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ORDI to host â??Racefor7â?? to raise awareness on Rare Diseases in 15 cities on Feb 25

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7-kilometer marathon aims to raise awareness and funds to help patients with rare diseases



The Organisation for Rare Diseases India (ORDI), a decade old non-profit patient-centered organisation with the mission to improve the health of patients with rare diseases across India, is set to host its 9th annual flagship event, ‘Racefor7’, in 15 cities across the country on February 25, 2024.

Racefor7 is an annual awareness run organised in alignment with World Rare Diseases Day to be observed on February 29. Since its inception in 2016 in Bengaluru, the event has expanded nationwide, with an expected participation of over 20,000 individuals this year scheduled on February 25 across the cities of Bengaluru, Mumbai, Delhi, Hyderabad, Kolkata, Ahmedabad, Chennai, Kochi, Pune, Mysuru, Davangere, Hubballi, Asansol, Kozhikode, Coimbatore in line with the theme ONE NATION, ONE DAY – TOGETHER FOR RARE.

The 7-kilometer marathon aims to raise awareness and funds to help patients with rare diseases. Through their annual marathon event, ORDI aims to convey the message of community support and tackle stigma. The localized public event aims to be a platform for ORDI to send a strong message to the national level, as well as to global level markets in terms of clinical trials and research – a message that India is a growing market for channeling new and improved therapeutic approaches for rare diseases – facilitating accessibility of resources to patients and families.

Prasanna Kumar Shirol, Co-founder & Executive Director of ORDI, commented, "Racefor7 stands as the sole mass awareness initiative in India for the past 8 years. This event has played a pivotal role, both directly and indirectly, in the comprehensive development of the Rare Disease ecosystem in India. By capturing the attention of policymakers, stakeholders, and the global community, Racefor7 has positioned India on the global map in the field of Rare Diseases.”

Shirol further said “This year's Theme is ONE NATION, ONE DAY- TOGETHER FOR RARE emphasizes an amplified movement for all the stakeholders across the country, uniting for the support of rare disease patients. The focus is on enhancing access to therapies under policy guidelines, establishing an ecosystem for long-term care and support, fostering research and development, and ultimately creating a collective moment of 'I care for Rare.”

Image caption- (From left) Prasanna Kumar Shirol, Co-founder & Executive Director of ORDI; Dr Meenakshi Bhatt, Professor & Mazumdar-Shaw Research Chair, Centre for Human Genetics ORDI and Jinu Jose, Vice President, Research & Development Solutions, IQVIA India.