

3rd International conference on **Rare Diseases: Greek chapter**

Leveraging the momentum for a comprehensive rare disease strategy



PRESS RELEASE

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“Leveraging the momentum for a comprehensive rare disease strategy”

Athens February 13, 2023 – In the context of this year's World Rare Disease Day, which is celebrated every year on the last day of February, Rare Diseases Greece (RDG), “95” Rare Alliance Greece and BOUSSIAS, are organizing the 3rd International Conference on Rare Diseases. The conference will take place at the Technopolis City of Athens Gasholder 1 – Auditorium “Miltiadis Evert”, on February 28 (Hybrid) and March 1, 2023 (Digital). Its proceedings will also be broadcast live via an online platform.

Following on from last year's successful conference, which was attended by **57 distinguished Greek and foreign speakers and more than 450 delegates from 30 countries around the world, this year's conference will focus on the theme: "Leveraging momentum for a comprehensive rare disease strategy"**. The goal of the conference is to raise awareness and promote policies aimed at improving the "Diagnostic Odyssey", treatment and equal access of rare patients to quality health services. Leveraging the experience and knowledge of international partners and taking into account the mobility and initiatives of patient organizations in our country, the conference will continue the dialogue in Greece by presenting the current political developments in Europe and **will focus on the need to draw up a new national strategy for rare diseases in our country with the ultimate goal of creating and implementing the National Action Plan for Rare Diseases within 2023.**

The development and implementation of a long-term national strategy for rare diseases is necessary not only for the health system and patients but also for the economy and society as a whole. Such a strategy enables prevention, early diagnosis, longer duration and better quality of life for the patient, taking into account the needs of his caregivers, with lower costs for the national health service and increased revenue for the economy. Greece and the health system must face the challenges, but also take advantage of the opportunities and possibilities presented.

The Central Coordinators of the conference will be **Dimitrios Athanasiou**, President RDG, EMA Pediatric Committee, EPF, WDO, EAE Board Member, and **Vassilis Karatzias**, RDG Vice President, President of the Hellenic Association Ataxia Friedreich, Director of the Office of Legal Advisers, NATO Rapid Deployable Corps, Greece.

The first day of the Conference will be held in Greek with simultaneous translation into English and will focus on the needs of rare patients in Greece. Among others, the Deputy Minister of Health, **Mina Gaga**, the Minister of Labor and Social Affairs, **Kostis Hatzidakis**, the Managing Director of IFET, **Giannis Sotiriou**, the Professor, Director of the Laboratory of Economics and Management (LabHEM), University of Piraeus, **Athanasios Vozikis** are expected to participate

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in the dialogue, along with representatives of patient associations, representatives of the pharmaceutical industry and main representatives of agencies and organizations dealing with rare diseases, in order to jointly discuss the framework of a National Action Plan within 2023.

With esteemed international speakers, the Conference will open its proceedings on the second day, which will be dedicated to the international developments around rare diseases. Among the speakers are the Commissioner for Health and Food Safety of the European Commission, **Stella Kyriakides**, the President of the Committee for Orphan Medicines of the European Medicines Agency (EMA), **Violeta Stoyanova-Beninska**, the Coordinator of the Joint European Program for Rare Ailments, **Daria Julkowska**, Executive Director of Scientific Policy and Regulatory Affairs at EFPIA, **Magda Chlebus**, Special Advisor, Chief Methodologist in Regulatory and Pharmacoeconomic Statistics, NoMA, Teamleader International HTA (iHTA, NoMA), Vice-President CSCQ JSC (EUnetHTA21), Member of the Scientific Advisory Working Group (SAWP), at the European Medicines Agency (EMA), **Anja Schiel**, the Secretary General of EUCOPE, **Alexander Natz**, and the Senior Policy Officer for Research Programmes, Rare Diseases, Health Data, Artificial Intelligence at Health and Ecosystem Innovation Unit, Directorate General for Research and Innovation in Europe Secular Committee **Christina Kyriakopoulou**.

The conference is expected to be a central point of interest for all those involved with rare diseases all over the world, in Europe and in Greece, both at an institutional and academic level on highly topical issues such as:

- Policy Landscape on Rare Diseases
- Regulatory Ecosystem Evolution
- Initiatives Updates (SRIA EJPRD, S4C, ERICA, TOGETHER4RARE, TRANSFORM, MOONSHOT, and others)
- Prevention and Early Diagnosis: The Development of prenatal and neonatal screening programs
- Development and Integration of the European reference centers (ERNs) in the National Health System
- Research, Clinical Trials as part of the care
- Patient Data and RWE: Collection of valid and reliable information and the Rare Disease registry
- Strategic Planning for Rare Diseases in Greece
- RD Patients Registry and the Greek National Action Plan for Rare Diseases
- Supporting Education for Patients and Healthcare Professionals

The Conference is **under the auspices of the European Organization for Rare Diseases (EURORDIS - Rare Diseases Europe)**, while it is held **with the support of the Hellenic Ministry of Health, the European Federation of Pharmaceutical Industries and Associations (EFPIA), the European Confederation of Pharmaceutical Entrepreneurs (EUCOPE), the Greek Patients' Association (EAE), Greek Branch of the European Patients' Academy (EUPATI Greece), the Institute of Pharmaceutical Research and Technology (IFET), the Hellenic Association of Pharmaceutical Companies (SFEE) and the PhRMA Innovation Forum (PIF).**

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More on Rare Diseases:

There are currently estimated to be around 6,000-8,000 rare diseases, affecting around 30 million European citizens, up to 6% of the total population of the European Union (EU) at some point in their lives, and 300 million people worldwide. In Greece, it is estimated that rare diseases affect 5% to 7% of the country's population. Taking into account family members and their caregivers, there are more than 1,500,000 people in our country who are directly or indirectly affected by rare diseases.

The lack of specific health policies for rare diseases and insufficient information and awareness lead to late and incorrect diagnoses and difficult access to care. This leads to increased physical, psychological and mental effects, inadequate treatments, as well as a loss of trust in the health care system. However, some rare diseases can be compatible with a quality lifestyle if diagnosed early and treated appropriately. Improving health care delivery is a major challenge for public health due to the lack of epidemiological data, data that assess and evaluate the consequences of these pathologies on the quality of life of patients and their families as well as the existing needs in the areas of diagnosis and treatment.

For more information:

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