

PATIENT INFORMATION LEAFLET

**DEPARTMENT OF MEDICINE, UNIVERSITY OF THESSALY
NATIONAL EXPERTISE CENTER OF GREECE IN AUTOIMMUNE LIVER DISEASES
UNIVERSITY HOSPITAL OF LARISSA**

INTRODUCTION – DEPARTMENT MEDICINE, UNIVERSITY HOSPITAL OF LARISSA

The **Department of Medicine at the University Hospital of Larissa** and especially the **Liver Outpatient Clinic** as well as the **affiliated Research Laboratory of Medicine of the University of Thessaly** are characterized by their **deep and longstanding commitment to liver disease**.

Chronic viral hepatitis, alcoholic liver disease, non-alcoholic fatty liver disease (steatosis/steatohepatitis) and autoimmune liver diseases (Autoimmune Hepatitis, Primary Biliary Cholangitis, Primary Sclerosing Cholangitis and Autoimmune Hepatitis «variants») represent some common entities included in this spectrum in addition to more rare diseases (Wilson's disease etc).

AIMS

Since its establishment the Department aims: (a) to **assist to the finest treatment of patients with Rare Liver Disease in both clinical and laboratory terms**, (b) to **the full collaboration with other specialties** involved in the disease treatment, (c) to **fully collaborate with other Research Laboratories of Public Institutions, Organizations, Boroughs, Municipalities and other scientific and social bodies, non-profit charitable foundations and institutions** in order to inform, prevent and timely diagnose rare liver diseases, (d) to provide **high quality training and academic education to medical students, doctors (trainees and specialists), nurses** and paramedical personnel, (e) to **design and perform clinical and laboratory studies** in collaboration with other Greek and international centers regarding the pathogenesis, prognostic markers and new therapies for these diseases, (f) to organize **lectures, meetings, congresses, seminars, postgraduate courses and the authorship of international and Greek publications** that contribute to liver disease education.

GREEK AND INTERNATIONAL RECOGNITION

In Greece, the University Hospital of Larissa through its Department of Medicine has been recognised by the Greek Ministry of Health as **“National Expertise Center of Greece in Autoimmune Liver Diseases”** (GG 4040/B/05.11.2019). Additionally, the **Department of Medicine** has already been recognized as "Centre for rare diseases (with an emphasis on autoimmune hepatitis)" by the Scientific and Administrative Board of the University General Hospital of Larissa, by the General Assembly of the Faculty of Medicine (School of Health

Sciences, University of Thessaly) and the Greek Centre for Disease Control and Prevention (KEELNPO).

At **international level** the Department of Medicine of the University of Thessaly at the University Hospital of Larissa participates at the International Autoimmune Hepatitis Group (IAIHG), the GLOBAL Primary Biliary Cholangitis Study (GPBCSG, <http://www.globalpbc.com>) and the World Primary Sclerosing Cholangitis Study and registry Group (International PSC Study Group, IPSCSG, <http://www.ipscsg.org>).

The **Director of the Department of Medicine of the University Hospital of Larissa, Professor G.N. Dalekos**, is deeply and thoroughly involved with Autoimmune Hepatitis for many years and serves as a member of IAIHG, as he was part of the committee that composed the new simplified criteria for the diagnosis of Autoimmune Hepatitis, one of the seven-member international panel that published the Clinical Practice Guidelines for Autoimmune Hepatitis on behalf of the European Association for the Study of Liver (EASL) and the coordinator of the working group of the Hellenic Association for the Study of the Liver (HASL) for the authorship of Clinical Practice Guidelines for Autoimmune Hepatitis. Moreover, he represents the Hellenic Society of Gastroenterology and HASL at the European Autoimmune Hepatitis Registry Network.

The Department of Medicine of the University of Thessaly at the University Hospital of Larissa was established in 1999 and has a long-term follow up of approximately 6605 patients, with an annual rate of 6000 visits (2017 data). A significant proportion of the abovementioned patients (898) suffer from liver disease (14% of the overall patients).

The Liver Outpatient Clinic is inextricably linked to **the Research Laboratory of the Internal Medicine of the University of Thessaly** as the diagnosis of autoimmune liver disease requires specific laboratory testing that can be performed at highly experienced laboratories. The Research Laboratory is capable of performing a series of diagnostic tests using various *in-house* techniques developed after long-term training of the members of the Group within the country or abroad that **CANNOT** be performed with similar standardized techniques **anywhere else in GREECE**. Subsequently the Research Laboratory has been identified as a Referral Center for the diagnostic workup of autoimmune liver disease, **testing sera from undiagnosed patients including pediatric patients from the largest Hospitals of the country but also Private Hospitals and privately practicing doctors from all over the country and**

Cyprus. Feedback that is sent back to these medical centers includes answers on autoantibody detection together with **advice and recommendations in terms of diagnosis and treatment of the patients**, whereas several patients are eventually referred to the Department of Medicine of the University of Thessaly for further evaluation, treatment and follow up.

COLLABORATION WITH MEDICAL COMMUNITY

The Department of Medicine of the University of Thessaly at the University Hospital of Larissa is constantly connected to the medical community as it provides special consultation/ second opinion to other clinicians (colleagues) either directly or via email or phone. During the last calendar year, the number of consultations to doctors from different specialties (i.e. gastroenterologists, pediatricians, internists, general practitioners etc.) was at least 290 and included doctors not only from the Municipality of Thessaly but **the entire Greece and Cyprus.**

Moreover, our Center liaises with pediatric Units, in order to ensure the **on-going treatment during the transition from childhood to adolescence and adult life.**

LIVER PATIENT- CENTERED CARE

During your follow-up at the Liver Outpatient Clinic of the Department of Medicine of the University of Thessaly the patient represents the center of the approach, so that **you have a key-role in decision-making regarding your treatment.**

MULTIDISCIPLINARY TEAM APPROACH

The Center provides **an interdisciplinary approach in order to cover all patient needs.** Based on your individual needs- indications an entire team of scientists of different specialties at the University Hospital of Larissa contribute to your management: Internists-Hepatologists, Gastroenterologists, Radiologists, Microbiologists, Pathologists, Biochemists, Laboratory Technicians, Nurses, Dieticians, Social workers and Psychologists.

In detail, the **«core» multidisciplinary team** consists of Prof G.N. Dalekos (Professor in Medicine-Scientific Supervisor-Chief of the Multidisciplinary Team), Dr E.I. Rigopoulou,

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University Hospital of Larissa

(Associate Professor in Medicine-Vice Scientific Supervisor), Dr K. Zachou (Associate Professor in Medicine), Dr N.K. Gatselis (Assistant Professor in Medicine), Dr S. Gabeta (Consultant in Medicine), Mrs. A. Lyberopoulou (Biochemist), Mrs. E. Exarchou (Laboratory Technician), Mr. K. Galanis (Health Visitor), Mrs. S. Kapeti (Secretary), Prof. G.K. Koukoulis (Professor in Pathology), Prof. M. Vlychou (Professor in Radiology), Dr C. Rountas (Assistant Professor in Radiology), Dr E. Alexiou (Consultant in Radiology), Mr. A. Tzikas (IT services), Mrs. M. Daliou (Social Worker), Mrs. K. Tsolaki (Dietician-Nutrition specialist) and Mrs. T. Kandri (Psychologist). This team is supported by an «extended» interdisciplinary team with the following participants: Prof. G. Simos (Professor in Biochemistry), Prof. K. Tepetes (Professor in Surgery), Prof. D. Zacharoulis (Professor in Surgery), Prof. E. Peteinaki (Professor in Microbiology), Prof. D. Kyriakou (Professor in Transfusion Medicine), Prof. S. Potamianos (Professor in Gastroenterology), Prof. A. Kapsoritakis (Professor in Gastroenterology), Dr G. Papadamou (Consultant in Emergency Department), Dr R. Papamichali (Consultant in Pathology), Mrs. A Mpliatou/ Mrs. I. Tsiouri (Psychologists)

The curriculum vitae of the scientists are available at the following sites:

<http://83.212.32.147/internalmedicine/index.php/en/center-en>

<http://83.212.32.147/internalmedicine/index.php/el/center>

<http://www.med.uth.gr/internalmedicine/index.php/el/clinic/staff>

<http://www.med.uth.gr/meloiDEP.aspx>

INFORMATION LEAFLETS

Information leaflets regarding your disease are available. In these leaflets you will find a detailed description of your disease, including symptoms and the impact on everyday life as well as possible modifications-interventions you might need to do, the possible disease progression and the potential therapeutic options.

FOLLOW-UP PROCEDURE

Before any treatment initiation, you will be fully informed about your condition and therapeutic plan. The decision about treatment administration is based upon international

and national guidelines. We would also like to stress that you have the right to ask for a second opinion.

During your visits at the Liver Outpatient Clinic you will be asked questions about your health, your compliance to treatment, any potential side-effects and meanwhile diagnostic tests will be ordered and evaluated.

During your follow-up (apart from your scheduled visits) **you will be contacted by the Health Visitor of the Liver Outpatient clinic** (Mr. Konstantinos Galanis) regarding prescriptions, compliance to treatment and general guidance given by the doctors.

Regarding invasive procedures that are possibly essential to the diagnosis or management of your disease (i.e. liver biopsy, upper GI tract endoscopy etc.), information leaflets are available. Before the procedure you will have to sign a consent form following extensive information for the necessity, the procedure per se and the potential complications.

COLLECTION AND STORAGE OF PATIENT DATA

A detailed health record (on an electronic database) of all demographic, clinical, laboratory, serological, genetic and histological data is kept in our Center per visit. Data are recorded both electronically and also in printed form (every patient has a unique file-record kept at the Liver Outpatient Clinic).

Data from your medical records can be given to you at any time point upon request, whereas the Information Discharge Summary contains data on your medical history and therapeutic recommendations.

RIGHTS AND RESPONSIBILITIES

Your personal data are effectively protected in accordance to the Greek and the European General Data Protection Regulation (GDPR). Therefore, you have every right regarding data protection, including the right to information, access and objection. Collected data will remain confidential.

In case that your data (always anonymously) are used in processing (i.e. for a study), you will be informed beforehand about the aim, the significance and the evidence and afterwards you

will be asked to give consent. Potential refusal to participate will not interfere with your follow-up at our Center.

You have the right to participate or not in clinical trials as you may have been recommended, without your negative or positive answer influencing the care you receive at our Center.

Whenever you wish to, you can have access to your medical records, while you will be informed about any potential treatment that you may receive upon agreement. We will respect your cultural and religious beliefs and you will not receive any discrimination regarding your race, origin, religion, sex or culture.

You have the right to decline treatment or even the participation of selected people in your treatment. It is also your right to actively participate in every stage of therapy and take your own decisions. You could also designate a person to represent you in decision making if you wish so.

Regarding your obligations you should give precise information and refer side-effects and complications, as these elements could help us in treatment of other patients.

During your follow-up you have the right as well as the responsibility to express together with your family any potential considerations/complain regarding your follow-up. Hospital documents that you can complete are at your disposal. Moreover, instructions and detailed documents could be searched at the following electronic address:
<http://www.uhl.gr/erotimatologia.html>.

PATIENTS' ASSOCIATIONS IN GREECE

Our Center is at close contact with the following patients associations:

- Association of Liver Patients «**PROMETHEUS**»
- Union of Liver Transplant Recipients of Greece «**YPARCHO**»
- Centers of Therapy of Addicted Individuals «**EXODOS**»

SCIENTIFIC ASSOCIATIONS

- Hellenic Association for the Study of the Liver (HASL)- <http://www.eemh.gr>
- Hellenic Association of Internal medicine- <http://www.hsintmed.gr>

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- Hellenic Society of Gastroenterology- <https://www.hsg.gr>
- European Association for the Study of the Liver (EASL) - <http://www.easl.eu>
- American Association for the Study of the Liver (AASLD)- <https://www.aasld.org>
- European Federation of Internal Medicine - <http://www.efim.org>
- International Autoimmune Hepatitis Group (IAIHG) - <https://www.iaihg.org>
- Global Primary Biliary Cholangitis Study Group (GPBCSG) - <https://www.globalpbc.com>
- International Primary Sclerosing Cholangitis Study Group (IPSCSG)- <https://www.ipscsg.org>

CONTACT

In case of any queries or emergency, do not hesitate to contact the Liver Outpatient Clinic lines (+302413502436, +302413502437, Monday-Friday working hours) but also the Department of Medicine (+302413501513, +302413502884 and +302413502885) 24/24 and 7/7.

For any further questions you could visit the electronic address of the Department of Medicine, namely

<http://83.212.32.147/internalmedicine/index.php/en/>

The present leaflet was drafted by the Department of Medicine of the University of Thessaly at the University Hospital of Larissa.

Department of Medicine

National Expertise Center of Greece in Autoimmune Liver Diseases

University Hospital of Larissa



Mezourlo, 41110, Larissa

Tel.: +302413502285

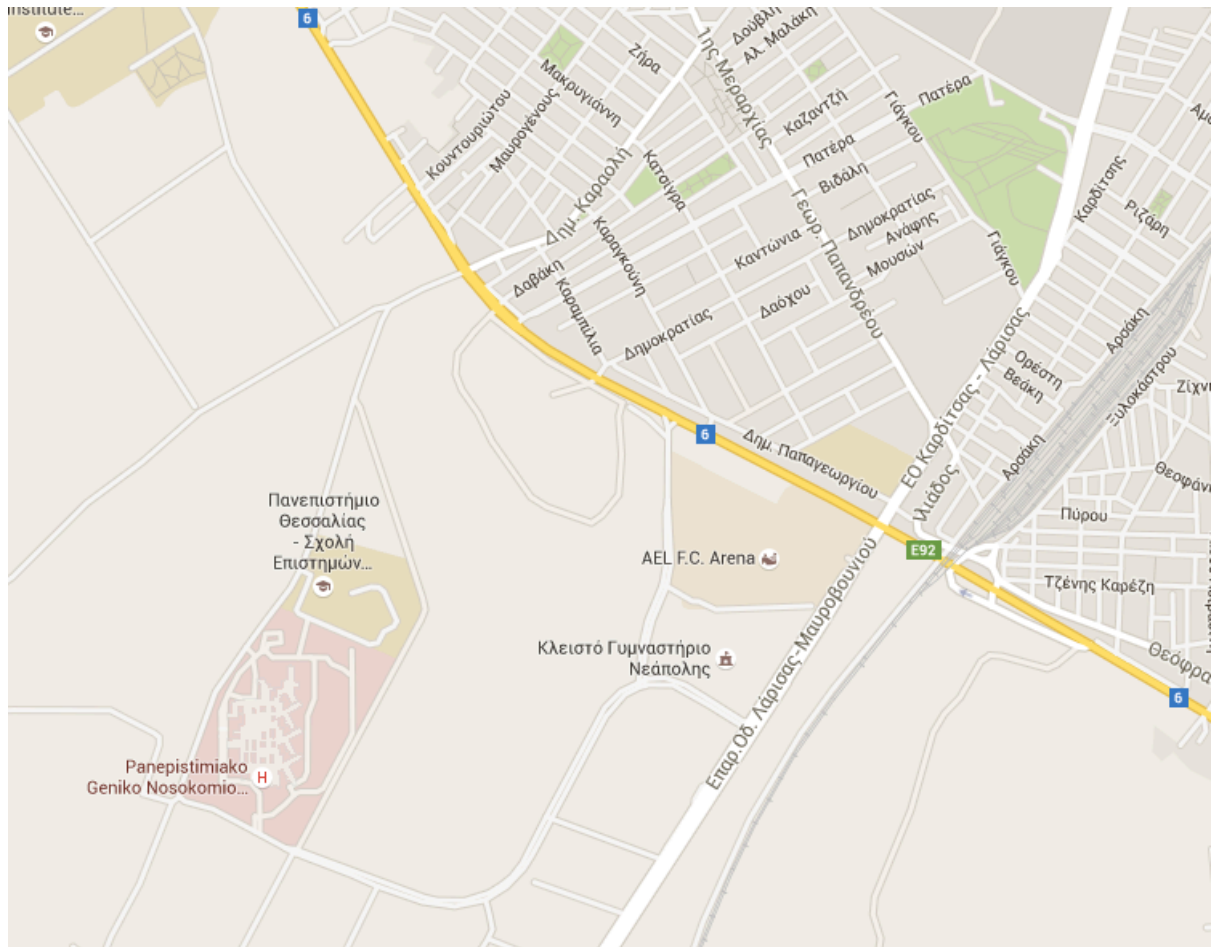
Fax: +302413501557

email: skapeti1@gmail.com

Electronic address:

<http://83.212.32.147/internalmedicine/index.php/en/>

ACCESS TO THE UNIVERSITY HOSPITAL OF LARISSA- MAP



- **Liver Outpatient Clinic of the Department of Medicine of the University Hospital of Larissa (1st floor– Office 64-65)**
- **Research Laboratory of Internal Medicine of the University of Thessaly (Medical School of Larissa, 3 Panepistimiou Str, Biopolis, Ground Floor, Wing 1^A, Laboratory 12)**