

Chiesi Global Rare Diseases Launches New Research Grant Initiative to Support Research Excellence in Lysosomal Storage Disorders

Applications for the independently assessed, expert-led Research Grant Initiative, Find For Rare, are open from today, with experts calling for innovative research to broaden the level of understanding into three lysosomal storage disorders and, ultimately, improve patient care and management.

Researchers can apply for grants up to €50,000 – the research grants are designed to support original research projects that aim to advance knowledge in the field of: Fabry disease, alpha-mannosidosis, and cystinosis.

All applications will be independently reviewed and assessed by a Steering Committee of leading experts in the lysosomal storage disorders field, who have been identified, contracted and funded by Chiesi, with the successful applicants announced in Q1 2025.

PARMA, Italy, August 15 2024 – Chiesi Global Rare Diseases, a business unit of the Chiesi Group established to deliver innovative therapies and solutions for people living with rare diseases, has today announced a new Research Grant Initiative, *Find For Rare*. Researchers are invited to apply for grants up to €50,000 to support their research into lysosomal storage disorders (LSDs).

LSDs are inborn errors of metabolism, rare genetic disorders characterized by defective functioning of lysosomes.¹ Whilst the disorders can be rare individually, their prevalence is significant at a global level with an estimated 1 in 8000 people diagnosed.¹ To address current gaps in understanding, Chiesi Global Rare Diseases is organizing and funding the new call for research into three LSDs – Fabry disease, alpha-mannosidosis, and cystinosis.

The initiative's ambition is to provide a platform for innovative research into improving the understanding of the factors affecting the diseases as well as patient-tailored clinical management. All submitted research proposals will be evaluated by the *Find For Rare* Steering Committee, an independent scientific board of 10 leading experts in the field of LSDs, chaired by three of the experts, including Professor Christoph Wanner.

"Find For Rare is calling for all principal investigators and scientists with an interest in lysosomal storage disorders to apply for this fantastic research opportunity," said Professor Christoph Wanner, a Chair of the *Find For Rare* Steering Committee and Professor of Medicine and Chief of the Division of Nephrology and Hypertension at the University Hospital of Würzburg, Germany. *"Whilst we have expanded our knowledge into LSDs in the last*

decade, we still need to generate greater understanding into the factors affecting the disorders from pathogenesis to progression.”

“Find For Rare represents an opportunity to discover new thinking and ambition to meet our ultimate goal of improved patient care. The Steering Committee is eagerly awaiting the opportunity to review new ideas from across the globe and hopefully identify excellent candidates to receive the grants.”

Applications will be evaluated by the independent Steering Committee according to defined assessment criteria: strength of the proposed research project, innovation and novelty, relevance and impact, and potential for success. Depending on the number and quality of applications, based on the review by the Steering Committee, the total number of grants and total amount per project awarded may vary. However, the resources set aside by Chiesi Global Rare Diseases for this initiative amount to a total of €150,000, and researchers can apply for grants up to €50,000 per project. Although Chiesi Global Rare Diseases are organizing and funding the Research Grant Initiative, Chiesi will not in any way influence the application, evaluation, nor grant selection process.

“Find For Rare is an important platform for the generation of new ideas and identification of future clinical leaders in the rare disease landscape. There is a societal obligation to address issues impacting the estimated 400 million living with a rare disease,” said **Enrico Piccinini, Head of Europe & International, Chiesi Global Rare Diseases.** *“Similar to all of our activities, the inspiration behind this initiative is the rare disease community. We pride ourselves on listening closely to their needs and delivering what will truly benefit patients – our real hope is this year’s Find For Rare initiative will provide future solutions to today’s challenging rare conditions.”*

Further information regarding the initiative and the application process can be found at www.findforrare.com. The application process is simple and at no cost to the researcher. The application deadline is 31 October 2024, and the grants will be awarded in Q1 2025.

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About Find For Rare

The Find For Rare Research Grant Initiative has been designed to support original research projects that advance knowledge in the fields of Fabry disease, alpha-mannosidosis, and cystinosis. The categories of research eligible for funding are projects aimed at improving understanding of the factors affecting diseases, from pathogenesis to progression, and studies of patient tailored clinical management.

Research grants will be provided to organizations operating in the health or scientific research sector. Proposals are welcome from all global regions other than the Americas, with application documents required to be in English.

For more information and to apply, visit <https://www.findforrare.com/>. The application process is simple and free of charge. Simply complete the application form on the website and submit it with your CV and cover letter to FindForRare@ashfieldmedcomms.com. The application deadline is 31 October 2024, and the grants will be awarded in Q1 2025.

About lysosomal storage disorders

LSDs are inborn errors of metabolism that are characterized by an abnormal build-up of substances in the body's cells as a result of enzyme deficiencies.¹ 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.¹

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 a 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 to therapy 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 a voice to underserved people in the healthcare system.

About Chiesi Group

Chiesi is 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, and France, Chiesi's commitment to create shared value for society as a whole is legally binding and central to company-wide decision-making. As a certified B Corp since 2019, we're part of a global community of businesses that meet high standards of social and environmental impact. The company aims to reach Net-Zero greenhouse gases (GHG) emissions by 2035.

With over 85 years of experience, Chiesi is headquartered in Parma (Italy), with 31 affiliates worldwide, and counts more than 7,000 employees. The Group's

research and development centre in Parma works alongside 6 other important R&D hubs in France, the US, Canada, China, the UK, and Sweden.

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References

¹ NCBI. Lysosomal Storage Disease. Available at:

[https://www.ncbi.nlm.nih.gov/books/NBK563270/#:~:text=Lysosomal%20storage%20diseases%20\(LSDs\)%20are,to%20great%20morbidity%20and%20mortality.](https://www.ncbi.nlm.nih.gov/books/NBK563270/#:~:text=Lysosomal%20storage%20diseases%20(LSDs)%20are,to%20great%20morbidity%20and%20mortality.)