

## GeNeEvent - National Initiative for Rare Diseases Consultation Meeting



To pave the way for addressing Rare Diseases in India, the National Initiative for Rare Diseases (NIRD) was conceptualized. NIRD is a partnership of AIIMS (All India Institute of Medical Sciences), ICMR (Indian Council of Medical Research), PRESIDE (Pediatric Research and Education Society of India) and JNU (Jawaharlal Nehru University), supported by leading institutes of India. It was held on 26<sup>th</sup> and 27<sup>th</sup> April 2017, in the India International Centre, New Delhi. The two-day event focused on coming up with guidelines and recommendations for addressing Rare Disease through a policy. The objectives of NIRD are to bring all stakeholders on a common platform and evolve a strategy to address rare disorders in India through a mix of Policy, Access, Research, Treatment and Technology. The key highlight of the event was the launch of the Indian Rare Disease Registry by Dr Soumya Swaminathan, Director General, ICMR. The recommendations of NIRD would be presented to the Ministry of Health by mid-June 2017.

# GeNeEvent - ICMR-INSERM-DBT Symposium on Ethical and Scientific Issues of Gene Editing Using CRISPR-Cas9 Technology



A two day symposium- the 'ICMR-INSERM-DBT Symposium on Ethical and Scientific Issues of Gene Editing Using CRISPR-Cas9 Technology', was held on 27<sup>th</sup> and 28<sup>th</sup> April 2017 at the National Institute of Immunology, New Delhi. It was a joint venture of the Indian Council of Medical Research (ICMR), Department of Biotechnology (DBT) and the INSERM- French National Institute of Health and Medical Research. The symposium brought together Indian and European stallwarts from various life sciences-related disciplines. The gathering was addressed by the Secretary-Department of Health Research and the Director General-ICMR Dr Soumya Swaminathan, the Head of Basic Medical Sciences-ICMR Dr Vijay Kumar, the DBT Secretary Dr VijayRaghavan, and the Director General-Inserm Thierry Damerval. The scientific sessions included discussions about the application of genome editing techniques in cancers, single gene disorders like muscular dystrophy, stem cell research, embryonic stem cells, microbial genome etc. There were discussions and debates revolving around ethical issues, patient safety and outcome of such techniques on the environment and evolution. The two day symposium was a kick-start for introduction of the genome editing techniques in various fields of science in India.