Chiesi Global Rare Diseases to Launch the Second Edition of Find For Rare at 2026 ERA Congress to Advance Research in Lysosomal Storage Disorders

-- At ERA 2026, Chiesi will contribute to advancing the scientific understanding of Fabry disease and nephropathic cystinosis through real-world experience and clinical outcomes, supporting the needs of the community of today --

-- Chiesi will also launch the second edition of Find For Rare, an independently assessed, expert-led research grant initiative that supports innovative research in Fabry disease, alpha-mannosidosis and nephropathic cystinosis to advance disease understanding and care for generations to come --

PARMA, Italy – June 3, 2026 – Chiesi Global Rare Diseases, a business unit of the Chiesi Group, today announced its participation in the 63rd European Renal Association (ERA) Congress, taking place June 3–6, 2026, in Glasgow, Scotland, re-affirming its long-standing commitment to advancing understanding and care in lysosomal storage disorders (LSDs) over time. At ERA 2026, this commitment comes to life through the Company's contribution to ongoing scientific dialogue in areas such as Fabry disease and nephropathic cystinosis, while also extending beyond the congress through the launch of the second edition of Find For Rare, its research grant initiative designed to support future innovation in LSDs.

At ERA, Chiesi's scientific contributions will highlight real-world experience and clinical outcomes across Fabry disease and nephropathic cystinosis, focusing on treatment tolerability and immunogenicity in Fabry disease and nephrology-led multidisciplinary coordination to optimize care and outcomes for cystinosis. Through continued research and collaboration across disciplines, Chiesi Global Rare Diseases strives to create lasting, meaningful impact for the rare disease community for generations to come. This commitment also extends to rare conditions with significant renal impact, such as primary hyperoxaluria type 1 (pH1), which is part of the company's emerging pipeline focused on advancing innovative approaches for rare kidney diseases.

Building on this commitment, Chiesi Global Rare Diseases will launch, during ERA Congress, the second edition of Find For Rare -an independently assessed, expert-led research grant initiative designed to support innovative research in three lysosomal storage disorders: *Fabry disease, alpha-mannosidosis and nephropathic cystinosis*. By providing funding opportunities for original research projects and fostering collaboration across the scientific community, Find For Rare aims to help advance understanding of these complex conditions and contribute to improving disease management over time. Through this initiative, Chiesi seeks to help enable the research that will shape future care, extending today's scientific dialogue into meaningful progress for those who come next. For more information, visit www.findforare.com.

"Scientific progress in rare diseases is built over time, through continuous dialogue and collaboration," said Enrico Piccinini, Senior VP Europe and International, Chiesi Global Rare Diseases. "At ERA, we are proud to contribute to advancing understanding of lysosomal storage disorders. At the same time, with Find For Rare, we aim to go one step further supporting innovative research that can expand knowledge and help shape the future of care for generations to come."

About Fabry Disease

Fabry disease is a rare, inherited lysosomal storage disorder caused by mutations in the GLA gene, which leads to a deficiency of the enzyme alpha-galactosidase A. This deficiency results in an accumulation of a fatty substance called globotriaosylceramide (GL-3) in the body's cells, affecting the heart, kidneys, skin, nervous system, and other organs.[1] Fabry disease can cause a range of serious signs and symptoms, including fatigue, chronic pain, gastrointestinal issues, decreased ability to sweat, progressive kidney failure, heart complications, and increased risk of stroke.[2]

The condition affects both males and females and can present from childhood through adulthood, often with delayed diagnosis or misdiagnosis. While Fabry disease is rare, early detection and access to appropriate treatment — such as enzyme replacement therapy or pharmacological chaperone therapy — are critical in managing symptoms and slowing disease progression.[1]

About Cystinosis

Cystinosis is an ultra-rare genetic condition which affects fewer than 2 people in every million.[3] In people with cystinosis, an amino acid called cystine accumulates in a part of the cell called the lysosome, and the cells are unable to remove it.[3] When cystine builds up, it forms crystals within lysosomes that can cause long-term damage to organs, including at first the kidneys, eyes, muscles, pancreas, and brain.[3] This damage cannot be reversed, but it can be delayed or reduced.[4] There are three types of cystinosis. We are focusing on Nephropathic Cystinosis (NC), which is the most severe form of Cystinosis (95% of all cases) affecting about 2,000 patients worldwide, ~700 in Europe, ~500 in the US.[5] Because cystinosis is a multi-organ disease, its symptoms are very broad and diverse. Newborns with nephropathic cystinosis do not present any symptoms, but within the first months of life they often present signs that suggest their kidneys are not working as well as they should. This will result, sooner or later, depending on when the treatment starts, in the need for kidney transplant in all people living with nephropathic cystinosis forms. Patients may also have impaired growth, loss of appetite or rickets.[3,4] Although in nephropathic cystinosis, the kidneys are affected first, almost every organ in the body is at risk of damage,[3,4] Continuous, lifelong cystine accumulation potentially damages all organs and tissues, resulting in severe complications, such as kidney failure, blindness, muscle wasting, central nervous system damage, and reduced lung function.[3,4]

About Lysosomal Storage Disorders

LSDs are inborn errors of metabolism that are characterised by an abnormal build-up of substances in the body's cells as a result of enzyme deficiencies.[6] The build-up of these substances can affect different parts of the body, including the skeleton, central nervous system (brain), lungs, heart, and eyes. Whilst there has been progress in clinical knowledge, more research in LSDs can be beneficial.[6]

About Chiesi Group

Chiesi is a research-oriented international biopharmaceutical group that develops and markets innovative therapeutic solutions in respiratory health, rare diseases, and specialty care. The Company’s mission is to improve people’s quality of life and act responsibly towards both the community and the environment.

By changing its legal status to a Benefit Corporation in Italy, the US, France and Colombia, Chiesi’s commitment to creating shared value for society as a whole is

legally binding and central to company-wide decision-making. As a certified B Corp since 2019, Chiesi is part of a global community of businesses that meet verified standards of social and environmental impact. The Company aims to reach Net-Zero greenhouse gases (GHG) emissions by 2035.

With 90 years of experience, Chiesi is headquartered in Parma (Italy), with 31 affiliates worldwide, and counts more than 7,900 employees. The Group's research and development center in Parma works alongside 6 other important R&D hubs in France, the US, Canada, China, the UK, and Sweden.

About Chiesi Global Rare Diseases

Chiesi Global Rare Diseases is a business unit of the Chiesi Group established to deliver innovative therapies and solutions for people living with rare diseases. As a family business, Chiesi Group strives to create a world where it is common to have therapy for all diseases and acts as a force for good, for society and the planet. The goal of the Global Rare Diseases unit is to ensure equal access so as many people as possible can experience their most fulfilling life. The unit collaborates with the rare disease community around the globe to bring voice to underserved people in the health care system.

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