

2nd INTERNATIONAL CONFERENCE on ALS/MND

Jointly organized by **NIMHANS & Dr. Shyama Narang Foundation**®

21st & 22nd JUNE, 2023

Venue : NIMHANS Convention Center, Bangalore



National Institute of Mental Health and Neurosciences

राष्ट्रीय मानसिक स्वास्थ्य और तंत्रिका विज्ञान संस्थान
राष्ट्रीय मानसिक आरोग्य ಮತ್ತು ನರವಿಜ್ಞಾನ ಸಂಸ್ಥೆ



dr. shyama narang
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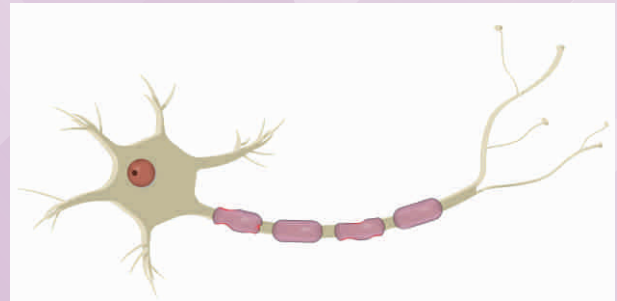
2nd INTERNATIONAL CONFERENCE on ALS/MND

This two day on-site International Conference is perhaps the first conference dedicated to ALS and MND research. Last year, due to COVID-19 situation, we had virtual session, which was jointly held with NIMHANS and IndoUSrare and had speakers from India, USA, and Europe. This year we bring together practicing neurologist (MND clinicians), researchers from around the world to share new understanding of amyotrophic lateral sclerosis and motor neurone disease.

The key to finding a cure for MND lies in fostering strong collaboration between clinicians and leading researchers and research institutions around the world, and sharing new understanding of the disease as rapidly as possible. Some of the speakers at this conference are on the threshold of finding a cure for this disease. We are proud to have been able to identify such eminent speakers to make this conference, on the World MND day, an unique experience to all the attendees.

The event will take place at the NIMHANS Convention Center, Hosur Road, Near Bangalore Milk Dairy, Bengaluru, 560029

Motor Neuron Disease



About the event

There is abundant research and clinical trials for MND happening across the world and surely the cure for MND-ALS is around the corner. It however, requires strong collaboration between clinicians, pharma companies, leading researchers around the world, to sharing their new understanding of the disease in a structured collaborative environment. This also requires funding organizations to be the backbone in their efforts towards the drug discovery. With this objective, Dr. Shyama Narang Foundation and NIMHANS have conceived the theme for this conference - Breaking Barriers in the Treatment of MND-ALS.

Last year, on the same dates, Dr. Shyama Narang Foundation in association with NIMHANS and IndoUSrare held an International webinar, which was very well attended. This year the conference is on site, however, since some of the key

speakers will be addressing virtually, we have made this conference hybrid to those who have registered online with us.

The topic chosen by each of the speakers represent their core competence and understanding of the disease over several years and hence will surely benefit neurologist, researchers, post graduate medical students and even patients and their care givers for discussion on the latest advances in research and clinical management.

We will be live streaming the Conference for those unable to attend in person (particularly people living with ALS/MND) to participate in the event. Live streaming is our way to connect with wider audience and make this program inclusive for those who are unable to attend the Conference, particularly people living with MND-ALS.

Registration

1. Subject to KMC regulations, "Three - Hours" of Accreditation will be awarded for this "Two-Days" conference to those who have registered 5 days on or before the start of the conference. As per KMC guidelines spot registration will not be considered for CME Credit points.
2. The registration is free to all attendees. Registration starts from **25th May 2023**.
3. Use the following link for Online registration mndtrust.co.in

Sponsors



About NIMHANS

The National Institute of Mental Health and Neuro Sciences (NIMHANS) is an Institute of National Importance (INI) and is recognized for its multidisciplinary approach for patient care and academic pursuit in the field of Mental Health and Neurosciences. NIMHANS has a rich history dating back to colonial times. In 1847, the Bangalore Lunatic Asylum was founded, and Dr. Charles Irwing Smith, a British medical practitioner in Bangalore. In 1925, the asylum was rebranded as Mental Hospital, signifying a change in the management of mental problems. The new Mental Hospital in Lakkasandra was constructed over 100 acres of land donated by the Maharaja of Mysore in 1936.

Dr. MV Govindaswamy, became the medical superintendent of the Mysore State Mental Hospital and transformed it into a modern institute of mental health and neuro sciences. He played a vital role in the formation of All India Institute Mental Health (AIIMH) and became its founder-Director. In 1974, AIIMH and Mental Hospital were amalgamated into NIMHANS.

NIMHANS has been at the forefront in the care of patients with neuromuscular disorders for nearly 50 years. Prof. dr. Gourie-Devi was a pioneer in the evaluation and management of neuromuscular disorders, especially MND and has contributed immensely to MND research.

Her effort is being carried forward by Prof. Dr. A Nalini who leads the neuromuscular team of NIMHANS and she has done the best work in India on MND. The hospital MND registry, maintained by her, has more than 3500 cases registered since 1976. The NMD team of NIMHANS caters to the care of about 20-30 patients of MND every month and multidisciplinary, holistic treatment is provided to each one of them.

Abundant experimental work is done on MND at NIMHANS to find a cause for this deadly disease. NIMHANS has numerous publications on MND including survival and natural history in thousands of patients with MND with recent publications on genetics and newer diagnostic modalities including ultrasound in ALS. Advanced research is being done in NIMHANS on genetics, biomarkers and stem cell research in ALS.

NIMHANS has also pioneered palliative care in MND. The unmet needs of patients and family are identified, home visits are carried out, psychosocial support is provided, and the best possible multidisciplinary care is offered.

NIMHANS is now recognized as an ADVANCED CENTER FOR NEUROMUSCULAR DISORDERS (NACNMD) and hopes to soon be recognized as a "Center of Excellence for Research in ALS / MND" for its treatment and research under the relentless efforts of the neuromuscular team, led by Prof. Nalini.

About Dr. Shyama Narang Foundation

The MND Trust formed under Dr. Shyama Narang Foundation, is a Registered Trust formed to raise awareness of Motor Neuron Disease and its impact on the community. Dr. Shyama Narang, a medical doctor, MD (OBG) was diagnosed with MND during 2015 and during her lifetime she strived to maintain her independence and enhanced her quality of life.

Despite all odds, during her lifetime she wanted to form a foundation to inculcate the same passion for living. Unfortunately, fate had other plans for her and she breathed her last on 2nd September 2019.

The Trustees and Advisors are committed to take forward her mission to find a cure for this disease. Though the Trust was established on 24th December 2020 but due to the COVID situation in the country the trust activities commenced from the 1st May 2021. With the COVID showing signs of

receding in India, the Trust has commenced its activities – its commitment to improve the lives of the people living with MND and support their caregiver as well.

In the last couple of months, we have been providing practical assistance to people with MND through physical and emotional support through a panel of doctors under various systems of medicine and through trained counsellors. Shortly, we will be providing opportunities, forums and events so that people with MND and their caregivers can meet and interact with others and share their feelings, struggles and achievements. We will also share with them the latest research and development across the world in finding a cure for MND. The Trust seeks community support for the MND warriors and we know you are there with us.

Supported by:



Dr. Bhargavi BM

Chief Coordinator

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Program details Day 1 : 21st June 2023

09:30 to 09:35		Vasanth Rao U. A. Founder Trustee Dr. Shyama Narang Foundation	Welcome address	On Site
09:35 to 9:50		T.K. Anil Kumar, IAS Principal Secretary to Govt. Health & Family Welfare Dept., Karnataka	Inauguration & Speech	On Site
09:50 to 10:00		Dr. Pratima Murthy Director NIMHANS, Bengaluru	Presidential Address	On Site
10:00 to 10:05		Dr. Giridhar Gyani Director General, Association of Healthcare Providers (India)	Guest of Honor address	On Site
10.05 to 10.10		Mr. N.Sivasailam IAS (Retd) Administrative Member Karnataka State Administrative Tribunal	Guest of Honor address	On Site
10:10 to 10:40		Prof. Dr. A. Nalini Department of Neurology NIMHANS, Bengaluru	Clinical phenotypes and Diagnosis of MND	On Site
10:40 to 11:10		Dr. B. K. Yamini Speech Pathology & Audiology, NIMHANS, Bengaluru	Navigating Speech, Communication Swallowing Challenges in ALS/MND	On Site
11:10 – 11:30 TEA BREAK				
11:30 to 12:00		Dr. Rajani Bhat Internal Medicine, Pulmonologist, Sparsh Hospital, Bangalore	Respiratory Involvement & symptoms management in MND	On Site
12:00 to 12:30		Dr. Roop Gursahani Consultant Neurologist, PJ Hinduja Hospital, Mumbai	Palliative Care in ALS	On Site
12:30 to 13:00		Dr. Suvarna Alladi Prof. and Head of Neurology NIMHANS, Bengaluru	Cognitive and behavioural changes in MND	On Site
13:00 – 14:00 STALL VISIT & NETWORKING LUNCH				
14:00 to 14:45		Dr. Gustavo Zubieta Head, High Altitude Pulmonary and Pathology Institute, La Paz, Boliva	Can Exposure to hypoxia and chronic hypoxia be beneficial in MND?	On Site
14:45 to 15:30		Dr. Corrado Angelini Former Director Neurology University of Padova, Italy	ALS and SMA Treatable Bioenergetic Prospective	Virtual Talk
15:30 – 16:00 NETWORKING TEA / COFFEE BREAK				

Program details Day 2 : 22nd June 2023

Timing	Speaker	Department / Specialisation	Format
10:00 to 10:30	 Dr. T. R. Raju Director - Research, Sankara Academy of Vision, Bangalore	Motor Neuron Disease Pathogenesis - Does CSF hold clues?"	On Site
10:30 to 11:00	 Dr. Gautham Arunachal Udupi Associate Professor, Dept. of human Genetic, NIMHANS	Genetic spectrum of Motor Neuron Disease: Indian scenario	On Site
11:00 to 11:30	 Dr. Harsha Rajasimha Founder & Executive Chairman, Indo US Organisation for Rare Diseases	Urgent need for a National Registry for Rare Diseases and the creation of a common platform for patients	On Site
11:30 - 11:50 TEA Break			
11:50 - 13:00	 Dr. Thomas Mathew MD, DM Prof and Head Department of Neurology St John's Medical College Hospital Bangalore	Moderator for Panel Discussion	On Site
	Dr. Vijayalakshmi K. Dr. Mohammed Faruq, Dr. Rakesh Mishra, Dr. Kushal Das, Dr. Priya Treesa Thomas	<div data-bbox="751 1149 1474 1364" style="border: 1px solid black; padding: 5px; text-align: center;"> PANELISTS  </div>	
13:00 to 13:30	 Prof. Dame Pamela Shaw Prof Neurology, University of Sheffield, UK	Recent Advances in Motor Neuron Disease and its therapeutics	Virtual Talk
13:30 - 14:45 STALL VISIT & NETWORKING LUNCH			
14:45 to 15:00	 Dr. Vamshi Krishna Thamtam Head - Genomics Dr. Lal Pathlab	Genetic Testing in Spinal Muscular Atrophy	On Site
15:00 to 15:30	 Dr. Jochen Weishaupt Prof of Neurology, University of Heidelberg, Germany	ALS Genetics and the design of respective therapies	Virtual Talk
15:30 to 15:35	 Dr. Thuppil Venkatesh CEO, Foundation for Quality (India)	Closing vote of thanks	On Site

Patrons



Dr. Pratima Murthy
Director
NIMHANS, Bengaluru



Dr. Giridhar Gyani
Director General
Association of Healthcare Providers (India)



Mr. N Sivasailam IAS (Retd.)
Administrative Member
Karnataka State Administrative Tribunal

Organising Committee

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Conference Chair	Dr. Nalini A.		
Co-Chair	Dr. Thuppil Venkatesh		
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National Institute of Mental Health and Neurosciences

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