

# Navigating Neurofibromatosis: An Update for Providers and Families



Thursday, Oct. 3, 2024  
7:30 a.m. - 2:30 p.m.

Akron Children's Hospital  
Considine Professional Building Auditorium  
215 W. Bowery St.  
Akron, OH 44308



**Akron  
Children's**

# Navigating Neurofibromatosis

## Who Should Attend

This conference is open to all Akron Children's staff across the organization as well as families and stakeholders interested in learning more about how to support and care for patients and families with Neurofibromatosis.

## Continuing Education

Akron Children's Hospital is accredited by the Ohio State Medical Association to provide continuing medical education for physicians.

Akron Children's Hospital designates this live activity for a maximum of 4.5 *AMA PRA Category 1 Credit™*.

Physicians should claim only the credit commensurate with the extent of their participation in this activity.

## Disclosure Statement

It is the policy of Akron Children's Hospital to ensure balance, independence, objectivity and scientific rigor in all its educational activities.

Anyone in a position to influence the content, such as planners, speakers, authors or others, must provide disclosure. The intent of this policy is not to prevent a speaker from making a presentation. It is intended only that any potential conflict of interest should be identified openly so that the listeners may form their own judgments about the presentation with the full disclosure of the facts.

Planners, faculty, or others who may control education content are requested to disclose all financial relationships that they have had in the past 24 months with ineligible companies. An ineligible company is any entity whose primary business is producing, marketing, selling, re-selling, or distributing health care products used by or on patients.

The following presenters have indicated that they have financial relationships.

Peter de Blank, MD  
Alexion Pharmaceuticals  
Pediatric Oncology Advisory Board

Nicholas Nguyen  
Verrica

Consultant, marketing advisory board, speaker

All relationships have been mitigated.

All remaining planning committee members, presenters and CME committee members have indicated that they have no relationships with ineligible companies.

## Objectives

1. Recognize common cutaneous manifestations of NF1 and what to look for on pediatric exam.
2. Define hypertension in NF1 and identify treatment options for these patients.
3. Illustrate the orthopedic approach to common manifestations of NF1, such as scoliosis and tibial bowing.
4. Recognize the utility of neuro imaging in pediatric patients with NF1 and common abnormalities that can be seen.
5. Describe new directions in NF1-associated pediatric brain tumors.
6. Identify the utility of peripheral nerve surgery in patients with NF1.
7. Describe the difficulties in transition from comprehensive pediatric care to adult care for these patients and how to mitigate these difficulties.
8. Describe hallmark features of NF1, associated medical complications and when to refer for testing.

## Conference Agenda

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|-------------------------|---|
| 7:30 – 8 a.m.           | <b>Registration and Breakfast</b>   |
| 8 – 8:15 a.m.           | <b>Welcome: Brief Overview of Neurofibromatosis and Conference</b>  |
| 8:15 – 9:15 a.m.        | <b>Keynote Presentation</b><br><b>Navigating NF1-OPG: Measuring Function to Improve Outcomes</b><br><i>Peter de Blank, MD, MSCE</i>   |
| 9:15 – 9:45 a.m.        | <b>Orthopedic Manifestations of Neurofibromatosis Type 1</b><br><i>Lorena Floccari, MD</i>  |
| 9:45 – 10:15 a.m.       | <b>Peripheral Nerve Surgery in the Setting of Neurofibromatosis</b><br><i>Stephanie Russo, MD, PhD</i>  |
| 10:15 – 10:30 a.m.      | <b>Break</b>  |
| 10:30 – 11 a.m.         | <b>Neurofibromatosis Type 1 and the Skin</b><br><i>Nicholas Nguyen, MD</i>  |
| 11 – 11:30 a.m.         | <b>Referral Criteria for NF1</b><br><i>Jennifer Stefanich, MSN, APRN-CNP</i>  |
| 11:30 a.m. – 12:30 p.m. | <b>Lunch Session</b><br><b>Panel Discussion: Navigating the Transition to Adulthood</b><br><i>Moderator: Erin Wright, MD</i><br><i>Panelists: Rebecca Teagarden, DO, MA</i><br><i>Victoria Walker, APRN-CNP</i> |
| 12:30 – 1 p.m.          | <b>Break / Resource Fair</b>  |
| 1 – 1:30 p.m.           | <b>Renal Manifestations encountered in Pediatric Patients with Neurofibromatosis Type 1</b><br><i>Stephen Cha, MD</i>   |
| 1:30 – 2 p.m.           | <b>Update on Neuroimaging in Neurofibromatosis</b><br><i>Matthew Ginsberg, MD</i><br><i>Erin Wright, MD</i>   |
| 2 – 2:15 p.m.           | <b>How to Sign Up for the Children’s Tumor Foundation Registry</b>  |
| 2:15 – 2:30 p.m.        | <b>Closing Comments and Questions</b>   |

# Keynote Speakers and Presenters

## Keynote Speaker

### **Peter de Blank, MD, MSCE**

Professor, Cincinnati Children's Hospital Medical Center; Department of Pediatrics; Co-Director of the Brain Tumor Center, Director of the Neurofibromatosis Clinic

## Additional Presenters

### **Stephen Cha, MD**

Interim Director, Division of Nephrology; Director, Continuing Medical Education, Akron Children's

### **Lorena Floccari, MD**

Orthopedic Surgeon, Department of Orthopedic Surgery; Director, Spine Center, Akron Children's

### **Matthew Ginsberg, MD**

James F. and Marguerite A. Pearson Endowed Chair in Neurodevelopmental Sciences and Rare Diseases Pediatric Neurologist, Division of Neurology, Akron Children's; Associate Professor of Pediatrics, Northeast Ohio Medical University

### **Nicholas Nguyen, MD**

Director, Pediatric Dermatology; Pediatric Dermatologist, Akron Children's

### **Stephanie Russo, MD, PhD**

Co-Director, Brachial Plexus Treatment Center; Pediatric Hand and Peripheral Nerve Surgeon, Akron Children's

### **Jennifer Stefanich, MSN, APRN-CNP**

Nurse Practitioner, Genetics Center, Akron Children's

### **Rebecca Teagarden, DO, MA**

Medical Director, Complex Care Clinic; Chair, Akron City Hospital Ethics Committee

### **Victoria Walker, APRN-CNP**

Adult Nurse Practitioner, Summa Health Comprehensive Care Clinic

### **Erin Wright, MD**

Director, Neuro-Oncology; Director, Shannon E. Wilkes Targeted Therapy Program; Co-Director, Neurofibromatosis Clinic; Pediatric Neuro-Oncologist, Akron Children's

## Planning Committee

### **Jacqueline Branch, MD, FAAP**

### **Matthew Ginsberg, MD**

### **Alexis Judd, PA-C**

### **Kaylee Kandel, MS, CGC**

### **Jason Laufman, MD**

### **Tiffany L. Leonard, MSN, APRN, CPNP-PC, PMHS**

### **Hannah Miller, BSN, RN, CPN**

### **Jennifer Stefanich, MSN, APRN-CNP**

### **Stephen Steiner, MD**

### **Katrina Wolford, BA**

### **Erin Wright, MD**

# Conference Registration



## Registration

Please register and pay online at [akronchildrens.org/nfconf](https://akronchildrens.org/nfconf)

**The registration deadline is Sept. 19, 2024.**

## Pricing

- Physicians, advanced practice providers and nurses: \$75
- Non-Akron Children's residents and medical students: \$45
- Akron Children's residents, fellows and emeritus staff: Free
- Patients and families: \$5

## Cancellation Policy

Please visit [www.akronchildrens.org/cme](https://www.akronchildrens.org/cme) to locate and review the CME cancellation/refund policy.

## Additional Information

For more information, please contact Hannah Miller at [HMiller@akronchildrens.org](mailto:HMiller@akronchildrens.org).

**This event is funded in part by the Children's Tumor Foundation.  
For more information, please visit [ctf.org](https://ctf.org).**