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Bangalore runs to raise voice of rare disease patients

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The objective was to raise awareness for the 70 million estimated patients in India suffering from a rare disease.

The 7km event was flagged off by South Indian Cine Star Mr Kishore Kumar G, Mr Rajeev Gowda, Member of Parliament, and Mr Naz Haji, Quintiles India Head at St. Joseph's Indian High School.

Running and walking through Cubbon Park amidst a highly charged atmosphere, the event saw over 50 patients with rare diseases participate, some coming from as far away as Mumbai and Delhi.

This included Mr Nihal Bitla, a patient suffering from Progeria (the medical condition which featured in the Hindi movie Paa) who travelled all the way from Mumbai to extend his support to the cause of rare diseases.

Speaking on the occasion, Kannada Cine Star, Mr Kishore Kumar G, said, "I am humbled to be part of this noble initiative which champions the rights of people living with rare disease. It's time we all get together, create awareness and extend our support in initiating change that will help improve the lives of patients living with rare diseases. You and I can make a difference!"

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The post event entertainment witnessed performances from some of the patients present for the event.

Ms Nidhi Shirol, a patient suffering from Pompe Disease, and Mr Jayanth Gowda, a patient suffering from MPS Type4, had the audience singing along and dancing to their song performances.

Mr Prasanna Kumar B Shirol, Founder Director, ORDI and the father of Ms Nidhi Shirol, "I am glad to see an overwhelming response to the first Race for 7. Today is a historic moment for us as it is for the first time in India we have seen so many people come together to create awareness for rare diseases. This support from each one of you has given us a voice which we hope reaches the policy makers. We require everyone's support to convert this hope into a resultant 'Rare Disease Policy'."

The participants were in high spirits and were seen shaking their legs enthusiastically to the music and Zumba performances by Quintiles employees, the primary sponsors of Race for 7.

"When we talk about rare diseases, it's all in terms of statistics...7000 rare disease, 700 million patients in India, an average of 7 years to diagnose, 50% of those affected are children...and so on," said Mr Naz Haji, Quintiles India Head."Behind all these statistics are real people...many born like you and me but who go through the rest of their lives challenged not just by their disabilities but by the lack of knowledge and awareness that exists abut rare diseases. That is why Race for 7 assumes so much importance. It is a platform to build awareness so that a strong ecosystem of various stakeholders can come together to help patients and their caregivers live their lives with hope and dignity so that rare diseases are no longer a statistic."

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 in India 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 India through awareness, advocacy, collaborations and information dissemination.

Mr Jayant Gowda, a youngster suffering from MPS, Type 4 disorder said, "Thank you everyone for coming here and supporting us in creating awareness. We hope all this translates into fruitful results and next year we meet again to celebrate and not just to create awareness."

Ms Dhanya, a patient suffering from Osteogenesis Imperfecta (a brittle bone disorder), said, "On behalf of all rare disease patients, we would like to thank each and every one for being a part of this event. We are greatly pleased with the response we have received and take pride in the fact that people have extended their support in improving and amplifying the voices of rare disease patients."