International Rare Disease Day 2026 Observed on 22nd February 2026 at SGPGI, Lucknow

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International Rare Disease Day was observed with great commitment and solidarity on 22nd February 2026 through a collaborative initiative of **Rare Diseases India Foundation (RDIF)** and Sanjay Gandhi Postgraduate Institute of Medical Sciences (SGPGI), Lucknow. The event witnessed the participation of hundreds of rare disease patients and their families, along with leading doctors, pediatric specialists, clinicians, physiotherapists, and healthcare professionals.

Lives cannot wait-RDIF observed International Rare Disease Day 2026 at SGPGI, Lucknow

A special **“Walk4Rare” Awareness Walk** was organized to spread awareness among the general public. The walk created significant visibility and sensitized the community about the challenges faced by rare disease patients and their families.

The primary objective of the event was to provide a comprehensive platform for patients and caregivers to address their concerns related to diagnosis, treatment options, caregiving challenges, physiotherapy, and other essential medical assistance. Experts conducted interactive sessions to answer general queries and guide families regarding available support systems. The program also included cultural performances by patients and families, celebrating resilience and hope within the rare disease community.

Dr. **Devendra Gupta**, Chief Medical Superintendent of SGPGI, underlined the critical role of Patient Advocacy Groups in bridging the gap between patients, healthcare providers, and policymakers. He stressed that collaborative efforts are essential to ensure early diagnosis, accessible treatment, and sustained care.

Dr. **Kaushik Mandal**, Head of the Department of Pediatrics, SGPGI Lucknow, assured the community that the medical fraternity stands firmly with rare disease patients. He stated, “*We are available 24×7 to support this community because we understand their suffering very closely*.”

Mr. **Saurabh Singh**, Co-Founder & Director of Rare Diseases India Foundation (RDIF), stated that the Rs. 50 lakh funding cap under the National Policy for Rare Diseases 2021 is insufficient for many high-cost and lifelong treatments, particularly for Group 3 patients. He expressed concern that several patients are deteriorating after exhausting the sanctioned funds, leading to interruption or stoppage of treatment. He also highlighted that some rare diseases are still awaiting inclusion under the policy framework. Emphasizing that patients are not seeking free services but affordable and sustainable access to medicines, he added that the community remains hopeful for positive intervention from the Supreme Court of India to ensure justice and continuity of care.

The Program concluded with a strong message of unity, awareness, and collective responsibility – reaffirming the commitment to build an inclusive healthcare ecosystem where rare disease patients are not invisible but empowered.