

Race For 7 sees participation from rare disease patients in Mumbai

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'Race For 7', an initiative championed by the Organization for Rare Diseases India (ORDI), was organized in Mumbai to raise awareness for rare disease patients, 50% of whom are children. Race for 7, a first of its kind event for rare diseases in the world, symbolically represents 7000 rare diseases with 7000 people running for 7 kilometers to represent the average number of years it takes to diagnose a rare disease.

Although an estimated 1 in 20 Indians suffers from a rare disease, lack of awareness and information has created several challenges for patients and their caregivers, most importantly delayed diagnosis, affordable and targeted care and treatment and access. Besides members of the general public, several rare disease patients and their families participated in 'Race for 7' to draw attention to the challenges faced by rare disease patients, especially children, and the urgency for governments and other institutions to recognize their unique needs and create enabling policies and a more supportive environment for them.

'Race for 7' is held in the month of February to commemorate World Rare Disease Day which falls on the last day of February. The theme for Rare Disease Day 2019 is 'Bridging health and social care', focusing on the need to better coordinate all aspects of care to improve the lives of people living with a rare disease. What started as an awareness walk to commemorate World Rare Disease Day in February 2016 has now grown into a significant campaign, conducted simultaneously in multiple cities and two countries – India and the USA.

Prasanna Shirol, Founder Director, ORDI, and father of a rare disease patient, says: "50% of all rare disease patients are children. This is a fact not many are aware of and supports our urgency of spreading awareness about rare diseases. In fact, 1 in every 20 Indians, is a rare disease patient. Besides lack of access to early intervention and treatment because of the lack of widespread awareness about rare diseases, the cost of treatment where available is often prohibitively expensive. Therefore, we urgently need national and state policies that address the unique requirements of the rare disease community and enable them to lead lives of dignity and self-worth. We also need institutions like corporates and schools and colleges to create a more inclusive environment for rare disease patients."

"IQVIA is delighted to be associated for the fourth consecutive year as the main sponsor of Race for 7, an event that has been growing in stature and impact. While rare diseases, by virtue of their definition, affect relatively fewer number of patients, the overall number of rare disease patients is large enough to warrant more focused attention. We hope that the public will come forward in large numbers to participate in Race for 7 and help amplify the voice of the rare disease community. Race for 7 is a unique way of engaging the community with those who matter most –patients and their caregivers - for a common cause," said Amit Mookim, Managing Director, IQVIA – South Asia. Rare Diseases is a key therapeutic focus for IQVIA who has provided clinical services for more than 258 rare disease studies in 87 countries worldwide since 2011.

Prasanna added the importance of having a rare disease policy and an Orphan drug Policy for holistic management of Rare Diseases for patients, in absence of any health care policy /insurance coverage and to support the Industry to develop newer drugs and research respectively.

ORDI has been working tirelessly among rare disease patients in India. Besides the annual 'Race for 7' run, ORDI also started the First Rare disease Helpline in India (+91 8892 555 000); RDCCC (Rare Disease Care Co-Ordination Center); First COERD (Center of Excellence for Rare Diseases) in India at Bengaluru; First Exclusive Day care center for Rare Diseases in India at Bengaluru; Second RDCCC center in Mysore in JSS Hospital; Campaign for National Rare Disease Policy; First NMD (Neuromuscular Clinic in India); India's First Assisted Living facility for Rare Disease patients in Bengaluru to name a few.