Press Release

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biobank.cy
Center of Excellence in Biobanking and Biomedical Research

biobank.cy Center of Excellence: Official launch of the European ALP-RARE Project at the International Workshop on Alport Syndrome

The research team of the biobank.cy Centre of Excellence at the University of Cyprus presented the objectives and methodology of the project to the international scientific community, as well as to patients and representatives of the Alport community from around the world.

The European research project ALP-RARE, coordinated by the biobank.cy Center of Excellence, was officially launched on 8 September during the International Workshop on Alport Syndrome 2026, held in Budapest from 5–8 September. The workshop is the leading international meeting organised by the global Alport patient initiative to promote collaboration, awareness, research, clinical management, and the development of new therapeutic approaches for this rare kidney disease.

Participation in the event provided the research team of the biobank.cy CoE and the partners of the ALP-RARE consortium with an opportunity to present and discuss the project's objectives and scientific approach with scientists and experts from different countries, as well as with patients and representatives of the Alport community from across Europe.

The focused discussions highlighted the needs, experiences, and priorities of people living with Alport Spectrum Disorders and their families. Their active involvement is, moreover, a key component of ALP-RARE. It goes beyond keeping patients informed about the progress of the research and extends to shaping priorities in treatment-discovery strategies and identifying needs that have genuine relevance to their everyday lives. More specifically, through ALP-RARE, patients with Alport syndrome will, for the first time, have the opportunity to establish measures for assessing their own personal status and well-being during a clinical trial.

As noted by Christof Finkler, representative of the German Alport patient support organisation, Alport Selbsthilfe e.V.: "As *an official consortium partner in ALP-RARE, Alport Selbsthilfe e.V. leads the involvement of patients and integrates lived patients experience into preclinical research to shape priorities and help to*

define patient-meaningful outcomes. This collaboration aligns scientific and clinical milestones directly with the daily needs of individuals and families affected by Alport Spectrum Disorders. From the patient perspective, the project strives to advance targeted therapies that meaningfully slow disease progression and preserve kidney function for longer."

From preclinical research to new therapeutic options

Alport spectrum disorders are a group of rare inherited kidney diseases that occur with high frequency in the Cypriot population. They are associated with pathogenic variants in the COL4A3, COL4A4, and COL4A5 genes, which encode chains of type IV collagen, the main structural component of the glomerular basement membrane in the kidney. Disruption of the functional structure of the basement membrane due to such variants most commonly leads to microscopic haematuria, proteinuria and, potentially, end-stage kidney disease.

Current treatment options can slow the progression of kidney disease, but they do not address the underlying genetic and molecular cause.

The three-year ALP-RARE preclinical research programme aims to help address this therapeutic gap. **As Dr Gregory Papagregoriou, Coordinator of ALP-RARE and Chief Scientist / Group Leader at the biobank.cy Center of Excellence, explains**: *"ALP-RARE aims to accelerate the development of therapeutic approaches for Alport spectrum disorders by leveraging knowledge and candidate therapies that have already emerged from previous research. We are not starting from scratch. We are evaluating and, most importantly, combining existing therapeutic approaches with newer small-molecule interventions, some of which have already been studied and published by members of the consortium. In brief, three such therapeutic pathways, each of which has independently been shown to positively target a different aspect of the overall clinical or molecular profile of Alport syndrome, will be studied both individually and in combination with current treatments that, although not specific to Alport syndrome, are already used in clinical practice. The aim is to identify more effective and beneficial therapeutic strategies for further development. For this preclinical study, experimental animal models of Alport disease will be used, carrying genetic defects similar to those found in patients. Consequently, the direct involvement of patients is an essential part of this process, as it helps us ensure that our research remains aligned with their real-world needs and priorities. Ultimately, our goal is to develop therapeutic profiles that can progress rapidly to clinical trials in humans, with the potential to substantially slow disease progression and preserve kidney function for a longer period of time."*

Cyprus as the central coordination hub of the European consortium

The **ALP-RARE European consortium** brings together expertise spanning basic and translational research, clinical nephrology, biotechnology and patient engagement.

Participating institutions include **Karolinska Institutet** and **RenCo Pharma AB (ex Guard Therapeutics International)** in Sweden, **Ludwig Maximilian University of Munich** and **University Medical Center Göttingen** in Germany, **Erasmus University Rotterdam** in the Netherlands, **Meyer Children's Hospital** in Italy and the **Alport Selbsthilfegruppe** patient association in Germany. **University College London** in the United Kingdom and the **European Kidney Patients' Federation**, based in Spain, also participate.

In Cyprus, the biobank.cy Center of Excellence will conduct most of the preclinical studies using mice carrying a pathogenic variant in the COL4A3 gene. This variant is found exclusively in the Cypriot population and was previously identified by the Center under the coordination of Prof. Constantinos Deltas, together with Dr Constantinos Voskarides and Dr Alkis Pierides. The preclinical studies within ALP-RARE are being coordinated at the Center by Dr Christoforos Odiatis, with the participation of Dr Pavlos Ioannou and Ms Melina Pitsillidou.

Commenting on the scientific collaboration within ALP-RARE, representatives of the project partners stated:

"Ludwig Maximilian University of Munich is pleased to contribute its scientific expertise to ALP-RARE and to work alongside leading European partners to advance promising therapeutic approaches for Alport Spectrum Disorders. Through this collaboration, we aim to strengthen the evidence needed to move innovative treatments closer to patients". **Prof. Dr. Hans-Joachim Anders, Department of Medicine IV, LMU University Hospital, Munich, Germany**

"At Karolinska Institutet, we are excited to contribute our expertise in experimental nephrology and Alport disease to the ALP-RARE project. We will lead the preclinical evaluation of A1M-based therapies in Alport mouse models and contribute to the multicentre validation of promising treatments. Through this collaboration, we hope to help advance robust, translational evidence that can bring new therapies closer to patients". **Hannes Olauson, MD - Karolinska Institutet, Stockholm, Sweden.**

"The University Medical Center Goettingen leads the work package of ALP-RARE dedicated to establishing surrogate endpoints for future clinical trials in Alport spectrum disease (ASD): markers that may allow treatment effects to be detected within a feasible trial period. We contribute one of the world's largest collections of clinical samples from people with ASD, together with our experience in designing trials in ASD to regulatory standards". **Dr. med. Jan Böckhaus, Department of Nephrology and Rheumatology, University Medical Center Göttingen, Germany**

"We are pleased to participate in ALP-RARE and contribute to the advancement of both existing and novel therapies for patients with Alport syndrome. Our team brings extensive experience in the development of therapies for kidney diseases and views participation in ALP-RARE as an important opportunity to help accelerate the translation of promising scientific discoveries into clinical benefit. Through our expertise in drug development, translational medicine, regulatory strategy, and clinical development, we look forward to supporting ALP-RARE's mission to improve outcomes and expand treatment options for patients with Alport syndrome". **Tobias Agervald, RenCo Pharma AB, Sweden**

"*We are delighted to contribute to ALP-RARE by sharing expertise in Alport syndrome natural history and clinical research. By working together across the consortium, we hope to build the evidence needed to move the most promising new approaches towards clinical trials and, ultimately, better treatments for patients"* **Prof. Daniel Gale, Renal Medicine, University College London, UK (RaDaR Trial)**

Πανεπιστήμιο Κύπρου

The participation of both consortium partners and the patient community in the **2026 International Workshop on Alport Syndrome** reflected in practice the interdisciplinary and participatory approach at the core of ALP-RARE. Scientific knowledge, clinical expertise and the lived experience of patients represent complementary elements in the effort to develop more effective therapeutic approaches.

The project has been selected for funding through the competitive call of the **European Rare Diseases Research Alliance (ERDERA)**, with national support in Cyprus provided by the **Research and Innovation Foundation (RIF)**.

More about ALP RARE: https://biobank.cy/portfolio/alp-rare/

End of announcement