

## Race for 7- Bengaluru & Mumbai walk for Rare Diseases

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**Race for 7 was first held in India in 2016 on the last Sunday of February to commemorate World Rare Disease Day which falls on February 28th.**



Lending their collective voice to the rare disease community in India, an enthusiastic 5300+ participants, including 60 rare disease patients and their caregivers, took part in Race for 7 in Bengaluru and Mumbai. Race for 7 is an awareness walk/run organized by the Organization for Rare Diseases (ORDI), an NGO committed to addressing the challenges faced by those living with rare diseases. The objective of Race for 7 is to raise awareness for the 7000 documented rare diseases and the estimated 70 million patients in India suffering from a rare disease. Rare Disease patients who participated included a Boston Marathon runner and paralympian champions.

Race for 7 was first held in India in 2016 on the last Sunday of February to commemorate World Rare Disease Day which falls on February 28<sup>th</sup>. This year, Race for 7 was held simultaneously in two countries and three cities, namely Bengaluru, Mumbai and Washington DC with a smaller event in Jaipur and South Carolina.

**Prasanna Kumar B Shirol, Founder Director, ORDI and the father of Nidhi Shirol**, a rare disease patient, said, “An event like Race for 7 is a reminder that we are not alone in championing the cause of the rare disease community. It was heartening to see so many people of all ages support us today. The success of Race for 7 in previous years has gone a long way in creating better awareness and enabling us to extend our support to more rare disease patients be it in the area of early diagnosis, treatment and care and even in the advancement of policies for rare disease patients. This year’s Race for 7 focus is on ‘Rare Disease Policies’ and we hope that Central and State Governments will expedite policies for rare disease patients.”

“We are extremely proud to be the main sponsors of this event. What started as one event in Bengaluru has not just expanded to other cities in India, but also to the USA, making Race for 7 a truly **Make in India** initiative. Awareness for rare diseases though should not just be restricted to this event and I encourage all of you to talk about it beyond and initiate dialogues with universities and researchers to help improve the lives of rare disease patients,” said **Naz Haji, IQVIA India Managing Director**. “

Several rare disease patients and their caregivers spoke on the occasion and, while expressing gratitude for the increased awareness and access for rare disease patients made possible by events such as Race for 7, also highlighted the need for continued awareness and education in the area. **Toushif, diagnosed with pachydermoperiostosis said**, “The challenges faced by those of us that live with rare diseases are many. I am happy that ORDI has stepped in to help present our unique needs to the concerned authorities and is pushing for policies that will benefit us in the long run. Rare disease patients require help and support and we are so happy that so many members of the public are here to support our cause.”

ORDI was founded to address the many challenges in the management of rare disease in India. It aims to address the unmet needs of rare disease patients and serves as an umbrella organization for rare disease patients and other stakeholders throughout the country. The funds raised from Race for 7 will be utilized to help ORDI in its mission to improve health of patients with rare diseases across the country through awareness, advocacy, collaborations and information dissemination.