rationale, also based on safety data, must be provided upon submission.
- Support the validation of a novel NF target. Targets may have been described as potentially relevant in NF or may be de novo. To that end, we encourage the mining of existing publicly available datasets. Target validation experiments should not be limited to the testing of compounds of limited or unknown specificity and should include target engagement experiments using direct biochemical methods or genetic interactions.

CLINICAL RESEARCH AWARD (CRA)

The Clinical Research Award (CRA) program aims to advance the development of effective clinical treatments, interventions, and management of patients living with NF. Priority consideration will be given to proposals that

- investigate bold, forward-thinking solutions and treatments that could improve the everyday functioning of people with NF; and
- promote new directions for disease management that would likely progress to future large-scale studies with the potential to compete for additional external funding.

CONTRACT AWARD (CA)

The Contract Awards (CA) are 'by-invitation only' special awards established to fund research that is outside the scope of the above programs. The funding amount and duration depend on the nature of the proposed study.

For Pharma/Biotech companies : If you have any products that could have applicability in NF, we would like to hear from you. CTF is actively seeking opportunities to collaborate with companies interested in developing assets for neurofibromatosis or schwannomatosis. Please contact **abakker@ctf.org**.

For updates and more information please visit: **ctf.org/funding-opportunities**

CHILDREN'S TUMOR FOUNDATION
ENDING NF THROUGH RESEARCH

engage
PATIENT ENGAGEMENT INITIATIVE

NF RESEARCHERS: WORK WITH OUR PATIENTS

CTF ENGAGE IS THE PATIENT ENGAGEMENT INITIATIVE OF THE CHILDREN'S TUMOR FOUNDATION, dedicated to transforming the landscape of NF research through the curation of quality, meaningful interactions between patients and families with research stakeholders. Our mission is to support scientific projects of merit that generate value for the NF community.

By collaborating with Patient Representatives, you can improve your studies, accelerate the research process, and make vital connections with the NF community.

Patient Representatives are trained in research concepts and regulatory affairs and are prepared to lend their perspectives to your projects. They can:

- **Guide research priorities** and help you select a research question that matters to the community
- **Review specific study materials**, such as protocols and recruitment materials
- **Serve as study advisors** (i.e. community advisory boards) and co-investigators
- **Disseminate your results to the community**, such as writing lay summaries and relaying findings at patient events

> "The role played by patient representatives has drawn our attention to some of the most important problems faced by NF patients. We are strongly convinced that the continuous interaction between scientists, physicians, and patient advocates will help us immensely to focus on the key unsolved issues on which we should direct our research efforts, in order to build tangible benefits for patients affected by neurofibromatosis."

ANTONIO IAVARONE, MD
Professor of Pathology and Cell Biology and Neurology
Columbia University

If you are looking to work in collaboration with Children's Tumor Foundation Patient Representatives, please reach out to **engage@ctf.org** to discuss how we can work together.

WOMEN IN NF

Join us on a journey into the heart and history of NF basic and clinical research with "Women in NF," a series of essays submitted by women who have been involved in shaping the landscape of NF understanding and treatment. Launched during the 2024 Global NF Conference, this collection of essays showcases the invaluable perspectives and insights of some of the women who have dedicated a decade or more of their careers to advancing the NF field.

More than just a collection of narratives, "Women in NF" serves as a testament to women's indispensable role in the effort to end NF. Spearheaded by Drs. Meena Upadhyaya and Peggy Wallace, this set of contributions provides history but also underscores the importance of diversity and inclusion in biomedical research, patient care, and volunteer activities. We hope these essays inspire, educate, and empower others, igniting a new era of awareness and appreciation for the vital role of women in shaping the future of NF research and treatment.

The launch of this essay series was dedicated to geneticist Dr. Ludwine Messiaen in honor of her legacy of extraordinary impact in the NF field.

ESSAYISTS INCLUDE:

Margaret "Peggy" Wallace, PhD
Meena Upadhyaya, OBE, FRCPath, FLSW
Corina Anastasaki, PhD
Dusica Babovic-Vuksanovic, MD
Annette Bakker, PhD
Patricia Birch, BSc, MSc, RN
Rosalie Ferner, MD, FRCP
Sue Huson, MD, FRCP
Karin Soares Cunha, PhD
Conxi Lazaro, PhD
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Nancy Ratner, PhD
Elizabeth "Betty" Schorry, MD
Kristine S. Vogel, PhD
Deeann Wallis, PhD
Adrienne L. Watson, PhD
Brigitte Widemann, MD
Katharina Wimmer, PhD

The "Women in NF" essay collection is available to read on the Children's Tumor Foundation website at **ctf.org/womeninnf**

CHILDREN'S TUMOR FOUNDATION
ENDING NF THROUGH RESEARCH

Help us get CTF Resources In the Hands of NF Patients

The brochures listed below are available to read or download in English and Spanish, and select titles are available in additional languages, which may include French, German, Italian, or Mandarin.

To read, download, or request **free print copies mailed directly to your clinic,** go to **ctf.org/education** or scan the code to the right.

About the Children's Tumor Foundation
This trifold brochure shares the CTF mission and ways to get involved.

Frequently Asked Questions
This trifold brochure covers the basics of all forms of NF.

NF Registry
This trifold brochure contains information about the NF Registry and how to join.

Diagnosed with Neurofibromatosis Type 1
This booklet is for individuals and families diagnosed with neurofibromatosis type 1 (NF1).

Diagnosed with *NF2*-related schwannomatosis
This booklet is for individuals diagnosed with *NF2*-related schwannomatosis (*NF2*-SWN).

Diagnosed with Schwannomatosis
This booklet is for individuals diagnosed with all other types of schwannomatosis (SWN), excluding *NF2*-SWN.

NF1: A Guide for Adults
This booklet for adults living with NF1 offers insight and information.

NF1: Guide for Educators
This booklet for educators is about the specific needs of a student with NF1.

NF1: About Learning Challenges
This booklet discusses the cognitive and behavioral manifestations of NF1.

Talking to Your Child About NF1
This caregiver's guide offers practical tips on sharing an NF1 diagnosis with children.

Super Emerson
A children's book that explains NF1 through story. This book accompanies the *Talking to Your Child About NF1* parent guide.

Café Au Lait: A Story of NF1 and My Special Spots
A picture book for young children about a young boy who learns about NF1.

NF1 Parent Guidebook
This 160-page workbook provides support and education to families living with NF1 and associated learning, behavioral, or social challenges.

Moxie & Sparx Comic Books & Coloring Pages
These fun-to-read comic books and coloring pages will educate and entertain kids and their friends.

Understanding *NF2*-SWN Comic
"Understanding *NF2*-SWN" is an informative and inspiring comic book explaining the condition with graphic medicine storytelling.

Fact Sheets and Infographics
Numerous fact sheets and infographics about all types of NF are available to help spread education and awareness.

Patient Information Documents
Printable pamphlets are available on specific care topics including café-au-lait spots, MEK-inhibitor drugs, and clinical trials.

CHILDREN'S TUMOR FOUNDATION
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ctf.org | info@ctf.org | 1-800-323-7938 | 212-344-6633 @childrenstumor

CTF Resource Library
ctf.org/education

CHILDREN'S TUMOR FOUNDATION
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THROUGH RESEARCH

NF Professionals:
We Need Your Help to Protect NF Research

YOUR WORK MATTERS. AND YOUR VOICE MATTERS MORE THAN EVER

At a time when federal research funding is being cut across the country, we know how much is at stake, for you, your work, and the future of NF research.

At the Children's Tumor Foundation, we believe *your story matters — and needs to be heard*: the challenges you're facing, the breakthroughs you're working toward, the careers now in jeopardy — these must be shared.

We are gathering personal stories from NF researchers & clinicians to help raise awareness and advocate for strong, sustained funding.

If you are willing, we invite you to share your experience — your voice could make a big difference. We hope to amplify your voice through our website, newsletters, social media, and direct outreach.

If you are interested, please submit your story to **ctf.org/FundNFResearch**

We understand that this is a sensitive moment. You will have the opportunity to review and approve any public use of your story.

Thank you,
Children's Tumor Foundation

CHILDREN'S TUMOR FOUNDATION
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THROUGH RESEARCH

NF ENDURANCE

The Children's Tumor Foundation NF Endurance Team gives participants the opportunity to run in endurance events around the world. **Get a guaranteed spot in premier and often sold-out races!**

TOKYO MARATHON 2026	tcs LONDON MARATHON	Sanlam CAPE TOWN MARATHON	tcs SYDNEY MARATHON	BMW BERLIN MARATHON	BANK OF AMERICA CHICAGO MARATHON	OFFICIAL CHARITY PARTNER tcs NEW YORK CITY MARATHON
MAR. 1, 2026	APR. 26, 2026	MAY 25, 2026	AUG. 2026	SEPT. 2026	OCT. 11, 2026	NOV. 2026

LEARN MORE AT **nfendurance.org/worldmajors**

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OUR THANKS ALSO TO THE FOLLOWING INDIVIDUALS FOR THEIR EFFORTS:

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NF CONFERENCE
JUNE 26 - 30, 2026
DENVER, COLORADO
nfconference.org
For more information, contact nfconference@ctf.org

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Children's Tumor Foundation United States

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