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Press Release
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1 in 20 Indians suffers from a Rare Disease: Need More Clinical Research in India on Rare Diseases says ISCR

Patient Voice Theme of World Rare Disease Day

New Delhi, February 29, 2016: There are close to 7000 known rare diseases today¹, most of which are progressive, life-threatening and chronically debilitating conditions. There is no treatment for more than 90% of these diseases and the number of patients with rare diseases continues to increase every year¹. The vast majority of rare diseases are genetically inherited and exist over the lifetime of a patient. Approximately 50% of those affected by rare diseases are children, of whom around 30% will not live to see their fifth birthday¹. On an average, it takes around seven years to diagnose a rare disease. In India alone, there are an estimated 70 million patients living with a rare disease, many of whom do not know they have a rare disease and even when they do, they either have no access to treatment or cannot afford it. These statistics alone highlight the compelling need for more clinical research in rare diseases in India

“It is ironic that rare diseases are no longer a rare occurrence. Although we have made tremendous progress in science and medicine, very little has been invested in India in understanding rare diseases and their management,” said **Ms. Suneela Thatte, President, ISCR.** *“We need a more concerted effort to promote clinical research in India to find newer, affordable and effective therapies for the 70+ million patients in India who suffer from a rare disease who have an equal right to benefit from new medicines and treatment available to patients in other parts of the world.”*

Every year, the last day of February is observed as Rare Disease Day to raise awareness about rare diseases. The theme this year is **“Patient Voice”**, which recognises the crucial role that patients play in voicing their needs and in instigating change that improves their lives and the lives of their families and caregivers. *“Our children have a right to live with dignity and in an environment where there are*



investments being made in clinical research that could help them lead a better quality of life. We seek the support of the media in highlighting the cause of rare diseases in India and the challenges of patients living with illnesses for which there is no known cure,” **said Samir Sethi, President, Indian Rett Syndrome Foundation and parent of a daughter diagnosed with Rett Syndrome.**

“Awareness, accessibility and affordability are key needs of patients suffering from rare disease and early diagnosis is a critical challenge in the management of rare diseases,” **said Prasanna Shirol, Founder Member, Organisation for Rare Disease India (ORDI)** whose daughter suffers from a rare disease. *“The cost of treatment for rare disorders is very high and a lifelong expense running into tens of lakhs of rupees each year. Most patients and their families find this an enormous economic burden. There exists an urgent need for clinical research to ensure better and more affordable medicines for rare diseases so we can provide sustainable care to patients. From a policy perspective, we need legislation that specifically targets budgetary support, access, innovation, and investment for rare disease treatment in India.”*

We invite you to join us in making the voice of rare diseases heard appeals to a wider audience, those that are not living with or directly affected by a rare disease, to join the rare disease community in making known the impact of rare diseases.

Data Source:

- 1) RARE Diseases: Facts and Statistics <https://globalgenes.org/rare-diseases-facts-statistics/>
- 2) Rare Diseases and Disorders Research, Resource and Repository for South Asia. Estimated rare diseases population in South Asian countries. Rare diseases and Disorders (RDD) population statistically derived from published data of respective national population census of 2011 or later.
- 3) 1 in 20 Indians suffers from rare diseases: Organization for Rare Diseases India (ORDI).



About ISCR

The Indian Society for Clinical Research (ISCR) is an association of clinical research professionals that aims to build awareness of clinical research as a specialty in India and to facilitate its growth in the country while helping to evolve the highest standards of quality and ethics. To that extent, we are fully supportive of the initiatives undertaken by regulatory authorities to create a more robust and regulated environment in India for the conduct of clinical research and will continue to work very closely with different stakeholders in the development of regulations that will safeguard and protect patients in a clinical trial. For more information, visit www.iscr.org

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