

3rd
ANNUAL
CONFERENCE



Awareness,
Care & Management of
Motor Neuron Disease

26 | JUNE | 2024

Venue :

NIMHANS Convention Centre,
Hosur Road, Bangalore 560029

Jointly organized by NIMHANS & Dr. Shyama Narang Foundation®



National Institute of Mental Health and Neurosciences
राष्ट्रीय मानसिक स्वास्थ्य और तंत्रिका विज्ञान संस्थान
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About the Conference

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Building upon the success of our previous international conference in 2023, which featured prominent Indian and international speakers, we remain committed to advancing our collective understanding of motor neuron disease (MND).

Despite ongoing research and clinical trials, substantial progress in drug discovery remains elusive. Therefore, this year, we are shifting our focus toward comprehensive disease management strategies, prioritizing the needs of those affected by MND/ALS. The theme of this year Conference is Awareness, Care & Management of MND/ALS.

Motor neuron diseases (MNDs) are a group of progressive neurological disorders that destroy motor neurons, the cells that control skeletal muscle activity such as walking, breathing, speaking, and swallowing. This group includes diseases such as amyotrophic lateral sclerosis (ALS), progressive bulbar palsy, primary lateral sclerosis, progressive muscular atrophy, spinal muscular atrophy, Kennedy's disease, and post-polio syndrome.

Currently, there is no cure or standard treatment for MNDs. However, we believe that MND/ALS can be effectively managed through symptomatic and supportive treatments that help people maintain their quality of life. Direct engagement with patients and caregivers, alongside collaborative sessions involving healthcare professionals such as physiotherapists, speech therapists, occupational therapists, respiratory therapists, community rehabilitation experts, counselors, social workers, and others, will be beneficial for both professionals and patients.

Morning Session : Scientific Program

The morning session will feature a comprehensive scientific program covering:

- Overview of MND/ALS, including diagnosis and assessment
- Management strategies
- Speech and swallowing assessments and management
- Adaptive devices
- Respiratory management
- Psychological and social aspects

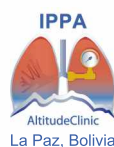
Afternoon Session : Specialized Camps

In the afternoon, we will conduct specialized camps within the Convention Centre to cater to the specific needs of MND/ALS patients. We expect about 30-40 MND/ALS patients to participate, with doctors and therapy practitioners from NIMHANS addressing their specific needs. The interaction between specialists and patients will provide participating therapists with firsthand knowledge and skills in managing MND patients.

CONFERENCE GOALS

This conference aims to provide various practicing therapists with a sound scientific background of the disease and combine the scientific sessions with exposure to the practical management and care required in treating MND. By fostering collaboration and direct engagement with the therapists, we hope to enhance the quality of life for those affected by MND/ALS.

Supported by:



MULTIDISCIPLINARY MANAGEMENT AND CARE IN ALS

Motor Neuron Disease (MND) presents multiple challenges with no known causes or tools to predict progression. Each patient faces a unique course of illness, creating significant uncertainty for both patients and caregivers. This uncertainty, coupled with practical caregiving tasks, can be particularly challenging.

Contrary to common belief, much can be done to improve the quality of life for people with MND and their care partners. MND symptoms include trouble with eating, speaking, drooling, joint stiffness and pain, repeated falls, fatigue, sleep problems, and mental health issues. Early identification and intervention are crucial in managing these symptoms effectively. An expert neurologist specializing in neuromuscular disorders is essential for preventing disease complications.

Currently, two drugs available in India, Riluzole and Edaravone, modestly affect the disease process. Neurologists or general physicians can prescribe various medications to treat symptoms like drooling, pain, cramps, stiffness, insomnia, and depression.

ROLE OF MULTIDISCIPLINARY TEAM

Speech-Language Pathologists: These professionals evaluate communication difficulties and suggest ways to enhance communication through alternative and augmentative communication methods tailored to the patient. They also address swallowing difficulties to prevent aspiration complications, ensuring safer eating and drinking practices.

Dieticians: Dieticians develop personalized diet plans to help maintain a healthy weight and proper nutrition. They assess the patient's nutritional needs and recommend dietary adjustments to manage symptoms and improve overall health.

Physiotherapists: Physiotherapists play a crucial role in maintaining muscle function and joint mobility. They prescribe specific exercises and therapies to sustain muscle strength for as long as possible and advise on appropriate mobility aids to enhance independence and prevent joint deformity and pain.

Occupational Therapists: These therapists focus on maximizing the patient's independence in daily activities. They suggest modifications in activity performance, recommend assistive devices, and provide techniques for easier patient transfers, reducing strain on caregivers. Home environment modifications are also advised to accommodate the progression of disability.

Psychiatric Social Workers: Trained in mental health, psychiatric social workers offer counseling to help patients and families cope with the emotional aspects of MND. They connect patients with community resources and provide ongoing support to both patients and care partners, fostering a positive outlook.

Assistive Devices and Palliative Care

Assistive Devices: Essential in MND care, these devices support breathing, nutrition, transfer, and mobility. The multidisciplinary team helps in selecting and timing the use of these devices according to patient needs, ensuring comfort and safety.

Palliative Care: A specialized palliative care team assists patients and families in making difficult decisions, ensuring that care remains patient centric. They discuss care goals collaboratively, helping to reduce symptom burden and improve quality of life. Regular follow-ups allow for modifications in interventions to meet the patient's changing needs.

Specialized Home Care Support for ALS

Advanced disease stages make it challenging for patients to seek medical help. At NIMHANS, Bengaluru, a specialized home care team from the Neuropalliative care team supports patients through home visits. This team includes a medical officer, palliative care nurse, social workers, occupational therapist, and speech-language pathologist. They visit patients frequently, offering support and empowering family caregivers. This service, supported by Cipla Foundation and Dr. Shyama Narang Foundation (MND Trust) is provided free of cost.

FOR HOME CARE SERVICES, CONTACT : +91 90366 49138

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