

The logo for ELPA (European Liver Patients' Association) features the acronym 'ELPA' in a bold, white, sans-serif font. The letters are set against a light orange, irregular, cloud-like shape. The background of the entire page is a vibrant orange with abstract, flowing geometric shapes in various shades of orange and yellow, creating a dynamic and modern feel.

ELPA

European Liver  
Patients' Association

# At the forefront of Patient Engagement

**ANNUAL REPORT 2024**

**At the forefront of Patient Engagement**

ANNUAL REPORT 2024

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## ACRONYMS

**ACHIEVE** - Associations Collaborating on Hepatitis to Immunise and Eliminate the Viruses in Europe  
**AASLD** - American Association for the Study of Liver Diseases  
**ACLF** - Acute-on-Chronic Liver Failure  
**AWARH** - Awareness Week on Alcohol-Related Harm  
**CEHC** - Central European Hepatologic Collaboration  
**CHB** - Chronic Hepatitis B  
**CSF** - Civil Society Forum  
**DG** - Directorate General  
**DiCE** - Digestive Cancers Europe  
**DILI** - Drug-Induced Liver Injury  
**EASL** - European Association for the Study of the Liver  
**ECDC** - European Centre for Disease Prevention and Control  
**ECPC** - European Cancer Patient Coalition  
**EF Clif** - European Foundation for the study of chronic liver failure  
**EIT** - European Institute for Innovation and Technology  
**EKPF** - European Kidney Patients' Federation  
**EMA** - European Medicine Agency  
**EMCDDA** - European Monitoring Centre for Drugs and Drug Addiction  
**EPF** - European Patients' Forum  
**ESCMID** - European Society of Clinical Microbiology and Infectious Diseases  
**ESMO** - European Society for Medical Oncology  
**ESPGHAN** - European Society for Paediatric Gastroenterology Hepatology and Nutrition  
**EU** - European Union  
**EURODIS** - Rare Diseases Europe  
**ETW** - European Testing Week  
**HBV** - Hepatitis B Virus  
**HCV** - Hepatitis C Virus  
**HDV** - Hepatitis D Virus  
**HE** - Hepatic Encephalopathy  
**HEP** - Hepatitis  
**HERA** - Health Emergency Preparedness and Response Authority  
**HTAI** - Health Technology Assessment International  
**ILC** - International Liver Congress  
**ILCA** - International Liver Cancer Association  
**LALD** - Lysosomal Acid Lipase Deficiency  
**LCAM** - Liver Cancer Awareness Month  
**MAFLD** - Metabolic-Associated Fatty Liver Disease  
**MoU** - Memorandum of Understanding  
**NAFLD** - Non-Alcoholic Fatty Liver Disease  
**NASH** - Non-Alcoholic Steatohepatitis  
**NGO** - Non-Governmental Organization  
**PCWP** - Patients' and Consumers' Working Party  
**PFMD** - Patient Focused Medicines Development  
**PWID** - People Who Inject Drugs  
**SLTC** - Screening and Linkage to Care  
**TAG** - Technical Advisory Group  
**TB** - Tuberculosis  
**UNAIDS** - United Nations Programme on HIV/AIDS  
**VHPB** - Viral Hepatitis Prevention Board  
**WHO** - World Health Organisation





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# Our Mission

The European Liver Patients' Association - ELPA - emerged in 2005 from a desire amongst European liver patients groups to share their experiences on the different approaches adopted in other countries. Nowadays, ELPA is an umbrella association representing 39 members from 29 different countries.

ELPA aims to promote the interests of people with liver disease and, in particular: to highlight the size of the problem, to promote awareness and prevention, to address the low profile of liver disease; to share the experience of successful initiatives; to work with professional bodies to ensure that treatment and care are harmonised across Europe to the highest standards. ELPA's vision is that all liver patients are diagnosed in time, are treated with respect, and have equal access to the best standard of medical care – regardless of origin, lifestyle, and type of liver disease.

ELPA's efforts are focused on three main pillars.

## Member Empowerment

ELPA was established by patients, is governed by patients, and represents patients. We put much effort into organising training, promoting capacity building, and stimulating networking. We have eight different working groups to boost expert patients to acquire knowledge in a specific field of liver disease.

## Policy and Advocacy

As an umbrella patients' association, ELPA acts as an intermediary between all the involved stakeholders - the national patients' communities, the scientific community, the industry, and the policymakers. We provide a crucial perspective due to our immediate and direct access to the patients' lives and to the best practices in a national and regional context.

ELPA is a member of:

- Advisory forum and expert group on HBV and HCV at ECDC.
- Patient and Consumer Working Party and Pharmacovigilance Risk Assessment Committee at EMA.
- Advisory Forum - Civil Society Forum at HERA.
- Expert group on HIV, TB, and hepatitis at WHO.
- Expert board at VHPB.
- HTA Stakeholder Network at DG SANTE.
- Advisory Council for Europe, Middle East & Africa (ACEMEA) in the framework of the Drug Information Association (DIA).

To better communicate with supporters and stakeholders, ELPA has obtained the ISO 9001:2015 quality standard in 2021, making it the 1<sup>st</sup> umbrella patients' association in Europe with a quality management system.

## Participation in Medical Research Projects

ELPA is part of 20 EU-funded medical research projects. The participation of patients' associations in these projects is relatively new; nevertheless, being part of them enriches the research field.

## ELPA Values



Equality



Respect for  
diversity



Patient  
driven



Commitment



Transparency



# Foreword of the President

## Dear Members, Partners, and Friends of ELPA,

It is a privilege to present the 2024 Annual Report of the European Liver Patient Association (ELPA). As we look back on the past year's achievements and challenges, one thing remains clear—our dedication to enhancing the lives of liver patients is unwavering.

Our work is centred around three fundamental pillars: strengthening our members, driving policy and advocacy efforts, and engaging in scientific advancements.

Our members' collective strength is at the heart of ELPA. This year, we have continued to invest in building their capacities through specialised programs, workshops, and collaborative projects. By equipping our member organisations with essential knowledge, skills, and resources, we empower them to provide outstanding support to liver patients across Europe.

Advocating for liver patients remains a key priority. Throughout 2024, ELPA has actively worked with policymakers, healthcare professionals, and key stakeholders to push for policies that prioritize patient well-being. By raising awareness and

championing patient-focused initiatives, we strive to create an environment where liver patients receive the recognition, care, and support they need.

Scientific progress is crucial in transforming the future of liver health. ELPA has strengthened its collaboration with the scientific community, ensuring that patient voices are integrated into cutting-edge research and innovative treatments. Our active engagement helps drive advancements that improve both prognosis and quality of life for those affected by liver diseases.

As we navigate the evolving landscape of liver health, ELPA remains a symbol of hope, a driver of change, and a force for progress. The road ahead may be challenging, but our determination to overcome obstacles is stronger than ever.

I sincerely thank our members and partners for their steadfast support. Together, we will continue to make a meaningful difference in the lives of those with liver diseases.

Together we are stronger!

Marko Korenjak

# ELPA Members in 2024



## ALBANIA

- Albanian Association "Patients with hepatitis"



## BELGIUM

- Vlaams Hepatitis Contactpunt - VHC



## BOSNIA & HERZEGOVINA

- The Chronic Viral Hepatitis Patients Association - B18



## CROATIA

- HUHIV - Croatian Association for HIV and viral hepatitis



## CYPRUS

- Cyprus Liver Patients Association - Promitheas



## DENMARK

- Leverforeningen



## EGYPT

- Association of Liver Patients' Care – ALPC



## FINLAND

- The Finnish Kidney and Liver Association



## FRANCE

- Fédération SOS hépatites & Maladies du foie,
- Fédération des Déficiants et Transplantés Hépatiques - TRANSHÉPATE



## GEORGIA

- Hepatitis C Cured Patient Association



## HUNGARY

- Hungarian Association of Chronic Hepatitis Patients - VIMOR



## IRELAND

- Hepatitis C Partnership



## ISRAEL

- Israeli Association For The Health Of the Liver - Hetz



## ITALY

- Italian Association for Research on Primary Sclerosing Cholangitis - AIRCS



**KAZAKHSTAN**

- Anti Hepatitis C Organisation - AGEPC

**MONTENEGRO**

- 4Life

**NORTH MACEDONIA**

- Association for health education, prevention and better treatment - HEPTA,
- Hepar Centar - Bitola

**NORWAY**

- proLAR

**POLAND**

- Star of Hope Foundation

**PORTUGAL**

- SOS Hépatis Portugal

**ROMANIA**

- Patients with hepatic impairment Association of Romania - APAH-RO

**RUSSIA**

- Humanitarian Action, United Against Hepatitis

**SERBIA**

- Association for helping patients with chronic viral hepatitis - HRONOS

**SLOVAKIA**

- HEP HELP KLUB, Šanca pre pečej,
- Slovak Coalition of People with Obesity and Overweight - SKLON

**SLOVENIA**

- Association - SLOVENIJA HEP

**SPAIN**

- Catalan Association of Liver Patients - ASSCAT,
- Catalan Federation of Rare Diseases - FECAMM,
- National Federation of Liver Patients and Transplanted - FNETH,
- Spanish Association for Lysosomal Acid Lipase Deficiency - AELALD

**SWEDEN**

- Riksföreningen Hepatit C – RHC

**TURKEY**

- Living with Hepatitis Association - HEPYAŞAM

**UNITED KINGDOM**

- British Liver Trust,
- Hep C Positive,
- Liver4Life





# **2024 HIGHLIGHTS**



## 7 new members

ELPA is also thrilled to announce that the ELPA family is growing! We have welcomed 7 new members (Albania, France, Italy, Kazakhstan, Montenegro, Slovakia, Spain). This expansion marks a significant milestone in ELPA's mission to improve liver health across Europe.



## ISO QUALITY STANDARD CERTIFICATE 1<sup>st</sup> patients' association in Europe

ELPA is now the FIRST umbrella liver patient association in Europe with the official certification of the Quality Management System in place. ELPA managed to build a quality system of its work, was recognised by an external certification body and got the ISO 9001:2015 certificate related to its Management in Communication with Supporters and Stakeholders.

The purpose of ISO 9001:2015 is to help an organisation develop a robust Quality Management System to respond to evolving quality requirements in line with changing social, economic, and environmental expectations.

Implementing a Quality Management System in a nonprofit organisation like ELPA means:

- To rethink an organisation: why it exists; what are the priorities; how does it relate to its environment; how does it work; and what should be measured and improved.
- To develop a consistent way of working and monitoring thanks to the process approach and risk management.
- It serves internally to make deadlines and processes clear.
- To reinforce the message of clarity, trust, and professionalism towards supporters and donors.
- To enhance donors, supporters, beneficiaries, the general public, and stakeholders' satisfaction.



ELPA's work is reassessed each year, and 2024 marked the fourth year of the confirmation of the system. ELPA will continue improving its communication with Supporters and Stakeholders, showing its high level of professionalism and commitment towards liver patients.

# LIVER CANCER

## European Liver Screening Week 2024

The European Liver Screening Week 2024, held from September 30 to October 4, 2024, marked a significant step forward in raising awareness about liver health across Europe.

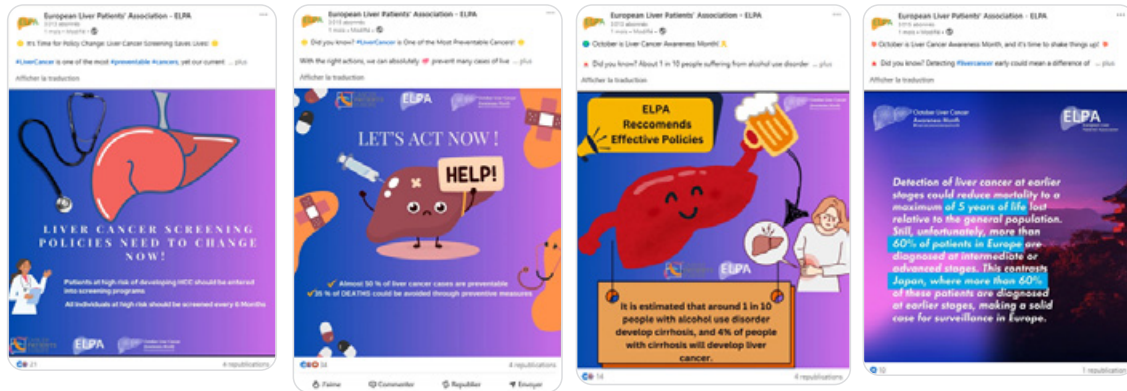
Organised by the European Liver Patients' Association (ELPA) together with ELPA members from France (SOS hépatites) and the UK (Liver4Life), under the Patronage of the European Parliament, this impactful event brought together healthcare professionals, patient organisations, civil society organisations, and policymakers in a united effort to promote early detection of liver disease. Through free liver health screenings, educational materials, and a questionnaire about liver health, the initiative empowered individuals to take control of their liver health and encouraged policymakers to prioritise preventive actions. The success of the European Liver Screening Week 2024 underscored the critical role of awareness and collaboration in combating liver disease. ELPA extends its gratitude to all partners, healthcare providers, and volunteers who made this initiative possible.



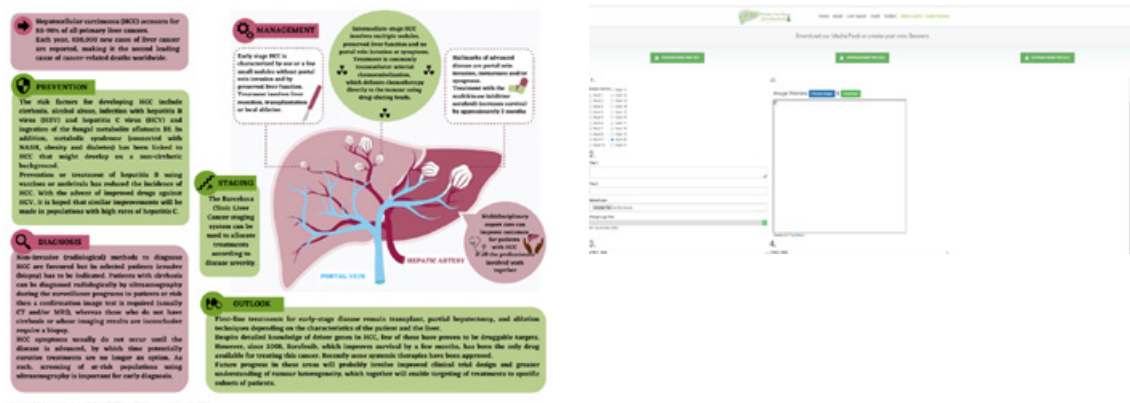
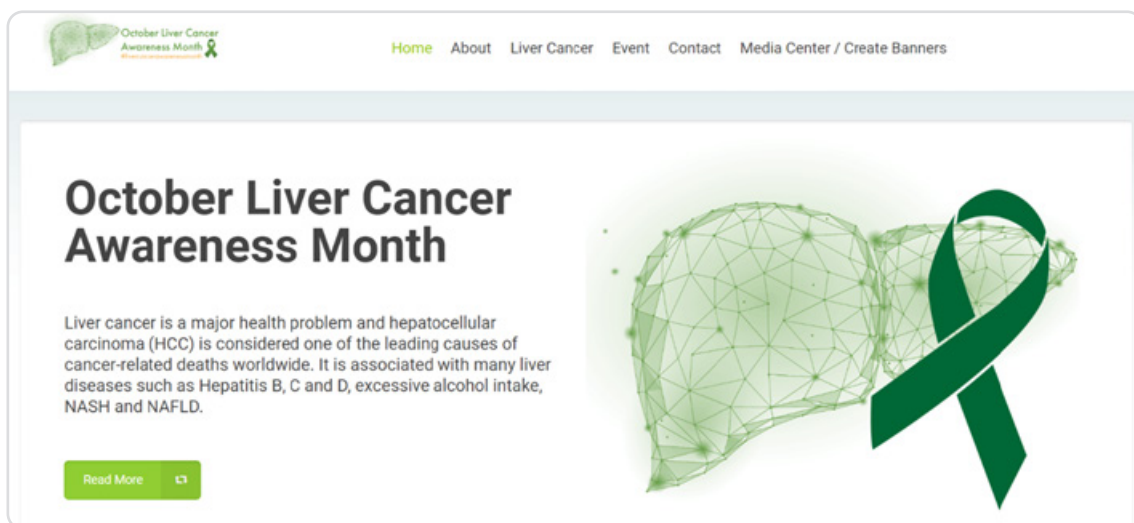
## October Liver Cancer Awareness Month– campaign and website

As every year, October brings liver cancer into focus to increase understanding of the disease, including its prevalence, approaches to screening and prevention, and treatment options. Liver Cancer Awareness Month (LCAM) is a great time to learn more about this vital organ's role and how to keep it healthy and raise awareness of the local and global impact among patients, family members, healthcare professionals, other stakeholders, and the general public. 2024 ELPA's social media campaign was based on the dissemination of updated and scientific information primarily focused on prevention since nobody is better than patients

at informing other patients. This year, ELPA focused deeper on the importance of the correlation between liver cancer and obesity, alcohol consumption, hepatitis and cirrhosis. Part of the campaign was also dedicated to raising awareness among policymakers through some specific policy asks.



The website <https://livercancermonth.eu/>, which is entirely dedicated to liver cancer and was successfully inaugurated three years ago, allowed all ELPA friends to be involved in the campaign this year, too. Different banners, pictures and frameworks were available to download and personalise from the Media Centre to boost the dissemination of content in other contexts.





## High-level policy meeting. Improving Prevention in the EP new mandate agenda. The case of liver cancer

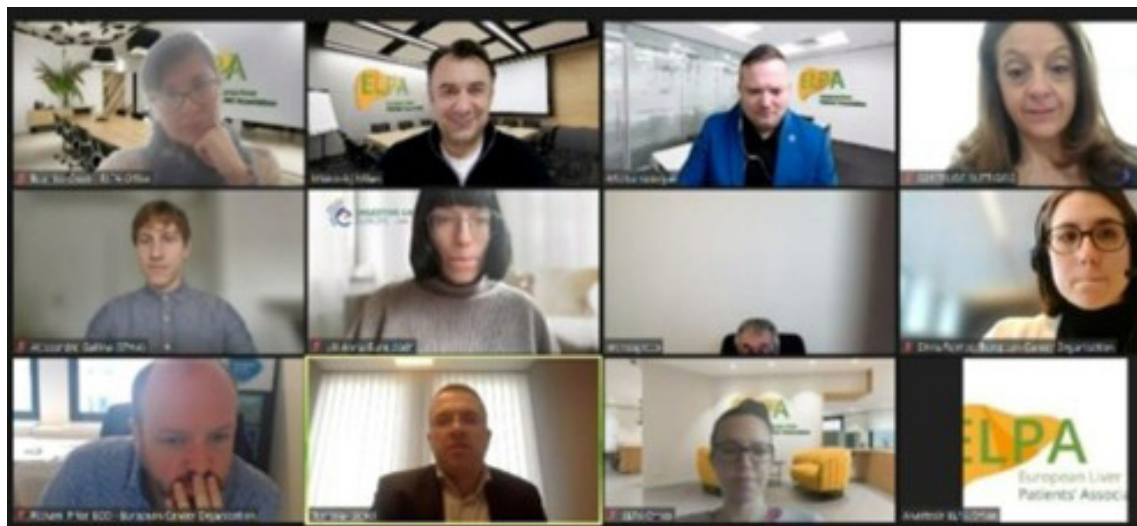
On February 20, 2024, ELPA hosted a roundtable on liver cancer.

Invited speakers were:

- **Marco Greco**, President of the European Patients Forum (EPF)
- **Alessandro Gallina**, Policy Manager, European Public Health Alliance (EPHA)
- **Richard Price**, Head of Policy, Silvia Romeo, Policy Officer, European Cancer Organisation (ECO)
- **Gertrude Buttigieg**, Chairperson, Malta Health Network (MHN)
- **Lili Gundelach**, Medical and Scientific Project Coordinator, Digestive Cancer Europe (DiCE)

The discussion revolved around inequities in access to cancer care and how we can work together in the scope of prevention and better health literacy, early diagnosis and treatment.

A large group of MEPs endorsed the event through video messages.



## ELPA High-Level Policy Event on Liver Cancer

On November 20, 2024, the European Liver Patients' Association (ELPA) convened a high-level policy meeting in Brussels, focusing on the prevention, early detection, and treatment of liver cancer. This significant event, in collaboration with newly elected Members of the European Parliament (MEPs), aimed to modernise EU healthcare policies to prioritise liver health. The session began with a networking lunch, followed by welcoming speeches from key figures, including Marko Korenjak (President, ELPA), Antonella Cardone (CEO, Cancer Patients Europe), and video messages from Prof Dr Aleksander Krag (Secretary General, EASL) and notable policymakers such as MEP Vytenis Andriukaitis. Then, Prof. Dr. Manuel Romero Gomez highlighted liver cancer's growing threat to public health, stressing the urgency of prevention, early screening, and addressing underlying risk factors like fatty liver disease, hepatitis, and rare liver conditions. To conclude, a dynamic roundtable featured contributions from influential stakeholders, including:



- **MEP András Tivadar Kulja**
- **MEP Francesco Torselli**
- **Frazer Goodwin** (Senior Communications & Advocacy Manager, European Public Health Alliance – EPHA)
- **Vicki Mooney** (Executive Director, European Coalition for People living with Obesity – ECPO)
- **Geraldine Joanny** (Scientific Officer, Innovative Health Initiative – IHI)
- **MEP Michalis Hadjipantela**

MEP Hadjipantela and Marko Korenjak concluded the event with a call to action, urging stakeholders to work together to reduce inequalities in cancer care and strengthen liver health strategies.



*Milan Mishkovikj, ELPA Director - MEP Vytenis Povilas Andriukaitis - Marko Korenjak, ELPA President, ELPA High-Level Policy Event on Liver Cancer*



*Marko Korenjak, ELPA President, ELPA High-Level Policy Event on Liver Cancer*

# FATTY LIVER

## High-level roundtable. Steatotic (Fatty) Liver Disease – Strategies for Early Detection and Intervention

On June 13, 2024, Global Fatty Liver Day, ELPA organised a high-level roundtable to discuss Fatty Liver from different perspectives.

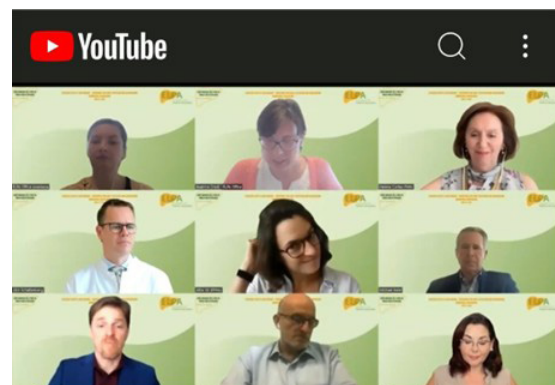
The meeting started with a welcome speech and greetings by Marko Korenjak, ELPA President. This was followed by two medical presentations delivered by Prof Dr **Romero Gómez**, MD, PhD, Professor of Medicine at the University of Seville, Head of Digestive Diseases Department at Virgen del Rocío University Hospitals, Spain and Prof Dr **Helena Cortez Pinto**, MD, PhD, Professor of Medicine in Faculdade de Medicina, Universidade de Lisboa, Vice-President of the United European Gastroenterology (UEG), Portugal to frame the disease from a medical point of view.

After that, a question-and-answer session allowed the audience to understand the disease's implications and complexity: its intertwining with other diseases and the struggle to hold policymakers accountable for public health interventions tackling alcohol, commercial determinants of health, and sedentary habits.

In addition, the participation of patient associations from outside Europe gives a broader perspective on the advocacy of good practices and activities.

List of participants:

- Prof Dr **Jörn M. Schattenberg**, MD, PhD, Member of the Policy, Public Health and Advocacy Committee of the European Association for the Study of the Liver (EASL), Switzerland
- **Jeff McIntyre**, Vice President, Liver Health Programs, Global Liver Institute, United States
- **Alba Gil**, Policy Manager, European Public Health Alliance, Belgium
- **Vicki Mooney**, Executive Director, European Coalition for People living with Obesity (ECPO), Ireland
- **Michael Betel**, President and CEO of the Fatty Liver Alliance, Canada



## Fatty Liver Month, ELPA Campaign

The European Liver Patients Association (ELPA), in close collaboration with the ELPA Fatty Liver Working Group, organised the social media campaign #FattyLiverMonth. The campaign revolved around different messages. Some informed about the diseases. Some reminded patients, partners, experts, policy decision-makers, stakeholders, and the general audience that Fatty Liver is our next most significant challenge in Europe as its rate among the population is increasing. It is a priority to push forward the discussion about these diseases and promote better and more comprehensive communication on this topic. In particular, the campaign focused on prevention and explored solutions contributing to tackling Fatty Liver. As there is still no treatment, the best way of dealing with the condition is for the patient to implement lifestyle changes, giving up to unhealthy diet and sedentary culture. In addition, a series of statements by the members of the ELPA Fatty Liver working group was posted for a week.





## ELPA Clinical Trials Programme 2024

The last cohort of ELPA members, composed of 8 participants from 7 countries, successfully completed the programme. The training focused on equipping participants with advanced knowledge and practical skills essential for understanding and engaging in clinical trials in this critical area of liver health. The conclusion of this program marks a significant milestone in ELPA's ongoing efforts to increase its members' knowledge and involvement in drug development and ultimately combat liver disease through education and research.



# HEPATITIS

## World Hepatitis Day campaign

In July 2024, the European Liver Patients Association (ELPA) organised a monthly social media campaign focused on Hepatitis. Run during the entire month; it had its highest expression on World Hepatitis Day on July 28, 2024. The campaign revolved around different messages. Some informed about the different types of Viral Hepatitis. Some reminded patients, partners, experts, policy decision-makers, stakeholders, and the general audience that Viral Hepatitis is still a significant challenge in Europe, and it is a priority to push forward the discussion about its elimination and promote better and more comprehensive communication on this topic. In particular, the campaign focused on prevention and explored solutions that contributed to tackling mainly Hepatitis B, D, and C.





## Hepatitis&Liver – debunking some myths

On the occasion of World Hepatitis Day 2024, ELPA released the new video series Hepatitis&Liver – debunking some myths.

In the framework of the IP-cure-B EU-funded project, ELPA, as a partner responsible for communication and dissemination, collaborated with the Principal Investigator to publish short videos debunking some common myths about hepatitis for the general public.



Prof Dr Massimo Leviero, MD IP cure B  
Principal Investigator



Prof Dr Maria Buti, MD - IP-cure-B Principal  
Investigator



Prof Dr Gabriele Missale, MD IP cure B  
Principal Investigator



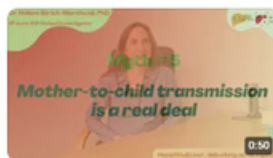
Prof Dr Pietro Lampertico, MD IP cure B  
Principal Investigator



Prof Dr Linda Wittkop, MD IP cure B Principal  
Investigator

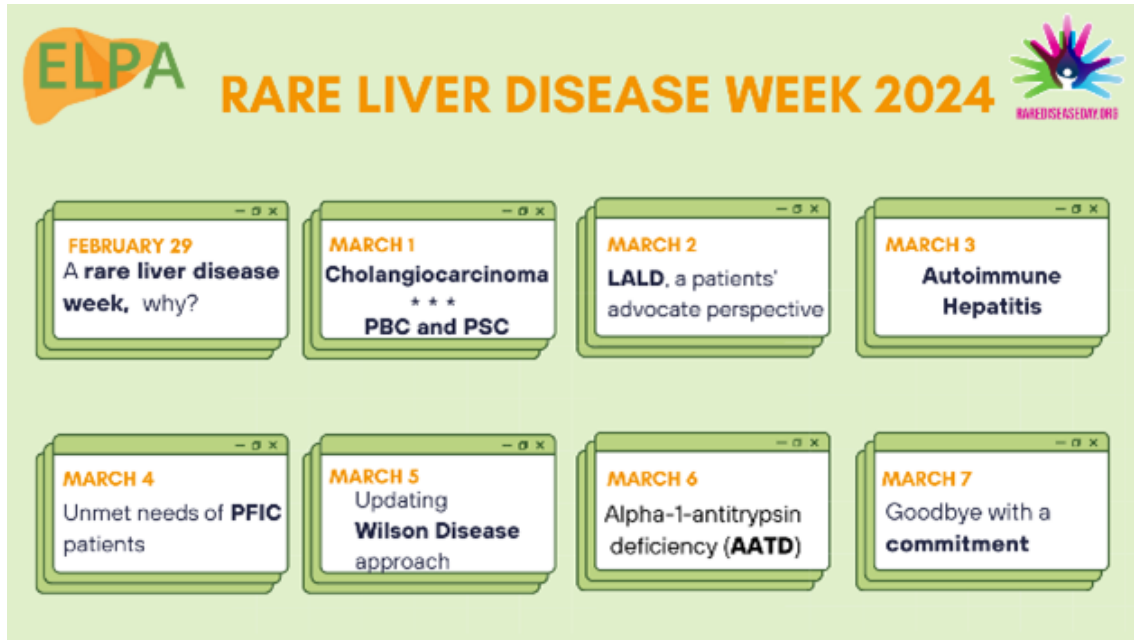


Prof Dr Fabien Zoulim, MD IP cure B  
Principal Investigator



Dr Hélène Strick Marchand, PhD IP cure B  
Principal Investigator

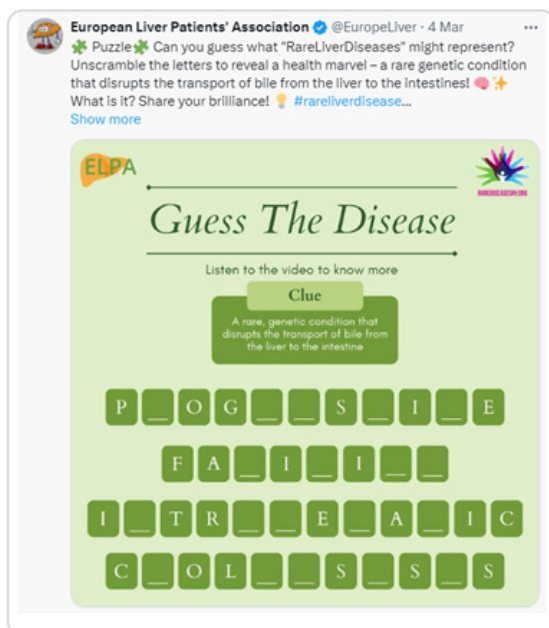
# RARE LIVER DISEASES



## ELPA rare liver diseases week

In 2024 ELPA celebrated, as every year, Rare Disease Day on February 28. However, ELPA decided to build a one-week campaign focusing on Rare Liver Diseases. It started with a message from the Leader of the ELPA Working Group on Rare Liver Disease. Then, it continued tackling a different liver disease every day from different angles. ELPA collected contributions from not only the medical and scientific community but

also patients, patients' family members, and patient advocates. Videos were done in the form of lectures or interviews.





## International PBC Day

ELPA was honoured to celebrate International PBC Day on September 8, 2024. ELPA's social media campaign has been a great occasion to raise awareness on primary biliary cholangitis (PBC) among the decision-makers, engage patients, clinicians, and policymakers, push forward the discussion about this disease, and promote better and more comprehensive communication on this topic. In particular, ELPA's campaign focused on how too many liver disease patients fall victim to the unknown. For many liver diseases, their causes and effective diagnostics, treatments and cures remain unclear, which is the reality of rare liver diseases like primary biliary cholangitis (PBC), however, ELPA shared hope and reasons for optimism.



## Global PSC Awareness Day - campaign and webinar

Primary Sclerosing Cholangitis (PSC) knows no boundaries. It is a rare, immune-mediated liver disease that affects the bile ducts and liver. On October 29, 2024, Global PSC Awareness Day, ELPA organised a social media campaign and partnered with different patient organisations to bring you testimonies of caregivers.





## MORE AND MORE

### **Bridging the Gap: Collaborative Efforts on Liver Health, Obesity, and Diabetes**

The European Liver Patients' Association (ELPA) successfully organised the landmark event, 'Bridging the Gap: Collaborative Efforts on Liver Health, Obesity, and Diabetes.' With the collaboration of the European Coalition for People Living with Obesity (ECPO) and the International Diabetes Federation (IDF) – Europe, The event was held in Lisbon, Portugal, on November 29-30, 2024. This two-day meeting brought together patients, medical experts, and advocacy leaders to address the complex interplay between liver diseases, obesity, cardiovascular disease and diabetes, fostering collaboration across disciplines.

#### **Day 1**

The event began with a warm welcome, setting the stage for discussions on patient involvement in healthcare policies by Prof. Dr. Rui Tato Marinho (University Hospital Center of North Lisbon), Marko Korenjak (President, ELPA), Vicki Mooney (Executive Director, ECPO), Iryna Vlasenko (Vice President, IDF), and David Kelly (Operations Manager, Global Heart Hub). The plenary session featured insights from a diverse panel of experts. First, Dr. Ana Sofia Martins and Dr. Sofia Trantza (PRAC Committee Representatives, EMA). Then, the discussion 'Intersecting Paths: Addressing Overlapping Issues in Liver, Diabetes, and Obesity' emphasised holistic care and collaborative solutions for these overlapping health challenges featuring Prof. Rogerio Ribeiro (Portuguese Diabetes Association), Dr. Jonathan M. Hazlehurst (University of Birmingham), Neus Llarch Alfonso and Dr. Isabel Graupera (Hospital Clínic of Barcelona).

The afternoon's workshop, led by Prof. Serena Barelo (University of Pavia), Dr. Ximena Ramos Salas (EASO), and Prof. Sarah Bigi (Università Cattolica del Sacro Cuore), focused on empowering patient advocates



to advance systemic change and achieve better health outcomes. The workshop titled 'Breaking Stereotypes and Countering Stigma: Strategies for Effective Patient Advocacy' aimed to equip participants with insights into how stereotypes are formed, the impact of stigma on persons with a disease experience, and strategies for reframing language in public campaigns to foster positive change.

## Day 2

The second day continued with a hands-on workshop featuring Prof. Barello, Dr. Ramos Salas, and Prof. Bigi. This second part of the workshop explored strategies to enhance advocacy and strengthen collaboration among patient organisations addressing liver health, obesity, cardiovascular diseases, and diabetes. The event concluded with a networking lunch, celebrating the collective commitment to advancing patient care and fostering collaboration between experts and advocates. ELPA thanks all participants for their invaluable contributions and looks forward to building on this momentum to address pressing health challenges across Europe.



*Bridging the Gap: Collaborative Efforts on Liver Health, Obesity, and Diabetes, group picture*



*Prof. Sarah Bigi, Università Cattolica del Sacro Cuore - Prof. Serena Barello, University of Pavia - Francesc Cayuela, President of FECAMM - Moisés Serrano Carrillo, FNETH - Yiannoula Koulla, President of Promitheas, Bridging the Gap: Collaborative Efforts on Liver Health, Obesity, and Diabetes*

## **“Made with Patients” Awards 2024 - Rising Star to ELPA President Marko Korenjak**

*Marko  
Korenjak,  
ELPA  
President,  
“Made with  
Patients”  
Awards 2024*



## **International Patient Advocacy Management Master’s graduation**

On May 10, 2024, ELPA President Marko Korenjak, ELPA Director Milan Mishkovikj and ELPA Head of Office Beatrice Credi graduated with a master's degree in International Patient Advocacy Management.

The course provided the student with the management skills required for the successful coordination and development of the activities of patients' organisations in the reference healthcare scenario. The lessons covered Healthcare management, European Legislation on health, Patient Involvement, fundraising, strategic communication, planning and bookkeeping, stakeholder management, and more. The master is organised by the European Patient Forum – EPF, in collaboration with Cattolica University (Patient Advocacy Lab, of the Graduate School of Economics and Management of Healthcare Organizations (ALTEMS), of the Graduate School of Psychology Agostino Gemelli (ASAG), of the Faculty of Economics and the Faculty of Medicine “A. Gemelli”, in collaboration with EngageMinds Hub - Consumer, Food & Health Engagement Research Center of Università Cattolica and the Foundation Policlinico universitario “Agostino Gemelli” IRCCS).



*International Patient Advocacy Management Master’s graduation, group picture*



## ELPA Members Project Support 2024

After the success of the previous editions, in 2024, ELPA worked even closer with its members on projects developed at the national level.

In 2024, ELPA supported the projects of 18 associations in 14 different countries:

**Bosnia&Herzegovina, Croatia, Egypt, Finland, France, North Macedonia, Romania, Serbia, Slovakia, Slovenia, Spain, Sweden, Turkey, United Kingdom.**











## International Day of Women and Girls in Science and International Women's day

On March 8, 2024, ELPA celebrated, as every year, International Women's Day, and as every year, with the pleasure of talking with powerful and inspiring women. This year we published an interview with Prof Dr Helena Cortez-Pinto M.D. who gave us a very interesting testimony of her personal and professional life.

On February 11, 2023, ELPA celebrated the International Day of Women and Girls in Science, supporting some statements on this topic by doctors collaborating with ELPA.







# **POLICY AND ADVOCACY ACTIVITIES**





# Focus on European Health Policy

## Europe's Beating Cancer Plan: Joining Forces

On January 31, 2024, ELPA President Marko Korenjak and ELPA Director Milan Mishkovikj attended the 'Europe's Beating Cancer Plan: Joining Forces' event. It was organised by the European Commission to celebrate World Cancer Day. It's been three years since the adoption of Europe's Beating Cancer Plan. Stella Kyriakides, European Commissioner for Health and Food Safety, was the host of this event, assessing Europe's efforts to enhance lives affected by cancer and leading the fight against the disease. The event included the participation of patients, patient representatives, experts, policymakers, and officials from across the EU, operating at both European and national levels.



*Marko Korenjak, ELPA President - Stella Kyriakides, European Commissioner for Health and Food Safety - Milan Mishkovikj, ELPA Director*

## HERA Civil Society Forum Meetings

Being Part of the HERA Civil Society Forum, some ELPA representatives participated in all the CSF group meetings. The work of CSF is organised in three working groups, and ELPA is involved in Working Group 1.

### Working Group 1 – Future of HERA

### Working Group 2 – Identified health threats (AMR, pathogens with high pandemic potential, CBRN threats)

### Working Group 3 – Training programme and information

Working group 1 also drafted a discussion paper in which the HERA Civil Society Forum recommends stronger investment in health emergency preparedness and response capacities. The document can be found [here](#).

In 2022, ELPA was appointed as a member of the HERA Civil Society Advisory Forum. The Advisory Forum is the highest body in HERA for discussing the strategic focus and setting tactical goals with high-level management. The Health Emergency Preparedness and Response (HERA) department aims to prevent, detect, and rapidly respond to health emergencies. HERA, created in the aftermath of the COVID-19 pandemic, will anticipate threats and potential health crises through intelligence gathering and building the necessary response capacities.

## **EUROCARE policy meetings**

As a Eurocare member, ELPA took part in all the EURO CARE policy meetings to discuss the future association's steps in the field of advocacy monthly organised. Eurocare is an alliance of non-governmental and public health organisations across Europe advocating for the prevention and reduction of alcohol-related harm. Member organisations are involved in advocacy and research, providing information and training on alcohol issues and services for people whose lives are affected by alcohol problems. EURO CARE's mission is to promote policies that prevent and reduce alcohol-related harm.

## **Barriers and facilitators towards the digital inclusion of all citizens**

As the world rapidly goes through a process of digitalisation, health systems are being transformed. The European Health Data Space aims to empower patients to be in control of their own digital health records; telemedicine services are becoming more widely available; artificial intelligence is revolutionising clinical decision support systems; infodemics spread faster than ever, leading to mistrust in health authorities. Are all European citizens prepared to advocate for their health in this digital transformation? Ensuring that nobody is left behind requires addressing the digital determinants of health, which include digital skills, digital health literacy, access to digital devices and facilitated engagement with digital platforms and tools. This webinar, organised by the European Public Health Alliance - EPHA on January 30, 2024, aimed to give voice to underrepresented communities that may encounter specific barriers in the digital transformation of health systems. During the meeting, the difficulties that these communities face were discussed, but their strengths and the opportunities for ensuring their digital inclusion were also highlighted.

## **EKHA workshop on organ donation and transplantation**

On January 25, 2024, the European Kidney Health Association - EKHA organised a workshop on organ donation and transplantation in the European Union (EU). This workshop was convened with the support of the Hungarian Permanent Representation to the EU. It provided a unique occasion for assessing opportunities and challenges in the field in anticipation of the upcoming Hungarian Presidency of the Council of the EU. The workshop brought together stakeholders from across the European organ donation and transplantation landscape and included healthcare professionals, patient representatives, and national and European policymakers. Through plenary presentations and discussion groups, the workshop assessed the positive impact of the 2009-2015 EU Action Plan on Organ Donation and Transplantation. Moreover, the gathering explored obstacles preventing the further uptake of donation and transplantation in Europe, with discussions highlighting the need for continued EU support and guidance. Discussions

focused on the institutional and policy frameworks related to donation and transplantation, the optimisation of processes, research funding, education and training, inequities, as well as benchmarking. Workshop participants agreed that a second EU Action Plan could bring considerable improvements to the field. ELPA was represented by its Spanish member, FNETH, who participated in the discussion, giving its perspective as a patient association active at the national level and having worked on this topic for many years. The outcomes of the workshop will help to inform the actions on organ donation and transplantation that the Hungarian Council Presidency will launch from July 2024 onwards.

## **The Cancer Momentum: Fighting Inequalities in Europe**

Cancer mortality varies widely across Europe, and survival depends on where you live. In particular, the inequality between countries in Central and South-Eastern Europe (CEE) and Western Europe (WE) is striking. We need to act now. This is why the Central European Cooperative Oncology Group (CECOG) and Cancer Patients Europe (CPE) organised the meeting: “The Cancer Momentum: Fighting Inequalities in Europe” held at the European Parliament and hosted by MEP Cristian Busoi, MEP Tomislav Sokol, and MEP Andreas Schieder on February 14, 2024. The Central European Cooperative Oncology Group (CECOG), together with several cancer stakeholders, Members of the European Parliament, and EU and national institutions, have created a platform to reduce health inequalities and improve patient access to cancer care. This platform was initiated in 2018 and delivered several stakeholder exchanges and publications.

## **Strengthening vaccination policies towards the European elections: from recommendations to concrete experiences**

As the European elections approach, numerous recommendations are proposed on the priorities of the new institutions. Yet, there is a risk of overlooking the substantial work already underway. Therefore, Cittadinanzattiva - Active Citizenship Network aim is to address this oversight, with the aspiration that the newly elected politicians will continue to recognise and advance these initiatives. Therefore, it is imperative to highlight the concrete actions taken by key stakeholders in several sectors. For this reason, this institutional event, hosted by MEP Beatrice Covassi (S&D) with the support of the MEPs Interest Group “European Patients’ Rights and Cross-border Healthcare” on February 14, 2024, aimed to present concrete activities carried out - in the field of vaccination policies - by different stakeholders, including civil society organisations, the private sector, European project consortia, etc. in order to promote the importance of vaccinations and the need for effective communication strategies by presenting good practices aimed at improving access to and uptake of vaccines.

## **Launch of the report “Beating Cancer Inequalities in the EU: Spotlight on cancer prevention and early detection”**

On February 5, 2024, ELPA representatives have the pleasure of participating in the launch of the OECD report “Beating Cancer Inequalities in the EU: Spotlight on prevention and early detection”. This is the third milestone of the European Cancer Inequalities Registry. This report, prepared in collaboration with the OECD, completes the first cycle of the initiative, complementing the work already achieved through the Data Tool and the Country Cancer Profiles. It examines policies and actions to tackle cancer care across the

EU 27, Norway and Iceland, with a specific focus on addressing preventable risk factors and improving the reach of screening and early diagnosis to counter concerning cancer trends and inequalities.

## DIA Europe 2024

DIA Europe is the largest European event in the life science industry – the knowledge hub between science, healthcare, and regulation – and the place to discuss health priorities. From the environmental impact of pharmaceuticals and drug development lifecycle to sustainable partnerships and healthcare systems, DIA Europe 2024, taking place in Brussels from March 12 to 14, was an excellent opportunity to discuss how collaboration and innovation can support sustainability in healthcare and each stakeholder's role in making it happen. ELPA was part of a panel discussion focused on Unmet medical needs in the new Pharmaceutical EU legislation framework. The concept of unmet medical need (UMN) plays a vital role in investment and priority-setting decisions by various stakeholders, including patients, regulators, HTA agencies, payers, academics and the pharmaceutical industry. Identifying a particular condition or disease area as an UMN is intended to signal its health policy significance, stimulate research activities and incentivise the development of innovative treatments, diagnoses or health technologies in these areas. Incentives associated with the identification of an UMN can take the form of preferential access to public research funds, access to alternative or accelerated regulatory pathways, consideration of UMN as a value element in HTA, and financial incentives or innovative payment models in reimbursing the health benefits a new treatment delivers. As the European Commission proposed to define the concept of UMN in the current legislative review, the concept is broadly discussed with divergent views. The session brought together key players in pharmaceutical innovation, including developers, health and regulatory authorities, and patients, to discuss Europe's ambition to define unmet medical needs, what is needed, and the challenges.



## 18<sup>th</sup> European Patients' Rights Day

Also this year, Active Citizenship Network celebrated the European Patients' Rights Day - which has reached its 18<sup>th</sup> edition - with a conference that was held at the European Parliament in Brussels on March 20, 2024. Hosted by MEP Brando Benifei (S&D) and organised with the support of the MEPs Interest Group

“European Patients’ Rights & Cross-Border Healthcare”, this year’s edition was dedicated to the topic of combining the protection of patients’ rights with skills shortage, medical desertification and job strain. Speakers stressed the crucial role of HCPs for a healthier Europe and the fact that neglecting the health workforce crisis jeopardises current and future preventive and care options for citizens. Doctors, nurses, and pharmacists are essential within healthcare systems, ensuring the well-being of citizens and fostering trust in the system. Their support is paramount. Origin & value of the European Patients’ Rights Day In 2002, Active Citizenship Network (ACN), together with a group of European citizens organisations, drafted the European Charter of Patients’ Rights, which has been translated into 16 languages and includes the following 14 rights: the right to preventive measures; access care; information; consent; free choice; privacy and confidentiality; respect of patients’ time; observance of quality standards; safety; innovation; avoidance of unnecessary suffering and pain; personalised treatment; to complain; to receive compensation. All these rights, based on the Charter of Fundamental Rights of the European Union, are crucial for European citizens and healthcare services. Most of these rights were also embodied within the Council conclusions on Common values and principles in EU Health Systems adopted in June 2006.

## AgeingFit conference

On March 10-12, 2024, ELPA representatives participated in the AgeingFit annual conference. The conference served as a dynamic platform for stakeholders to explore innovative solutions and initiatives to promote healthy ageing and address the unique health challenges older adults face. ELPA’s participation was characterised by insightful contributions, highlighting the importance of liver health within the broader context of ageing. In particular, ELPA’s engagement at the conference was marked by a presentation delivered by ELPA President Marko Korenjak about the Health Technology Assessment, how patients can contribute to the process and what challenges are on the horizon regarding the new EU regulation.



*Jackie Marshall-Cyrus, Senior Lecturer Adult Nursing, University of Worcester - Viola Baumgärtner, Project Leader, German Korian Foundation - Monica Moldovan, Founder, The Care Hub Marko Korenjak, ELPA President - Per Simonsson, CEO & Founder, Hestia Agora, AgeingFit conference*



## VHPB Technical meeting: Addressing Viral Hepatitis Among Europe's Migrant and Refugee Population: lessons learnt and the way forward

On March 26 and 27, 2024, ELPA Vice President Ivana Dragojević attended the Viral Hepatitis Prevention Board annual technical meeting. The meeting focused on addressing viral hepatitis among Europe's migrant and refugee populations. ELPA's participation was marked by a profound exchange of insights, experiences, and strategies aimed at tackling the unique challenges faced by these vulnerable demographics. Through active engagement and stakeholder collaboration, ELPA contributed valuable lessons learned and advocated for inclusive policies and interventions. By fostering dialogue and sharing best practices, ELPA exemplified its commitment to advancing hepatitis prevention, diagnosis, and care for all, regardless of background or circumstance. Moving forward, ELPA continues to champion the imperative of equitable access to healthcare and the importance of tailored approaches to address the needs of migrant and refugee communities across Europe.

## EU-X-CT Public Stakeholders' Forum 2024

On April 10, 2024, ELPA attended the EU-X-CT Public Stakeholders' Forum. The pan-European public-private EU-X-CT Initiative aims at facilitating cross-border access to clinical trials in concrete terms. The initiative collects information on the regulatory, ethical, healthcare system, and organisational conditions of the stakeholders involved, as well as their experiences and best practices in all European countries. This Public Stakeholders' Forum was the opportunity to jointly review the national conditions for patients, clinical investigators, academia/public funders and industry sponsors in need of cross-border participation of patients in clinical trials. The EU-X-CT gap analysis was the basis for our panel and open forum discussions to draw conclusions about the most efficient European and national strategies and activities for immediate and mid-term improvements.



*Milan Mishkovikj, ELPA Director - other participants, EU-X-CT Public Stakeholders' Forum 2024*

## ESPGHAN 2024

The European Liver Patients' Association (ELPA) participated in the 2024 annual meeting of the European Society for Paediatric Gastroenterology, Hepatology and Nutrition (ESPGHAN). This involvement, which had its maximum expression in the symposium organised by ELPA around the topic of transplantation, underscored ELPA's commitment to fostering collaboration and advancing research in liver diseases, particularly within the pediatric population. ELPA's presence at ESPGHAN 2024 also provided a platform for patient advocacy, allowing for the exchange of valuable insights between healthcare professionals and liver disease patients. Their participation aimed to highlight the importance of patient-centered care and to advocate for innovative treatments and policies to improve the quality of life for children affected by liver conditions. This engagement is anticipated to strengthen the partnership between medical experts and patient communities, driving forward the mission of enhancing liver health across Europe.



*Milan Mishkovikj, ELPA Director - Prof Dr Patrizia Burra M.D., Full Professor of Gastroenterology, Head of the Gastroenterology Unit, and Head of the Multivisceral Transplantation Unit at the Department of Surgery, Oncology and Gastroenterology, Padua University Hospital - Prof Dr Ulrich Baumann M.D., ESPGHAN President - Marko Korenjak, ELPA President - Prof Dr Gamal Shiha M.D., ELPA Director - Ivana Dragojević, ELPA Vice President - Dr. Yael Mozer-Glassberg - Director of the Pediatric Liver Transplantation Unit Schneider Children's Medical Center Israel - Julio Burman, ELPA Vice President - Tove Frisch, ELPA Vice President - ESPGHAN 2024*

## ECO 2024

Some ELPA representatives attended the European Congress on Obesity between May 12 and 15, 2024. They benefitted from an innovative and interactive program covering many facets of obesity. The program was designed to be engaging and to promote interaction and discussion around the hottest topics in the field of obesity. Programme topics were organised into four main areas; 'Basic Science', 'Behavioural and Public Health', 'Childhood and Adolescent Obesity', and 'Management and Intervention'. Delegates interacted with presenters in plenary and topic sessions, teaching workshops, and moderated research communication sessions. Also, the congress featured a poster by ELPA presenting the results of the European Screening Week held in Brussels in October 2023.



*Veronika Všetickova, ELPA Head of EU Affairs - Anastasiya Semeiskaya ELPA Office - Ivana Dragojević, ELPA Vice President, ECO 2024*

## EU4Health Stakeholders' Conference 2024

ELPA attended the EU4Health Stakeholders' Conference 2024, underscoring its dedication to improving liver health and patient care across Europe. At the conference, held on June 19, 2024, ELPA highlighted the urgent need for comprehensive strategies in the prevention, early diagnosis, and treatment of liver diseases. By engaging with policymakers, healthcare professionals, and other patient organisations, ELPA advocated for increased funding and support for liver health initiatives. Their presence at the conference emphasised the importance of collaborative action in addressing the significant public health challenge posed by liver diseases. Through active participation, ELPA reinforced its commitment to contributing to the EU4Health program's goals of enhancing health outcomes and reducing health disparities throughout the European Union.

## EU Cancer Mission Understanding Cluster Policy webinar

On July 4, 2024, ELPA served as a panellist at the EU Cancer Mission Understanding Cluster Policy webinar organised by the European Commission. During the event, ELPA Head of Office Beatrice Credi contributed her insights into the intersection of liver disease and cancer, emphasising the importance of integrated policies in addressing these critical health challenges. By participating in this high-level discussion, ELPA highlighted the need for collaborative approaches within the EU's cluster policy to enhance cancer prevention, early detection, and treatment strategies. Their involvement reinforced the role of patient organisations in shaping policies that drive effective and equitable healthcare solutions across Europe.

## Cancer Patients Europe - General Assembly

As a full Cancer Patients Europe (CPE) member, ELPA participated in the General Assembly on July 18, 2024. ELPA joined forces with patient representatives from across Europe to advance the collective interests of those impacted by cancer. The assembly served as a vital platform for exchanging ideas, strategies, and



best practices aimed at enhancing patient advocacy and support throughout the cancer care continuum. ELPA's participation highlighted its dedication to working collaboratively with other CPE members to amplify the voices of cancer patients and to influence policies that drive improvements in care, access, and overall outcomes. By engaging in this important dialogue, ELPA reaffirmed its commitment to strengthening the collective efforts of patient organisations across Europe, ensuring that the needs and perspectives of cancer patients are at the forefront of healthcare decision-making.

### 3<sup>rd</sup> CEE Patient Engagement Forum

On September 26 and 27, 2024, ELPA attended the 3<sup>rd</sup> in Central and Eastern Europe (CEE) Patient Engagement Forum. ELPA President Marko Korenjak participated in the session about what the European Health Data Space (EHDS) means for patients in the CEE. The session offered an Overview of the European Health Data Space and its importance for innovation, now that secondary use is likely to be voluntary, raising patient awareness about the potential benefits of EHDS. It also focused on the issue of trust in health data sharing and the role of Patient Organisations in EHDS implementation at the national level. ELPA President was also a panellist in the masterclass on patient engagement and involvement in Health Technology Assessment (HTA) in the CEE region. This session aimed to contribute to CEE patient organisations' knowledge about HTA and empower them to bring the voice of CEE patients at national and EU levels in HTA processes. With the upcoming entry into force of the EU HTA Regulation in January 2025, this session provided an overview of HTA processes and why they matter to patient communities in Central and Eastern Europe (CEE), broke down the HTA changes that the new EU Regulation brings, highlighted the expected challenges and opportunities, and put forward recommendations for improved patient involvement in HTA in the CEE region.



### ESMO Congress 2024

Several representatives from the European Liver Patients' Association (ELPA) took part in the European Society for Medical Oncology (ESMO) Congress 2024, held from September 13 to 17, 2024. Their participation was a cornerstone of ELPA's ongoing mission to advocate for liver cancer patients, bringing attention to the specific challenges these patients face and pushing for greater awareness, improved treatment options, and increased funding for research. During the congress, ELPA representatives not only engaged with leading oncology experts and researchers but also formed meaningful connections with other cancer patient advocates from across Europe. These collaborations fostered a united front in the fight against cancer, allowing for the exchange of ideas and strategies to ensure that patient-centred approaches remain at the forefront of cancer research and policy. By strengthening ties with other advocacy groups, ELPA aimed to amplify the collective voice of cancer patients, reinforcing the need for a more comprehensive and inclusive

approach to cancer care, especially for those battling liver cancer. Their active involvement at ESMO 2024 emphasised the critical role of patient advocacy in shaping the future of oncology.

## **From theory to practice: Implementing the EU Health Technology Assessment Regulation**

On September 6, 2024, the European Commission and the Heads of Health Technology Assessment (HTA) Agencies Group (HAG) convened their sixth in a series of seven regional events across the European Union.

This Budapest gathering brought together representatives from Slovenia, Hungary, Croatia, Czechia, and Slovakia, continuing the EU's initiative to engage neighbouring countries in each session. The primary objective of the event was to inform stakeholders about the impending changes due to the new HTA regulation, set to take effect in January 2025, and to prepare for broader awareness campaigns in each participating country. Attendees represented a diverse cross-section of the healthcare ecosystem, including national HTA administrators, patient associations, health professionals, scientific societies, industry representatives, national decision-makers, and regional health authorities. The official proceedings, hosted at the National Centre for Public Health and Pharmacy, focused on three key areas:

- Understanding key elements of the EU HTA Regulation.
- Challenges and opportunities in the implementation process.
- Involving stakeholders in EU HTA implementation.

Two-panel discussions emerged as highlights of the event. The first featured Heads of HTA Agencies. The second panel brought together various stakeholders affected by HTA, with notable participation from ELPA President Marko Korenjak. A key takeaway from the event was the imminent integration of the HTA process into Europe's clinical, medical, and research landscape. HTA builds upon existing regulatory frameworks, envisioning a unified approach to drug development, medical devices, and healthcare management. This convergence is increasingly necessary as more therapies emerge in hybrid forms, combining drugs with medical devices and specific provisioning regimes—all crucial elements for achieving optimal therapeutic outcomes.

## **The new keywords in the management of MASLD: Innovation, Prevention and Multidisciplinarity**

On September 20 and 21, 2024, ELPA was at the University of Padova.

The conference "The New Keywords in the Management of Metabolic Dysfunction Associated Liver Disease (MASLD): Innovation, Prevention, and Multidisciplinarity" brought together experts, healthcare professionals, and patient advocates to discuss innovative approaches to MASLD. Key themes included cutting-edge research, early diagnosis, and personalised treatments under the umbrella of Innovation, while Prevention focused on public health measures to mitigate risk factors like obesity and diabetes. The importance of Multidisciplinarity was highlighted, with experts advocating for integrated care involving hepatologists, endocrinologists, dietitians, and mental health professionals. Marko Korenjak, President of the European Liver Patients' Association (ELPA), delivered a talk on "The Role of Patients and Their Associations in Responding to Stigma and Discrimination of Patients with MASLD." He emphasised the need for patient

advocacy to combat the stigma associated with liver diseases and called for greater collaboration between healthcare professionals and patient organisations. Korenjak stressed the importance of empowering patients through education and support networks, advocating for an inclusive approach to treatment. The conference ended with a call for continued innovation, prevention-focused healthcare, and multidisciplinary collaboration to improve MASLD management.

## United Against Liver Cancer - DiCE webinar

On October 1, 2024, “United Against Liver Cancer” kicked off Liver Cancer Awareness Month. This webinar was a collaboration with leading organisations in the field: EASL, ELPA, ILCA, ILCM, and DiCE. During this engaging online session, experts from various backgrounds shared their insights on liver cancer in Europe and globally. The agenda featured a holistic overview of the situation in Europe, followed by a political endorsement that emphasises the sustainability of the EU Cancer Plan. Experts from EASL and ILCA delved into prevention strategies and the importance of early diagnosis, respectively. Representatives from DiCE and the ELPA Director Milan Mshkovikj, highlighted significant research findings and advocacy efforts in Europe, while an ILCM expert discussed global advocacy strategies.



## UEG Week 2024

ELPA played a pivotal role at the UEG Week 2024 (October 12-15), demonstrating its unwavering commitment to improving patient care in hepatology. A significant highlight of ELPA's involvement in the United European Gastroenterology congress was its active participation in a high-profile round table discussion on patient management. This event brought together patient representatives from various

esteemed organisations, creating a dynamic platform for sharing experiences, challenges, and innovative solutions. ELPA's representative contributed valuable insights, emphasising the importance of patient-centric approaches in liver disease management and advocating for integrating patients' voices in healthcare decision-making processes. The round table provided an opportunity to discuss collaborative strategies to enhance early diagnosis, treatment accessibility, and holistic care models. ELPA's participation underscored its leadership in fostering dialogue between patients, clinicians, and policymakers. By working hand-in-hand with other patient organisations, ELPA reaffirmed its dedication to ensuring that liver patients across Europe receive equitable, high-quality care tailored to their needs. This engagement at UEG Week 2024 further cemented ELPA's reputation as a champion for the liver patient community.



*Anastassiya Semeiskaya ELPA Office - Veronika Všetickova, ELPA Head of EU Affairs, UEG Week 2024*

## VHPB Regional Meeting

The VHPB Regional Meeting, titled "Elimination of Viral Hepatitis in the Czech Republic, Hungary, Poland, and Slovakia: Lessons Learnt and the Way Forward," occurred in Prague, Czech Republic, on October 29-30, 2024. The event brought together public health experts, policymakers, and patient representatives to share insights and strategies for achieving the WHO's goal of eliminating viral hepatitis as a major public health threat by 2030. Key learning objectives included evaluating the current state of viral hepatitis surveillance, prevention, and treatment in the region, discussing national hepatitis plans, and addressing the barriers to elimination. Discussions also focused on innovative prevention strategies and the implementation of new control



*Ivana Dragojević, ELPA Vice President - Dr. Helena Glasová M.D., Slovak Medical University, Hep Help Klub - VHPB Regional Meeting*





measures in the Czech Republic, Hungary, Poland, and Slovakia. Dr. Helena Glasová, representing the Slovak Medical University, Hep Help Klub, and the European Liver Patient Association (ELPA), presented “The Role of Patient Organizations in Hepatitis Elimination, local Slovakian Example and International / Global Insights”. Her presentation highlighted the contributions of the Slovak patient associations Hep Help Klub and Šanca pre pečeň, ELPA members, and other civil society organisations. In addition, she offered insights into global and international collaboration. Ivana Dragojević, ELPA Vice President, also participated in the event, underscoring the importance of patient advocacy in the elimination effort. This collaborative meeting provided a platform to share successes, address challenges, and chart the way forward toward the elimination of viral hepatitis in the region.

## European Cancer Summit 2024

Ivana Dragojević, ELPA Vice President, attended the European Cancer Summit 2024, scheduled on November 20 and 21, 2024, in Brussels. The prestigious event, organised by the European Cancer Organization, brings together leading experts, policymakers, and advocates to advance cancer care and prevention across Europe every year. As a member of the Patient Advisory Committee (PAC), Dragojević’s presence highlighted the importance of incorporating patient perspectives into the development of cancer policies and strategies. Her attendance reinforces ELPA’s ongoing efforts to address liver-related cancer issues and advocate for patient-centric solutions in the fight against cancer.



*Ivana Dragojević, ELPA Vice President - other participants, European Cancer Summit 2024*

## EPHA General Assembly

On December 10, 2024, ELPA representatives participated in the General Assembly of the European Public Health Alliance (EPHA), an event that brought together a diverse network of organisations dedicated to improving public health across Europe. As a proud and longstanding member of EPHA, ELPA used this opportunity to emphasise the critical importance of liver health within the broader public health agenda. Representing the voice of liver patients across Europe, ELPA actively contributed to discussions on health equity, policy innovation, and collaborative strategies to tackle pressing health challenges. The General Assembly served as a vital platform for ELPA to advocate for comprehensive and inclusive policies prioritising prevention, early diagnosis, and access to effective treatment for liver diseases. By engaging with fellow EPHA members, policymakers, and public health stakeholders, ELPA reaffirmed its commitment to fostering stronger alliances and amplifying the patient perspective in shaping European health policies. This participation highlights ELPA's dedication to being an active and influential partner within EPHA, championing shared goals and working collaboratively toward a healthier and more equitable future for all.

## Inauguration of the European Alcohol Awareness Week

December 3, 2024, marked the launch of Alcohol Awareness Week 2024 (#AWARH24), bringing together key voices in public health to address the pressing issue of alcohol-related harm. The event featured a series of powerful speeches, including those by MEP Vytenis Andriukaitis and WHO Europe's Carina Ferreira-Borges, both calling for mandatory alcohol labelling as a critical step to safeguard citizens' right to make informed health choices. In addition, UEG Past President Helena Cortez Pinto highlighted the importance of evidence-based strategies to reduce alcohol-related harm from a medical and scientific perspective. Until December 6, an exhibition stand at the European Parliament continued to spotlight this critical issue, advocating for mandatory alcohol labelling to empower informed decision-making.



## Stakeholder webinar on the Cancer Inequalities Registry

DG SANTE held the 9<sup>th</sup> webinar on the Cancer Inequalities Registry on December 11, 2024, in the EU Health Policy Platform framework. The OECD provided participants with an update on the work towards the second cycle of 29 Country Cancer Profiles, to be published in February 2025. The profiles will maintain the same outline as the previous cycle but will include a new section on wellbeing and quality of life, as well as a spotlight on paediatric cancer. The Country Profiles will be published as a package accompanied by a Synthesis Report and a Cancer Performance Tracker, which will provide an overview of the country's performance compared to the EU average for cancer indicators. The JRC officially launched the new version of the ECIR data tool. JRC presented the revamped tool to the participants, outlining its improved user friendliness and layout. The data tool will be further enhanced in 2025 with the addition of several new indicators outlined in the 2024-2025 ECIR roadmap. IARC presented the refined methodology and outcomes of the EUCanIneq project, which generated and projected data on educational inequalities in cancer mortality for 27 EU countries plus Iceland and Norway. The study shows that the size of the social gradient observed in cancer mortality differs between countries. The project will result in 29 country factsheets to be published next year. PwC presented the study's goals on the Quality of Life for cancer patients and survivors, which was recently kicked off. This study will help to identify common indicators to collect data on quality of life across the Member States, Norway and Iceland. It takes a broader approach to understanding and measuring Quality of Life, which integrates the social policy perspective beyond measuring the individual patient experience. The study will include several consultation activities where stakeholder input will be required. The study outcomes will provide new data for the Cancer Inequalities Registry. The Chair informed that a launch event for the Country Cancer Profiles will take place in early February 2025.

## Leveraging evidence to transform health systems: Passing the baton at the Observatory

Policymakers face a complex set of health system challenges. The issues – workforce shortages, financial sustainability, the growing burden of chronic diseases, longstanding access and equity concerns – are clear. The solutions are less so. There are competing approaches to fragmented care and prevention, competing non-health system areas clamouring for resources and what can feel like a string of shocks and crises. Policymakers are expected to respond with strategic choices that fit their particular health system context. They need timely and relevant evidence. They also need effective knowledge translation to make that evidence accessible and relevant to them. On December 10, 2024, the symposium organised by the European Observatory on Health Systems addressed the questions – ‘What do we need to know to improve policy decisions?’ and ‘How do we use what we know to achieve change?’. Speakers explored the types of evidence policymakers need, and the kinds of knowledge-brokering that can help them translate evidence into health system transformation. It also marked a leadership transition at the Observatory, with Ewout van Ginneken succeeding Josep Figueras as Director in January 2025 and taking forward the Observatory's mission to generate and share evidence that enables policy. Keynote speakers included Hans Kluge, Regional Director of WHO Europe; Sandra Gallina, Director General of DG SANTE; and Liisa Maria Voipio-Pulkki, Chair of the Steering Committee of the Observatory. Josep Figueras is the current director; Ewout van Ginneken is the incoming director; and Suszy Lessof is the Deputy Director.

# EASL Meetings

## EASL Liver Cancer Summit 2024

On February 22-24, 2024, ELPA Vice President Julio Burman attended the EASL Liver Cancer Summit. Primary liver tumours are a major health problem and hepatocellular carcinoma (HCC) and biliary tract cancer (BTC) are leading causes of cancer-related deaths globally. Tumour development is frequently associated with different liver diseases, including viral infection, alcohol abuse and metabolic disorders such as MASH and MASLD. The management of patients with liver cancers has significantly improved over the past years. While in both tumour types, immunotherapies are now an integral part of systemic treatment, targeted therapies have been specifically introduced in BTC. Nevertheless, there is still significant room for improvement in the screening, diagnosis and treatment of patients with primary liver cancer. To address these critical issues, the Summit gathered key stakeholders engaged in fighting liver cancer, including clinicians, scientists, nurses, patient representatives and industry professionals. The programme of the summit showcased the most recent advances in the understanding of the pathogenesis of the two most common primary liver malignancies – hepatocellular and cholangiocellular carcinoma – and debated the state-of-the art in the diagnosis and treatment of patients affected by these primary liver tumours.



*Julio Burman, ELPA Vice President, EASL Liver Cancer Summit 2024*



## EASL Congress 2024

The European Liver Patient Association (ELPA) attended the EASL Congress 2024 with a full contingent of its members, continuing its tradition of active participation.

As in previous years, from June 5 to 8, 2024, ELPA's robust delegation underscored its commitment to representing liver patients' interests and contributing to the hepatology field. Throughout the congress, ELPA members engaged in a variety of meetings, workshops, and discussions, ensuring that the patient perspective was well-represented in policy-making and scientific discourse. Their presence at EASL 2024 reinforced the association's role in advocating for improved liver health outcomes and fostering collaboration among healthcare professionals, researchers, and patients.



Milan Mishkovikj, ELPA Director - Anastassiya Semeiskaya ELPA Office - Marko Korenjak, ELPA President - Prof Dr Jonel Trebicka M.D., Director Department of Internal Medicine B, University Clinic Münster - Veronika Všetickova, ELPA Head of EU Affairs - Donna R. Cryer, JD, Founder of Global Liver Institute (GLI), Prof Dr Pietro Lampertico M.D., Fondazione IRCCS Ca' Granda, Ospedale Maggiore Policlinico, University of Milan, Veronika Všetickova, ELPA Head of EU Affairs - Beatrice Credi, ELPA Head of Office - Diana Castillo ECPO President - Prof Dr Romero Gómez M.D., Professor of Medicine at the University of Seville, Head of Digestive Diseases Department at Virgen del Rocío University Hospitals - Prof Dr Helena Cortez Pinto, M.D., Professor of Medicine in Faculdade de Medicina, Universidade de Lisboa - Prof Dr Jörn M. Schattenberg, MD, PhD, Member of the Policy, Public Health and Advocacy Committee of the European Association for the Study of the Liver (EASL) - Michael Betel, President and CEO of the Fatty Liver Alliance, Canada - Julio Burman, ELPA Vice President, Ivana Dragojević, ELPA Vice President, EASL Congress

Specifically, ELPA representatives were involved in:

- EASL Patient Forum - panellist
- EF-CLIF/GENFIT Joint event - panellist
- Interprofessional Forum: Developing successful nurse-led clinics. A multidisciplinary perspective. Developing successful nurse-led clinics - panellist
- Track Hub: Public Health – presentation of ELPA activities by ELPA members
- Participation in many EU-funded scientific project sessions as a partner in the consortium.

## EPF and EUPATI Meetings

ELPA joined the European Patient Forum (EPF) in 2011, and the collaboration is still going on very fruitfully. ELPA started collaborating with EUPATI many years ago and, as a sustainable partner and having many representatives involved in the Fellow Programme, ELPA participated in many meetings.

### EPF Annual General Meeting

The European Liver Patients' Association (ELPA) actively participated in the European Patients' Forum (EPF) Annual General Meeting 2024, reinforcing its commitment as a key EPF member. ELPA engaged in crucial discussions on advancing patient advocacy and influencing European health policy. A significant aspect of the meeting was the workshop on artificial intelligence (AI) in healthcare. At the 2024 AGM, participants reviewed EPF's collective accomplishments of the past year to continue developing the work plan for 2024 and, with a longer-term perspective, explore how to ensure the visibility and sustainability of patients' movement in the years to come. The meetings took place on April 13 and 14, 2024.



## EPF High-Level Policy Event

On October 16, 2024, ELPA President Marko Korenjak was a panellist in the EPF High-Level Policy Event. The high-level policy event aimed to conclude EPF's EU elections campaign by bringing together decision-makers, Members of the European Parliament (MEPs), and EPF members in a conversation about consolidating patient involvement in health policy in the new EU mandate. Building on the Patient Organisations' Manifesto adopted at EPF's 20<sup>th</sup>-anniversary event in 2023, the event focused on the progress in putting systemic patient involvement on the policy agenda and celebrated commitments made by candidates to support it during their mandate. This event also aimed at building connections and starting the work in the new EP to involve patients and patient organisations at all policy-making levels. In addition, it had the potential to promote this topic on the agenda of the next EU Commission by building awareness and support ahead of the Commissioner hearings in the European Parliament.



*Anca Toma EPF Executive Director - Marko Korenjak, ELPA President, Melanie Carr, Head of Stakeholder and Communication Division, European Medicines Agency - Maya Matthews, Head of Unit, DG SANTE, European Commission - Frederico Guanais, Deputy Head of the Health Division at the Organisation for Economic Co-operation and Development - Nathalie Moll, Director General of the European Federation of Pharmaceutical Industries and Associations, EPF High-Level Policy Event*

## EUPATI online Spring SPA meeting

Together with 50 sustaining partners, ELPA participated in the EUPATI Spring SPA meeting on February 15, 2024. Together, we looked back on 2023 and forward into 2024. We discussed the EUPATI work plan for this year and co-created the agenda for the in-person EUPATI AGM in September 2024. EUPATI's vision is to improve health outcomes through the contribution of patients and patient representatives as valued stakeholders. EUPATI's mission is to provide accessible, innovative and inclusive education that empowers patients and patient representatives with the right knowledge, skills and competencies to effectively engage and partner with all other stakeholders in medicines R&D. EUPATI is committed to enhancing patient engagement through patient education.



## EUPATI AGM 2024

ELPA participated in the EUPATI Annual General Meeting (AGM) on September 26 and 27, 2024. ELPA was engaged in two thematic workshops. The first one was dedicated to the EUPATI fellows, attended by ELPA Member and EUPATI Fellow Zdenko Simonovic, and it was the occasion for graduated patient advocates to exchange on future trajectories. The second focused on Diversity, Equity, and Inclusion (DEI) in Patient Engagement. This insightful session, led by Tamas Bereczky (Deutsche Aidshilfe) and Dominique Hamerlijnck (EUPATI Fellow), offered valuable perspectives on how DEI can be seamlessly integrated into patient engagement initiatives. ELPA had the opportunity to exchange ideas with EUPATI fellows and partners during this event, and we look forward to further deepening this important collaboration.



*Maria Dutarte EUPATI Executive Director - Beatrice Credi, ELPA Head of Office - Zdenko Simonović, The Chronic Viral Hepatitis Patients Association, "B18", EUPATI AGM 2024*

# ELPA in international meetings

## Paris Hepatology Conference 2024

On March 18 and 19, 2024, our patient organisation had the honour of participating in the Paris Hepatology Meeting, a prestigious event bringing together experts and stakeholders in liver health worldwide. ELPA proudly presented a poster showcasing the results of the ELPA European Screening Week held in Brussels in October 2023. On top of the results, the poster showed our organisation's dedication to supporting and advocating for individuals affected by liver diseases. It served as a powerful call to action towards policymakers regarding the importance of patient-centred care and the pivotal role that patient organisations play in shaping policies, research, and healthcare practices. Engaging with clinicians, researchers, and fellow advocates at the Paris meeting was not just an opportunity to share our work but also a chance to amplify the voice of those we serve, fostering collaborations and driving meaningful change in the field of hepatology.



Anastassiya Semeiskaya ELPA Office - Beatrice Credi, ELPA Head of Office, Paris Hepatology Conference 2024



## World Hepatitis Summit 2024

The World Hepatitis Summit 2024, a pivotal event in the global health calendar, was hosted from April 9 to 11, 2024. The event aimed to accelerate progress towards the elimination of hepatitis. Bringing together policymakers, health professionals, researchers, and advocates, the summit focused on innovative strategies and collaborative efforts to combat hepatitis. With some of its representatives' participation, the European Liver Patients' Association (ELPA) played a significant role in this year's summit, showcasing their advocacy work and initiatives to support liver patients across Europe and sharing important testimonies. ELPA's participation includes presentations on patient-centred care, policy development, the importance of early diagnosis and treatment and stigma. By sharing their expertise and experiences, ELPA hopes to inspire actionable solutions and foster international partnerships in the fight against hepatitis.



## GLI event on the sidelines of the 77<sup>th</sup> World Health Assembly

On May 29, 2024, the Global Liver Institute (GLI) organised an event on the sidelines of the 77<sup>th</sup> World Health Assembly in Geneva, Switzerland. GLI convened numerous esteemed key opinion leaders for the event entitled "Together for Better Liver Health: Amplifying Best Practices Globally," in partnership with the European Association for the Study of the Liver (EASL). ELPA Director Milan Mishkovikj participated in the second panel, during which liver health perspectives were highlighted by different key stakeholders. To complement the event, GLI released [Best Practices in Liver Health Policy: A Liver Health is Public Health Report](#), which evaluates successes that certain countries have had in liver health policy to give insight and promote effective policies worldwide. The report highlights persistent challenges that patients face globally and policies addressing these challenges.



*Dr Kremlin Wickramasinghe, PhD Regional Adviser for Nutrition, Physical Activity and Obesity, World Health Organization Regional Office for Europe - Milan Mishkovikj, ELPA Director - Prof Dr Sven Francque, M.D., Hepatologist and Educational Councillor, European Association for the Study of the Liver - Dr Catherine Duggan, PhD CEO, International Pharmaceutical Federation, GLI event on the sidelines of the 77th World Health Assembly*

## 7<sup>th</sup> Global MASLD Congress

On June 24 and 25, 2024, ELPA actively participated in the 7<sup>th</sup> Global Metabolic Associated Steatohepatitis (MASLD) Congress. Through a presentation delivered by ELPA Vice President Julio Burman, ELPA reaffirmed its commitment to tackling liver diseases on a global scale. During the congress, ELPA representatives engaged with leading researchers, clinicians, and fellow patient advocates to discuss the latest advancements in the diagnosis, management, and treatment of MASLD. Their participation highlighted the critical role of patient advocacy in shaping research agendas and healthcare policies. ELPA emphasised the need for increased awareness, early detection, and comprehensive care strategies for those affected by MASLD. By contributing patient perspectives and advocating for enhanced support and resources, ELPA played a pivotal role in driving forward the global agenda to combat this rapidly growing liver health issue.



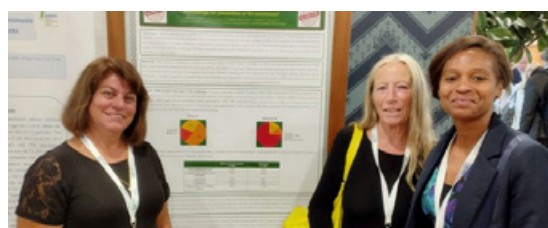
*Richard Hall Liver4Life President - Julio Burman, ELPA Vice President, 7th Global MASLD Congress*

## WHO Global hepatitis webinar – It’s time for action!

ELPA attended the Global Hepatitis Webinar titled “It’s Time for Action!” organised by the WHO on World Hepatitis Day 2024. The event focused on the “It’s Time for Action” campaign theme and the sub-theme “Global Hepatitis Response: Closing the Gap Towards the 2030 Elimination Goals.” This theme emphasised the urgent need to reignite progress toward eliminating viral hepatitis by 2030, as previous efforts had stalled. The webinar featured high-level international and national leaders, including Ministers of Health, national program managers, policymakers, representatives from UN organisations, civil society, and people with lived experience. ELPA’s active participation underscored its commitment to combating hepatitis worldwide and contributing to the global efforts spotlighted during the event, particularly in enhancing case finding for hepatitis B and C and transforming the hepatitis B response into a public health approach.

## Paris MASH Meeting 2024

Several representatives from the European Liver Patients’ Association (ELPA) participated in the Paris NASH Meeting, which took place on September 5 and 6, 2024. At this highly anticipated event, focused on MASH and liver health, ELPA presented a poster on the success of the European Liver Screening Week 2023. The poster highlighted the outcomes and key findings of the screening initiative, emphasising the importance of early detection and raising awareness about liver diseases, including MASH, across Europe. Also, SOS Hépatites, an ELPA member from France, presented a poster on their activities in the field of Fatty Liver. ELPA’s participation underscored their commitment to patient advocacy and education, aiming to improve liver health outcomes through preventive measures and screenings. During the meeting, ELPA also engaged with healthcare professionals, researchers, and other patient advocacy groups, fostering collaborations essential to advancing liver disease awareness and treatment. Their presence at the Paris MASH Meeting showcased ELPA’s leadership in promoting liver health initiatives. It reinforced the critical role of patient organisations in driving early diagnosis and comprehensive care strategies.



*Yiannoula Koulla, President of Promitheas - Tove Frisch, ELPA Vice President - Selly Sickout, Fédération SOS Hépatites & Maladies du foie, Paris MASH Meeting 2024*

## Delta Cure International Meeting

The 3<sup>rd</sup> Edition of the Delta Cure International Meeting was held in Milan on October 11-12, 2024. The meeting reviewed the latest evidence regarding virology, pathogenesis, epidemiology, diagnosis, and endpoints. Two full sessions were dedicated to thoughtfully debating the most recent advances in current and new antiviral treatments. Suggestions for treatment algorithms were also discussed. The Faculty involved an excellent panel of experts who guided the attendees through this disease’s challenges. ELPA President Marko Korenjak participated in a roundtable discussion about hot topics in HDV management, representing the liver patients’ community at the European level.

## AASLD, The Liver Meeting 2024

ELPA was proud to participate in the 2024 AASLD congress held from November 15 - 19. This prestigious event brought together thousands of experts, researchers, and policymakers to discuss the latest advancements in hepatology. Representatives from ELPA actively engaged in sessions focused on patient advocacy, liver disease management, and global health. As part of ELPA's mission to amplify the voice of liver patients, the representatives highlighted the importance of including patient perspectives in research and policymaking. They also networked with international stakeholders opening pathways for new collaborations. ELPA's participation underscores its commitment to fostering global partnerships and advocating for better patient outcomes. The congress provided a platform to emphasise the role of patient organisations in shaping the future of liver health.



*Milan Mishkovikj, ELPA Director - Julio Burman, ELPA Vice President, AASLD, The Liver Meeting 2024*







**EMPOWERING OUR  
MEMBERS AND  
STRENGTHENING  
OUR ASSOCIATION**



## High-level meeting at the Romanian Parliament

On March 14, 2024, ELPA members from Romania organised a round table discussion in the Romanian Parliament about Viral hepatitis in Romania - stages on the road to elimination. Among many speakers invited by Marinela Debu, President of APAH-RO, ELPA member, ELPA was represented by Dr Teresa Casanovas, ELPA Scientific Committee Leader. She presented the Spanish and European experience and the role of non-governmental organisations in promoting prevention and early detection. The event was also the occasion to discuss multidisciplinary collaboration and the family doctor's role in detecting and monitoring liver patients, and the National Framework Plan for the Elimination of Viral Hepatitis in Romania – ensuring access to testing, continuing investigations, and appropriate therapy. Also, some time was dedicated to the lesson of testing programs through European funds and the treatment program for hepatitis C in Romania.



*Marinela Debu, President of APAH-RO, High-level meeting at the Romanian Parliament*

## Visit to the Hospital Saúde Santa Maria in Lisbon

On April 11, 2024, some ELPA Directors visited the Hospital Saúde Santa Maria in Lisbon. Milan Mishkovikj, Julio Burman, Tove Frisch, Ivana Dragojević together with Dr John Ward, director of Coalition for Global Hepatitis Elimination and ex-director of U.S. Centers for Disease Control and Prevention, visited the most significant unit for Hepatitis in Portugal. They were invited by Prof Dr Rui Tato Marinho (MD, PhD), Hospital director at Saúde Santa Maria, Medical School of Lisbon, academic medical Centre of Lisboa and Prof Dr Carlos Neves Martins - Chairman of the Board - Unidade Local de Saúde Santa Maria. In the heart of Lisbon, this public Central Hospital serves as a lifeline to the Greater Lisbon area and, indeed, to all of Portugal. It's the largest hospital in Lisbon, a testament to its vital role in healthcare. But what truly sets it apart is its relentless pursuit of progress in treating patients with hepatitis and pushing elimination in the country forward.



*Milan Mishkovikj, ELPA Director - Dr John Ward, Coalition for Global Hepatitis Elimination - Prof Dr Rui Tato Marinho M.D., Hospital director at Saúde Santa Maria, Medical School of Lisbon, academic medical Centre of Lisboa - Prof Dr Carlos Neves Martins M.D., Chairman of the Board - Unidade Local de Saúde Santa Maria - Tove Frisch, ELPA Vice President - Ivana Dragojević, ELPA Vice President, Visit to the Hospital Saúde Santa Maria in Lisbon*

## ELPA @ the University of Pavia

ELPA President, Directors and staff were invited by Prof Serena Barello to share ELPA's experience in patient advocacy at the University of Pavia. They met with the students during a Health Psychology class within the Master's degree in Psychology, Neuroscience, and Human Sciences. This program, newly established by the Department of Brain and Behavioral Sciences of the University of Pavia (DBBS) and the Department of Humanities and Life Sciences of the University School for Advanced Studies (IUSS)



*Marko Korenjak, ELPA President, Tove Frisch, ELPA Vice President - Milan Mishkovikj, ELPA Director - Ivana Dragojević, ELPA Vice President, Beatrice Credi, ELPA Head of Office - Anastassiya Semeiskaya ELPA Office - Prof. Serena Barello, University of Pavia, ELPA @ the University of Pavia*

Pavia, aims to cultivate bright minds in the psychological field. The engagement and interest shown by the master's students during the ELPA team's presentation were commendable. The discussion shed light on the indispensable role of patient advocacy and engagement in shaping health policy, raising awareness, and fostering scientific collaboration. Particularly noteworthy was their emphasis on the multidisciplinary, multistakeholder approach and the significance of patient-centric involvement across various domains, including artificial intelligence, health technology assessment (HTA), and clinical trials.

## **EUCAPA training on HTA**

ELPA President Marko Korenjak and ELPA Head of Office Beatrice Credi have actively participated in the EUCAPA (European Capacity Building for Patients) training. The training focused on the EU Health Technology Assessment (HTA) new Regulation, furthering their commitment to enhancing advocacy skills and broadening their impact within the European landscape. Their enrollment in this specialised training program on HTA reflects ELPA's dedication to advancing liver health policy and patient representation at the highest levels. By deepening their understanding of HTA and public advocacy, Korenjak and Credi are better equipped to navigate the complex policy environment, advocate for liver patients' rights, and influence key decision-makers in the European Union. Their involvement underscores ELPA's proactive approach to ensuring that liver health remains a priority on the EU public health agenda, fostering collaboration with stakeholders and strengthening the voice of liver patients across Europe.



*EUCAPA training on HTA, group picture*





*Valentina Strammiello, EPF - Marko Korenjak, ELPA President, EUCAPA training on HTA*

## PEOF 2024

From May 21-23, 2024, ELPA President Marko Korenjak and ELPA Director Milan Mishkovikj participated in the Patient Engagement Open Forum (PEOF). The Forum is a gateway to effect real change, bringing together an unparalleled network of patient advocates, industry pioneers, and regulatory powerhouses, both virtually and in person. Patients' insights, coupled with cutting-edge discussions with leaders from academia and other sectors, are vital in sculpting the future of patient engagement. During the ceremony of the "Made with Patients" Awards 2024, ELPA President Marko Korenjak was awarded a Rising Star for his remarkable contributions to patient advocacy and healthcare innovation.



*Milan Mishkovikj, ELPA Director, PEOF 2024*

## ELPA educational training and training on patient engagement

ELPA's stay in Milan during the EASL Congress in June also enabled all ELPA members to participate in many training sessions organised by ELPA. The first session hosted some Genfit representatives presenting their pipeline on acute-on-chronic liver failure (ACLF). ACLF presents as a syndrome defined by a combination of hepatic and extrahepatic organ dysfunctions and failures and a uniformly poor prognosis. In patients with liver cirrhosis and acute hepatic decompensation, ACLF can be triggered by a precipitating event (e.g., an infection) leading to a progressive functional deterioration of multiple organs with high short-term mortality.



*Prof. Serena Barello, University of Pavia, ELPA training on patient engagement*



The second training was led by Prof Serena Barello from the University of Pavia, with whom all ELPA members worked in a workshop setting to increase their skills in patient advocacy and engagement. Together, we delved into various interactive activities, including best practices sharing and case study analyses, which provided us with practical insights into effective communication strategies, patient empowerment techniques, and collaborative decision-making processes. This hands-on approach not only enriched our understanding but also allowed us to practice and refine our skills in a supportive environment, fostering a sense of camaraderie and shared purpose among participants.

## ELPA Annual General Meeting 2024

The European Liver Patient Association (ELPA) held its Annual General Meeting, a pivotal event that every year brings together ELPA members from across Europe and beyond. This meeting serves as a platform for members to discuss advancements in liver disease research, patient care, and advocacy strategies. Attendees have the opportunity to exchange knowledge, share best practices, and collaborate on initiatives aimed at improving the lives of individuals affected by liver conditions. The AGM also provides a forum for reviewing the association's progress in advocating for liver disease patients, enhancing public awareness, and influencing health policy at the European level over the past year. In addition, it set strategic priorities for the future and reinforced the organisation's commitment to elevating liver health and patient support on a continental scale. The AGM also celebrated notable achievements within the liver patient community, underscoring ELPA's dedication to advancing liver health and patient advocacy.



## Global Heart Hub 4<sup>th</sup> Unite Summit

For the first time, ELPA representatives joined the Global Heart Hub on November 3 – 5, 2024, for the 4<sup>th</sup> Annual GHH Unite Patient Summit. This meeting brought together patient organisation leaders, patient advocates & carers, together with clinical experts, researchers, policymakers, and a range of key healthcare stakeholders from around the world to discuss the challenges of living with heart disease and its interconnected conditions, such as stroke, diabetes, chronic kidney disease, liver disease and obesity. The two-day event focused on the challenges of the lived experience, and several individuals living with multiple long-term connected conditions shared their experiences. Those attending also discussed and heard

about innovations in treatment and care for multiple long-term CVD-related conditions. A key aspiration of the summit was to explore solutions and actionable priorities to improve patient care and quality of life.



*Marko Korenjak, ELPA President, Veronika Všetickova, ELPA Head of EU Affairs, Global Heart Hub 4th Unite Summit*

## ELPA Extraordinary General Meeting

The European Liver Patients' Association (ELPA) convened its Extraordinary General Meeting (EGM) on November 28, 2024, with members joining in-person in Lisbon. This critical gathering set the stage for a year of impactful advocacy and action. **One of the highlights of the meeting was the introduction of new**



*Eduardo López, President of AELALD - Milan Mishkovikj, ELPA Director, ELPA Extraordinary General Meeting*

**ELPA members, who bring fresh perspectives and energy to the organisation.** Their expertise and passion will further strengthen ELPA's mission to represent liver patients' voices at national and international levels. A key development was the launch of a new Working Group (WG) focused on alcohol and liver health. **Recognising the significant burden of alcohol-related liver disease, this WG will drive awareness campaigns, policy advocacy, and patient support initiatives.** Updates from existing WGs showcased the remarkable progress made on hepatitis elimination, SLD, rare liver disease and liver cancer. Each WG presented detailed work plans for 2025, emphasising innovative strategies to tackle liver health challenges. The meeting concluded with a renewed commitment to collaboration and advocacy.

## EUPATI Patient Expert Training Programme

**Two ELPA members proudly graduated as EUPATI Fellows** during the second in-person event of the Expert Training Programme Cohort 7 on October 21-24, 2024. During the training, before graduation, ELPA President Marko Korenjak gave a presentation on Patient Involvement at European Regulatory Agencies. The EUPATI Patient Expert Training Programme is a training about the medicines' development process. It covers the entire lifecycle of medicines research and development (R&D), from the design and execution of research projects and clinical trials to regulatory processes and Health Technology Assessment (HTA).



*Ivana Dragojević, ELPA Vice President, Tarja Teitto-Tuckett, The Finnish Kidney and Liver Association, EUPATI Patient Expert Training Programme*





# **ELPA IN SCIENTIFIC RESEARCH PROJECTS**





LiverScreen has received funding from the European Union's Horizon 2020 research and innovation programme under grant agreement No. 847989

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LIVERHOPE has received funding from the European Union's Horizon 2020 research and innovation programme under grant agreement No. 731875

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IP-cure-B has received funding from the European Union's Horizon 2020 research and innovation programme under grant agreement No. 847939

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MICROB-PREDICT has received funding from the European Union's Horizon 2020 research and innovation programme under grant agreement No. 825694

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GALAXY has received funding from the European Union's Horizon 2020 research and innovation programme under grant agreement No. 668031

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DECISION has received funding from the European Union's Horizon 2020 research and innovation programme under grant agreement No. 847949

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A-TANGO has received funding from the European Union's Horizon 2020 research and innovation programme under grant agreement No. 945096

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ESCALON has received funding from the European Union's Horizon 2020 research and innovation programme under grant agreement No. 825510

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Artemis Project has received funding from the European Union's Horizon Europe research and innovation programme under grant agreement No 101136299

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Liveration Project has received funding from the European Union's Horizon Europe research and innovation programme under grant agreement No 101104360

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THRIVE Project has received funding from the European Union's Horizon Europe research and innovation programme under grant agreement No 101136622



GENIAL Project has received funding from the European Union's Horizon Europe research and innovation programme under grant agreement No 101096312



LEOPARD Project has received funding from the European Union's Horizon Europe research and innovation programme under grant agreement No 101080964



GRIPonMASH Project is supported by the Innovative Health Initiative Joint Undertaking (IHI JU) under grant agreement No 101132946. The JU receives support from the European Union's Horizon Europe research and innovation programme and COCIR, Efpia, EuropaBio, MedTech Europe, Vaccines Europe and Mercodia Aktiebolag, Metadeq Limited and Julius Clinical Research BV.



LIVERAIM Project is supported by the Innovative Health Initiative Joint Undertaking (IHI JU) under grant agreement No 101132901. The JU receives support from the European Union's Horizon Europe research and innovation programme and EFPIA, COCIR, MedTech Europe, Vaccines Europe and EuropaBio.



HL4EU Project has received funding from the European Union's Erasmus+ programme for education, training, youth and sport under grant agreement No 101133773



FisPlat has received funding from the EIT Health under grant agreement No. 20308



## Medical research project Galaxy, Horizon 2020

Medical research project GALAXY brings together partners with unique research competences in clinical hepatology, microbiome, multi-omics, biomarkers and bioinformatics. The aim of the project partners is to develop novel systems medicine tools which integrate clinical, multi-omics and lifestyle information from alcohol over-users at various stages of the disease and healthy individuals in order to: 1) identify signatures of host-microbial cross-talk during disease development and progression, 2) translate this into biomarkers for diagnosis, stratification and treatment monitoring in alcohol over users, and 3) evaluate new interventions to modulate gut microbiota towards prevention and mitigation of the disease in at-risk individuals. Project partners will also study societal and economic impact of medical research project GALAXY biomarkers and treatments to accelerate future development.



## Medical research project Liverhope, Horizon 2020

The objective of Liverhope is to evaluate a novel therapeutic strategy for patients with decompensated cirrhosis based on targeting the main pathophysiological mechanisms of disease progression in cirrhosis, namely the impairment in the gut-liver axis and the persistent hepatic and systemic inflammatory response.

This dual therapeutic approach is supported by preclinical data showing that rifaximin modulates the disturbed microbiota and decreases gut permeability and systemic endotoxin levels characteristics of cirrhosis. Moreover, simvastatin decreases systemic and hepatic inflammation, improves the altered hepatic microcirculation, decreases portal hypertension, and reduces fibrosis progression.



## Medical research project Microb-Predict, Horizon 2020

Within medical research project Microb-Predict, project partners are investigating the human microbiome to identify predictors and mechanisms associated with the development of decompensation of cirrhosis and progression to acute-on-chronic liver failure (ACLF) and death. The project gathers 22 partner organizations working in different fields.





## Medical research project Liverscreen, Horizon 2020

The aim of medical research project LiverScreen is to develop a targeted screening methodology to identify persons with asymptomatic liver fibrosis and cirrhosis among the general population. This methodology involves:

- 1) identification of groups from the general population at high risk of having chronic liver disease,
- 2) screening their liver stiffness with the innovative transient elastography (TE) technology (until now only validated in patients with known liver disease) for diagnosis, and
- 3) determining the right follow-up screening regime. Within the LiverScreen project 8 European countries are collaborating and performing research in over 34,000 subjects to develop the screening methodology and demonstrate its accuracy, clinical value, costeffectiveness, acceptability, and potential to be implemented by healthcare systems throughout Europe.



## Medical research project IP Cure B, Horizon 2020

The objective of the EU-funded medical research project IP-cure-B « Immune profiling to guide host-directed interventions to cure HBV infections» is to develop novel curative concepts for chronic hepatitis B (CHB). The project aim is to improve the cure rate of CHB by boosting innate immunity with immune modulators and stimulating adaptive immune responses with a novel therapeutic vaccine. Researchers are also identifying immune and viral biomarkers for patient stratification and treatment response monitoring. Integration of biological and clinical data enable models for the best combination treatment and effectiveness of novel curative therapies with respect to disease spectrum and patient heterogeneity. The preclinical platform will be evaluated in humanised mice, combining immune-modulatory strategies to stimulate innate immunity, rescue exhausted HBV-specific T cells and generate anti-HBV adaptive responses. Proof of concept is to obtain in a clinical trial of a combination of novel compounds stimulating innate immunity.



## **Medical research project FiSplat, European Institute for Innovation and Tehnology – EIT Health**

FibroScan Screening Platform (FiSplat) assess the presence of significant liver fibrosis with an accuracy at least equivalent to the one of the current FibroScan devices (with a sensitivity of 93% and a specificity of 78% using a cutoff of 9.2 kPa). An ergonomic, training procedure, results output and interpretation assistance and an innovative business model, makes the technology usable in a cost-effective manner for mass screening by nurses and general practitioners. This allow earlier decision-making and a personalized follow up. All together prevent the progression of the disease to liver cirrhosis, its associated worldwide morbidity and mortality, as well as reduce liver cirrhosis management costs.



## **Medical research project Decision, Horizon 2020**

The objective of medical research project DECISION is to enhance our understanding, at systems level, of the pathophysiology of decompensation of cirrhosis leading to ACLF or death. For that purpose, project partners perform a multi-omic profiling of already existing large and clinically well characterized cohorts including 2,200 patients with available standardized biobank samples. The gained knowledge during the process allows the development of prognostic and response tests and of combinatorial therapies tailored to the needs of individual patients or identified groups of patients with acute decompensation of cirrhosis. All these efforts aim to decrease the risk of short-term death of patients with acute decompensation of cirrhosis.



## **Medical research project A-TANGO, Horizon 2020**

In Europe, about 30,000 people die every year from alcohol related cirrhosis, a form of chronic, non-communicable disease. The patients that are at highest risk of death are those with superimposed alcoholic hepatitis (AH) who do not respond to therapy and develop acute on chronic liver failure (ACLF), a newly described syndrome characterised by multiorgan failure. Treatment of ACLF is an unmet need. Based upon their clinical and pre-clinical studies, the A-TANGO consortium aims to perform Phase 2 clinical trials of a novel, patented and innovative therapeutic strategy by repurposing a toll-like 4 receptor

antagonist (TAK242, Technology Readiness Level (TRL) 8), which targets inflammation, and combining it with granulocyte colony-stimulating factor (G-CSF, TRL9) that improves hepatocyte proliferation (G-TAK, TRL4). A successful trial will advance G-TAK to TRL8. Additionally, A-TANGO aims to discover novel biomarkers for patient selection and defining prognosis, building health economics models and reimbursement strategies to allow maximal dissemination and exploitation.

## ESCALON

### ESCALON

ESCALON is a project involving a unique team of specialists in different areas (both academic and geographical areas) that aims to create databases and biobanks (both cross-sectional and prospectively) to evaluate biomarkers in blood that could predict hepatocellular carcinoma, cholangiocarcinoma and gallbladder cancer. The project considers various clinical, environmental and genetic factors for each cancer that could shed light on the mechanisms leading to carcinogenesis and help us understand potential prevention points. The study will lead to the discovery and utilization of biomarkers that could be applied worldwide for early diagnosis and detection of hepatocellular carcinoma, cholangiocarcinoma and gallbladder cancer, improve the understanding and provide identification of risk factors associated with hepatobiliary carcinogenesis that could be targeted for prevention and treatment of such cancers. The consortium is formed by physicians, scientists, epidemiologists, statisticians and media specialists in multiple countries across Europe and South America. Each task, designed to work on a different hepatobiliary cancer, is led by a centre in one continent in close collaboration with a centre in a different continent (Europe and South America).



### COBALT

The Covid-19 pandemic has disproportionately affected liver patients - patients with chronic liver disease have around 5-times increased mortality from Covid-19 compared to individuals without liver disease. Therefore, the development of vaccines is a welcomed step, but we don't yet know if they are fully protected in liver patients. Early data from the US demonstrates that two-thirds of liver transplant patients don't have detectable antibodies to the coronavirus after one dose of the mRNA vaccine (Boyarsky et al., 2021). Therefore, there is an urgent need to determine how effective these vaccines are in liver patients to determine if extra protection is needed - such as extra vaccine doses, additional medications, or continued shielding. The COBALT study is taking place across Europe to urgently address this question by measuring responses to vaccination in liver patients. It is designed to report back quickly to inform patients and policy-makers, although further support is needed to accelerate this process and make policy decisions rapidly.



## FACILITATE

FACILITATE is a 4-year project launched by the Innovative Medicines Initiative (IMI) whose primary aim is to enable clinical trial participants to access and make use of their personal health data gathered during studies to allow a better shared medical decision-making with the health professionals involved in their care and to create a process that allows data to be also re-used in future research. Its overall goal is to develop an innovative data-sharing and re-use process within a General Data Protection Regulation (GDPR) compliant and approved ethical framework, not only to allow the access and portability of patient data but also to change the role of patients in the strategy and design of clinical trials – with many new rights and responsibilities – becoming an active component of the drug development process.



## Medical research project GENIAL, Horizon Europe

Alcohol-related hepatocellular carcinoma (ALD-HCC) is, in Europe, the leading cause of liver cancer (2<sup>nd</sup> most common cause of cancer-related death worldwide, affecting both men and women). GENIAL brings together partners with unique expertise in clinical hepatology, single-cell and spatial multi-omics, artificial intelligence (AI) and communication and dissemination capacities. The aim is to 1) portray genetic and environmental determinants promoting ALD-HCC; 2) evaluate how they interact at cellular level in human samples and preclinical models to get novel insights into liver carcinogenesis, and identify chemopreventive targets; and 3) assess how these determinants modulate the ALD-HCC risk in prospective cohorts of patients included in HCC surveillance programs. Environmental factors will be comprehensively characterised in an ongoing clinical trial designed to evaluate alternative methods for early-stage HCC detection. Finally, AI models, reaching the minimal viable product stage by the end of GENIAL, will be used to integrate genetic and non-genetic information (including digital imaging) to develop novel cost-effective strategies towards prevention and early-stage detection of ALD-HCC in at-risk individuals.



## Medical research project Liveration, Horizon Europe

Colorectal cancer (CRC) ranks fourth in cancer deaths worldwide. Between 20% and 30% of patients with advanced CRC have liver metastases (CRLM). Liver cancer ranks second in cancer deaths worldwide, including hepatocellular carcinoma (HCC). Despite recent advances, liver resection offers the only chance of cure for patients with liver metastases. However, the recurrence rate of these tumours is high even after post-resection. The presence of positive margins in the remaining liver after resection correlates with increased local recurrence and decreased overall survival, the only factor where prognosis could be influenced by the performance of surgery. However, at present, the extent of an R-negative status remains debatable and varies widely from one publication to another. Currently, there are radiofrequency ablation studies that, based on preliminary retrospective human clinical trials, are able to correlate an additional coagulation of tumor margins with a reduction on local recurrence. However, there is no prospective and pragmatic controlled study that accurately measures this additional margin and its impact on oncological outcomes. The aim of LIVERATION is to conduct an ambitious, pragmatic multicenter clinical trial with 720 patients with CRLM and HCC at 24 clinical centres in 6 different countries to determine whether additional ablated margin produced by radiofrequency can decrease the recurrence rate and improve patient survival.



## Medical research project GRIPonMASH, European Institute for Innovation and Technology – EIT Health

GRIP on MASH will address the unmet public health need to reduce disease burden and comorbidities associated with Metabolic dysfunction-Associated Steatotic Liver Disease (MASLD). Together with seven medical technology, pharmaceutical and biotechnology companies, ELPA will devise a sustainable and scalable GRIPonMASH Platform that will enable access to at-risk patients developing or having MASLD through the early detection of this condition at the primary care level.





## HL4EU, Erasmus +

The Healthy Lifestyles for Europe project (HL4EU) will foster a cross-sectoral approach to healthy lifestyles promotion among a variety of stakeholders, in line with the European Commission and WHO's vision and existing policy initiatives, and in sight of tackling the increasing burden of NCDs and of reducing health inequalities across Europe. The consortium consists of leading national and European representative organisations from different sectors, including, fitness, physical activity, outdoors, health (doctors, patients, and carers) and mobility.



## Medical research project LEOPARD, Horizon Europe

The LEOPARD project stands as a pioneering effort in the field of liver transplantation (LT), uniting stakeholders across Europe to revolutionise organ allocation strategies for individuals with decompensated cirrhosis (DC) and hepatocellular carcinoma (HCC). Among patients currently listed for liver transplantation in Europe, mortality/drop-out on the waitlist averages 15-20% with large disparities across European countries. In recognition of the critical need to prioritise LT candidates based on mortality risk, particularly in the context of organ shortages, and the limitations of existing predictive models such as the Model for End-Stage Liver Disease (MELD) in accurately assessing this risk, there is a growing urgency for updated algorithms to refine organ offering schemes.



## Medical research project ARTEMIS, Horizon Europe

The ARTEMIS project aims to consolidate existing computational mechanistic and machine-learning models at different scales to deliver 'virtual twins' embedded in a clinical decision support system (CDSS). The CDSS will provide clinically meaningful information to clinicians, for a more personalised management of the whole spectrum of Metabolic Associated Fatty Liver Disease (MAFLD). MAFLD, with an estimated prevalence of about 25%, goes from an undetected sleeping disease, to inflammation (hepatitis), to fibrosis development (cirrhosis) and/or hepatocellular carcinoma (HCC), decompensated cirrhosis and HCC being the final stages of the disease. However, many MAFLD patients do not die from the liver disease itself, but from cardiovascular comorbidities or complications.



## Medical research project LIVERAIM, European Institute for Innovation and Technology – EIT Health

The LIVERAIM project concentrates a team of renowned clinical centres and Industrial partners, including SMEs, with great expertise in the field of Liver Disease, the aim being to design and validate a screening platform with biomarkers for population screening to use across Europe. The objective is to identify liver disease early and apply personalised therapeutic interventions. A large number of existing biomarkers will be tested for fibrosis prediction accuracy using biobank plasma samples from 40,000 subjects from previous H2020 EU-funded cohorts.

*As part of many medical research projects, ELPA representatives participated in meetings and initiatives to implement and monitor them.*

## LEOPARD kick-off meeting

Liver transplantation (LT) is a life-saving procedure for decompensated cirrhosis (DC) and hepato-cellular carcinoma (HCC). Its efficacy is hampered by the risk of death/drop-out on the Wait List (WL). This risk is driven by organ shortage and is mitigated by organ offering schemes. According to a sickest first policy, offering schemes prioritise LT candidates with the highest risk of dying, as assessed by predictive models. To drive allocation, Organ Sharing Organizations (OSOs) use a 20-year-old model, the MELD, predicting mortality in DC but not in HCC. Because of a dramatic increase in the percentage of HCC candidates (40% against 10% in the early 20ties), MELD schemes are increasingly inaccurate, with persisting 15 to 30%



*LEOPARD kick-off meeting, group picture*

mortality in countries with low/medium donation rates. This scenario, together with advances in prognosis in DC and HCC candidates and statistics, prompts the LT community to look for updated algorithms to refine offering schemes. To address this issue, key European LT stakeholders, including ELPA, OSOs, experts in LT, Statisticians, Research Labs and SMEs, joined LEOPARD (Liver Electronic Offering Platform with Artificial intelligence-based Devices). Building on an innovative, harmonised OSOs pre-LT dataset and advances in modelling, LEOPARD proposes to design and validate 1) an AI-based LEOPARD predictive algorithm outperforming current allocation models by better-stratifying patients on the risk of mortality, to be proposed OSOs to drive allocation; 2) DC & HCC LEOPARD calculators available for professional for assistance in complex decision-making processes; 3) OMICs/radiomics predictive signatures integrated in a prototype 3<sup>rd</sup>-generation exploratory model. We expect to generate computational tools to improve candidates' outcomes, with more patients transplanted on time. Adoption of these tools should result in the harmonisation of the European heterogeneous prioritisation schemes and in a significant reduction in disparities of access to LT. LEOPARD should place Europe in a leading position for organ offering schemes. The kick-off meeting took place in Paris on January 25-26, 2024.

## THRIVE kick-off meeting



*THRIVE kick-off meeting, group picture*

The European Union's THRIVE project (Tumour host interactions in liver cancer for childhood and adults) held its kick-off meeting on January 12, 2024. Thirty-five people, including ELPA representatives, attended the meeting, which took place in the Esteve Auditorium of the Esther Koplowitz Centre, where IDIBAPS' headquarters are located. Liver cancer is a major health problem, with 1 million cases diagnosed each year worldwide (60,000 cases per year in Europe). It is the third-leading cause of cancer-related mortality in the world. Hepatocellular carcinoma (HCC) in adults and hepatoblastoma (HB) in children are considered little-known cancers and have a poor prognosis if detected late. THRIVE is the liver cancer project best funded by the European Union. It has a budget of €12 million and 13 organisations from eight European countries. It is funded as part of the European Commission's 'Mission on Cancer', which aims to improve the lives of over three million people by 2030. The ultimate goal of THRIVE is to improve the survival rates of both paediatric and adult liver cancer patients by understanding at-risk populations and tumour-host interactions and developing biomarkers for current therapies, as well as affordable new treatments to overcome drug

resistance. Around 6,500 liver cancer cell samples (hepatocellular carcinoma and hepatoblastoma) will be used for this purpose, analysed with the most advanced technologies such as single-cell sequencing, spatial transcriptomics, microbiome research, artificial intelligence and next-generation sequencing, as well as patient-derived organoids and xeno-implants. Among other things, the THRIVE project aims to:

- Define the molecular characteristics of predisposition to cancer and of populations at risk of developing liver cancer, particularly of patients associated with metabolic syndrome
- Identify molecular and AI response markers for immunotherapies.
- Develop a complete blueprint of liver cancer and the elements involved.
- Implement a pre-clinical drug testing platform for the discovery of affordable new therapies with a high impact and level of social acceptance.
- Maximise the impact on European society by integrating the humanities and the social sciences and provide accessible and reusable data and tools to support other EU initiatives.

In summary, the THRIVE project strives to understand better the main liver cancers in the adult and paediatric population so they can be treated more effectively.

## ARTEMIs kick-off meeting

The ARTEMIs project aims to consolidate existing computational mechanistic and machine-learning models at different scales to deliver 'virtual twins' embedded in a clinical decision support system (CDSS). The CDSS will provide clinically meaningful information to clinicians for a more personalised management of the whole spectrum of Metabolic Associated Fatty Liver Disease (MAFLD). MAFLD, with an estimated prevalence of about 25%, goes from an undetected sleeping disease to inflammation (hepatitis), to fibrosis development (cirrhosis) and/or hepatocellular carcinoma (HCC), decompensated cirrhosis and HCC being the final stages of the disease. However, many MAFLD patients do not die from the liver disease



*ARTEMIs kick-off meeting, group picture*



itself but from cardiovascular comorbidities or complications. The project will contribute to the earlier management of MAFLD patients by prognosing the development of more advanced forms of the disease and cardiovascular comorbidities and promoting active surveillance of patients at risk. The system will predict the impact of novel drug treatments, procedures, or better life habits. The system will, therefore, serve as a clinical decision-aid tool and an educational tool for patients to promote better nutritional and lifestyle behaviours. In more advanced forms of the disease, therapeutic interventions include TIPS (Transjugular intrahepatic portosystemic shunt) to manage portal hypertension, partial hepatectomy, and partial or complete liver transplant. ARTEMIs will contribute to predicting pre - or post-intervention heart failure, building on existing microcirculation hemodynamics models. The model developers will benefit from a large distributed patient cohort and data exploration environment to identify patterns in data, draw new theories on the liver-heart metabolic axis and validate the performance of their models. The project includes a proof-of-concept feasibility study assessing the utility of the integrated virtual twins and CDSS in the clinical context.

## Healthy Lifestyle for Europe kick-off meeting



*Healthy Lifestyle for Europe kick-off meeting, group picture*

The Healthy Lifestyles for Europe project (HL4EU) will foster a cross-sectoral approach to healthy lifestyles promotion among a variety of stakeholders. The project is in line with the European Commission and WHO's vision and existing policy initiatives and in sight of tackling the increasing burden of NCDs and of reducing health inequalities across Europe. The consortium consists of leading national and European representative organisations from different sectors, including fitness, physical activity, outdoors, health (doctors, patients, and carers) and mobility. During the project's 30-month duration, the partners will raise awareness of the importance of cross-sectoral healthy lifestyle promotion, facilitate cross-sectoral collaboration through the development of a dedicated stakeholder platform, identify and share good



practices of cross-sectoral collaboration, and provide input for future policy developments on the topic through a set of policy recommendations. Through these actions, HL4EU will strengthen the sustainability and legacy of the European Commission's 'HealthyLifestyles4All' campaign and provide support to future European policy initiatives in this direction. A variety of actions will be developed to reach the project's objectives, including the publication of a Call to Action, the identification of good practices through both desk research and active outreach, the development of a stakeholder platform listing good practices, focus group sessions to capture practice-based feedback that will contribute to the policy recommendations, as well as a community building conference and a final conference. The HL4EU project aims to be the start of a structural collaboration between consortium partners and to bring the different sectoral networks closer together to facilitate the implementation of cross-sectoral healthy lifestyles and to spark new collaborations, long outlasting the duration of the project.

## LIVERAIM kick-off meeting

The kick-off meeting of a new project of which ELPA is part took place in Barcelona on March 21 and 22, 2024. Liver cirrhosis and liver cancer are common and responsible for high morbidity, impaired quality of life, and significant costs for healthcare systems, causing 300K deaths per year in Europe. Predominant etiological factors are obesity, type 2 diabetes, and increased alcohol intake, which are all on the rise. It is predicted that healthy life expectancy will decrease in Europe over the next 30 years because of deaths due to liver disease. Liver cirrhosis develops after a very long period of asymptomatic liver fibrosis, staying undetected until patients develop severe complications due to cirrhosis or liver cancer. Currently, the only effective treatment available is liver transplantation, which is not applicable to all patients. If fibrosis is detected early to target the course of liver disease, then liver fibrosis is reversible. The LIVERAIM project concentrates a team of renowned clinical centres and Industrial partners, including SMEs, with great expertise in the field of liver disease, the aim being to design and validate a screening platform with



*LIVERAIM kick-off meeting, group picture*

biomarkers for population screening to use across Europe. The objective is to identify liver disease early and apply personalised therapeutic interventions. A large number of existing biomarkers will be tested for fibrosis prediction accuracy using biobank plasma samples from 40,000 subjects from previous H2020 EU-funded cohorts. LIVERAIM will develop a screening platform with biomarkers using AI for personalised early fibrosis diagnosis to be validated in a randomised controlled trial of 100K subjects from 6 representative EU countries. The platform will be linked to tailored, personalised therapeutic interventions to halt fibrosis progression. With LIVERAIM, early diagnosis and personalised intervention can stop liver disease progression and help decrease morbidity and mortality and the associated societal burdens.

## **IP-cure-B Steering Committee meeting**

On January 16, 2024, ELPA took part in the meetings of the IP-Cure-B Steering Committee. The project's objective is to develop novel curative concepts for chronic hepatitis B (CHB). Within the medical research project IP-cure-B, ELPA is responsible for disseminating and communicating the research results and any other information that can benefit patients and patient communities. ELPA is actively engaged in translating the project results and milestones into "patient-friendly" language and incorporating the patient view during the dissemination process. ELPA is also consulted to ensure that the ethics documents, information sheet, and patient consent form for the proof of concept (PoC) clinical trial are understood by patients. The process of dissemination and communication involves all ELPA's communication channels, and we actively participate in all events organised by the medical research project IP-cure-B. ELPA participated in the creation of webpage social media platforms and made sure of their updates with relevant information.

## **IPCureB annual meeting**

On April 3 and 4, 2024, ELPA representatives participated in the IPCureB project annual meeting. The objective of the project is to develop novel curative concepts for chronic hepatitis B (CHB). Specific aims will be to: i) improve the rate of functional cure of CHB by boosting innate immunity with immune modulators and stimulating adaptive immune responses with a novel therapeutic vaccine; ii) characterise immune and viral biomarker signatures for patient stratification and treatment response monitoring; iii) integrate biological and clinical data to model the best combination treatment for future trials; iv) model the effectiveness of novel curative therapies with respect to disease spectrum, patient heterogeneity, and constraints of National Health Systems. The project organisation will combine: 1) a Proof of Concept clinical trial of a combination of 2 novel compounds stimulating innate immunity; 2) a preclinical immune therapy platform in humanised mice combining immune-modulatory strategies to stimulate innate immunity, rescue exhausted HBV-specific T cells and generated anti- HBV adaptive responses; 3) extensive virologic and immune profiling to identify correlates of cure in patients, 4) the integration of large biological and clinical datasets, 5) a cost-effectiveness modelling of new therapeutic interventions, 6) project management, vii) results exploitation and dissemination. The proposal responds to the work program by: 1) including the evaluation of emerging concepts in drug and vaccine development to discover a curative strategy for CHB, a major public health concern for Europe, 2) capitalising on knowledge of host-pathogen interactions to develop novel immune-based therapies, 3) considering age, gender and viral genetic variations, 4) comprising a clinical trial and a preclinical platform for the discovery of novel immune interventions, and

selection of relevant biomarkers for validation in established clinical cohorts, 5) addressing conditions for effective uptake of the new curative interventions by National Health Systems.



*Prof Dr Pietro Lampertico M.D., Principal Investigator - Veronika Všetickova, ELPA Head of EU Affairs - Prof Dr Massimo Leviero M.D., Principal Investigator - Prof Dr Fabien Zoulim M.D., Principal Investigator - Milan Mishkovikj, ELPA Director, IP-cure-B annual meeting*

## MICROB-PREDICT 6<sup>th</sup> GA Meeting

From 20-22 March 2024, the MICROB-PREDICT consortium met in Ljubljana, Slovenia. All the attendees contributed to engaging discussions during work package presentations and productive sessions in the paper-writing workshop. Decompensation of liver cirrhosis and the progression towards acute-on-chronic liver failure (ACLF) cause 1.2 million deaths/per year. The microbiome is causally involved in cirrhosis progression and is, for drugs, the first interaction point with the patients. Drugs can alter the microbiome, leading to unwanted effects or even facilitating their effects. Still, the microbiome metabolises the drugs, shapes their effects, and possibly determines the host's drug response. As each person carries an individual microbiome, insight into these processes should help stratify or even personalise patient health care and treatment. The aims of MICROB-PREDICT are 1) to better understand the role of microbiome and the gut-liver-axis interactome with respect to microbiome functionalities, 2) to identify and validate microbiome-based biomarkers and signatures for personalised prediction of decompensation and ACLF, and response to treatment, 3) to design three new tests as easy-to-use tools and point-of-care, smartphone-connected nano biosensors, and 4) to validate them in a randomised controlled trial. MICROB-PREDICT will assemble existing data and samples from major microbiome initiatives in hepatology (12 international studies, >10,000 patients) and enrich them with holistic and in-depth analysis using cutting-edge multi-omics technologies of host and microbiome from different body sites in samples of >1,000 patients collected in a longitudinal manner with sequential visits and controlling for confounders. MICROB-PREDICT results will foster more accurate, personalised risk stratification and significant steps towards personalised decompensated cirrhosis and ACLF treatment. World-leading microbiome specialists, technology leaders



and clinical experts make this a programme of scientific excellence; patient organisations (ELPA) and the European Association for the Study of the Liver (EASL) will channel our results into a powerful dissemination, communication and exploitation programme.



*MICROB-PREDICT 6th GA Meeting, group picture*

## GENIAL General Assembly

On April 23-25, 2024, ELPA representatives participated in the GENIAL project General Assembly. Alcohol-related hepatocellular carcinoma (ALD-HCC) is, in Europe, the leading cause of liver cancer. ALD-HCC has a median 5-year survival rate of 15%. Yet, the prognosis is driven by the tumour stage, with curative options



*GENIAL General Assembly, group picture*

providing a 5-year survival exceeding 70% for early-stage HCC (<20% of cases). Therefore, interventions aiming to improve prevention and early detection are fundamental. ALD-HCC results from the interplay between environmental determinants and genetic variations. A comprehensive characterisation of environmental factors (e.g. diet, lifestyle) linked to ALD-HCC is still lacking. The 1<sup>st</sup> genome-wide association study of ALD-HCC was recently performed, identifying predisposing genetic variations. However, their role in alcohol-related liver carcinogenesis needs clarification, and the genetic architecture of ALD-HCC remains mostly unknown. GENIAL brings together partners with unique expertise in clinical hepatology, single-cell and spatial multi-omics, artificial intelligence (AI) and communication and dissemination capacities. The aim is to 1) portray genetic and environmental determinants promoting ALD-HCC; 2) evaluate how they interact at the cellular level in human samples and preclinical models to get novel insights into liver carcinogenesis and identify chemopreventive targets; and 3) assess how these determinants modulate the ALD-HCC risk in prospective cohorts of patients included in HCC surveillance programs. Environmental factors will be comprehensively characterised in an ongoing clinical trial designed to evaluate alternative methods for early-stage HCC detection. Finally, AI models, reaching the minimal viable product stage by the end of GENIAL, will be used to integrate genetic and non-genetic information (including digital imaging) to develop novel, cost-effective strategies towards prevention and early-stage detection of ALD-HCC in at-risk individuals. It is part of the Cancer Mission cluster 'Understanding.'

## Layperson events @EASL Congress

During the EASL Congress in Milan in June 2024, ELPA organised three layperson events dedicated to EU-funded medical projects in which ELPA is a partner.

The first event focused on **GRIPonMASH**, a project aiming to develop innovative screening strategies for managing metabolic-associated steatohepatitis (MASH). Participants learned about how the project aims to increase the number of patients diagnosed and aware of the lifestyle changes needed and decrease the number of people with MASH and liver cancer. In addition, they heard about the latest research findings, potential therapeutic approaches, and the project's progress in improving patient outcomes. The session included presentations from leading researchers, interactive Q&A segments, and patient testimonials highlighting the real-world impact of the project.







*Prof Dr Patrizia Burra M.D., Principal Investigator, Layperson events @EASL Congress*

novel diagnostic tools for earlier and better patient stratification and to establish personalised and effective treatment strategies. The event featured a panel discussion with microbiologists, hepatologists, and patient representatives, fostering a deeper understanding of the project's objectives and its implications for future healthcare.

The third event highlighted **LEOPARD**, a project dedicated to enhancing liver transplantation outcomes by creating and validating an AI-based predictive algorithm, considering recently identified predictors, that surpasses current models in stratifying both decompensated cirrhosis (DC) and hepatocellular carcinoma (HCC) patients by mortality/dropout risks on the waiting list. Experts in the field shared insights on how the project aims to improve patient outcomes by ensuring timely transplantations, harmonising European prioritisation schemes, and advocating for equitable access to liver transplantation to significantly reduce mortality on the waiting list.

These events not only provided valuable information to the lay audience but also emphasised the importance of patient engagement and advocacy in advancing medical research and improving healthcare outcomes. Through these interactive sessions, ELPA successfully bridged the gap between complex scientific research and patients' everyday experiences, empowering attendees with knowledge and encouraging active participation in ongoing medical projects.

The second event centred on **MICROB-PREDICT**, which investigates the role of the microbiome in predicting and treating liver diseases. Attendees were introduced to cutting-edge techniques to identify microbiome-based biomarkers and mechanisms that predict in advance when the body can no longer compensate for the dysfunctional liver (decompensated cirrhosis) when such decompensated cirrhosis progresses to acute-on-chronic liver failure (ACLF) and how to provide a patient's individual treatment response. Based on such biomarkers, the project strives to develop



*Marko Korenjak, ELPA President, - Prof Dr Manuel Castro Cabezas M.D., Principal Investigator Layperson events @ EASL Congress*

## LiverScreen General Assembly Meeting 2024

On September 20, 2024, ELPA President Marko Korenjak participated in the LiverScreen General Assembly. The LiverScreen project will screen a total of 30.000 people recruited from different European countries. By analysing the results from the 30.000 people recruited, the LiverScreen consortium can validate the diagnostic accuracy, cost-effectiveness and acceptability of using the TE technology to case-find advanced liver fibrosis in the general population. Moreover, LiverScreen will assess the prevalence of liver fibrosis within certain subpopulations based on health risk factors and will use this knowledge to fine-tune the case-finding. At project completion, it aims to have a targeted, population-based screening intervention program for chronic liver diseases in Europe, ready for implementation.



*Marko Korenjak, ELPA President, LiverScreen General Assembly Meeting*

## GRIPonMASH Executive Board Meeting

GRIPonMASH Executive Board Meeting took place on September 19 and 20, 2024. Partners discussed the current state of affairs and updated each other on their respective activities. GRIPonMASH will address the unmet public health need to reduce disease burden and comorbidities associated with Metabolic dysfunction-Associated Steatotic Liver Disease (MASLD). The consortium will focus on developing the



*GRIPonMASH Executive Board Meeting, group picture*

GRIPonMASH Diagnostic Platform, which will allow for the early detection of patients with MASH, better patient stratification, and personalised lifestyle advice. The four-year project's goal is to increase the number of people diagnosed and aware of the lifestyle changes needed and decrease the number of people with MASH and liver cancer. 30% of the world population suffers from Steatotic Liver Disease, of which MASLD is one of the clinical presentations. Of these patients, about one in five will develop MASH, an advanced stage of MASLD in which liver inflammation occurs and the liver becomes severely damaged. Moreover, 5% will develop fibrotic MASH (liver scarring). Whilst MASLD is reversible, MASH and especially fibrotic MASH, leads to irreversible complications and could even lead to liver decompensation or liver cancer. It is expected that by 2030, MASH will be the leading cause of liver transplants worldwide. Early detection of the disease is vital to ensure that the care burden is lowered and that patients can recover from MASH before it becomes chronic or even fatal.

## LIVERATION annual meeting

The first annual meeting of LIVERATION, took place on September 23-25, 2024. All the project partners gather to discuss the milestones achieved during the first year and plan the next steps. Milan Mishkivikj, ELPA Director, shared ELPA's vision on the importance of organising political meetings to further advance liver cancer research and treatment. Collaboration between patient associations and policymakers is crucial to ensure a positive impact on patients' lives. LIVERATION is a comprehensive, practical, and multinational clinical trial spanning six countries, with the objective of investigating if the enlargement of the ablated margin through radiofrequency can reduce the recurrence of Colorectal Cancer Liver Metastasis (CRLM) and enhance patient longevity. Colorectal cancer (CRC) is the third most common tumour in men and the second in women, with an estimate of 1.9 million new cases worldwide (450K in Europe) and approximately 900,000 deaths in 2020. Hepatic metastases develop in approximately 50% of colorectal cancer cases. The liver, in addition to being the most common site of metastases, is also the first and only area of spread

in 30–40% of patients. Surgery is considered the gold standard treatment and the only potentially curative option for colorectal liver metastases (CRLM). LIVERATION leverages a prospective pragmatic clinical trial coordinated by expert clinicians and surgeons on liver cancer that had achieved promising preliminary results: a reduction of cancer local recurrence by adding an additional coagulation of the margin (ACM) with radiofrequency (RF) ablation devices compared to conventional hemostatic techniques in a retrospective clinical trial. The main aim of LIVERATION is to evaluate the real-world effectiveness of ACM after liver resection in order to decrease liver cancer recurrence through a pragmatic clinical trial.



*Milan Mishkivikj, ELPA Director, LIVERATION annual meeting*

## ARTEMIs consortium meeting

ELPA representatives participated in the ARTEMIs consortium meeting on September 26 and 27, 2024. The ARTEMIs project aims to consolidate existing computational mechanistic and machine-learning models at different scales to deliver 'virtual twins' embedded in a clinical decision support system (CDSS). The CDSS will provide clinically meaningful information to clinicians for a more personalised management of the whole spectrum of Metabolic Associated Fatty Liver Disease (MAFLD). MAFLD, with an estimated prevalence of about 25%, goes from an undetected sleeping disease to inflammation (hepatitis), to fibrosis development (cirrhosis) and/or hepatocellular carcinoma (HCC), decompensated cirrhosis and HCC being the final stages of the disease. However, many MAFLD patients do not die from the liver disease itself but from cardiovascular comorbidities or complications. The project will contribute to the earlier management of MAFLD patients by prognosing the development of more advanced forms of the disease and cardiovascular comorbidities and promoting active surveillance of patients at risk. The system will predict the impact of novel drug treatments, procedures, or better life habits. The system will, therefore, serve as a clinical decision-aid tool and an educational tool for patients to promote better nutritional and lifestyle behaviours. In more advanced forms of the disease, therapeutic interventions include TIPS (Transjugular intrahepatic portosystemic shunt) to manage portal hypertension, partial hepatectomy, and partial or complete liver transplant. ARTEMIs will contribute to predicting pre - or post-intervention heart failure, building on existing microcirculation hemodynamics models. The model developers will benefit from a large distributed patient cohort and data exploration environment to identify patterns in data, draw new theories on the liver-heart metabolic axis and validate the performance of their models. The project includes a proof-of-concept feasibility study assessing the utility of the integrated virtual twins and CDSS in the clinical context.



*Veronika Všetickova, ELPA Head of EU Affairs, ARTEMIs consortium meeting*

## DECISION General Assembly

The DECISION project held its 6<sup>th</sup> General Assembly from October 16–18, 2024, focusing on novel therapies, biomarker validation, and clinical translation for acutely decompensated cirrhosis. ELPA, as a partner, was present, ensuring the voice of liver patients. DECISION strives to better understand the pathophysiology of decompensated cirrhosis leading to acute-on-chronic liver failure (ACLF) at the systems



level by taking advantage of already existing large and clinically well-characterized patient cohorts. The ultimate goal is to significantly reduce mortality through combinatorial therapies that are tailored to the specific needs of individual patients. Part of this endeavour is to develop (1) a reliable prognostic test to identify patients that are at risk for a poor outcome following standard therapy but who may benefit from a novel and personalised combinatorial therapy, and (2) a robust response test to predict the success of a novel combinatorial therapy as opposed to more aggressive solutions like a liver transplant. The assembly concluded with a summary of progress in identifying new therapeutic strategies for liver disease, underscoring the consortium's dedication to translating research into clinical practice. We are also pleased to announce that 10 % of the DECISION Phase 2 study patients have been recruited! This is an important milestone in the DECISION clinical trial, and it reflects the dedication and hard work of everyone involved.



*DECISION General Assembly, group picture*

## **HL4EU Community Building Conference Advancing Healthier Lifestyles Across Europe**

On November 5, 2024, the Healthy Lifestyles for Europe (HL4EU) Community Building Conference – Advancing Healthier Lifestyles Across Europe took place in Brussels. The successful conference brought together policymakers, industry leaders, and project partners to promote cross-sector collaboration for healthier lifestyles across Europe, underscoring the project's vision, mission, and objectives. The HL4EU project, of which ELPA is a partner, spans 30 months, during which a consortium of leading national and European organisations from the fitness, physical activity, outdoors, patient advocacy, health, and mobility sectors is dedicated to raising awareness about the importance of cross-sectoral healthy lifestyle promotion. The project also addresses how to tackle the growing burden of non-communicable diseases (NCDs) and reduce health inequalities across Europe. The event provided not only an opportunity to discuss the potential of physical activity in promoting healthy lifestyles and the need for cross-sectoral collaboration to shift from a curative to a preventive public health model but also to engage in dialogue



on the European Commission's Healthy Lifestyle 4 All campaign and the recent WHO report on physical inactivity among adults, which highlights that 31% of adults do not meet recommended levels of physical activity. The report also provides key recommendations to support Member States' efforts in this area.



*HL4EU Community Building Conference Advancing Healthier Lifestyles Across Europe, group picture*

## **FACILITATE webinars**

On April 19, 2024, ELPA attended the webinar organised in the framework of the EU-funded project FACILITATE. Participants delved into maximising the societal benefit of clinical trials and empowering participants for impactful data return. They also gained valuable insights into the FACILITATE project's promising innovations and enjoyed diverse perspectives from key stakeholders. FACILITATE is a 4-year project launched by the Innovative Medicines Initiative (IMI) whose primary aim is to enable clinical trial participants to access and make use of their personal health data gathered during studies to allow a better shared medical decision-making with the health professionals involved in their care and to create a process that allows data to be re-used also in future research.

On December 11, 2024, ELPA attended the engaging roundtable discussion centered around the FACILITATE EU funded project and the perspectives of various stakeholders involved in clinical trials. This session focused on the importance of the secondary use of data collected during these trials. What distinguished this online session is the diverse range of perspectives from key stakeholders. Alongside patient testimonials, we could hear insights from clinicians, representatives from industry, and regulatory bodies. This inclusive panel ensured a holistic discussion that fostered collaboration among all involved. The webinar agenda included a brief introduction to FACILITATE work and a stakeholder's virtual roundtable on how the secondary use of data impacts their lives (as citizens and patients) or professional work (as clinicians, pharma companies, regulators, etc.).



# **SOCIAL MEDIA ACTIVITIES**



**SOCIAL MEDIA ACTIVITIES** Report by Milan Mishkovikj**ELPA Website**

TOTAL VISITS:

**928,310****X**

FOLLOWERS

**10,000****Facebook**

FOLLOWERS

**3,000****LinkedIn**

FOLLOWERS

**3,000****X, Facebook  
& Others**

IMPRESSIONS

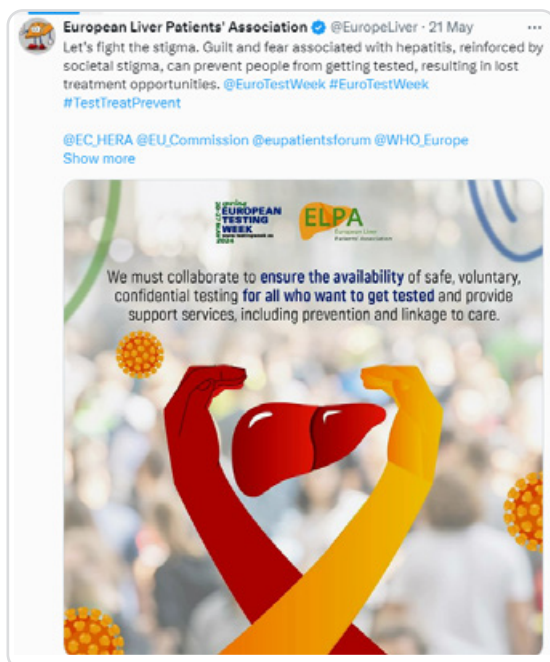
**1.2 Billion**

# ELPA's most successful Social Media Campaigns

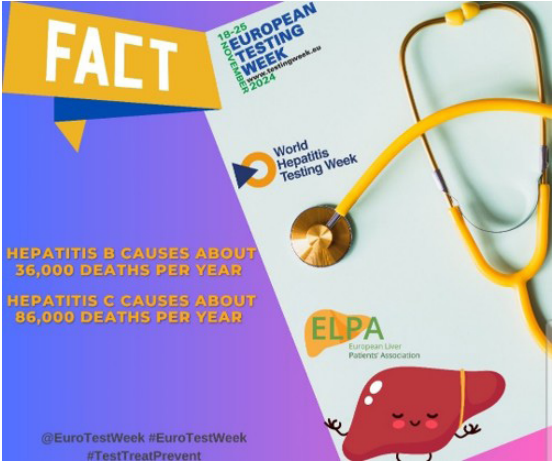
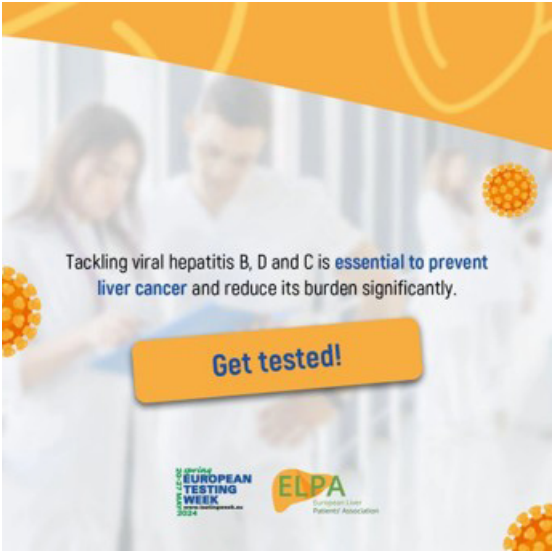
## #EuroTestWeek - Spring and Autumn edition

Like every year, ELPA participated in the European online campaign #EuroTestWeek Spring and Autumn edition. The European Testing Week is a Europe-wide campaign that encourages public and partner organizations, communities, and public health institutes throughout the WHO European Region to unite for one week, twice a year, to scale up voluntary testing. The ultimate goal of ETW is to increase efforts to make testing more accessible and communicate the benefits of earlier testing for hepatitis, HIV, and STIs. The ongoing tagline for ETW is Test. Treat. Prevent., with the aim of supporting ongoing dialogue between all partners in the HIV, hepatitis, and STI communities, in order to:

- Encourage people who could be at risk of HIV, hepatitis, and/or STIs to get tested.
- Encourage healthcare professionals to offer integrated testing for HIV, hepatitis, and/or STIs as part of routine care in specific settings and conditions (in line with current European guidelines).
- Support and unite community organisations to scale up access to integrated HIV, hepatitis, and STI testing as far as possible and share lessons learned between countries.
- Make more government bodies aware of the individual, societal and economic benefits of integrated HIV, hepatitis, and STI testing initiatives and how to evaluate testing practices.





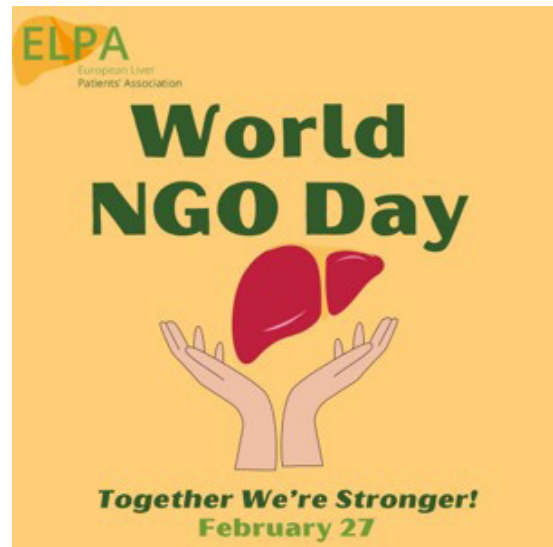


## World Cancer Day and World Cholangiocarcinoma Day

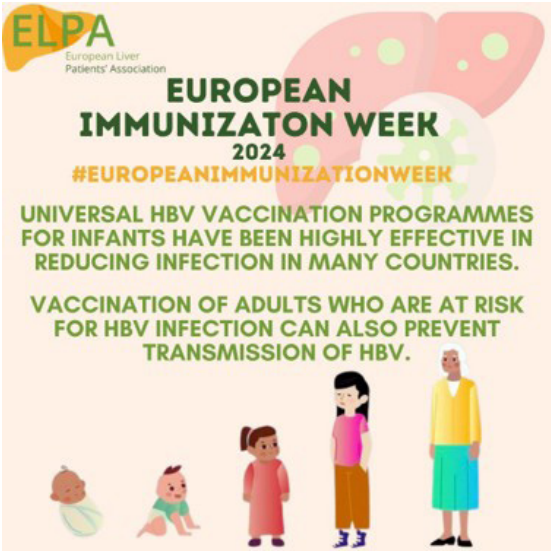
In 2024 ELPA celebrated, as every year, World Cancer Day on February 4. However, ELPA decided to go beyond World Day and run a longer campaign also including World Cholangiocarcinoma Day. The purpose was to establish a focus on liver cancer in the framework of a broader message. This goal was also pursued through the division of the messages into different categories such as data, scientific information, lifestyle, EU health policy. This assured a complete coverage of the topic.



## ELPA's support to its members, stakeholders, supporters and friends' campaigns





















# **ELPA STRUCTURE**








## ELPA Board of Directors

President	Marko Korenjak, M.A., M.A., M.A.		Slovenia
Vice-President	Julio Burman		Israel
Vice-President	Dr. Tove Frisch Ph.D.		Sweden
Vice-President and ELPA Treasurer	Ivana Dragojević		Serbia
ELPA Director	MSc. Milan Mishkovikj		North Macedonia
ELPA Director	Prof. Dr. Gamal Shiha M.D.		Egypt

## ELPA Scientific Committee

Scientific Committee leader	Prof. Dr. Paolo Angeli M.D.		Italy
	Dr. Helena Glasová M.D.		Slovakia
	Dr. Reham Soliman M.D.		Egypt
	Dr. Salvatore Piano M.D.		Italy
	Dr. Savvas Milios M.D.		Cyprus







## ELPA Advisors

Richard Hall		UK
Greg Bologna		USA
Dr. Marco Greco Ph.D.		Belgium
Prof. Dr. Rui Tato Marinho M.D.		Portugal
Prof. Shira Zelber-Sagi Ph.D.		Israel

## Editorial Team

Leader	Dr. Hilal Ünalmiş Duda Ph.D.		Turkey
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## ELPA Brussels office

Head of EU affairs	Veronika Všetíčková		Czech Republic		Belgium
Head of ELPA office	Beatrice Credi		Italy		Belgium
Project assistant	Loane Block		France		Belgium













# **ELPA WORKING GROUPS**



In 2024, ELPA officially had ten Working Groups. ELPA Working Groups are a way to create Expert Patients in a specific field of liver diseases.

ELPA Working Group on Rare Liver Diseases

LEADER	Sindee Weinbaum		Israel
MEMBERS	Richard Hall		UK
	Lone McColaugh		Denmark
	Tarja Teitto-Tuckett		Finland
	Eduardo Lopez		Spain
	Dr. Teresa Casanovas Taltavull M.D.		Spain

In 2024, the Group coordinated many campaigns on ELPA channels: Facebook, Twitter, Instagram, and YouTube.

- Rare Liver Disease Week.
- International PBC Day social media awareness campaign.
- PFIC International Day social media awareness campaign.
- Global PSC Awareness Day: social media awareness campaign, ‘Unmet needs of PSC patients’, roundtable discussions with physicians and PSC patient organisations from around the world.





Also, the group actively participated in many events:

- PSC Forum, Forum for Collaborative Research
- PSC Patients Seeking a Cure
- PBC International Summit
- Global Liber Institute: Pediatric and Rare Disease Council – Representing ELPA in periodical virtual meetings.

Working with the clinical trials Working Group, the group explained clinical trials and the importance of participating in helping find a cure and/or treatment.




Engagement with all major PSC support groups worldwide—USA, Canada, Australia, UK, Spain, France, Italy, Norway, Denmark, Finland, Macedonia, and Israel—continued. In addition, the Group renewed its commitment as part of many other groups.

## ELPA Working Group on Primary Liver Cancer

LEADER	Milan Mishkovikj		North Macedonia
MEMBERS	Lone McColaugh		Denmark
	Sindee Weinbaum		Israel
	Marko Korenjak		Slovenia


2024 was an extraordinary year for liver cancer advocacy within ELPA, ensuring liver cancer was on the radar of the most influential European institutions. The Group proudly took part in high-level events organized by the European Parliament, European Commission, and other EU institutions, making enormous contributions to ensure liver cancer and liver patients were part of every major discussion—from World Cancer Day events to key EU Summits and health conferences. These efforts reached a peak with the 2<sup>nd</sup> European Liver Screening Week in October, October liver cancer month and a high-level policy event for Liver Cancer Awareness, supported by four MEPs public health organisations, patient associations, and corporate partners. They ensured that early detection, prevention, equity, and access to treatment were top priorities on the EU health agenda. Liver cancer wasn't just a topic for one month or one day—it was part of many other ELPA activities. From Fatty Liver Month, World Hepatitis Day, European Hepatitis-HIV Weeks, Obesity Day, and Alcohol Awareness Week, the key risk factors were highlighted. ELPA advanced critical policy discussions, contributing to White Papers, Calls to Action, and aligning liver cancer within the EU Cancer Plan. However, fighting for the inclusion of liver cancer screening in the EU's official screening programs is the Group's biggest mission. They championed the use of cutting-edge biomarkers for early detection, pushing Europe toward a future where no patient is left behind.

## ELPA Working Group on Clinical Trials

LEADER	Julio Burman		Israel
MEMBERS	Dr. Teresa Casanovas Taltavull M.D.		Spain
	Yiannoula Koulla		Cyprus










They met several times virtually and put together their work plan for 2024. The group was also in contact with pharmaceutical companies, participated in many advisory boards, and participated in developing phase three of three SLD clinical trials. It was responsible for collecting and researching clinical trials in various countries to help ELPA members with up-to-date information. They participated in many meetings and webinars about this topic and encouraged two ELPA members to complete the EUPATI training and become Fellows. The group is constantly in touch with pharmaceutical companies to keep the clinical trial list updated for all ELPA members. They contributed to organising the ELPA Clinical Trials programme on SLD, a peer-to-peer educational programme to boost the ELPA members' knowledge about this topic.

## ELPA Working Group on Harm Reduction

LEADER	Aleksey Lakhov		Russia
MEMBER	Jovan Dašić		Montenegro

Harm reduction refers to policies, programs, and practices that aim to minimise adverse health, social and legal impacts associated with drug use, drug policies, and drug laws. Harm reduction is grounded in justice and human rights - it focuses on positive change and working with people without judgment, coercion, discrimination, or requiring that they stop using drugs as a precondition of support. Harm reduction is well-evidenced to prevent diseases such as HIV, viral hepatitis, and tuberculosis, among others. In 2023, the ELPA Working Group on Harm reduction made significant strides in advancing its mission to mitigate the negative consequences of substance use. The group focused on implementing evidence-based interventions and fostering collaborations with diverse stakeholders to promote harm reduction strategies. Activities included community outreach programs, educational initiatives, and policy advocacy to raise awareness about the importance of harm reduction. Additionally, the group worked towards destigmatising substance use disorders and enhancing access to harm reduction services. Looking ahead to 2024, the Group remains committed to expanding its efforts. Plans include the development of innovative harm reduction programs, continued advocacy for policy reforms, and the establishment of partnerships to strengthen their impact on individuals and communities affected by substance use further. The group is dedicated to building a safer and more supportive environment, prioritising the well-being of those struggling with substance use issues.

## ELPA Working Group on Steatotic Liver Disease (SLD)

LEADER	Yiannoula Koulla		Cyprus
MEMBERS	Lone McColaugh		Denmark
	Sindee Weinbaum		Israel
	Moisés Serrano Carrillo		Spain
	Tarja Teitto-Tuckett		Finland
	Veronika Všetíčková		Slovenia
	Dr. Teresa Casanovas Taltavull M.D.		Spain
	Dr. Reham Soliman M.D.		Egypt
	Selly Sickout		France

In 2024, the ELPA Working Group on Steatotic Liver Disease (SLD) strengthened its role as a leading advocate in the fight against SLD, including Metabolic dysfunction-Associated Steatotic Liver Disease (MASLD) and Metabolic dysfunction-Associated Steatohepatitis (MASH). Throughout the year, the group implemented a series of impactful initiatives aimed at raising awareness, influencing policy, and advancing research to improve the prevention, diagnosis, and treatment of SLD.






One of the key highlights of the year was the organization of high-profile awareness campaigns, which engaged both the general public and healthcare professionals. These campaigns featured educational webinars, patient stories, and expert discussions, effectively shedding light on the importance of early detection and lifestyle interventions. The working group also successfully hosted roundtable discussions, bringing together researchers, clinicians, policymakers, and patient representatives to explore the latest advancements and challenges in managing SLD.

A major milestone in 2024 was the release of an official statements from the ELPA Working Group on SLD, in which key members addressed the growing burden of the disease and outlined ELPA's commitment to advocacy and policy change. In thes statements, leading experts and patient advocates emphasised the need for stronger public health strategies, increased funding for research, and improved patient access to care. The initiative gained significant attention across social media platforms, further amplifying the group's message and engaging a wider audience in the conversation on SLD.

In collaboration with European health authorities and medical societies, the working group also played a crucial role in influencing policy discussions, advocating for SLD to be recognised as a major public health issue. Their efforts contributed to new policy recommendations aimed at integrating SLD screening and management into national healthcare systems, ensuring better support for patients at risk.

By the end of 2024, the ELPA Working Group on SLD had not only expanded its reach and impact but also strengthened collaborations with key stakeholders in the medical, research, and policymaking communities. Their vision of reducing the burden of SLD through education, research, and systemic policy change remained at the heart of their mission, ensuring continued progress in tackling this increasingly prevalent liver disease.

ELPA Working Group on Prevention

LEADER	Ivana Dragojević		Serbia
MEMBERS	Julio Burman		Israel
	Marko Korenjak		Slovenia

Primary prevention examines the phenomenon's assumptions, conditions, and causes and looks for ways to avoid them. Secondary prevention seeks to prevent the deepening of the spreading. It focuses on particularly vulnerable groups such as young people, minorities, or the socially disadvantaged. Tertiary prevention aims to prevent a recurrence. This group aims to promote prevention as a critical piece of the puzzle. We are trying to do that by developing two projects, HepFreeBadge -education of professionals in the beauty parlours and Women and HBV.

Long-term goals for the project HepFreeBadge are:

- Standardization of procedures in beauty parlours according to EU standards-sterilization protocol. Modernisation and increasing the level of service in beauty parlours.
- Extension of statutory regulations regarding additional controls that include sterilisation control.
- Reducing the possibility of transmitting viral hepatitis infection while providing services in beauty parlours and decreasing stigma and discrimination.



Women and HBV project will focus on women, who are someone's girlfriends, wives, and mothers, through 12 topics. So, the target group is women, but the focus is on the general population. The content of the given topic will be adapted to an ordinary woman without incomprehensible medical terms and focused on real-life situations.

## ELPA Working Group on Hepatitis B

LEADER	Ivana Dragojević		Serbia
MEMBERS	Marinela Debu		Romania
	Dr. Reham Soliman M.D.		Egypt
	Selly Sickout		France
	Jovan Dašić		Montenegro
	Dr. Vesna Lučić Samardžić M.D.		Bosnia & Herzegovina
	Zdenko Simonović		Bosnia & Herzegovina

Knowledge and awareness about Hepatitis B (HBV) have always been at the core of the association and a priority for its members. ELPA has been working on Hepatitis awareness and elimination since its creation. However, this Working Group has been collecting updated and relevant information to push forward Hepatitis B elimination and achieve this goal in collaboration with other Working Groups. This group aims to provide tools for chronic HBV patients to live their lives as safely as possible. In 2025, the Group welcomed new members and worked on its work plan, planning activities to support patients and collecting strong data to support its advocacy commitment.














## ELPA Working Group on Cirrhosis

LEADER	Marko Korenjak		Slovenia
MEMBER	Julio Burman		Israel

It has been a committed and worthwhile experience to work at the Working Group for Cirrhosis as a member of the European Liver Patient Association in 2023. The Group actively participated in multiple conversations addressing the intricate problems related to cirrhosis in an effort to enhance the quality of life for patients. One noteworthy accomplishment was growing the number of EU-funded initiatives in which ELPA is involved; several of these studies have the potential to improve the lives of people with cirrhosis significantly. The Group participated in a number of ELPA events, bringing attention to the serious issues surrounding cirrhosis in relation to viral infections like HBV and HCV and the potential for liver cancer. To improve patient advocacy, members kept a close eye on articles about cirrhosis. By taking part in ELPA's EU strategic screening week, the Group was able to locate and assist people with cirrhosis who needed help. Members aggressively promoted cirrhosis awareness towards the close of the year, concentrating on alcohol consumption throughout Europe. The Group stays steadfast in its commitment as it looks ahead to 2024. It will keep working to increase awareness, particularly on the problems associated with alcohol






misuse in Europe. As the Group works towards a better future for cirrhosis patients throughout Europe, it will continue to actively participate in all ELPA events that are directly related to the disease.

## The multicultural ELPA Working Group

LEADER	Dr Tove Frisch Ph.D.		Sweden		
MEMBERS	Dr Teresa Casanovas Taltavull M.D.		Spain		
	Eduardo López		Spain		
	Prof Dr Gamal Shiha M.D.		Egypt		
	Sindee Weinbaum		Israel		
	Richard Hall		UK		
	Dr Hilal Unalmış Duda Ph.D.		Turkey		
	Prof Dr Soo Aleman M.D., Ph.D.		Sweden		
	Dr Erik Baecklund		Sweden		
	Penilla Gunther		Sweden		
	Farhad Khaghani		Iran		Sweden
	Esso Ouro-Nimini		Togo		Sweden

In January and February, the group worked with the inquiry questions, discussions of relevance and early results. There is also a need to read literature about similar studies or other patient studies. During the first 6 months of the year, Tove went around Sweden to meet with members and patients, visit workplaces, and interview patients, doctors and others. Journeys gave a lot of new insights and knowledge about problems or joyfulness that might appear in the multicultural setting of Sweden. During the last six months, Tove has been in Turkey for a number of interviews, including interviews with doctors, politicians, patients, and family members, as well as workplace visits. Interviews with the UK were also made. In December, the hard work of listening to interviews, filling in gaps in notes taken and interviews done, and getting back and forth in the recordings was started in order to prepare for the coming analysis. During the year, there were meetings to discuss, for instance, study ethics, availability problems, results that stick out and results that are mainstream, to see what possible angles we have in the group and to find multicultural similarities and dissimilarities. They are trying to discover how underlying prejudgements or habits can influence how meetings between patients and healthcare staff are perceived and wished for. They also had meetings about scheduling the coming work during the last and third years of this project and for the final report.

ELPA Working Group on Alcohol and Liver Diseases

LEADER	Richard Hall		United Kingdom
MEMBERS	Sindee Weinbaum		Israel
	Tarja Teitto-Tuckett		Finland
	Dr. Teresa Casanovas Taltavull M.D.		Spain
	Dr. Savvas Milios M.D.		Cyprus

The ELPA Working Group on Alcohol and Liver Diseases was established in 2024 to address the increasing burden of alcohol-related liver diseases across Europe. With a strong commitment to raising awareness, the working group focuses on educating the public and healthcare providers about the risks of alcohol-related liver diseases while advocating for evidence-based policies to reduce harm. Through collaboration with researchers and institutions, the group also supports scientific advancements aimed at improving patient care and outcomes. Their vision is to create a future where alcohol-related liver diseases are significantly reduced through effective prevention strategies, early detection, and access to high-quality treatment. By fostering partnerships and promoting policy changes at national and European levels, the ELPA Working Group strives to ensure that patients receive the care they need while reducing the overall public health impact of alcohol-related liver conditions.







# **FINANCIAL ACCOUNTING AND TRANSPARENCY**



## Word from ELPA Treasurer

The financial position of the European Liver Patients' Association remained strong in the fiscal year 2024. ELPA achieved this through wise expense management combined with a successful fundraising performance.

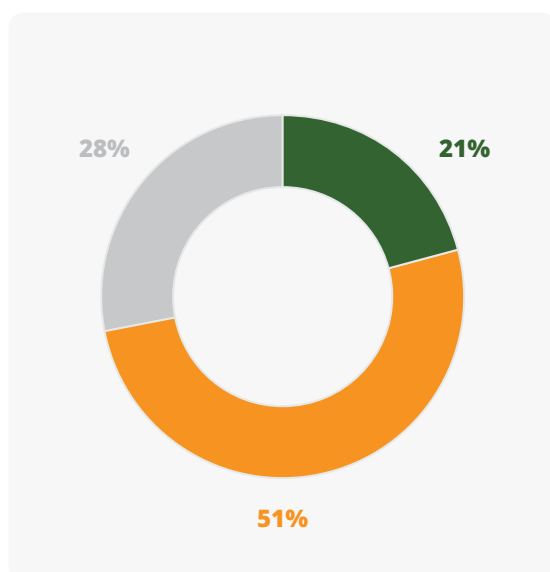
The fundraising activities conducted during 2024 made the association less dependent on pharmaceutical companies' contributions, expanding the proportion of funding coming from different sources.

Ivana Dragojević, ELPA Treasurer

## Publishing financial reports

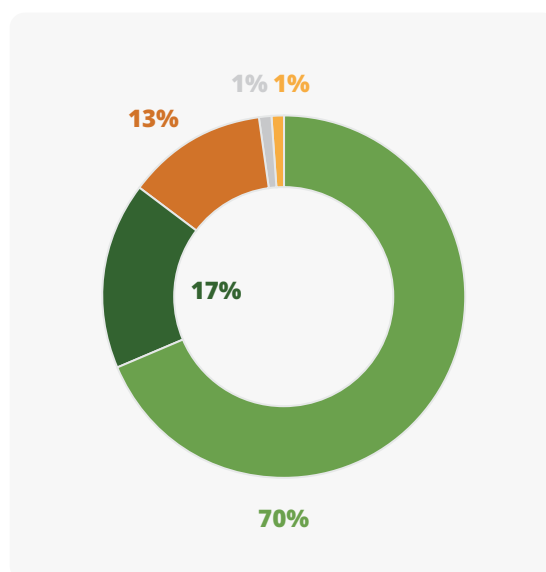
All financial reports of ELPA from 2007 are published every year and can be found on our webpage: [www.elpa.eu](http://www.elpa.eu)

### Revenue 2024



- Core funding
- ELPA's projects
- EU project

### Expenditure 2024



- ELPA work
- Operational expenses
- Wages and fees
- Depreciation
- Financial charges/income



(EUR)	31/12/2024	31/12/2023
<b>Assets</b>		
Fixed assets	30 176,20	37 118,83
III. Tangible fixed assets	26 776,20	33 718,83
B. Plant, machinery and equipment	26 776,20	33 470,16
C. Furniture and vehicles	0,00	248,67
IV. Financial fixed assets	3 400,00	3 400,00
C. Other financial fixed assets	3 400,00	3 400,00
2. Amounts receivable and cash guarantees	3 400,00	3 400,00
Current assets	797 006,59	932 781,72
VII. Amounts receivable within one year	5 000,00	5 000,00
B. Other amounts receivable	5 000,00	5 000,00
IX. Cash at bank and in hand	721 749,14	911 931,72
X. Accruals and deferred income	70 257,45	15 850,00
<b>Total assets</b>	<b>827 182,79</b>	<b>969 900,55</b>
<b>Equity and liabilities</b>		
Equity	719 456,54	923 176,02
III. Reserves	76 776,20	83 470,16
A. Reserves not available	76 776,20	83 470,16
4. Other	76 776,20	83 470,16
IV. Accumulated profits (+)/ losses (-)	642 680,34	839 705,86
Amounts payable	107 726,25	46 724,53
IX. Amounts payable within one year	39 413,22	29 724,53
C. Trade debts	16 444,51	5 701,49
1. Suppliers	16 444,51	5 701,49
E. Taxes, remuneration and social security	22 968,71	24 023,04
1. Taxes	4 413,15	12 349,03
2. Remuneration and social security	18 555,56	11 674,01
X. Accruals and deferred income	68 313,03	17 000,00
<b>Total liabilities</b>	<b>827 182,79</b>	<b>969 900,55</b>
<b>Profit and loss account</b>		
I. Operating income	865 881,53	870 277,66
A. Turnover	864 726,33	869 802,42
D. Other operating income	1 155,20	475,24
II. Operating charges	1 081 773,74	768 735,84
A. Goods for resale, raw materials and consumables	748 686,61	504 522,94
1. Purchases	748 686,61	504 522,94

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B. Services and other goods	180 971,69	175 932,29
C. Remunerations, social security costs and pensions	143 815,59	78 993,13
D. Amortisations of and other amounts written down on formation expenses, intangible and tangible fixed assets	6 942,63	6 953,64
G. Other operating charges	1 357,22	2 333,84
III. Operating profit/loss	-215 892,21	101 541,82
IV. Financial income	24 217,79	8 919,08
A. Income from financial fixed assets	425,37	242,92
C. Other financial income	23 792,42	8 676,16
V. Financial charges	12 045,06	18 516,98
A. Debt charges	350,20	2 806,48
C. Other financial charges	11 694,86	15 710,50
VI. Profit/loss of the period before taxes	-203 719,48	91 943,92
IX. Profit/loss of the period	-203 719,48	91 943,92
X. Transfer from/to untaxed reserves	6 693,96	20 081,84
A. Transfer from untaxed reserves	6 693,96	20 081,84
XI. Profit/loss of the period available for appropriation	-197 025,52	112 025,76
Appropriation account	0,00	0,00
A. Profit/loss to be appropriated	642 680,34	839 705,86
1. Profit/Loss of the period available for appropriation	-197 025,52	112 025,76
2. Profits/loss of the preceding period brought forward	839 705,86	727 680,10
D. Profit/loss to be carried forward	642 680,34	839 705,86
1. Profit to be carried forward	-642 680,34	-839 705,86







# **ACKNOWLEDGMENTS**



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