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ISCR reiterates need for investment in rare diseases research

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More Research Needed for Rare Diseases



On Rare Disease Day 2021, Indian Society for Clinical Research (ISCR) called upon all research stakeholders to invest in research across the spectrum so that rare disease patients and their caregivers can look forward to a better quality of life.

Rare Disease Day takes place on the last day of February each year to raise awareness amongst the general public and decision-makers about rare diseases and their impact on patients' lives.

Research can lead to the identification of previously unknown diseases, increase understanding of diseases, enable doctors to provide a correct diagnosis, lead to the development of new innovative treatments and possibly even a cure, reduce costs for healthcare systems, and improve the quality of life of patients and their families.

Noting the need for more research into rare diseases, Chirag Trivedi, President, ISCR said, “According to available data, 1 in 20 people will live with a rare disease at some point in their lives. The large number of rare disease patients living without access to treatment and management of their conditions either because of lack of awareness, lack of appropriate diagnosis and lack of treatment options should be a wake-up call for the clinical research community.”

The UN 2030 Agenda and its Sustainable Development Goals is addressing the needs of patients that are diagnosed with rare disease through their pledge to leave no one behind. Furthermore, the future goal of Rare Disease Day over the next decade would be to increase the equity for people living with a rare disease and their families.