

Rare Disease Day Related Events at Different Centres Across India



1st February 2024: The All India Institute of Medical Sciences (AIIMS), New Delhi conducted a CME titled 'Empowering Healthcare Professionals with Essential Insights for Diagnosing and Care of Rare Genetic Disorders' under the aegis of the Centre of Excellence (CoE) for Rare Diseases of the Ministry of Health and Family Welfare, Government of India, in association with the Society for Indian Academy of Medical Genetics (SIAMG) and the DBT Mission Program on Pediatric Rare Genetic Disorders.



3rd February 2024: The Department of Medical Genetics, Nizam's Institute of Medical Sciences (NIMS), Hyderabad in association with the Centre for DNA Fingerprinting and Diagnostics (CDFD), Hyderabad organized an awareness program and CME titled 'Management of Genetic Disorders: A Primer for Health Care Professionals' under the aegis of SIAMG and the DBT Mission Program on Pediatric Rare Genetic Disorders (PRaGeD)



22nd February 2024: The Institute of Medical Genetics and Genomics at Sir Ganga Ram Hospital, New Delhi commemorated Rare Disease Day with a symbolic walk through the hospital, with doctors, patients, and their families joining hands in solidarity, carrying banners that read "I care for rare". The event culminated with the release of balloons as a beacon of hope and a reminder that even in the face of challenges, there is a community ready to support and care!



24th February 2024: The Department of Medical Genetics, Sanjay Gandhi Postgraduate Institute of Medical Sciences, Lucknow in collaboration with the Academy of Pediatrics, Uttar Pradesh and Lucknow Academy of Pediatrics organized a Rare Disease Day event. The morning half was devoted to patients of spinal muscular atrophy, osteogenesis imperfecta, achondroplasia, and lysosomal storage disorders (LSDs) and their families. Adult patients with LSDs on enzyme replacement therapy shared their stories of triumph and struggle. The afternoon session was a CME on 'Inborn Errors of Metabolism' and was dedicated to Late Dr I C Verma.



24th February 2024: The Nodal Centre for Rare Diseases, JK Lone Hospital, Jaipur in collaboration with Rare Disease India Foundation (RDIF) celebrated Rare Disease Day at the Rajasthan International Centre, Jaipur. The event was an awareness program with poster release on the theme of 'Aware to Rare' and was well attended by around 120 doctors and healthcare personnel.



25th February 2024: Awareness Marathon on the theme 'One Nation, One Day Together for Rare' was organized by the Department of Medical Genetics, JSS Medical College, Mysuru in association with the Organization for Rare Diseases India (ORDI).

National Symposium on Rare Diseases



On the occasion of Rare Disease Day, the Ministry of Health & Family Welfare (MoHFW), Government of India, in collaboration with the World Health Organization (WHO), India organized a two-day multi-stakeholder consultation titled **'National Symposium on Rare Diseases: Challenges, Opportunities and Way Forward'** on 29th February-1st March 2024 at Radisson Blu Palace, Udaipur. The two-day event captured the progress made under the purview of the National Policy for Rare Diseases (NPRD). Participation of Ms. L. S Changsan (Additional Secretary, Department of Health and Family Welfare, MoHFW), Mr Rajiv Manjhi (Joint Secretary, MoHFW) and Dr L. Swasticharan (Additional Deputy Director General of Health Services, MoHFW), reiterated the huge will of the government to take forward the cause of rare diseases.

Down Syndrome Day Celebrations



The Genetic Clinic, Dwarka, New Delhi, in association with the Society for Indian Academy of Medical Genetics (SIAMG) celebrated Down syndrome day on 20th March 2024. The program was attended by children with Down syndrome and their parents. A Pediatric Cardiologist, who is the mother of a boy with Down syndrome, gave a talk on parenting tips for children with Down syndrome. Parents discussed their journey and the challenges faced by them and the means to overcome them. The need for creating awareness in society for supporting individuals with Down syndrome to help them lead a dignified and respectful life and to provide job opportunities for them, was also discussed.

Down Syndrome Day Celebrations



Down syndrome day was celebrated by the Department of Medical Genetics, Sanjay Gandhi Postgraduate Institute of Medical Sciences (SGPGIMS), Lucknow, on 21st March 2024. It was a fun-filled event, with activities such as singing, dancing, drawing and painting, etc. designed to celebrate the indomitable spirit of individuals with Down syndrome.