

Annual Report 2024-25



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Dr. Shyama Narang Foundation (Regd.)

Registered office: Zen Gardens, Artillery Road, Halsoor Bangalore 560008

Clinic: 2nd Floor, Khivraj Bajaj, Kasturba Road, Bangalore 560001

Message from the Founder Trustee:

Dear Supporters, Volunteers, and Well-wishers,

As we reflect on another year of our journey, I am filled with immense gratitude for the collective efforts that have strengthened our mission to support individuals with Motor Neuron Disease (MND). This year has been one of significant progress, marked by impactful collaborations, clinical research initiatives, and enhanced palliative care services. Our unwavering commitment to providing quality care, awareness, and advocacy has led to remarkable achievements, and we look forward to continuing this momentum in the coming year.

Thank you for your continued support and dedication.

Vasanth Rao

Founder Trustee,

Dr. Shyama Narang Foundation

About the Foundation

Dr. Shyama Narang Foundation has been at the forefront of providing support to individuals affected by MND since 2020. Our mission is to improve the quality of life for MND patients through medical assistance, palliative care, awareness programs, and research collaborations. We believe in a holistic approach that includes medical, psychological, and social support for patients and caregivers.

Key Highlights of 2024

The Foundation hosted the Third Annual Conference on Awareness, Care, and Management of MND at NIMHANS Convention Centre. It continued its Free Genetic Testing Program in collaboration with CSIR-IGIB, benefiting 28 patients. A Clinical Trial Study was initiated in partnership with Zydus Lifesciences and BrainS Super Speciality Hospital, Jayanagar 1st Block, Bangalore. Palliative Care Services were expanded, with 234 home visits conducted in and around Bangalore. A total of 15 wheelchairs were successfully distributed in Bangalore in collaboration with the Rotary Club. Additional wheelchairs were sent to four patients in Kolar, and one specially designed wheelchair was delivered to a patient in Mumbai. The Foundation strengthened its MND patient referral and counseling services with NIMHANS and received CSR Registration Approval from the Ministry of Corporate Affairs. The Foundation through its associated Foundation, Quality Diagnostic Foundation, help conduct free Newborn Screening for rare metabolic disorders for all babies born at the Bruhat Bengaluru Mahanagara Palike (BBMP). This initiative was taken up as a tribute to Dr. Shyama Narang (OBG and infertility specialist) who worked briefly at BBMP Maternity Hospital.

During the year, we receive support and CSR funding from Devraj Chordia Trust, Ample Technologies, Lal Path Lab, and Genotypic Technology Pvt. Ltd. We sincerely thank them for their continued support.

Activity Report

- The Third Annual Conference on MND Awareness and Care was held on June 26, 2024, at NIMHANS Convention Centre, Bangalore. The objective of the event was to bring together experts, caregivers, and patients to discuss MND care strategies. The conference successfully increased awareness and engagement among medical professionals and the MND community.
- The Free Genetic Testing, Assessment, and Counseling Program started in October 2023 and concluded in April 2024. Conducted in collaboration with CSIR-IGIB and BRAINS Super Speciality Hospital, it benefited 28 patients. Initially planned for a month, the program was extended due to high demand. Comprehensive genetic counseling was provided by Dr. Mohammed Faruk.
- A Clinical Trial Study was carried out with Zydus Lifesciences and BrainS Super Speciality Hospital, Jayanagar 1st Block, Bangalore, from January 12, 2024, to February 28, 2024. Three patients were screened, and one patient was enrolled. The study gathered valuable insights and opened opportunities for further research.
- The Foundation continued its Palliative Care Program in collaboration with NIMHANS. A total of 234 home visits were conducted, focusing on providing long-term, multidisciplinary neuro-palliative care within a 126-kilometer radius of Bangalore.
- The expansion of Palliative Care Services to surrounding districts is in the planning stage. Meetings have been conducted with Dr. Priya Thomas from NIMHANS. However, logistical hurdles remain a challenge, and partnerships with government hospitals and NGOs are being explored.
- To assist the State Government in formulating a palliative care policy, inputs were taken from Dr. Priya Thomas at NIMHANS, and a draft policy was submitted to the Principal Secretary, Health and Family Welfare, for consideration. The draft outlines the need for structured training for doctors and paramedical staff at NIMHANS, along with a proposed budget. We are pleased to report that this proposal is under active consideration by the government.
- Since the Rare Diseases Policy limits government funding to treat only curable rare diseases, over 95% of rare disease patients are left without financial or medical support from either the Central or State Government. The Foundation's Managing Trustee met Dr. L. Swasticharan, Additional Deputy Director General, Ministry of Health and Family Welfare, Government of India, and submitted a memorandum requesting funding for national institutions like NIMHANS and the State Government's Department of Health and Family Welfare. This support would ensure access to critical services for patients with MND/ALS and other rare diseases, including nursing and caregiver assistance, physiotherapy, multidisciplinary medical care, specialized equipment, supportive medicines, nutritional aid, assistive communication devices, and psychological counseling. These resources would significantly enhance the quality of life for patients and their families, ensuring comprehensive medical, emotional, and social support.

- The Wheelchair Distribution Program was conducted on September 19, 2024, in association with the Rotary Club. A total of 15 wheelchairs were distributed to MND patients, with additional wheelchairs couriered to outstation locations.
- The Foundation also received 15 Oxygen Concentrators from KVN Foundation and during the year, 5 Oxygen Concentrators were issued to MND patients both within the State and outside the state.
- The Foundation continued its Home Care Equipment Support Program, which provides free oxygen cylinders, BiPAP machines, wheelchairs, air mattresses, and nutritional supplements to patients in need. The MND Patient Referral Program to NIMHANS also continued, ensuring timely consultation, follow-ups, and palliative care arrangements.
- Over the past year, 126 email queries from MND patients and caregivers were answered. Additionally, the Foundation receives one to two calls per day, seeking guidance, moral support, and medical referrals.
- Our MND Registry continued to grow, with a total of 27 patients registered this year. Although we are in touch with over 350 patients across the country, many have not registered. We do not make registration obligatory, as the condition can be overwhelming for both patients and caregivers.
- The Newborn Screening, for babies born at the BBMP hospitals has gained recognition and in the next year we propose to include more government run hospitals so over a period of time every child, born at the government hospitals have the benefit of being screened for any possible rare diseases.
- The Foundation's social media presence remained strong, with an active Facebook community sharing updates and resources on MND. Networking with NGOs across India helped refer patients to the nearest support organizations.
- On December 14, 2024, a letter was sent to the State and Central Governments requesting support for clinical trials and the import of essential medicines. The Foundation also secured CSR Registration Approval from the Ministry of Corporate Affairs on March 19, 2024, under registration number CSR00069435, enabling it to partner with corporate entities for funding and support.
- A Meet & Greet event for MND patients and caregivers is planned for June 2025. The event will include educational sessions, networking opportunities, and the distribution of informational handouts. Discussions have also been initiated for a Clinical Trial with the National Institute of Ayurveda, Jaipur, focusing on ALS treatment through Ayurveda. This collaboration is currently in the pipeline.

Future Plans & Initiatives

The Foundation aims to expand its palliative care services across Karnataka by partnering with district hospitals and NGOs. Further research collaborations on MND treatment, including Ayurveda-based clinical trials, are being explored. Furthermore, we will explore potential collaborations for clinical trials for MND patients in Bangalore with pharmaceutical companies both within and outside the country. Awareness efforts will be amplified through digital campaigns and public engagement activities. The development of a Medical Record Software is also planned to streamline patient tracking and management.

Acknowledgments

The Foundation extends its heartfelt gratitude to its partners, donors, volunteers, and caregivers who have contributed to its mission. Special thanks go to the entire team of doctors at Neurology Department, NIMHANS and the Multidisciplinary Neuropalliative Care Team, NIMHANS, for their unwavering support.

We also extend our gratitude to the Government of Karnataka, Health and Family Welfare Department, for their support.

We are also deeply grateful to our Trustees and Advisors, particularly Dr. NK Venkataramana, Dr. TR Raju, Dr. Subhash, Dr. Mohammed Faruk, Dr. Thuppil Venkatesh, Mr. Ananth Ravi, and Mr. Madan Mohan, for their dedication and guidance. Dr. Bhargavi, the Chief Administrative Officer of the Foundation, has played a crucial role in coordinating daily activities and maintaining continuous communication with patients and caregivers. Their collective support has made a profound impact on the lives of MND patients and their families. Together, the Foundation remains committed to advancing its mission with compassion, research, and innovation.

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