

**SOCIETY FOR PATIENTS AND FRIENDS OF PATIENTS WITH INHERITED METABOLIC DISORDERS  
"KRIKOS ZOIS"**

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3<sup>RD</sup> March 2021

**«KRIKOS ZOIS» VIRTUAL 2-DAY WEBINAR 6-7<sup>th</sup> March 2021**

**Title: Inherited Metabolic Diseases: Rare but United in Arms!**

The challenges facing patients with inherited metabolic diseases (IMDs) in Greece are many and formidable and are highlighted due to the impact of Covid-19. More than 20% of inherited rare diseases are due to IMDs which are individually rare but in total 1350(!) and unknown to most including health professionals. The problems of delayed or incorrect diagnosis due to lack of awareness of these disorders and inadequate specialized services for diagnosis and follow up are accentuated by the limited number of metabolic specialists in Greece. Educational seminars are thus a priority of the Society of Patients and Friends of Patients with Inherited Metabolic Diseases KRIKOS ZOIS for increasing awareness of these disorders as well as providing specific information, advice and support to affected individuals and their families and facilitating networking of families with similar disorders.

Our 2021 RARE DISEASE DAY event will be a virtual two day event ( 6-7 March) focusing on the pivotal therapeutic role of diet in several categories of IMD's, promising clinical trials in progress including gene therapies for a number of IMDs giving hope for future cures, enzyme replacement therapy for PKU patients now starting in Greece, disruption in care due to Covid-19 with difficulties in securing Orphan drugs, everyday challenges for the IMD patient requiring expert guidance, the journey of an adult patient with Gaucher disease, the journey of a sibling of a patient with tyrosinemia I, the psychological impact of Covid -19 and adapting to the new reality, current status quo of policies for rare disorders in Greece and the rest of Europe, the recent Greek disability laws for rare disorders and social approaches to patients with chronic diseases via volunteerism and solidarity.

Many thanks to the Society for the Study of Inborn Errors of Metabolism SSIEM for honouring us with their funding award which contributed to the organization of our virtual event. The link for the event: <https://www.livemedia.gr/krikos21>

## **PROGRAM AGENDA**

**Welcome**

**Inherited metabolic disease and diet: from guidelines to reality in Greece**

**Ketogenic diet: which inherited metabolic disorders?**

**Dietary transition from childhood to adulthood**

**Bone health and inherited metabolic disease**

**Recent developments in the treatment of inherited metabolic disease and ongoing clinical trials**

**Access to Orphan drugs in times of economic duress**

**Inherited metabolic disease: Everyday challenges and the need of specialized support**

**Current state of the art at the Greek Institute of Child Health**

**Living with an inherited metabolic disorder: The journey of a patient with Gaucher's disease, the journey of a parent of a patient with Tyrosinemia type 1.**

**Exculpation of the chronic disease**

**Rare disease and Greek disability laws**

**Volunteerism as a means of dealing with social aspects of individuals with chronic disease**

On behalf of the Executive Board of KRIKOS ZOIS

Many thanks in advance

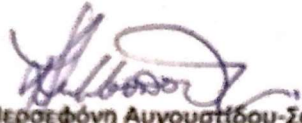
Yours sincerely

Persephone Augoustides Savvopoulou

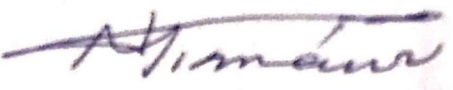
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