

May 17th

WORLD NEUROFIBROMATOSIS DAY



Association Of Child Neurology
India

IMPORTANCE OF NF DAY

1 NF affects millions of people worldwide, it occurs to 1 in 3000 people. Many a times, people don't know they have it. NF Day raises the awareness leading to early intervention.

2 Observing NF Awareness Day is a way to show that WE CARE **3** Connecting

Global Experts with the Indian Medical Fraternity, Parents.

4 Diseases specific awareness programs helps in gaining the attention of Policy Makers and Government Implementing agencies

AGENDA

TITLE:

An Interactive Webinar on
NF to Commemorate International NF Day.

DATE:
May 17th 2023

TIME:
3.30 PM to 5.30 PM

VENUE:
Auditorium AIIMS, New Delhi.

VIRTUAL :
Webinar link - Please Scan

TIME	EVENT DETAILS
3.30 PM	Introduction and Welcoming the Speakers.
3:35 PM	Opening Remark by Mr. Prasanna Shirol
3:40 PM	Overview of Neurofibromatosis by Dr Lokesh Lingappa
3:55 PM	Neurodevelopmental issues in Neurofibromatosis by Dr Sheffali Gulati.
4: 10 PM	Management of plexiform Neurofibromas in NF1 current concepts and Innovative therapies by Dr. Thorsten Rosenbaum
4:40 PM	Panel Discussion
5:00 PM	Open for Q&A
5:20 PM	Vote of Thanks - Mr. Prasanna Shirol followed by Supper.

OUR ESTEEMED PANELISTS:

Prof. Madhulika Kabra	Division of Genetics, Department of Paediatrics, All India Institute of Medical Sciences, New Delhi.
Dr Biswaroop Chakrabarty	Addl professor Child Neurology Division Department of Pediatrics, All India Institute of Medical Sciences, New Delhi.
Dr. Rachna Sehgal	Professor Pediatrics (Pediatric Neurologist), VMMC and Safderjung Hospital, New Delhi.
Prof. Soumesh Gupta	Department of Dermatology, AIIMS New Delhi.



PLEASE SCAN HERE TO REGISTER TO THE WEBINAR.

Please write to us with your name, organization and the mobile number to info@ordindia.in for registering to the event.

ABOUT NEUROFIBROMATOSIS:

Neurofibromatosis are a group of genetic disorders that cause tumors to form on nerve tissue. These tumors can develop anywhere in the nervous system, including the brain, spinal cord and nerves. There are three types of neurofibromatosis:

- **Neurofibromatosis 1 (NF1) •**
Neurofibromatosis 2 (NF2) •
Schwannomatosis.

NF1 is usually diagnosed in childhood, while NF2 and Schwannomatosis are usually diagnosed in early adulthood.

The tumors in these disorders are usually noncancerous (benign), but sometimes can become cancerous (malignant). Symptoms are often mild. However, complications of neurofibromatosis can include hearing loss, learning impairment, heart and blood vessel (cardiovascular) problems, loss of vision, and severe pain.

However, Good News is there are new treatments being developed which needs to be communicated to the Key Stake holders.

ORDI founded in Feb 2014, setup as a section 25 non-profit company in India is a patient-centered organization with the mission to improve health of patients with rare diseases around India through awareness, advocacy, collaborations and information dissemination.

ORDI represents the collective voice of all patients with rare diseases in India to effect government policy making.

ORDI has identified the grand challenges faced by rare diseases community in India and is committed to systematically and holistically address these challenges. Our approach is to engage with key opinion leaders and rare disease experts nationally and internationally to design and implement innovative programs for the benefit of stakeholders in India.

Team ORDI works to connect rare disease patients, policy makers, medical fraternity, and Health Care Industry through various initiatives to sensitize the public at large to acknowledge rare diseases.

Association of Child Neurology (AOCN) is an association of pediatricians, neurologists, pediatric neurologists, behavioral pediatricians, child psychologists, and allied professionals and everybody interested in the neurological, developmental and behavioral wellbeing of children.

The association was established in 2002

The association involves itself in educational/training activities and also advocacy issues related to child neurology.

CONTACT:



Association Of Child Neurology
India

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