Los Angeles, C.A. January 31, 2017. Rare Genomics Institute (RG) and the Organization for Rare Diseases India (ORDI) announced today that they are one of the recipients of Sanofi Genzyme's 6th annual Patient Advocacy Leadership (PAL) Awards for 2016. RG and ORDI have won financial support for the development and dissemination of specialized Rare Disease online training modules.

The project is directed by RG COO and VP of Patient Advocacy, Romina Ortiz.

"*The goal of the project is to develop an e-learning educational resource to train patient advocate associates, patients, caregivers, physicians, and researchers to strengthen and optimize rare disease patient advocacy for pre-sequencing and post-sequencing support functions,*" said Ms. Romina Ortiz, MHS. "*The content is highly specialized and includes genetics, heredity, next generation sequencing, with a special focus on rare disease, professional patient interaction, and privacy.*"

On this project, RG partnered with Dr. Harsha Karur Rajasimha and his team from ORDI, who will pioneer the first international distribution of these training materials, specifically contributing to the translation of these materials into Hindi and disseminating them amongst their rare disease network and direct content development for Lysosomal Storage Disorders. ORDI aims to connect with a subset of the roughly 490 million Hindi speaking population that consumes health information only in Hindi.

Web-based training materials are anticipated to be ready by Fall 2017, and will be disseminated directly to patient advocates working with thousands of disease-specific organizations. Materials will also be publically available for patients and caregivers through the RG and ORDI websites. If you are interested in knowing more about genome sequencing for rare diseases, please email: contact@raregenomics.org.

Â Â Â About Sanofi

Sanofi is a global healthcare leader in the discovery, development and distribution of therapies for patients suffering from debilitating diseases often difficult to diagnose and treat. Sanofi is composed of five global business units including: Diabetes and Cardiovascular, General Medicines and Emerging Markets, Sanofi Genzyme, Sanofi Pasteur and Merial. Sanofi Genzyme's global PAL Awards program supports non-profit organizations that serve patients living with lysosomal storage disorders (LSDs), a group of rare, genetic disorders that can cause progressive and debilitating health problems.

About Rare Genomics Institute

RG is a 501(c)(3) non-profit that makes cutting edge research technologies and experts accessible to rare disease patients. Partnering with top medical institutions, RG helps custom design personalized research projects for diseases so rare that no organization exists to help. By providing an expert network and an online crowdfunding mechanism, RG helps families source, design, and fund personalized research projects in diseases not otherwise studied. Ultimately, RG aims to expand on its current genome sequencing-focused approach to enable support for whatever type of research is necessary to get closer to rare disease therapeutics.

Website: www.raregenomics.org

About Organization For Rare Diseases India

ORDI (http://ordindia.org/) is a non-profit organization with the aim to empower patients with rare diseases and their families in India with access to national and international resources to improve their quality of life. A lack of awareness about rare diseases even among doctors means that a diagnosis often takes many years. The cost of diagnosis and treatment can also be prohibitively expensive. In the absence of a national government policy surrounding rare diseases, there is no push for the development of orphan drugs,Â the very medicines that can provide relief for patients with rare diseases.Â ORDI serves as a national umbrella organization for patients with rare diseases and other stakeholders. Our team consists of experts in genetics, molecular diagnostics, drug development, bioinformatics, communications, information technology, patient advocacy, and public service.

Website: http://ordindia.org/