Genzyme Convenes 14th Annual North American Lysosomal Storage Disorder Registries Meeting

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Thought leaders specializing in Gaucher, Pompe, Fabry and MPS diseases come together to discuss the registries’ role in optimizing patient care, now and in the future

CAMBRIDGE, Mass.--(BUSINESS WIRE)--Genzyme, a Sanofi company (EURONEXT: SAN and NYSE: SNY), today announced that the 14th North American Lysosomal Storage Disorder (LSD) Registries Meeting will take place June 13-14 in Chicago, Illinois. Sponsored by Genzyme, this scientific meeting brings together more than 50 registry investigators and 26 speakers, including physicians, academics, and researchers, as well as 100 nurses and genetic counselors to discuss novel insights garnered from studies in observational disease registries. The goal of these studies is to improve clinical care and to shape the future direction of research in the management of patients affected with LSDs. This year’s meeting is co-chaired by Pramod Mistry, MD, PhD, Professor of Medicine and Pediatrics and the Director of National Gaucher Disease Treatment Center at Yale University School of Medicine, New Haven, Connecticut and Lorne Clarke, MD, PhD, Professor Medical Genetics, University of British Columbia, Department of Medical Genetics, Vancouver, Canada.

“Over the last two decades, dedicated efforts of registry investigators across the world have uncovered unique insights into LSDs, not possible from single-center studies; these advances have led to improved patient care and informed the design of studies to further advance the field and shape clinical trials,” said Dr. Mistry. “This meeting represents a major milestone to assess the current status of observational registries in these rare diseases and to develop a roadmap towards patient-centered outcomes research to further enhance health outcomes for patients.”

The theme of this meeting is “Fostering Evidence-Based Medicine through Registries,” with special focus on patient-centered outcomes and insights regarding the diagnosis and management of patients affected with LSDs.

Among the topics for discussion:

- The evolution of registries and best practices in observational research
- Collecting data on endpoints that are meaningful to the patient
- Fueling future research via the registries
- Quality of life issues
- Emerging outcomes data
- Enhancing the value of the registry to physicians, payers, and patients

Since 1991, Genzyme has worked closely with the international LSD community to understand disease epidemiology, natural history and long-term treatment outcomes. Having one central repository of data for these rare diseases has been crucial to delineate variable disease progression and develop algorithms to optimize patient management.

“As a registry pioneer, Genzyme has gathered data to advance medical and scientific understanding of rare genetic disorders and to improve the quality of care of patients around the world,” said Genzyme’s Head of Rare Diseases Rogerio Vivakdi, MD. “As we look forward to the next twenty years, the need to continuously assess the long-term value of therapy will be fundamental to optimize patient outcomes.”

The North American LSD Registries are overseen by independent regional boards of scientific advisors. These advisors are external physicians that form the governance body, oversee the scientific integrity and guide research, publications and policy. Genzyme has provided financial support of the operations since 1991.

About Genzyme, a Sanofi Company

Genzyme has pioneered the development and delivery of transformative therapies for patients affected by rare and debilitating diseases for over 30 years. We accomplish our goals through world-class research and with the compassion and commitment of our employees. With a focus on rare diseases and multiple sclerosis, we are dedicated to making a positive impact on the lives of the patients and families we serve. This goal guides and inspires us every day. Genzyme’s portfolio of transformative therapies, which are marketed in countries around the world, represents groundbreaking and life-saving advances in medicine. As a Sanofi company, Genzyme benefits from the reach and resources of one of the world’s largest pharmaceutical companies, with a shared commitment to improving the lives of patients. Learn more at www.genzyme.com.
About Sanofi
Sanofi, an integrated global healthcare leader, discovers, develops and distributes therapeutic solutions focused on patients’ needs. Sanofi has core strengths in the field of healthcare with seven growth platforms: diabetes solutions, human vaccines, innovative drugs, consumer healthcare, emerging markets, animal health and the new Genzyme. Sanofi is listed in Paris (EURONEXT: SAN) and in New York (NYSE: SNY).

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