

SHORT COURSE: BEST PRACTICE IN NEUROFIBROMATOSIS TYPE 1 (NF1)

Thursday 5 November 2026, RCPCH London

PROGRAMME

09.00 **Registration and Refreshments**

09.20 **Welcome**

Dr Catherine Tuffrey and Dr Jill Cadwgan, Course Co-Chairs

09.30 **Introduction to NF1 - Clinical**

- Dr Ellie Day, Consultant Paediatrician, The Royal Free London NHS Foundation Trust
- Dr Bina Mukhtyar, Consultant Paediatrician, Norfolk & Norwich University Hospitals NHS Foundation Trust

10.00 **Surveillance and national guidelines**

- Dr Karine Lascelles, Consultant Paediatric Neurologist, Evelina London Children's Healthcare
- Dr Tricia Barlow, Consultant Paediatrician, Sheffield Children's NHS Foundation Trust

10.45 **Red flags for urgent referrals**

- Dr Jill Cadwgan, Consultant in Paediatric Neurodisability, Evelina London Children's Healthcare

11.30 Refreshment Break

11.50 **Introduction to NF1 – Service Provision Nationally**

- Dr Karine Lascelles
- Dr Grace Vassalo, Consultant Paediatric Neurologist, Royal Manchester Children's Hospital

12.20 **Small Group Workshops**

Setting up and running a Secondary care service

- Dr Zaby Bassi, Consultant in Paediatric Neurodisability, Alder Hey Children's NHS Foundation Trust
- Dr Catherine Tuffrey, Consultant Paediatrician, Hampshire and Isle of Wight Healthcare NHS Foundation Trust

Practical Management: Neurodivergence and Learning

- Dr Ellie Day
- Dr Ambika Rajesh, Consultant Paediatrician, Norfolk & Norwich University Hospitals NHS Foundation Trust
- Tracey Kenyon, Specialist Nurse, University Hospital Southampton NHS Trust

Practical Management: Muscle weakness and Fatigue

- Katrina Kettle, Specialist Nurse, Evelina London Children's Healthcare
- Dr Bina Mukhtyar

Practical Management: Itch and Pain

- Dr Jill Cadwgan
- Dr David Pang, Consultant in Anaesthesia and Pain Management, Evelina London Children's Healthcare

Transition

- Mandy Myers, Paediatric NF Clinical Nurse Specialist, Evelina London Children's Healthcare
- Dr Tricia Barlow

12.50	Lunch
13.30	Small Group Workshops repeated
14.05	Small Group Workshops repeated
14.40	Small Group Workshops repeated
15.10	Refreshment Break
15.30	Small Group Workshops repeated
16.00	Panel Discussion Quiz and Feedback
16.30	End

Summary of Learning Objectives

By the end of this short course, participants will be able to:

1. Strengthen Core Knowledge of NF1

- Understand the foundational science and clinical features of NF1.
- Recognise common and less typical clinical manifestations in children.

2. Apply National Surveillance Guidelines

- Gain confidence in following evidence-based surveillance pathways.
- Know what to monitor, when, and how often in secondary care settings.

3. Manage NF1 in Everyday Clinical Practice

- Develop practical skills for managing NF1 across childhood.
- Understand approaches to supporting both children and their families.
- Learn how to identify scenarios requiring escalation or intervention.

4. Coordinate Care and Specialist Referrals

- Identify when patients should be referred to specialist NF1 or tertiary services.
- Improve decision-making around multidisciplinary involvement.

5. Support Transition to Adult Services

- Learn best practices for transitioning adolescents with NF1 into adult care pathways.
- Understand what adult services expect and how to prepare young people and families.

6. Build Confidence Through Interactive Learning

- Apply knowledge through lectures and small-group workshops designed to increase confidence in diagnosing and managing NF1 in secondary care.