

Pledge4Rare: 3 decades of caring for Rare Diseases, from our home to yours

2021 marks the 30th Anniversary of the Humanitarian Program of Sanofi Genzyme. More than 3,200 patients with rare diseases in over 100 countries have received access to therapy since this program was introduced. Rare disease day was celebrated by Sanofi Genzyme virtually on 27th Feb, 2021. Dr IC Verma, Dr S Suresh, Dr Sujatha Jagadeesh, Dr Ashok Gupta and other panellists shared transformational stories of families with rare diseases. The key highlights of the event were the experiences from a patient's perspective shared by Ms Alka, Dr Aparna and Mr George.

SIAMG-ORDI lecture series

The Society for Indian Academy of Medical Genetics (SIAMG) in collaboration with Organisation for Rare Diseases, India (ORDI) conducted an online lecture series on common topics in medical genetics relevant for clinicians. There were 13 sessions with three topics in each session. The sessions were conducted virtually on Saturday afternoons from 10th October 2020 to January 23, 2021. Each lecture session was attended by more than 100 participants including paediatricians, obstetricians and other clinicians interested in clinical genetics.

Race for 7

The 'Race for 7', a seven-kilometers run for 7000 rare disorders, was organized by the Organization for Rare Disorders India (ORDI), on 28th February, 2021.



5th National conference of the Indian Society of Primary Immune Deficiency (ISPID)

The 5th National conference of the Indian Society of Primary Immune Deficiency (ISPID) was conducted virtually on March 6 and 7, 2021. The conference was organised by the Department of Clinical Immunology & Rheumatology, Sanjay Gandhi Postgraduate Institute of Medical Sciences (SGPGIMS) and the Department of Pediatrics, King George Medical University, Lucknow.

The theme for the meeting this year was autoinflammation and autoimmunity in primary immune deficiency disorders. Talks by eminent national and international experts in the field of autoinflammatory and autoimmune diseases were the highlights of this virtual meeting. More than 120 participants including rheumatologists, paediatricians and geneticists participated in this online event. The free paper and case presentation segment, where the residents and trainees showcased their work, was engrossing. There was a separate online poster presentation segment. Dr Manisha Madkaikar, Director, NIIH, Mumbai, addressed the gathering during the curtain raiser event to the Indian Council of Medical Research (ICMR) Primary Immune Deficiency registry. Dr Haseena Sait, DM trainee in Medical Genetics, SGPGIMS, Lucknow, won the first prize for the case presentation. The meeting ended with an online quiz program for residents and trainees in clinical immunology and rheumatology.