

ELPA

European Liver
Patients' Association

Back to the face-to- face leadership of patient associations

ANNUAL REPORT 2022

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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
EUPATI - European Patients' Academy on Therapeutic Innovation
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
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 32 members from 25 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.
- Policy and public health committee and Taskforce on Liver Cancer at EASL.
- Advisory Forum at HERA.
- Expert group on HIV, TB, and hepatitis at WHO.
- Expert board at VHPB.

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

Participation in Medical Research Projects

ELPA is part of 11 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,

I am thrilled to present the 2022 Annual Report of the European Liver Patient Association (ELPA) to you all. It is my honour to serve for four years more as the President of such a remarkable organisation that has been striving for the well-being of liver patients in Europe for years.

November 18, 2022, was an exceptional, meaningful, and emotional day for me. The members of the European Liver Patients' Association recognised the work that was done in the association in the last years under my leadership. We managed to make quality and quantity changes in our work, and today, we are working on more projects with higher quality.

Twenty countries (from ELPA members) that were part of the General Assembly in Barcelona voted unanimously for my position as ELPA president for another term, from 2022 to 2026.

This provides us with an opportunity to continue with our work and develop ELPA further.

This year's report focuses on the challenges and triumphs that we, as an organisation, have experienced as we navigated the COVID-19 pandemic.

The pandemic has brought unprecedented challenges to our organisation and its members. Face-to-face meetings, which are vital for networking, sharing experiences, and learning from one another, became impossible. However, as an organisation, we remained committed to serving our members and continued to provide support and information through virtual channels.

As we begin to emerge from the pandemic, we are excited about the prospect of resuming face-to-face meetings. These meetings are essential for our members' well-being and provide an opportunity to connect with one another and with experts in



Marko Korenjak

the field. We look forward to reconnecting with our members and partners in person more and more.

Our focus on member empowerment and advocacy remains at the forefront of our work. We believe that empowering our members is crucial to the success of our organisation, and we are committed to providing the necessary resources and support to enable our members to take an active role at the national level. This is why we have been investing in training and capacity-building programs to enhance the skills of our members and enable them to be effective advocates for their communities.

Finally, we are proud of the partnerships we have developed with like-minded organisations, healthcare professionals, scientists, policymakers, and industry leaders over the years. Our partnerships have been instrumental in helping us achieve our goals and have allowed us to broaden our reach and impact. We remain committed to fostering strong relationships with our partners and working collaboratively to improve the lives of liver patients across Europe. We have been actively

involved in raising awareness about the importance of early detection and prevention of liver diseases. We have also been advocating for better access to treatment and care for patients and have been working to reduce the stigma associated with liver diseases as well as increase awareness and understanding of these conditions among the general public.

In conclusion, I would like to extend my gratitude to our members, partners, and staff for their continued support and dedication to our cause. Together, we can make a difference in the lives of liver patients and their families across Europe.

Looking ahead, we remain committed to our mission of improving the lives of liver patients and their families. We will continue to work tirelessly towards this goal, and we invite you all to join us in this vital work.

Together, we can achieve much more than we can alone because together, we are stronger!

Marko Korenjak, President of the European Liver Patients' Association (ELPA)



ELPA Elections, Group Picture



Marko Korenjak, ELPA President - Commissioner for Health Stella Kyriakides

ELPA Members in 2022



BELGIUM

- VHC - Vlaams Hepatitis Contactpunt



FINLAND

- The Finnish Kidney and Liver Association



BOSNIA & HERZEGOVINA

- B18 - The Chronic Viral Hepatitis Patients Association



FRANCE

- SOS Hépatites Fédération



CROATIA

- HUHIV - Croatian Association for HIV and viral hepatitis



GEORGIA

- Hepatitis C Cured Patient Association



CYPRUS

- Cyprus Liver Patients Association, Promitheas



HUNGARY

- VIMOR - Hungarian Association of Chronic Hepatitis Patients



DENMARK

- Leverforeningen



IRELAND

- Hepatitis C Partnership



EGYPT

- ALPC - Association of Liver Patients' Care



ISRAEL

- Hetz - Israeli Association For The Health Of the Liver

**MACEDONIA**

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

**NORWAY**

- proLAR

**POLAND**

- Star of Hope Foundation

**PORTUGAL**

- SOS Hépatites Portugal

**ROMANIA**

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

**RUSSIA**

- Humanitarian Action
- United Against Hepatitis

**SERBIA**

- HRONOS - Association for helping patients with chronic viral hepatitis

**SLOVAKIA**

- HEP HELP KLUB
- Šanca pre pečeň

**SLOVENIA**

- Association - SLOVENIJA HEP

**SPAIN**

- ASSCAT - Catalan Association of Liver Patients
- FNETH - National Federation of Liver Patients and Transplanted
- AELALD - Spanish Patient Organization Lysosomal Acid Lipase Deficiency

**SWEDEN**

- RHC - Riksföreningen Hepatit C

**TURKEY**

- HEPYAŞAM - Living with Hepatitis Association

**UNITED KINGDOM**

- British Liver Trust
- Hep C Positive
- Liver4Life



2022 HIGHLIGHTS

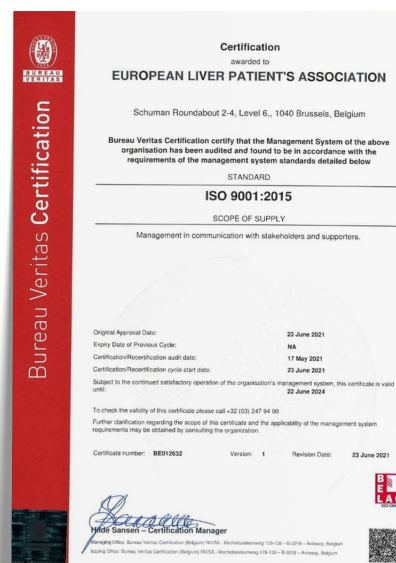
ISO QUALITY STANDARD CERTIFICATE 1st patients' association in Europe

ELPA is now the FIRST 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 2022 marked the second year of the confirmation of the system that will expire in 2023. This is the reason why ELPA will continue improving its communication with Supporters and Stakeholders, showing its high level of professionalism and commitment towards liver patients.

ELPA President became PCWP co-chair

At its exceptional December 2022 meeting, EMA's Patients' and Consumers' Working Party (PCWP) elected ELPA President Marko Korenjak as PCWP co-chair. Marko and Dr Rosa Giuliani M.D. of the European Society for Medical Oncology (ESMO) will co-chair the meetings of the PCWP with the coordination of Juan Garcia Burgos, Head of Public Engagement at EMA.

ELPA is extremely proud and confident that this new appointment will push liver and all patients' interests further up the European health policy agenda.

Congratulations!



Marko Korenjak, ELPA President - Juan Garcia Burgos

Finally, back to the in-person meetings, in 2022, ELPA met with many policymakers in the field of EU health.



Marko Korenjak, ELPA President - Commissioner for Health Stella Kyriakides



LIVER CANCER

Liver Cancer Awareness Month– campaign and website

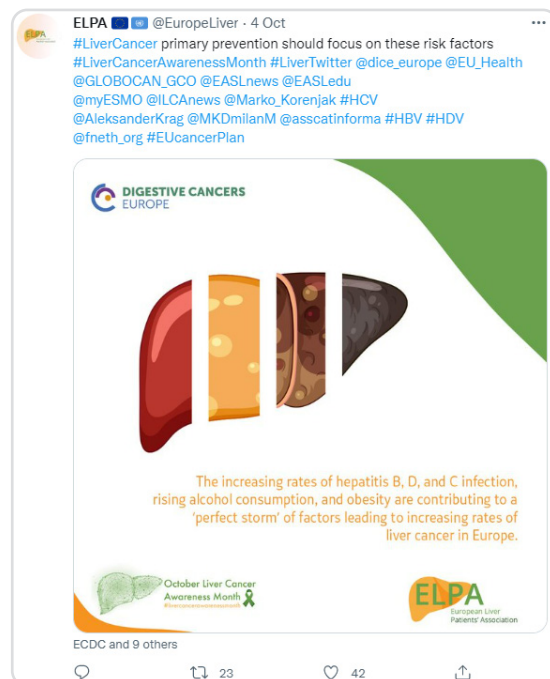
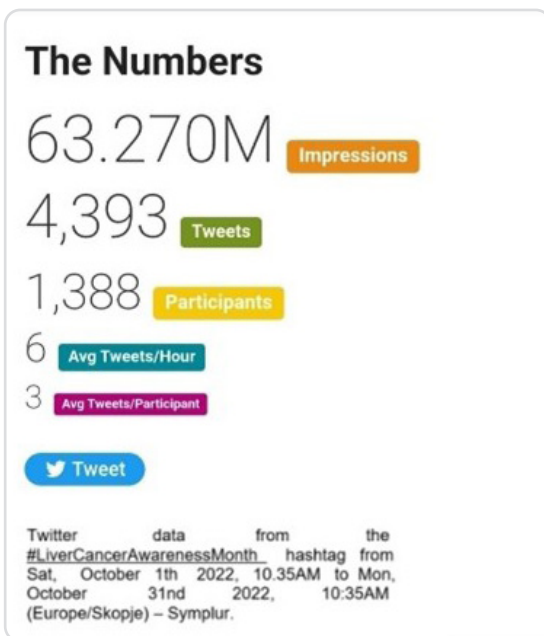
Every year, October brings liver cancer into focus to increase understanding of the disease, including its prevalence, approaches to screening and prevention, and treatment options. Liver Cancer Awareness Month (LCAM) is a great time to learn more about this vital organ’s role and how to keep it healthy and raise awareness of the local and global impact among patients, families members, healthcare professionals, other stakeholders, and the general public.


2022 ELPA’s social media campaign revolved around four categories of messages: the disease, primary and secondary prevention, treatment and care, and policy asks.

The role of Liver Patients’ Associations is crucial, and it is based on the dissemination of updated scientific information primarily focused on prevention since nobody is better than patients to inform other patients.

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

The campaign reached more than 60 million impressions.






October Liver Cancer Awareness Month

[Home](#) [About](#) [Liver Cancer](#) [Event](#) [Contact](#) [Media Center / Create Banners](#)

October Liver Cancer Awareness Month

Liver cancer is a major health problem and hepatocellular carcinoma (HCC) is considered one of the leading causes of cancer-related deaths worldwide. It is associated with many liver diseases such as Hepatitis B, C and D, excessive alcohol intake, NASH and NAFLD.

[Read More](#)



PREVENTION

The risk factors for developing HCC include cirrhosis, alcohol abuse, infection with hepatitis B virus (HBV) and hepatitis C virus (HCV) and ingestion of the fungal metabolite aflatoxin B1. In addition, metabolic syndrome (connected with NASH, obesity and diabetes) has been linked to HCC that might develop on a non-cirrhotic background.

Prevention or treatment of hepatitis B using vaccines or antivirals has reduced the incidence of HCC. With the advent of improved drugs against HCV, it is hoped that similar improvements will be made in populations with high rates of hepatitis C.

MANAGEMENT

Early stage HCC is characterized by one or a few small nodules without portal vein invasion and by preserved liver function. Treatment involves liver resection, transplantation or local ablation.

INTERMEDIATE-STAGE HCC involves multiple nodules, preserved liver function and no portal vein invasion or resection. Treatment is commonly transarterial chemoembolization, which delivers chemotherapy directly to the tumour using drug-eluting beads.

HALLMARKS OF ADVANCED DISEASE are portal vein invasion, metastases and/or symptoms. Treatment with the multitargeted inhibitor sorafenib increases survival by approximately 3 months.

STAGING

The Barcelona Clinic Liver Cancer staging system can be used to allocate treatments according to disease severity.

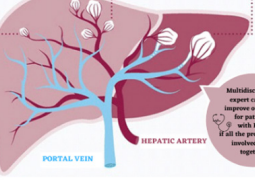
OUTLOOK

First-line treatments for early-stage disease remain transplant, partial hepatectomy, and ablation techniques depending on the characteristics of the patient and the liver. Despite detailed knowledge of driver genes in HCC, few of these have proven to be druggable targets. However, since 2006, sorafenib, which improves survival by a few months, has been the only drug available for treating this cancer. Recently some systemic therapies have been approved. Future progress in these areas will probably involve improved clinical trial design and greater understanding of tumour heterogeneity, which together will enable targeting of treatments to specific subsets of patients.

DIAGNOSIS

Non-invasive (radiological) methods to diagnose HCC are favoured but in selected patients invasive (biopsy) has to be indicated. Patients with cirrhosis can be diagnosed radiologically by ultrasonography during the surveillance programs in patients at risk then a confirmation image test is required (usually CT and/or MRI), whereas those who do not have cirrhosis or whose imaging results are inconclusive require a biopsy.

HCC symptoms usually do not occur until the disease is advanced, by which time potentially curative treatments are no longer an option. As such, screening of at-risk populations using ultrasonography is important for early diagnosis.






While liver cancer remains one of the few cancers with increasing incidence and mortality, public awareness of liver cancer appears to be much lower than for other cancers. The EU and its Member States should ensure adequate awareness, prevention, and management standards for liver cancer.




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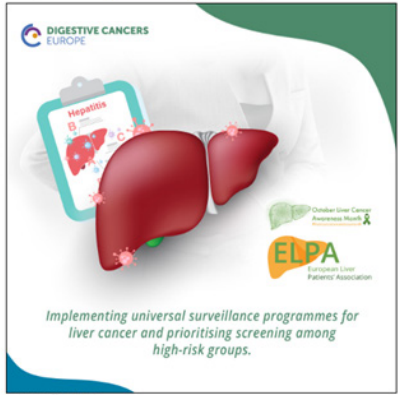
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Roundtable discussion - LIVER CANCER AND SUPPORT FOR PATIENTS, FAMILIES AND CAREGIVERS

On February 25, 2022, ELPA organised a roundtable discussion on liver cancer, hosting representatives from liver patients and the scientific community to approach the issue from different angles.

Speakers:

- Dr **José D. Debes** - Department of Med. The University of Minnesota US. Department of Gastro/Hepatol. Erasmus Med Center. Rotterdam, Netherlands.
- Dr **Joana Ferrer** - Hepato-Biliary-Pancreatic Surgery and Liver Transplant Unit. BCLC. Hospital Clinic. Barcelona, Spain.
- Mrs **Neus Llarch** - Senior nurse BCLC. Hospital Clinic. Barcelona, Spain.
- Ms **Anikó Bezegné** and Ms **Sarah Zwingman** - Liver Patients.
- Mr **Marko Korenjak** - ELPA President.
- Dr **Teresa Casanovas** - Coordinator of ELPA Scientific Committee and ELPA Director.

TAKE-HOME MESSAGE

To beat Liver Cancer, major **health policy interventions** should secure:

- Information to the general population about liver diseases
- Screening patients at risk
- Universal vaccination against HBV
- Universal treatment of HCV, if indicated
- Prevention of heavy alcohol intake - be ambitious regarding alcohol-specific legislation
- Prevention and control strategies of overweight and obesity - Integrate MAFLD into public health policies
- The promotion of education on healthy lifestyle
- Universal implementation of surveillance programmes
- New tools for early liver cancer detection
- Development of new therapies for improving outcome

ELPA @EuropeLiver · 25 Feb
 Communicating the diagnosis of **#livercancer** to the patient and family
 Dr José D. Debes
 Department of Med. University of Minnesota US. Department of Gastro/Hepatol. Erasmus Med Center. Rotterdam, Netherlands
[@EU_Health @eupatientsforum](#)
 Join us LIVE 🗣️🗣️🗣️
[fb.watch/bom4j2SZDK/](#)

What to ask your provider

- Are you sure with certainty be aware of the risk?
- Don't live waiting for repetition or how to think, is it variable or not?
- Are not variable what all options do I have?
- Personalized medicine?
- Personalized treatment?
- Personalized approach focus on quality or quantity of life?
- What is a treatment to you?
- What are the most important things to be aware of?

Liver cancer

The word "cancer"

- Fear**
 - Associated to death or lack of cure
- Confusion**
 - Different cancers and treatments are complex
 - Overwhelming
 - Related to death (and to family caring for family)
 - Ask for support
 - What did it all be disease that? why?

EASO and 9 others

Feelings related to liver cancer disease process

Stage	Emotions
Detection	Surprise
Diagnosis and staging	Anger, Denial, Sadness, Nerves
Treatment and Follow up	Suffering, Guilt, Acceptance, Fear

Uncertainty of hope But also the uncertainty of



Liver Cancer: No Patient Left Behind, Optimising the European Response

ELPA and Digestive Cancers Europe (DiCE) hosted an online European policy event on October 12, 2022. Check more details here.

Bringing together experts, policymakers, patients, and other stakeholders active in the field of liver cancer to explore what we can all do to ensure that no patient in Europe is left behind.

Speakers:

- Ms **Lieve Wierinck**, Digestive Cancers Europe (DiCE).
- Dr. **Bruno Sangro**, International Liver Cancer Association (ILCA).
- Prof. **Jeroen Dekervel**, Katholieke Universiteit Leuven.
- Ms **Zorana Maravic**, Digestive Cancers Europe (DiCE).
- Prof. **Peter Jepsen**, European Association for the Study of the Liver (EASL).
- Prof. **Sven Francque**, European Association for the Study of the Liver (EASL).
- Prof. **Jörn Schattenberg**, European Association for the Study of the Liver (EASL).
- Mr **Marko Korenjak**, European Liver Patient Association (ELPA).
- Mr **Tomislav Sokol**, Member of the European Parliament, Croatia, EPP.

- Ensure liver cancer research incorporates the patient perspective.
- We have had a lot of scientific developments in liver cancer, but they need to be better communicated to policymakers and advocacy groups.
- Ensure there is a systematic approach to collecting real-world patient experiences and needs throughout the patient pathway.
- Focus on primary care.
- We must implement screening programmes.
- A multidisciplinary team must be mandatory.
- Health literacy is a critical empowerment strategy.
- Patient organisations focusing on liver diseases and liver cancer can provide a wealth of information and support for patients.
- In medicine, language matters, mainly because it might be related to stigma.



Marko Korenjak, ELPA President - Prof Dr Bruno Sangro

A Memorandum of Understanding with the International Liver Cancer Association (ILCA)

ELPA is happy and proud to have signed a new Memorandum of Understanding with the International Liver Cancer Association (ILCA). ILCA is the only international organisation devoted exclusively to liver cancer research for experts from all related disciplines. It promotes novel pathogenic, diagnostic and therapeutic interventions for

liver cancer by taking a transversal approach to research and bringing together scientists, physicians and allied professionals from all interrelated fields.

Liver Health 2022 | The Guardian

In March 2022 ELPA contributed to the Liver Health campaign launched on March 30. The campaign had national distribution through The Guardian as well as online featuring editorial insights from the British Liver Trust (ELPA Member) amongst others. It looked to showcase the work that is being done towards the prevention, early detection and screening and treatment of all types of liver disease in the UK. The campaign looked at how lifestyle choices can help to prevent the onset of some liver-related illnesses, whilst also highlighting the support networks that are available for those that suffer from these conditions. ELPA wrote two articles about liver cancer and NASH.

ELPA's articles: <https://bit.ly/3uppyQi> and <https://bit.ly/35wsugu>.



NASH

Let's talk about fatty liver! Roundtable discussion

On June 9, 2022, International NASH Day, ELPA organised a roundtable to discuss fatty liver from different perspectives. The meeting started with a welcome speech and greetings by Mr **Marko Korenjak**, ELPA President, followed by the Member of the European Parliament, Mr **Loucas Fourlas**, Group of the European People's Party (Christian Democrats), Vice-President of the Special Committee on Beating Cancer, the Republic of Cyprus addressing the topic from a political point of view. Dr **Teresa Casanovas**, Coordinator of ELPA Scientific Committee and ELPA Director, President of ASSCAT, Spain and Dr **Reham Soliman**, Association of Liver Patients' Care – ALPC, Egypt, presented about NAFLD/NASH terminology and the change from NAFLD to MAFLD.

Childhood obesity and fatty liver disease were the topic explained by Prof Dr **Henning Groenbaek**, Department of Hepatology & Gastroenterology, Aarhus University Hospital, Aarhus, Denmark.

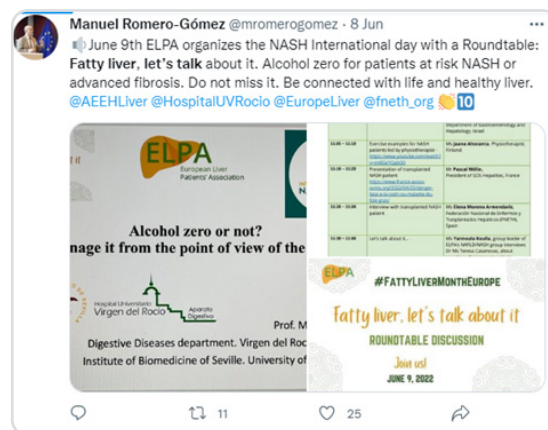
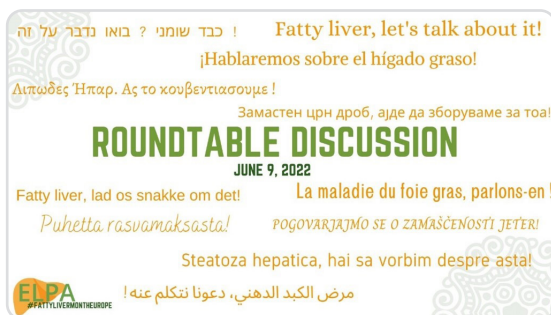
Prof Dr **Manuel Romero Gómez**, Director of the Gastroenterology Service, Hospital Universitario Virgen del Rocío, Sevilla, Spain, talked about the dilemma of alcohol zero or not and how to manage it from the point of view of the hepatologist.

His presentation was followed by Prof **Shira Zelber-Sagi**, Associate Professor Head of School of Public Health, Faculty of Social Welfare and Health Sciences, University of Haifa the Tel-Aviv Medical Center, Department of Gastroenterology and Hepatology, Israel. She stressed the importance of the prevention of NAFLD in children and adults.

Ms **Jaana Ahoranta**, a Physiotherapist from Finland, showed some exercise examples for NASH patients.

Two transplanted NASH patients shared their experience. One was presented by Mr **Pascal Mélin**, President of SOS Hepatitis, France and one by Ms **Elena Moreno Armendariz**, Federación Nacional de Enfermos y Trasplantados Hepáticos (FNETH), Spain.

Before the closing remarks by Mr **Marko Korenjak**, ELPA President, Ms **Yannoula Koulla**, leader of ELPA's MAFLD/NASH group, interviewed Dr **Teresa Casanovas** about topics that interest patients.



A global multi-stakeholder endorsement of the MAFLD definition

On March 3, 2022, the Lancet Gastroenterology Hepatology published online a global multi-stakeholder endorsement of the MAFLD definition.

Over 1000 signatories representative of multiple stakeholders, including hepatologists, internists, diabetologists, endocrinologists, paediatricians, primary-care providers, nephrologists, cardiologists, pathologists, patient advocates - included ELPA representatives - nurses, nutritionists, and pharmaceutical experts from over 134 countries, endorsed both the name metabolic (dysfunction)- associated fatty liver disease (MAFLD) as an overarching term and its definition for fatty liver diseases associated with metabolic dysregulation.

They advocate for this change because it more accurately reflects the underlying pathogenesis of the disease than does the previously used term, nonalcoholic fatty liver disease (NAFLD). Furthermore, they believe that this designation will enhance the ability to advance the science of fatty liver disease and to improve patient care.

This open letter represents the voices of individuals and multiple stakeholders across the global liver health community.

[https://www.thelancet.com/journals/langas/article/PIIS2468-1253\(22\)00062-0/fulltext](https://www.thelancet.com/journals/langas/article/PIIS2468-1253(22)00062-0/fulltext)

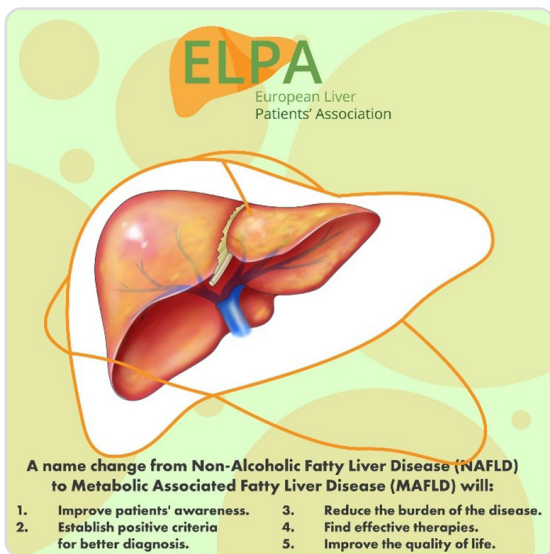
Fatty Liver Month, ELPA Campaign - 2022

The European Liver Patients Association (ELPA), in close collaboration with the ELPA MAFLD/NASH Working Group, organised the social media campaign #FattyLiverMonth. Run in June 2022; it had its highest expression on International NASH Day on June 9, 2022, in the roundtable discussion 'Fatty liver, let's talk about it.'

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 MAFLD/NASH 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 the disease. As there is still no treatment for NASH, the best way of dealing with the condition is for the patient to implement lifestyle changes, giving up to an unhealthy diet and sedentary culture.

This year, the campaign wanted to focus also on the name change from NAFLD to MAFLD, stressing how important this is for the liver patients community.

ELPA Clinical Trials Programme 2022

For its members, ELPA launched the ELPA Clinical Programme 2022 - Building patient experts - understanding clinical trials on November 20, 2022. The programme aims to improve patient centricity by training patient experts. The area of interest is NASH and NAFLD, a topic of increasing importance. It is a peer-to-peer training where some EUPATI fellows and some topic experts from ELPA members will be the trainers. The first part of the programme focused the following topics:

- Overview Research & Development
- Patient participation in clinical trials – The role of patients and patients organisations
- Understanding Preclinical Drug Development
- Clinical Trials and Patients - Part 1
- Clinical Trials and Patients - Part 2



ELPA Clinical Trials Programme, Group Picture

MAFLD 2022: An ELPA/ALPA/EASO-ECPO joint statement on disease stigma

In August 2022, ELPA co-authored an article that investigate the NAFLD acronym. The article points out how, from the perspective of patient advocacy, the non-alcoholic fatty liver disease (NAFLD) acronym is extremely problematic in terms of stigmatisation, confusion, trivialisation, and unsuitability for all patients and patient groups across the globe. [https://www.journal-of-hepatology.eu/article/S0168-8278\(22\)03058-6/fulltext](https://www.journal-of-hepatology.eu/article/S0168-8278(22)03058-6/fulltext)

A Memorandum of Understanding with the Fatty Liver Alliance

It is with great pleasure that we announce a collaborative partnership between ELPA and the Fatty Liver Alliance. An association that raises awareness and educates Canadians about the risk, causes and complications of fatty liver disease. We will fight together to promote the awareness and prevention of liver disease and care deeply about elevating the voice and needs of the patient.



Marko Korenjak, ELPA President - Michael Betel

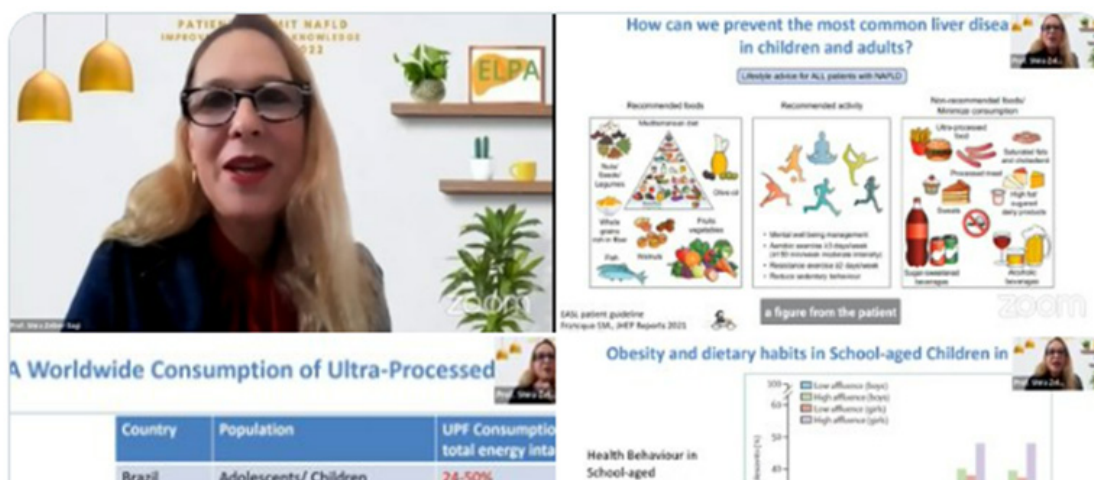
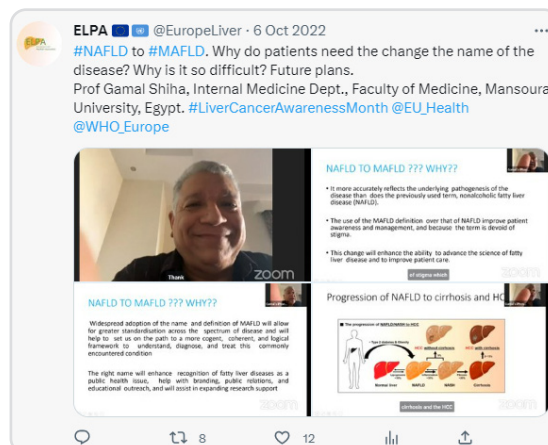
ELPA Patient Summit NAFLD, improving patient's knowledge

On October 6, 2022, ELPA organised the Patient Summit NAFLD, improving patient's knowledge. The recording is available here. The event brought together many experts and patients' representatives.

Speakers:

- Mr **Mike Betel**, Fatty Liver Alliance, Canada.
- Prof **Manuel Romero Gómez**, Director of the Gastroenterology Service, Hospital Universitario Virgen del Rocío, Sevilla, Spain.
- Prof **Gamal Shiha**, Internal Medicine Dept., Faculty of Medicine, Mansoura University, Egypt. Founder and Chairman, Egyptian Liver Research Institute and Hospital (ELRIAH), Mansoura, Egypt.

- Prof **Shira Zelber-Sagi**, Associate Professor Head of School of Public Health, Faculty of Social Welfare and Health Sciences, University of Haifa The Tel-Aviv Medical Center, Department of Gastroenterology and Hepatology, Israel.
- Ms **Veronika Všetickova**, Physiotherapist, Head of ELPA EU Affairs, Belgium.
- Dr **Michail Papoulas**, General Hospital of Nicosia, Transplant Clinic, Republic of Cyprus.
- Ms **Yiannoula Koulla**, President of Cyprus Liver Patients' Association, Leader of ELPA NAFLD / NASH group, Republic of Cyprus.
- Ms **Selly Sickout**, SOS Hepatites, France.



Prof Shira Zelber-Sagi, ELPA Patient Summit NAFLD, improving patient's knowledge

HEPATITIS

Raising awareness of Viral Hepatitis Elimination

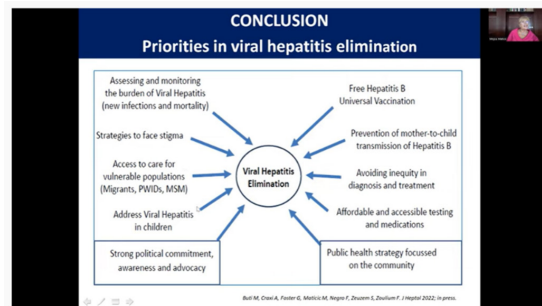
The webinar 'Raising awareness of Viral Hepatitis Elimination' took place on July 28, 2022, World Hepatitis Day. The event was organised by ELPA in the framework of the IP-Cure-B project with the collaboration of INSERM and under the patronage of the French research agency ANRS.

Speakers:

- Mr **Marko Korenjak**, ELPA President.
- Prof Dr **Fabien Zoulim**, Professor of Medicine, Lyon University Head of Hepatology Department, Hospices Civils de Lyon, Head of Viral Hepatitis Team, INSERM U1052 - Cancer Research Center of Lyon (CRCL), France.
- Prof **Mojca Matičič**, MD, PhD, Head, Unit for Viral Hepatitis Clinic for Infectious Diseases and Febrile Illnesses, University Medical Centre Ljubljana, Slovenia.
- Dr **Marc Bourlière**, French Agency for AIDS and hepatitis research (ANRS), Head of Hepato-Gastroenterology department, Hôpital Saint Joseph, France.
- Prof Dr **Massimo Levrero** Professeur des Universités - Praticien Hospitalier, Université Claude Bernard Lyon 1, Service d'Hépatologie et Gastroentérologie, Hôpital de la Croix-Rousse, Hospices Civils de Lyon, France.

The speakers discussed the state of the art of hepatitis elimination in Europe and gave details regarding the IPCureB research that aims at finding a cure for HBV infection.

They also interacted with many liver patient representatives who asked questions and gave their opinions regarding the addressed topics.

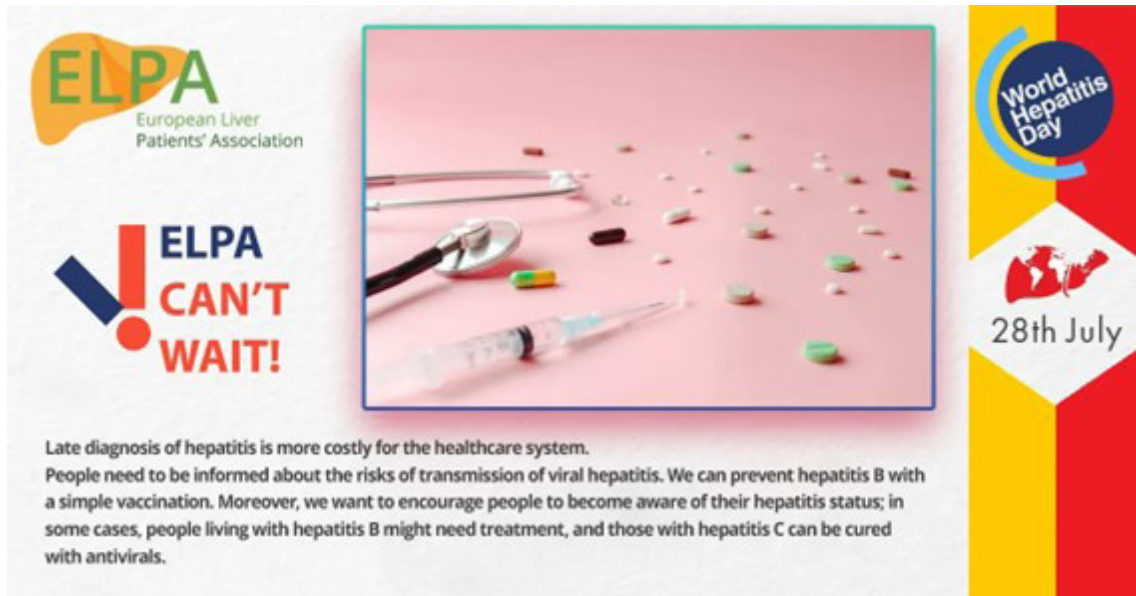


World Hepatitis Day – campaign

The World Hepatitis Alliance and their global network of over 300 members in 100 countries were proud to launch the 2022 campaign. The campaign highlighted the need to accelerate hepatitis elimination efforts. Alongside this, it also highlighted the social injustice and inequity caused by the current lack of action on hepatitis elimination, and it focused on the positive action needed to get on track to meet the 2030 elimination goals. It is a community-led campaign, and individuals and organisations can get involved to make sure that the world knows that Hepatitis Can't Wait. There was a wide range of ways to get involved in the



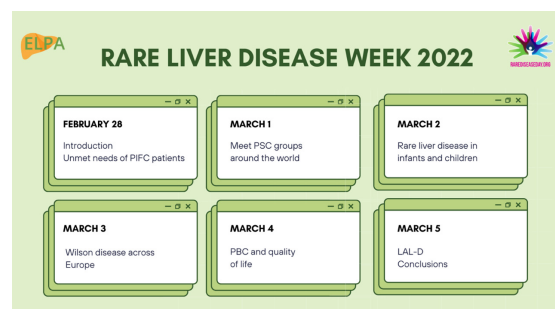
campaign, including adaptable campaign materials, tips and resources to use in every community. ELPA was proud to support the campaign.

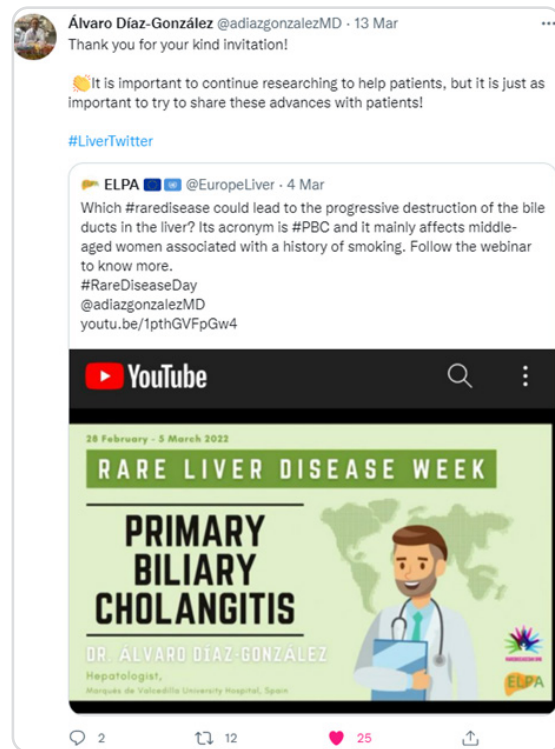
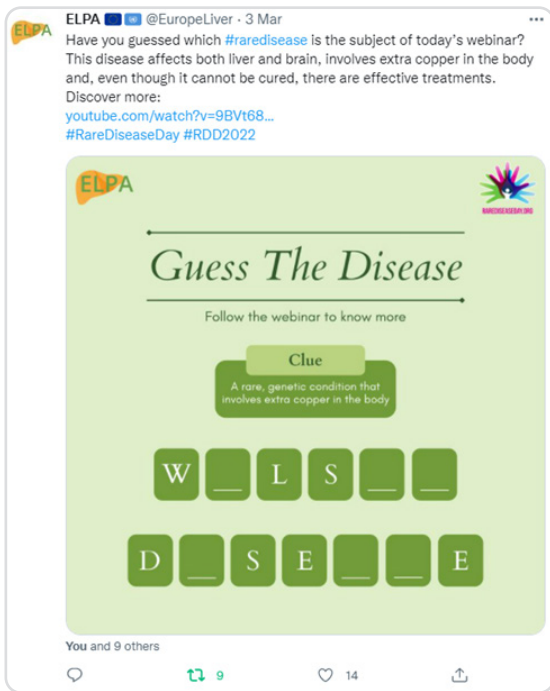


RARE LIVER DISEASES

ELPA rare liver diseases week

In 2022 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 ELPA President and the Leader of the ELPA Working Group on Rare Liver Disease on February 28, 2022. Then, it continued tackling a different liver disease every day from different angles. ELPA collected contributions from the medical scientific community but also patients, patients' family members, and patient advocates. Videos were done in the form of lectures or interviews. Each disease was introduced by a post regarding the disease that led to the specific video contribution still available on the ELPA YouTube profile.

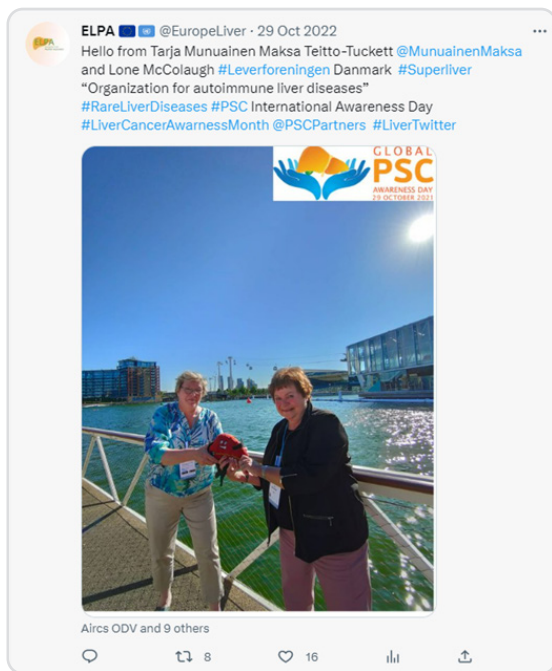




Global PSC Awareness Day - campaign and webinar

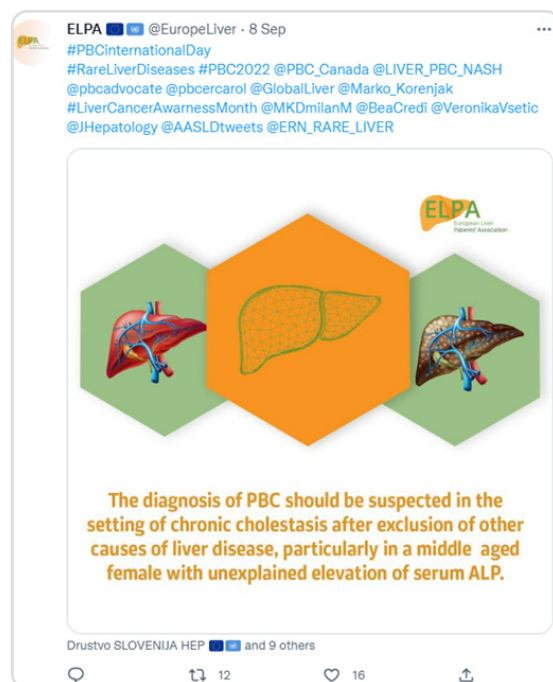
Primary Sclerosing Cholangitis (PSC) knows no boundaries. It is a rare, immune-mediated liver disease that affects the bile ducts and liver. On October 29, 2022, Global PSC Awareness Day, ELPA organized a social media campaign and partnered with different patients' organizations to bring you a selection of presentations with experts from around the world. The webinar can be watched on the ELPA YouTube channel.





International PBC Day 2022

ELPA was honoured to celebrate International PBC Day on September 11, 2022. 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).





MORE AND MORE

Meet the principal Investigators!

In 2022 ELPA continued to team up with some of the Principal Investigators involved in the IPcureB and LiverScreen projects, releasing some videos revolving around the scope and the content of the projects. Videos can be watched on the ELPA YouTube channels and on the projects' websites.



Dr. Isabel Graupera-Liver Screen



Some ELPA representatives asked questions to the scientific coordinators of DECISION, A-TANGO and MICROB-PREDIC about the projects, clinical implications and potential complications. The interviews were conducted during the International Liver Congress (ILC) in London, United Kingdom.



Dr Cornelius Engel - Veronika Všetickova, ELPA Head of EU Affairs



Beatrice Credi, ELPA Head of Office



Prof Dr Pierre-Emmanuel Rautou

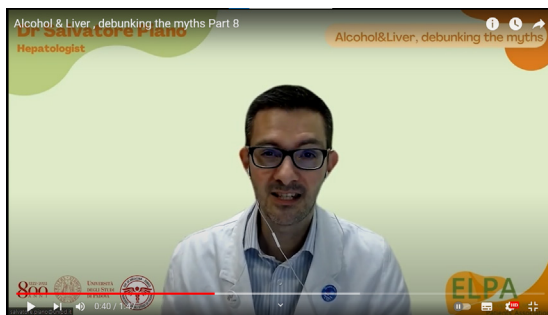


Dr Cornelius Engel, Marinela Debu

Alcohol & Liver, debunking the myths The 2022 ELPA campaign for alcohol awareness

This year ELPA prepared a special campaign to inform about alcohol-related harm publishing short videos featuring Dr Salvatore Piano, M.D., busting some common perceptions about alcohol and liver.

Watch all the videos on ELPA YouTube channel!



ELPA Members Project Support 2022

After the success of the 2021 edition, in 2022, ELPA worked even closer with its members on projects developed at the national level.

In 2022, ELPA supported the projects of 18 associations in 15 different countries:

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



International Women’s day and International Day of Women and Girls in Science

On March 8, 2022, Live on Facebook, different speakers discussed the role of women in scientific environments and the valuable contributions they give in the workplace and in society.

Participants:

- **Zakia Khattabi** - Minister for Climate, Environment, Sustainable Development and Green Deal of Belgium since 2020.
- **Laila Haidari** - Founder of Mother Camp & Taj-Begum Restaurant, to empower Afghan women and fight against addiction in Afghanistan.
- Prof Dr **Shira Zelber-Sagi** - clinical dietitian, Epidemiologist and researcher in nutritional epidemiology. School of Public Health, University of Haifa, Mount Carmel, Haifa.
- Dr **Reham Soliman** - lecturer of Infectious diseases, Port Said University, Egypt and Consultant hepatologist at the Egyptian Liver Research Institute and Hospital.
- **Lone McColough** - President of Leverforeningen, Denmark.
- **Yiannoula Koulla** - President of the Cyprus Liver Patients Association.
- **Michelle Marchione** - Global Oncology Patient Affairs at AstraZeneca.

Watch it in on ELPA YouTube channel.

On February 11, 2022, ELPA celebrate the International Day of Women and Girls in Science, supporting some statements on this topic by doctors collaborating with ELPA.



EUPATI Fellow Graduation

Congratulation! In October 2022, 47 individuals from 22 countries worldwide graduated to become EUPATI Fellows concluding the Patient Expert Training Programme with the face-to-face event in Madrid. Among them, there were also some ELPA representatives. They now join more than 200 Patient Experts who have given their time and dedication to empowering their learning journey. ELPA is very excited to see your next steps.



Marko Korenjak, ELPA President - Julio Burman, ELPA Vice-President - Yiannoula Koulla - Zdenko Simonović - Milan Mishkovikj, ELPA Director, EUPATI Fellow Graduation



Yiannoula Koulla - Nicola Bedlington, EUPATI Fellow Graduation

HERA Civil Society Advisory Forum

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.

ELPA Wikipedia page

ELPA has a brand-new [Wikipedia page](#) where everybody can find information about the association and its activities.





POLICY AND ADVOCACY ACTIVITIES

Focus on European Health Policy

European Health Parliament, 1st and 2nd Plenary

ELPA President Marko Korenjak participated as a mentor in the First and Second Plenary of the European Health Parliament on January 27, and on March 1, 2022. ELPA President worked in the Committee 'Preventive and Self-Care' together with young, motivated Europeans for six months. Each year the EHP convenes a diverse group of 60 young professionals representing all healthcare sectors. Participants work together to develop policy recommendations that address today's most pressing European health issues, which are picked in cooperation with the European Commission. EHP participants are selected for their contribution to and potential to lead in European health policy and come from a range of educational and occupational backgrounds. The recommendations were published in Summer 2022.

Oslo Medicines Initiative 2022 - webinar series

The Oslo Medicines Initiative, a joint initiative between WHO/Europe and the Government of Norway, has launched a new series of webinars that are open to the public. The webinars will take place between January 13, and February 10, 2022.

The new webinars hope to create debate and raise awareness around the importance of improving people's access to effective, novel medicines, which often come with a very high price tag. Equitable and sustainable access to safe, effective, affordable and quality-assured medicines is critical to achieving universal health coverage.

Despite this goal being shared by the public and private sectors, achieving it has been difficult. Patients, health systems and governments expect to have the right to reasonably priced pharmaceuticals that meet their needs, while investors and the pharmaceutical industry expect to earn sufficient profit to compensate for the risks inherent in developing or manufacturing those medicines.

In January, ELPA Representatives have attended three meetings held on January 13, 20, and 27, 2022. These webinars gathered experts and practitioners to discuss:

- Reflections on the markets for innovative medicines in the WHO European Region.
- Models for financing novel medicines to support innovation as a global public good.
- Pricing, reimbursement and coverage policies for sustainable access to affordable innovative medicines.

EU4Health 2022 work programme Information Session for Operating Grants

On January 20, 2022, ELPA members attended the info session presenting the procedures for NGOs operating grants under the EU4Health 2022. It was organized by the European Commission and the Health and Digital Executive Agency (HaDEA).

On January 14, 2022, the Commission adopted the annual EU4Health work programme Search for available translations of the preceding setting out the priorities and actions for the year, including resource allocation for the implementation of the EU4Health Programme.

The EU4Health programme represents an unprecedented Union level financial commitment for health actions in comparison with previous health programmes. It will work in synergy with and in a manner

that complements other Union policies, programmes and funds. The EU4Health programme will provide funding to eligible legal entities from the Member States, third countries associated to it or third countries listed in the annual work programme, created under Union law or an international organisation such as health organisations, non-governmental organisations (NGOs), the private sector and other eligible legal entities. The funding will be provided in the form of grants, procurement and prizes, directly by the Commission or by HaDEA.

Regulatory science research needs - launch event

On January 18, 2021, ELPA president attended the Regulatory Science Research Needs (RSRN) launch event, hosted by the European Medicines Agency (EMA). The online event was organised to inform the public and stakeholders, such as researchers and research funders, on the RSRN initiative.

The Regulatory Science Research Needs list is a periodically updated list that provides an overview of approximately one hundred topics identified by EMA that require additional research to address knowledge gaps in regulatory science. Research in these areas can support medicine development and evaluation, ultimately helping patients in the European Union (EU) to access innovative medicines that address their unmet needs.

The inspiring launch event was attended by several Regulatory Science Network Netherlands' (RSNN) representatives. "RSNN is fully prepared to be engaged in contributing to the EMA RSRN agenda and strategy," said Bert Leufkens (Chair of RSNN). RSNN provides a neutral platform to discuss implementation challenges of regulatory science innovations for its stakeholders through e.g., its regular small scale topical expert meetings. RSNN welcomes the RSRN initiative and is looking forward to helping address the needs identified by EMA.

4th ECDC Advisory Forum COVID-19 Consultation Series meeting

As part of the European Centre for Disease Prevention and Control - ECDC Advisory Forum, ELPA joined the 4th Consultation Series on COVID-19 on February 9, 2022. The Advisory Forum is composed of senior representatives of national public health institutes and agencies, nominated by the Member States based on their scientific competence, and a public health official from the European Commission. The European

scientific associations and civil society groups also send observers to the Advisory Forum. The ECDC Director invites WHO to attend the meetings to ensure synergy in work. As well as supporting ECDC's scientific work, the Advisory Forum is also a mechanism for exchanging information, pooling health knowledge and furthering public health cooperation.

68th ECDC Advisory Forum Meeting

As part of the European Centre for Disease Prevention and Control - ECDC Advisory Forum, ELPA joined the 68th meeting on February 22-23, 2022. The Advisory Forum is composed of senior representatives of national public health institutes and agencies, nominated by the Member States on the basis of their scientific competence, and a public health official from the European Commission. The European scientific associations and civil society groups also send observers to the Advisory Forum. The ECDC Director invites WHO to attend the meetings to ensure synergy in the work. As well as supporting ECDC's scientific work, the Advisory Forum is also a mechanism for exchanging information, pooling health knowledge and furthering public health cooperation.

Healthier Together - EU NCD Initiative

On February 3, 2022, ELPA representatives had the opportunity to learn more about the 'Healthier together'- EU NCD Initiative. Also, they could share their views on:

- Priorities for action in each of the EU NCD Initiative strands.
- Effective policies, best practices, promising approaches, innovative actions to effectively address the priorities.
- The role of stakeholders for achieving those priorities, and the actions that the stakeholders can do in collaboration with other concerned parties.

The webinar was organized by the EU Health Policy Platform for the stakeholders who are part of the platform.

State of Health in the EU: Stakeholders' perspective on digital innovation in health care and rethinking health workforce strategies

The European Policy Centre organised an online Policy Dialogue on February 8, 2022. On December 13, 2021, the European Commission, the Organisation for Economic Co-operation and Development (OECD) and the European Observatory on Health Systems and Policies (Observatory) launched the State of Health in the EU Country Profiles 2021 and Companion report. This Policy Dialogue reflected on the main issues contained in the Companion report and the Country profiles, which was presented by representatives from the European Commission, the OECD and the Observatory. Two-panel discussions with stakeholders focused on key 'takeaways' identified in the Companion report. The first panel, moderated by Hans Martens, EPC Senior Adviser, focused on Locking in the advantages of digital innovation in healthcare delivery and

public health, while the second, moderated by EPC Chief Operating Officer Emma Woodford, discussed Rethinking health workforce strategies and planning after the COVID-19 pandemic.

RCE-ESMO-ESO Training Course for Rare Cancer Patient Advocates 2022

On February 8-10, 2022, ELPA representatives participated in the RCE-ESMO-ESO Training Course for Rare Cancer Patient Advocates. Throughout three sessions, participants were informed about the latest relevant updates on the European policy agenda, as well as being able to network and exchange best practices from their local activities. Attendees also had the opportunity to participate in Patient Cafés focused on rare cancers in the new COVID-19 era and on how digitalisation can benefit rare cancer patients.

The training course was an excellent opportunity for all interested rare cancer patient advocates. It saw speakers from across the European rare cancer community, including rare cancer patient advocates, researchers, oncologists, and other relevant stakeholders.

EHMA Workshop - Building a healthcare system one individual at a time

This was the second episode of a 4-part executive workshop series addressing good leadership, person-centred care, resilient healthcare systems, and value-based approaches organized by the European Health Management Association (EHMA). 'The Many Avenues of Health Management' series will bring together different stakeholders across the healthcare ecosystem and present questions and examples future and current leaders should consider driving change in the health care sector. In this workshop, which took place on February 8, 2022, it was discussed how to design the service to enhance the patient experience, analysing business modelling logic and tools applied to health services. Looking at the segmentation, new service models, case management vs patient management, and trying to understand how we can connect providers and industry around the 'patient journey'.

WHO RCC -THV meeting

The Regional Collaborating Committee on Accelerated Response to Tuberculosis, HIV and Viral Hepatitis (RCC-THV) is a European platform for interactive exchange of information and strengthened involvement of national and international partners, including civil society organizations, in the prevention, diagnosis, treatment and care of tuberculosis (TB), HIV and viral hepatitis, hosted by WHO/Europe. On February 15, 2022, some ELPA representatives participated in a meeting of the Committee. The RCC-THV aims to support the achievement in the WHO European Region of Sustainable Development Goal (SDG) target 3.3 – by ending the epidemics of HIV and TB by 2030 and combating hepatitis – and to ensure universal health coverage for the 3 diseases. The RCC-THV contributes by fostering collaborative efforts, including reinforcing partnerships, advocacy, communication and social mobilization, and facilitating an accelerated response to TB (including M/XDR-TB), HIV and viral hepatitis prevention, diagnosis, treatment and care.

European Medicines Agency (EMA) Patients' and Consumers' (PCWP) and Healthcare Professionals' (HCPWP) Working Parties joint meeting

On March 2 and 3, 2022, the first 'Patient and Consumer' (PCWP) and 'Healthcare Professionals' (HCPWP) Working Parties joint meeting of 2022 began with an update on COVID-19 vaccines and therapeutics and safety surveillance.

The first day of the meeting provided an update on EMA projects and initiatives, including:

- Accelerating clinical trials in the EU (ACT EU).
- Big data.
- Electronic product information (ePI).
- The Agency's extended mandate.

The second day of the meeting enabled discussion on advanced therapy medicinal products (ATMPs) and sharing of members' voices.

ESMO Targeted Anticancer Therapies Congress 2022

ESMO TAT, known as "The Home of Phase I in Oncology" offers participants a glimpse of the future of targeted anticancer therapies, focusing on promising new anticancer targets and agents, with a particular focus on those in early phase clinical development. This is the place where stakeholders from academia and industry get the chance to discuss with clinicians, researchers, and regulators the global dissemination of knowledge and clinical research expertise in the field of innovative cancer therapeutics, to the benefit of cancer patients worldwide. The 2022 edition of the congress, attended by ELPA representatives on March 7 and 8, unveiled the most exciting topics coming into the clinic at the moment, with scientific sessions bridging from new cellular therapies to target agents, from ADCs to protein degraders of molecular glues, and more.

Redefining Cancer Care: Accelerating Change Together Summit

Together with the Swedish Pavilion, AstraZeneca host the Redefining Cancer Care: Accelerating Change Together Summit taking place on March 11, 2022, at Expo 2020 Dubai. The Summit provided a unique opportunity to unite global thought leaders, policymakers, medical societies, patient groups, ELPA included, healthcare practitioners and the media to challenge traditional thinking and discuss the future direction of cancer care. Cancer remains a leading cause of death globally; in 2020, there were over 19 million cases worldwide and almost 10 million deaths from the disease. The burden of the disease continues to be felt more acutely in less developed countries, where national incidence rates are projected to rise by 95% by 2040.

Cancer Stakeholders Contact Group's

Under Europe's Beating Cancer Plan, the Commission committed to make in 2022 a proposal to update the 2003 Council Recommendation on cancer screening to ensure the latest available scientific evidence is reflected and to possibly extend cancer screening beyond the breast, colorectal and cervical cancer. The proposal will be informed by advice from the European Commission's Group of Chief Scientific Advisors (GCSA). Stakeholders were asked to provide feedback on a call for evidence in February 2022. The members

of the Cancer Stakeholders Contact Group's thematic groups on 'early diagnosis and treatment', 'research, innovation, digitalisation' and 'reducing inequalities', were invited to participate in a webinar on March 28, 2022, to be provided with an overview of the advice of the GSCA and initial results of the call for evidence.

EPRD 2022 - CONFERENCE ON THE FUTURE OF A HEALTHY EUROPE “Taking part in the decision-making process on health priorities”

On April 20-21, 2022, ELPA participated in the European celebration of the XVI European Patients' Rights Day (EPRD) organised by Active Citizenship Network (ACN). With its traditional format of a big multi-stakeholder conference, the event focused on the role played by key actors in the decision-making process on health priorities. Just before the end of the Conference on the Future of Europe (CoFoE), the expectations and requests of citizens and Patients' Advocacy Groups (PAGs) addressed to the institutions were analysed. What has been discussed? Why did only a small percentage of the initiatives promoted within the CoFoE concern health issues? How to ensure that the priorities defined in the context of CoFoE will be incorporated in the implementation of the National Recovery and Resilience Plans (NRRPs)? What is the level of involvement of citizens and patients' associations in defining the implementation process of the priorities that have been identified in the health sector?

The 2022 conference had a twofold structure: a first day dedicated to the presentation to the EU Institutions of the outputs of the themes that emerged from health-related initiatives organised in the framework of the Conference on the Future of Europe, and a second day focused on analysing the actual level of citizen involvement by the Member States close to the approval by the European Commission of most of the NRRPs and their implementation at the national level.

The sixteenth edition aimed at finding answers also to the above-mentioned questions thanks to the following preliminary actions:

- 1) The recognition of the main themes that emerged from the health-related initiatives hosted by the official portal “FuturEU platform”;
- 2) A European civic survey on the level of involvement of civic and patient associations in the definition of priorities in the health sector starting from those indicated in the National Recovery and Resilience Plans (NRRPs).

Multistakeholder workshop on EMA extended mandate

On April 1, 2022, Marko Korenjak ELPA President, participated in a virtual Multistakeholder Workshop on “EMA's extended mandate”. The objectives of the workshop were to:

- Inform stakeholders about the mandate extension.
- Explain plans for the implementation of new EMA processes and timelines.
- Listen to the stakeholders' views and any concerns.

The event also provided an opportunity for the public and stakeholders to inform EMA of their needs, and expectations and discuss opportunities for further engagement.

Data Quality Framework multi-stakeholder workshop

On April 7, 2022, the European Medicine Agency (EMA) hosted joint EMA/HMA/TEHDAS Data Quality Framework workshop.

One of the Priority Recommendations of the HMA-EMA joint Big Data Task Force is to establish an EU framework for data quality that will support the trust of patients and healthcare professionals in the decisions reached by regulators, when various types of data underpin those decisions. This workshop, attended by Marko Korenjak ELPA President, sought to engage stakeholders early in the drafting process of an EU Network data quality framework, to ensure a robust starting point, in line with their expectations and needs. The main objectives of the workshop were to:

- Engage stakeholders in a discussion on the content (e.g.: topics, table of contents) and approach to a Data Quality Framework, according to their needs.
- Collect input from experts in the field and learn from existing experiences.
- Prioritise use cases to focus an in-depth analysis.

Addressing cardiovascular health in a changed and changing world

ELPA representative participated in the online event 'Addressing cardiovascular health in a changed and changing world' organized by Friends of Europe on May 16, 2022. The webinar was organized by Friends of Europe in partnership with the European Alliance for Cardiovascular Health (EACH) and supported by the MEP Heart Group, bringing together policymakers, researchers, health professionals and citizens to reflect upon ways to improve cardiovascular health in Europe. The debate showed that we cannot focus only on what needs to be done, but how it is done. Participants raised the importance of health literacy and the implementation of digital solutions across the care pathway. They also discussed the impact of an ageing population on rising cases of CVD and increasing research needs. At the event, EACH unveiled the 'European Cardiovascular Health Plan'. The ambitious strategy, which calls for the development of a European Observatory and a European Knowledge Centre for cardiovascular health, includes actions around prevention, risk assessment, data sharing and multidisciplinary care pathways.

European Cancer Patient Coalition Conference 2022

ELPA representative participated in the European Cancer Patient Coalition (ECPC) Conference on May 27, 2022, in Brussels. The Annual Congress is part of the commitment to enhance cooperation and connect members through the sharing of best practices and experiences. The event gathered partners, patient organisations, and healthcare professionals from all over Europe representing different cancer types. The aim of the ECPC Conference was to share best practices and create new partnerships. Participants shared, learned, and explored new ideas and approaches with the aim of tackling the challenges facing cancer patients. There was an exciting mix of sessions, workshops, networking breaks, and social events, with the aim of facilitating important connections to advance the cancer agenda and make the voice of cancer patients heard across Europe. Among others, the event focused on 'The EU Cancer Plan, the Cancer Mission, and patient engagement' and 'Cancer in the meta-covid era'.

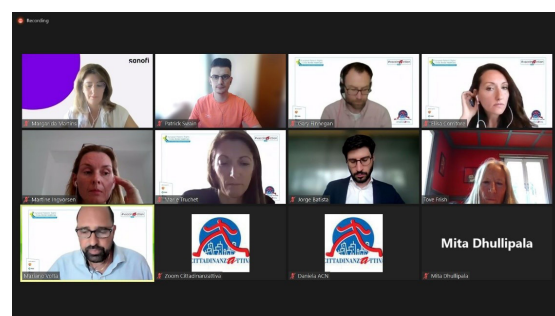


POLITICO - The unmet needs of immunocompromised patients post-COVID 19

On June 29, 2022, ELPA participated in the webinar 'The unmet needs of immunocompromised patients post-COVID 19' organised by POLITICO. European countries have switched to policies of living with COVID, relying almost entirely on vaccines to protect citizens from the most severe outcomes of infection. However, this approach precludes a key group of vulnerable people from being protected: the immunocompromised. Unable to mount a strong immune response with current vaccines, there is a need for more research into how to develop vaccines and treatments for these people. There is also a question of whether other non-pharmaceutical interventions should remain in place to protect them.

Towards the next Council conclusions: which role of adult vaccination?

On July 7, 2022, ELPA actively participated in the webinar 'Towards the next Council conclusions: which role of adult vaccination?' organised by Active Citizenship Network (ACN). As a follow-up to the Annual Meeting of the Coalition for Vaccination, and at the beginning of the Czech Semester (July 1 - December 31, 2022), the initiative allowed discussion of the EU Institutions' commitment to adult vaccination. This was an opportunity to share and discuss the importance of Hepatitis B vaccination in adults thanks to ELPA Vice-President Dr Tove Frisch who was among the speakers.



Towards the next Council conclusions: which role of adult vaccination?, Group Picture

What weight will the topic of vaccinations have in the Council Conclusions? And how the different health stakeholders (civil society, patients, health professionals, experts, and institutions) can work together on this, and what role adult vaccinations will play in the Conclusions? These are some of questions that the speakers tried to respond during the event.

The conference was organised within the framework of the VaccinAction2022 EU project, focused on supporting the need for strengthening adult vaccination in Europe and – starting from the citizens' and healthcare stakeholders' perspective – understanding the impact of the COVID-19 pandemic and vaccination campaign on the national immunisation plans, protecting the value of the adult immunisation and its gains.

EMA meeting on monkeypox

On August 23, 2022, ELPA President Marko Korenjak participated in a meeting organised by the European Medicine Agency (EMA) regarding the monkeypox outbreak. The World Health Organization declared the monkeypox outbreak a Public Health Emergency of International Concern (PHEIC) on 23 July 2022. Monkeypox disease is caused by the monkeypox virus, a human orthopoxvirus in the family Poxviridae, which is commonly found in Central and West Africa. It can spread from animals to humans, and between people through close contact. The current outbreak has been caused by a monkeypox virus from the West African clade. Monkeypox is like smallpox, but less severe. Symptoms normally last between two and four weeks and generally disappear without treatment. EMA's Emergency Task Force (ETF) is looking into available treatment options and other measures to combat the monkeypox outbreak. These include facilitating clinical trials and working with EU partners.

ESMO Congress 2022

ELPA Directors met in Paris from September 9 to 13, 2022 to participate in the annual congress of the European Society for Medical Oncology (ESMO). The ESMO Congress is Europe's most influential oncology platform for clinicians, researchers, patient advocates, journalists, and healthcare industry representatives worldwide. The ESMO 2022 congress presented the latest advances in cancer treatment and offered an excellent educational program, with a multitude of opportunities for exchange between participants. The 2022 Patient Advocates Track Sessions were designed by the Patient Advocates Working Group (PAWG) and represented an opportunity for all Congress delegates to learn, share and explore areas of collaboration while discussing topical issues for patients and survivors that directly impact cancer care and medical research.



Dr Teresa Casanovas, ELPA Scientific Committee Leader and ELPA Director – Dr Tove Frisch, ELPA Vice-President, ESMO Congress

EuroTEST meeting

The European Testing Week (ETW) has been running as a campaign for almost 10 years. In September 2022, a strategy meeting was held in Frankfurt with the ETW Working Group and other stakeholders to discuss future priorities for ETW. As part of the WG, Milan Mishkovikj, ELPA Director, attended the meeting giving his suggestions regarding the campaign, its challenges, and its future development.



Milan Mishkovikj, ELPA Director - other participants, EuroTEST meeting

Securing Equitable Patient Access to Advanced Therapies across Europe

On October 24, 2022, together with European institutions, academia, healthcare professionals, citizen organizations & Patient Advocacy Groups (PAGs), the private sector and key stakeholders, Active Citizenship Network discussed the disruptive aspects of ATMPs. All the participants focused on the opportunities and challenges of new advanced therapies, which are expected to increase significantly over the next decade: an encouraging but equally challenging scenario, considering the high costs and public budget constraints faced by several EU countries. How can European institutions facilitate this process? What decisions are taken at the level of each Member State to make these therapies accessible to the largest number of eligible patients? What role do PAGs play? On this occasion, the Call to Action “Advanced Therapies Medicinal Products revolution & the respect of the patients’ right to access to care”, so far endorsed by 37 PAGs, was officially presented at the European level.

The final push to eliminate viral hepatitis – how can the EU lead the successful achievement

In June 2022, WHO approved the Global Health Strategy Against Viral Hepatitis (2022-2030) which reaffirms the 2030 elimination target. However, progress in some Member States is lagging and mortality from hepatitis-related liver cancer is on the rise. The situation is even worse in some other World Regions. On October 25, 2022, kicked off by interventions by ACHIEVE and EASL, the conference explored:

- What can the EU do to lead and achieve this global public health goal?
- How can Europe’s Beating Cancer Plan support this aim?



Ivana Dragojević, ELPA Vice-President, ACHIEVE meeting

- Which are the funding needs from EU4Health for the years to come, and how can it be ensured that Member States and regions in greatest need will profit from this funding?
- How can good practices be shared and picked up?

Beating Cancer through prevention: A call for action on vaccine-preventable cancers across Europe

On October 25, 2022, Vaccines Europe hosted this hybrid event bringing together policymakers and key EU and national stakeholders to discuss how to increase awareness of the inclusion of vaccine-preventable cancers in the BECA report and the EBCP implementation roadmap in all Member States.

The event aimed to gather leading stakeholders to:

- Increase awareness and trigger actions at Member states level, such as expanding recommendations for HPV/HBV vaccines coverage and encourage Member States to update their National Cancer Control Plans with clear Vaccine Coverage Rate (VCR) goals on HPV and Hep B prevention.
- Explore ways to develop strategies to reflect the Europe Beating Cancer Plan's objectives, targets as part of the roadmaps towards HPV and HBV elimination.
- Incentivise Member States to make use of all available EU funding instruments to implement actions, especially for vaccine-preventable cancers.

Ivana Dragojević, ELPA Vice-President, gave a keynote speech regarding the situation in Europe. There are estimates of more than 60,000 deaths annually due to liver cancer, of which Hepatitis B is a risk factor. This infection can be prevented by the vaccine.



Ivana Dragojević, ELPA Vice-President - other participants, Vaccines Europe meeting

UEG Week 2022

ELPA representative attended the UEG Week 2022 taking place on October 8-11, 2022. Founded in 1992 United European Gastroenterology (UEG) is the leading non-profit organisation for excellence in digestive health in Europe and beyond. As Europe's home for multidisciplinary gastroenterology, UEG unites over 50,000 engaged professionals from national and specialist societies, individual digestive health experts and related scientists from all fields. The congress was a great opportunity for ELPA to make its work known in the medical community.



Veronika Všetickova, ELPA Head of EU Affairs - Marko Korenjak, ELPA President, UEG Week

The Economist 8th annual World Cancer Series Europe

ELPA President, Marko Korenjak, was invited as a speaker in The Economist's 8th Annual World Cancer Series Europe. The focus of this year's conference, that takes place in Brussels on November 8-9, 2022, was "innovation, equity, and excellence". The aim of the event was to identify strategies to accelerate innovation, reduce inequities across cancer control in Europe, and to build towards universally excellent cancer control and cancer outcomes across the continent. This timely and important discussion occurred against the backdrop of implementing the EU Beating Cancer Plan, recovery from the coronavirus pandemic, and a Europe facing security challenges and a major refugee crisis.

ELPA President, invited at the panel "Stepping up prevention - the foundation of cancer control", took the opportunity to emphasise the importance of preventive strategies in the Beating Cancer Plan and the specific interventions planned at an EU and country level. Measures should go further, and personalised and preventative health and digital tools should play a bigger role to reach vulnerable and underserved populations.



Marko Korenjak, ELPA President - panel "Stepping up prevention - the foundation of cancer control", The Economist 8th annual World Cancer Series Europe

European Cancer Summit

Every year, at the European Cancer Summit, the European Cancer Organisation brings together leading oncology experts, experienced patient advocates, key opinion leaders, policymakers and politicians to discuss key issues in reducing the burden of cancer, saving and improving the lives of patients and the public.

This year's European Cancer Summit was on November 16-17 and focused on delivery and collaboration, including through ten Focused Topic Networks.

This year's Summit was planned as a hybrid event with the majority of speakers and delegates getting a chance to meet face-to-face in Brussels and others able to join virtually, bringing together the European cancer community, including our Member Societies and Patient Advocacy groups. ELPA representative was the Vice-President Ivana Dragojević, who is a member of the Patients Advisory Committee of the European Cancer Organisation.

The European Cancer Summit is a key event whose goal is to showcase the multi-stakeholder, collaborative efforts to ensure tangible results, improve outcomes for cancer patients and raise awareness of the many significant challenges of cancer.

Webinar on the European Cancer Inequalities Registry

As member of the "Beating Cancer Stakeholder Contact Group" of the EU Health Policy Platform, ELPA attended the webinar on the European Cancer Inequalities Registry on November 9, 2022. The EU Cancer Plan puts forward the establishment of a Cancer Inequalities Registry, officially launched in February 2022. This initiative will identify trends, disparities and inequalities between Member States and regions. Alongside regular qualitative assessments of the country-specific situation, the Registry will identify challenges and specific areas of action to guide investment and interventions at EU, national and regional level under Europe's Beating Cancer Plan. The Registry will provide a regular reporting mechanism based on quantitative cancer indicators covering the whole cancer control continuum complemented by analytical reports providing contextual information and qualitative assessments.

The objectives of this meeting were to provide an update on the development of the EU Country Cancer Profiles by OECD (Organisation for Economic Cooperation and Development) and to launch the stakeholder consultation on the roadmap for the ECIR, which the Joint Research Centre presented at the meeting.

The BCLC 2022 update. Tackling the complexity of liver cancer management

ELPA Scientific Committee Leader and Director Dr Teresa Casanovas participated in the meeting organised by the BCLC group Hospital Clínic Barcelona about the complexity of liver cancer management. This was the first time that patients were invited, and Dr Casanovas stressed the role of liver patients organisation, the need of having a multidisciplinary team managing liver cancer patients and she presented the ELPA-DiCE White Paper on Liver Cancer. In her conclusions she pointed out how liver patients know the unmet needs related to liver cancer. Also, patients with chronic liver diseases of any aetiology are at risk of liver

cancer, so more knowledge about liver disease is crucial, particularly in prevention and in early diagnosis and treatment. The meeting took place in Barcelona on November 21-22, 2022.

HERA Yearly meeting

The European Health Emergency Preparedness and Response Authority (HERA), a key pillar of the European Health Union, celebrated its one-year anniversary. On this occasion, a meeting was organised in Brussels on December 8, 2022. Some ELPA representatives attended the conference “One Year of HERA” and this was the moment to reflect upon HERA’s development from emergency to structured response, to acknowledge its achievements during its first year of existence and explore its way forward to better preparedness. The give also the opportunities to share this momentum with all the stakeholders involved in the EU health policy.



Marko Korenjak, ELPA President - Director-General Pierre Delsaux, HERA Yearly meeting

EASL Meetings

EASL Liver Cancer Summit 2022

The scientific programme of the two-day Liver Cancer Summit 2022 (February 3 and 4) provided delegates, including ELPA representatives, with a live experience dedicated entirely to primary liver cancers. International experts delivered up-to-date talks on basic, translational, and clinical studies on hepatocellular carcinoma (HCC), cholangiocarcinoma (CCA), and rare primary liver cancers. The format combined state-of-the-art educational lectures and lively debates, with numerous occasions to interact with the experts. Because the boundaries are currently moving fast, global approaches were highlighted, whether this directly affects HCC and CCA in basic aspects, global epidemiology of liver tumours or treatment combination strategies.

EASL - Viral Hepatitis Elimination

The conference took place on February 24 and 25, 2022. It brought together world experts, from the World Health Organization and from countries with advanced hepatitis elimination programmes, to explore measures to mitigate this global health challenge. Speakers described methods with which to assess the burden of viral liver disease. The comparison of approaches based on modelling or direct measurement

provided delegates with a range of solutions to apply or adapt to their own programmes. The need for continuing surveillance for liver disease in those patients who have eliminated their viruses was also discussed. In addition, delegates learned from debates on recommendations for long-term follow-up. ELPA President, Marko Korenjak, actively participated in the session 'Open discussion with partners on leadership in awareness-raising, advocacy, and efforts towards viral hepatitis elimination' presenting ELPA activities in the elimination of Hepatitis B.

EASL launch of the MEP Liver Group

On March 15, 2022, EASL organized a conference on the relaunching of the MEP Friends of the Liver Group. This is an interest group at the European Parliament aiming to raise awareness, put liver health higher on the political agenda, and make policy recommendations. The objectives of the relaunch of the MEP Friends of the Liver European Parliament Interest Group are to:

- Raise awareness about the opportunities to significantly reduce the burden of liver cancer in Europe and discuss the challenges to reverse the negative trends already apparent in some countries with an increasing prevalence of the liver disease.
- Discuss these opportunities with EU policymakers in the light of the cancer prevention initiatives highlighted in the Beating Cancer Plan, e.g., promoting targeted liver cancer screening for at high-risk groups such as sex workers, homeless people, men who have sex with men, people who inject drugs (PWID), and immigrant populations, patients living with obesity and type 2 diabetes.
- Raise awareness of the importance of increasing health literacy in disadvantaged groups: social inequalities and the social determinants of health are intimately linked to susceptibility to liver disease, meaning dedicated strategies are needed to engage disadvantaged groups in care.

EASL Policy and Public Health Committee meeting

As part of the EASL Policy and Public Health Committee as a patient representative, Marko Korenjak, ELPA President, participated in a meeting of the Committee on April 25, 2022.

The mission of the Committee is to provide EASL with expert scientific and policy guidance to enable it to carry out its public affairs activities and achieve its public affairs goals and objectives.

The Policy and Public Health Committee members are responsible for coordinating the development of:

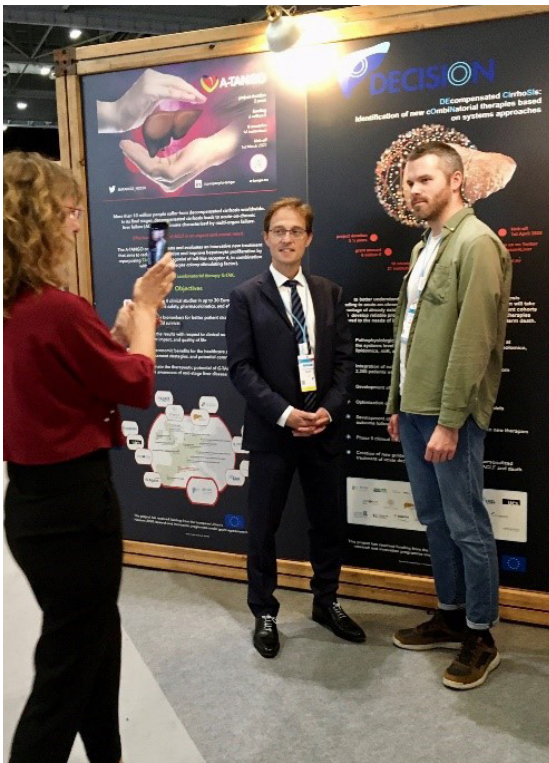
- EASL Policy and Public Health Strategy and Work Plan.
- New EASL Policy Statements, Position Statements, and EASL Public Health Policy Research.
- EASL Public Health sessions at EASL Public Health events.
- EASL cooperation with patient associations working in the field of liver conditions.

EASL-ILC 2022

As each year, ELPA members attended the EASL-ILC congress 2022. In person after a long time, the occasions to make the patients voices heard have not been missed. ELPA President Marko Korenjak's speech at the opening ceremony will be remembered as a pact between liver patients, medical doctors, scientists, and industry to work together for the liver patients' sake. ELPA representatives had also the opportunity to exchange views with some partners from the EU projects ELPA is involved in A-TANGO, DECISION and Micro-Predict. In addition, Dr Teresa Casanovas presented about DILI from patients' associations perspective, and she also illustrated a clinical case. Also, ELPA President Marko Korenjak chaired the



EASL Patient Forum 2022 - Understanding Barriers to Liver Diseases Care, the Impact of Stigma and Discrimination. During the Forum many patients' testimonies could be heard about this subject, among them one from ELPA representative Lone McColough, president of Leverforeningen, Danish ELPA member.



EASL NAFLD Summit 2022

NAFLD is the leading cause of chronic liver disease, along with higher risk of diabetes, cardiovascular disease, and cancer, and thus a major public health challenge. NAFLD represents a therapeutic area of as yet unmet clinical lead. This 4th edition of the EASL NAFLD Summit, held on September 15-17, 2022, brought together all stakeholders engaged in tackling NAFLD, including clinicians, researchers, policy and public health specialists, and industry professionals.

ELPA was represented by Ms Yiannoula Koulla, leader of the MAFLD/NASH working group, who delivered a presentation sharing with all the participants the patients' perspective of the disease and patients' unmet needs.



Yiannoula Koulla, EASL NAFLD Summit

EASL Policy Dialogues Episodes - The lives of liver patients: Prejudice and stigma

This fifth episode of the EASL Policy Dialogues Episodes gave the floor to patient advocates to discuss the issue of stigmatisation around liver disease. How and why does stigma affect people with liver disease? What are the consequences for people with liver disease facing stigma? Which actions should be prioritised to mitigate the impact of stigma?

Listen to ELPA President Marko Korenjak commenting on this important topic with Rachel Halford, CEO at The Hepatitis C Trust and part of the Board of Directors of Liver Patients International on the EASL website.

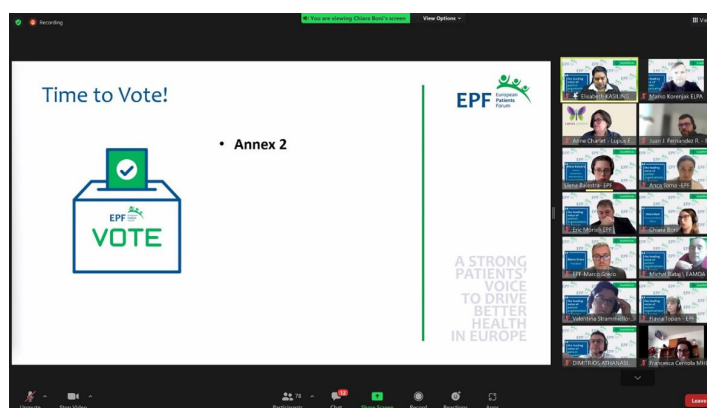


EPF and EUPATI Meetings

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

European Patients' Forum Annual General Meeting

As a member of the EPF, ELPA participated in the EPF's AGM on April 23, 2022. This year, the AGM provided EPF members with the opportunity to share their experiences and views and reflected on EPF's development and their role therein. The 2022 AGM was also the first occasion for members to e-meet EPF's new Executive Director. The assembly overlooked at collective accomplishments of the past year in the view of further developing together the work plan for 2022 and, with a longer-term perspective, exploring how the visibility and the sustainability of our movement can be ensured in the years to come.



EUPATI Expert Patient Kick-off webinar

On January 26, 2022, all the ELPA representatives enrolled in the EUPATI Fellow Programme participated in the kick-off webinar and shared their experiences with other fellows.

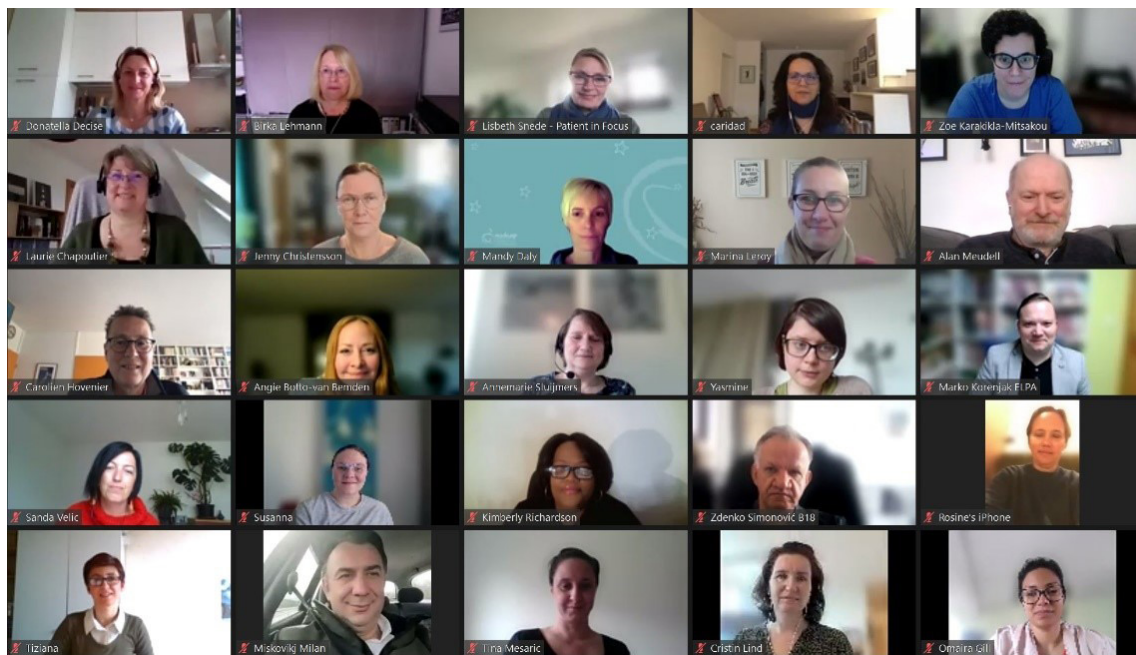
Graduates of the EUPATI Patient Expert Programme (EUPATI Fellow Programme) are also known as EUPATI Fellows or Alumni. The EUPATI Fellow title certifies the knowledge gained and gives graduates the opportunity to be recognised as expert patients. EUPATI Fellow is a widely well-known label within the patient engagement landscape. EUPATI fellows are highly sought-after partners by different stakeholders. As of 2021, more than 200 Fellows have graduated from the programme.

EUPATI Sustaining Partners Assembly Meeting

On February 17, 2022, ELPA participated in the EUPATI Sustaining Partners Assembly Meeting. ELPA is a EUPATI Sustaining Partner since March 2021. EUPATI is a public-private partnership composed of a multi-stakeholder structure representing patient organisations, not-for-profit, pharmaceutical industry and academic institutions. EUPATI's strength is its community of dedicated and committed organisations and individuals who believe in its mission to support quality patient engagement through education.

EUPATI Fellows' training days

For the ELPA representatives enrolled in the EUPATI Fellow Programme the first training event took place online on March 30 and 31 and April 4 and 5, 2022. During this event learners engaged in practical exercises led by representatives from the multi-stakeholder EUPATI Faculty. Also, the event was a great opportunity for participants to meet with each other, to interact, network and share experiences and learnings within the group.



EUPATI Fellows' training days, Group Picture

EUPATI 10th Anniversary

ELPA Vice-President, Julio Burman and ELPA Director Milan Mishkovikj participated in person at the EUPATI 10th Anniversary in Brussels on May 19 and 20, 2022. Various speakers and guests took the floor and participated in the 10-Year-Anniversary celebration in Brussels. The speakers discussed the challenging and evolving landscape of patient education, how to strengthen partnerships and achieve sustainability, the work of the EUPATI National Platforms and the vision for the future. The 2-days 10-Year Celebration event gathered in 2 different workshops on “Diversity & inclusion in health literacy” and “Changing role of patient experts and needs for further training & education”.

EUPATI Annual General Meeting

On September 22, 2022, ELPA Representatives participated in the EUPATI Annual General Meeting. With all the EUPATI stakeholders they discussed shared vision and patient-driven approach to improving health outcomes. As sustaining partner, ELPA will continue working with EUPATI to provide accessible, innovative, and inclusive education to empower patients. EUPATI is a public-private partnership composed of a multi-stakeholder structure representing patient organisations, not-for-profit, the pharmaceutical industry, and academic institutions. EUPATI's strength is its community of dedicated and committed organisations and individuals who believe in its mission to support quality patient engagement through education.



Julio Burman, ELPA Vice-President – Former Commissioner for Health Vytenis Andriukaitis - Milan Mishkovikj, ELPA Director, EUPATI 10th Anniversary

ELPA in international meetings

Optimizing HCV linkage to care: Experiences implementing laboratory-based reflex testing

On 27 January 2022, ELPA Representatives attended the webinar on laboratory-based HCV reflex testing, organized by the Coalition for Global Hepatitis Elimination (CGHE).

In Fall 2020, the (CGHE) was requested by the World Health Organization (WHO) to develop a body of programmatic evidence to inform WHO guidance on laboratory-based HCV reflex testing. This set of case studies described real-world experiences in implementing laboratory-based HCV reflex testing and highlighted operational considerations faced by clinics and laboratories.

This webinar included laboratorians, clinicians, and public health officials participating in the case studies and from others who have since been identified as pioneers in implementing HCV reflex testing in new settings. Speakers presented the HCV reflex testing algorithm used by their institution and discussed considerations on issues such as:

- Start-up investments in staff training, etc
- Revising lab ordering forms and electronic health records
- Specimen transfer and storage
- Quality control measures
- Costs and economic benefits
- Equipment requirements
- Impact on improving linkage to care

Solidarity and social contracts in the context of the United Nations Sustainable Development Goals (SDGs)

As life-saving products that promote health and alleviate illness, medicines are not a traditional commodity. The pharmaceutical market structure is a unique one not subject to the usual demand-supply structure and forces of other industrial products. Moreover, medicines occupy a unique position in global discussions around human rights – the right to health – and public goods. Countries across the globe are committed to achieving universal health coverage under goal 3 of the SDGs and access to safe, effective, quality, and affordable medicines is central to that aim. It is clear that both public and private sectors have important roles to play in this debate, which was the focus of this fifth and final webinar in the Oslo Medicines Initiative series on February 10, 2022. By applying the concept of a social contract, understood as an implicit acknowledgement of the duties and obligations of the different stakeholders to one another, speakers and panellists examined these roles, and ask how public and private stakeholders can work together to find win-win solutions that support the SDGs. The role of corporate social responsibility was also explored. A question-and-answer session with participants, ELPA representatives included, followed the discussion.



Global NASH Congress

ELPA President Marko Korenjak participated in the Global NASH Conference on May 26 and 27, 2022 in London and presented about the role of patient advocates in NAFLD and NASH. The Global NASH Conference was organized by Global Engage and focused on exciting advancements, such as improved



Marko Korenjak, ELPA President, Global NASH Congress

in vivo liver models, non-invasive diagnostic biomarkers, and a better understanding of the disease's mechanisms, as well as on the challenges of preclinical and clinical research in NASH. During the event various sessions covering regulation and business development, as well as a showcase of the most promising therapeutics in development took place. The Congress gathered experts working in all areas of non-alcoholic steatohepatitis, the conference examined the latest research and development in pathogenesis, diagnosis, and treatment of the disease. During the Congress, small-group roundtable discussions were held as well as networking.

Digital Health Advances Conference

ELPA representative participated in the Digital Health Advances Conference on May 12, 2022, in London. The event discussed the following topics:

- Digital Health Solutions
- Trends of AI and ML in Health Care
- Perspective and Strategy for Digital Therapeutics
- Post-Covid Learning and Acceleration
- New-tech and digital adoption

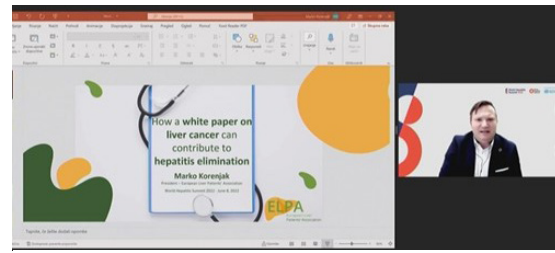
Some of the notable speakers were representing WHO, AstraZeneca, Alira Health, Johnson&Johnson, NHSX, the Crick Institute, and NHS Wales.



World Hepatitis Summit 2022

On June 7-10, 2022, ELPA President Marko Korenjak participated in the World Hepatitis Summit 2022. He was among the speakers, and he presented the White Paper on Liver Cancer published by ELPA. He stressed the link between hepatitis elimination and the fight against liver cancer showing also some advocacy activities ELPA has realized in this field. The World Hepatitis Summit (WHS) is an innovative, large-scale, global meeting to advance the viral hepatitis agenda and provide a platform for a broad hepatitis

community to take stock of progress to date, share ideas, experiences and best practices in addressing the many challenges of viral hepatitis. It is the only global hepatitis conference which is focused on public health and it provides an unrivalled opportunity to focus a global audience on the implementation of a viral hepatitis response and so drive progress to make the elimination of viral hepatitis a reality.



Marko Korenjak, ELPA President, World Hepatitis Summit 2022

AASLD/EASL HBV Endpoints Conference

On June 3 and 4, 2022 ELPA President Marko Korenjak participated in the AASLD/EASL HBV Endpoints Conference. He was among the speakers, and he presented about hepatitis D from patients' perspectives. The purpose of the conference was to bring together the academic, regulatory, pharmaceutical communities



Marko Korenjak, ELPA President, AASLD/EASL HBV Endpoints Conference

and patients' advocacy groups to discuss therapeutic endpoints, trial designs for appropriate patient populations and safety concerns with regard to novel therapeutic approaches for the treatment of chronic hepatitis B and D. The HBV therapeutic field is at a crossroads with many different approaches being considered but numerous regulatory issues, trial design issues and safety issues need to be addressed. This meeting was unique in that it brought all the important and relevant parties to the table to discuss these critical issues that will need to be resolved before substantial progress can be made in delivering the next generation of therapeutic agents to affected individuals with chronic hepatitis B and D.

NAFLD nomenclature consensus conference

There has been much progress regarding the ongoing discussions over nomenclature for nonalcoholic fatty liver disease (NAFLD). AASLD has been leading and participating in a global multi-stakeholder process that includes extensive involvement from patient groups to examine the options and ramifications around nomenclature in this condition. This nomenclature task force includes



Milan Mishkovic, ELPA Director - other participants, NAFLD nomenclature consensus conference

representatives from the largest pan-national liver societies. The task force will ultimately work out a name that addresses stigma and advances the understanding of disease subtypes, natural history and/or response to therapy, with the goal of achieving a global consensus on the choice of nomenclature. To ensure the process continues in a collaborative and inclusive manner, AASLD and EASL organised a new meeting to address the disease nomenclature and its impact on patients and the scientific community. The task force met in Chicago on July 8-9, 2022, and the ELPA representative was Director Milan Mishkovikj.

The 8th Paris NASH Meeting

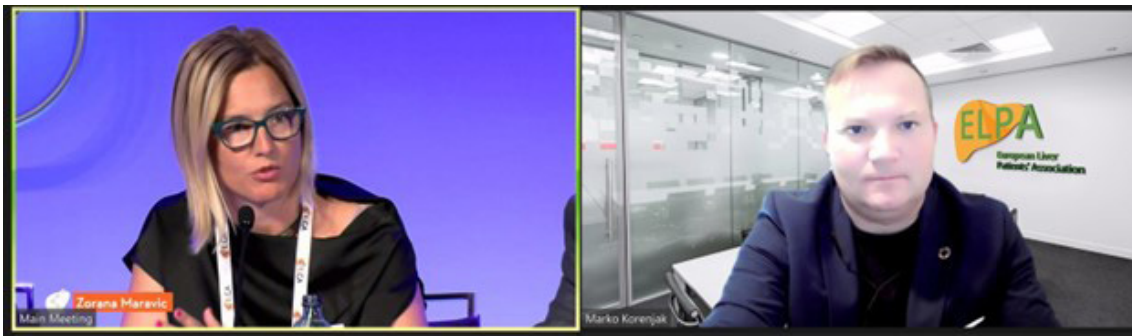
Some ELPA representative participated in the 8th Paris NASH Meeting on September 8 and 9, 2022. Key opinion leaders from both sides of the Atlantic came together to present pivotal learnings and hosted exciting discussions on fatty liver diseases.



Marko Korenjak, ELPA President - Dr Teresa Casanovas, ELPA Scientific Committee Leader and ELPA Director - Veronika Všetickova, ELPA Head of EU Affairs - Yiannoula Koulla, 8th Paris NASH Meeting

ILCA Annual Conference 2022

ELPA President, Marko Korenjak was part of the Advocacy session at the annual conference of the International Liver Cancer Association (ILCA). The ILCA Annual Conference is the leading scientific forum in the liver cancer field connecting hundreds of international participants from all related disciplines to exchange their knowledge and best practices with big idea presentations, symposia, workshops and networking sessions. ILCA 2022, held on September 1-4, 2022, provided a 3-day cutting-edge scientific programme with a multidisciplinary and transversal approach linking research to practice driving patient care.



Zorana Maravić - Marko Korenjak, ELPA President, ILCA Annual Conference

2022 International HBV Meeting

ELPA actively participated in the 2022 International HBV Meeting. The aim of the International HBV Meeting on the Molecular Biology of Hepatitis B Viruses is to bring together international scientists studying diverse aspects of hepatitis B and D viruses, related animal model viruses, and hepatitis B-induced hepatocellular carcinoma. The meeting provides opportunities for junior and senior scientists to engage in joint discussions of the latest conceptual and technical advances regarding these viral pathogens and related diseases. In addition to the International HBV Meeting, a community forum on hepatitis B was held to share the latest advances in HBV research. The purpose of the Forum was to facilitate engagement between attendees at the International HBV Meeting, public health workers and the broader hepatitis B-affected community, promoting communication between these groups to identify the best approaches to fast-track HBV cure and eliminate stigma and discrimination. The Forum was endorsed by ELPA, and Marinela Debu, President of the ELPA member association from Romania, presented her experience and represented the voice of patients during a session on September 22, 2022.

AASLD meeting 2022

On November 4-8, 2022, some ELPA representatives participated in the AASLD annual meeting. Patients and Advocates were encouraged to attend to learn about the latest science through abstract tours, and special educational sessions. A special track was designed to offer maximum interactive opportunities to ask questions, provide feedback and have discussions with the entire hepatology community. Patient programming was available both in-person and digitally, and included sessions on topics like:

- Meet and Greet sessions (in-person & virtual).
- Annual Forum.
- Patient Keynote Address: Liver Health Equity: Overcoming Stigma, Access, and Policy Barriers, featuring Donna Cryer, President Global Liver Institute.
- Clinical Trials in Liver Disease: Patient and Provider Engagement Strategies.
- HBV/HDV: Is There a Cure in Sight? Should I Be Treated Now?



Beatrice Credi, ELPA Head of Office – Sindee Wenbaum - Marko Korenjak, ELPA President, AASLD meeting

- Reaching HCV Elimination through Meeting the Needs of People Who Use Drugs and Other Overlooked Communities.
- Nutrition 201: Translating WHAT to Eat Into HOW to Eat.
- Strategies for Self-Care & Caregiver Advocacy with Providers.
- Liver Cancer Screening and Early Detection: How Can We Do Better to Save Lives?
- State-of-the-Art Lecture: Hepatocellular Carcinoma and NAFLD.
- Patient Debrief Topline Clinical Research – What this Means for Patients.
- Wrap-up and Feedback Open Discussion.

IVHEM 2022

ELPA representatives attended the International Viral Hepatitis Elimination Meeting (IVHEM) that took place as a hybrid meeting from 2-3 December 2022. Convened by Academic Medical Education, Virology Education, and the Coalition for Global Hepatitis Elimination (CGHE), IVHEM is a global forum for the exchange of practical experiences for translating diagnostic and therapy advances of viral hepatitis into broad applications that accelerate progress towards the elimination of viral hepatitis as a public health threat by 2030. Hepatitis B and C affect more than 354 million people globally and can lead to liver disease and mortality from liver failure and hepatocellular carcinoma. More than 296 million people (3.7% of the world's population) live with HBV, and over 820,000 deaths are attributable annually. An estimated 58 million people (globally, 0.73%) live with the hepatitis C virus (HCV), resulting in nearly 290,000 deaths annually. Key issues addressed were how to translate research outcomes into public health policy and practice to meet the 2030 elimination targets. During this two-day meeting, experts in viral hepatitis from around the globe examined current evidence on how to implement programs that improve the prevention of viral hepatitis and increase the number of people accessing testing and treatment. The program included practical examples of innovative intervention studies, country elimination programs, and novel funding mechanisms for testing and treatment.



Marinela Debu, IVHE Meeting

First Annual NAFLD and NASH Primary Care Summit

On December 1, 2022 Michael Betel, President and Founder of the Fatty Liver Alliance and Marko Korenjak, President of ELPA - European Liver Patients' Association introduced the First Annual NAFLD and NASH Primary Care Summit. This important multidisciplinary program wanted to raise awareness about some very crucial questions related to this liver disease. What are the knowledge gaps today? How are high-risk patients assessed? Is early detection possible? How can Primary Care Physicians tailor care for patients? Why is interdisciplinary care critical? What lifestyle modifications, or pharmacological treatments can be utilized? What are the interrelationships among Type-2 Diabetes, obesity and cardiovascular disease? What does the future hold for NAFLD and NASH?



First Annual NAFLD and NASH Primary Care Summit, Group Meeting



**EMPOWERING
OUR MEMBERS**

Clinical Trial Ambassador

ELPA Vice-President Julio Burman and ELPA member representative from Romania Marinela Debu took part in the Clinical Trial Ambassador programme organised by Boehringer Ingelheim RCV in Vienna on February 18 and 19, and July 8, 2022.

To help patients learn more about clinical trials in the future, Boehringer Ingelheim RCV launched the Clinical Trial Ambassador initiative together with patient organisations. The goal is to attract ambassadors for clinical trials who serve as experienced and objective contact points for patients and support them with their questions and concerns. Under the slogan “knowledge is power,” patients can be empowered with understandable information on clinical trials.

Topics included:

- Being a trial participant is not the same as being a patient - What is different and why?
- Participation in trials: basics on safety, study procedures, adverse events, concomitant medication.
- Trial end - What next?
- Taking patient engagement a step further - How to give input on the patient perspective.



Julio Burman, ELPA Vice-President - Marinela Debu - other participants, Clinical Trial Ambassador programme

Tackling Antimicrobial Resistance in Liver

On March 22, 2022, King's College London hosted the event 'Tackling Antimicrobial Resistance in Liver Disease' in the Churchill Rooms at the Houses of Parliament. The event was held in partnership with the ELPA Member British Liver Trust (BLT) and The All-Party Parliamentary Group (APPG) on Liver Disease and Liver Cancer. Also present were policymakers, public health leaders, representatives from the World Health Organisation, hepatologists, microbiologists, experts in antimicrobial resistance, European microbiome and Liver consortiums such as MICROB-PREDICT, EF-Clif, The European Academic FMT Network, The

British Association for the Study of Liver Disease (BASL) and the British Society for gastroenterology's Gut Microbiota for Health Expert Panel. Patients and patient representative groups, such as the BLT, Guts Charity UK, the European Liver Patients Association (ELPA), and UKRI funders were there to discuss new innovative research that hopes to tackle antimicrobial resistance (AMR). The event sought to highlight the evolving crisis of chronic liver disease in the UK with prevalence and mortality increasing exponentially. Drug-resistant infections have been causing half a million deaths every year worldwide and this number continues to grow. Patients with liver cirrhosis are at particularly high risk for antimicrobial resistance because they are predisposed to bacterial infection which typically results in hospitalisation, with high mortality.

HUHIV Conference

ELPA President Marko Korenjak participated in the conference organised by HUHIV, ELPA Member in Zagreb on March 25, 2022. The Croatian Institute of Public Health (HZJZ) and the Croatian Epidemiological Society (HLZ) were also among the organisers.



The meeting focused on working together to better prevent and treat viral hepatitis in drug users. The main purposes of the conference were the presentation of implementation, results and evaluation of ESF project "Deinstitutionalization of services for people with addiction - Development of social services network" and the presentation of activities and cooperation of participants in health and social services of prevention, treatment and support for drug users in Croatia.

ELPA Directors gathering in Cyprus

ELPA Directors met in Cyprus from April 6 to 11, 2022. During their first meeting in person after the pandemic, they have the possibility to discuss current topics and the development of the association in the upcoming future. Together with the president of the Cyprus liver patient association -Prometheas Ms. Yiannoula Koulla ELPA President met the Health Minister Mr. Hadjipantela who described his engagement in helping liver patients. ELPA representatives had also the occasion to attend a sports event organized by the Cyprus Archery Federation during which they have the opportunity to promote a healthy and active lifestyle.



Marko Korenjak, ELPA President - Cypriot Health Minister Michalis Hadjipantela- Yiannoula Koulla, in Cyprus



ELPA President - ELPA Directors - Veronika Všetickova, ELPA Head of EU Affairs, in Cyprus

The Health Commission of the Romanian Senate meeting

The Health Commission of the Romanian Senate organized a roundtable on the topic of the National Hepatitis Control Framework on May 12, 2022. ELPA President Marko Korenjak participated giving a speech focused on hepatitis elimination.

The chairman of the Health Commission, Dr Adrian Streinu-Cercel stated:

Now, the patients affected by liver virus infections have the opportunity to be tested diagnosed, examined and treated. However, this is not enough if we do not switch to an accelerated testing program provided by family doctors. At the same time, we are looking for a quick solution for those who are not insured and for vulnerable groups.

The representatives of the Association of Liver Diseases Patients in Romania (APAH-RO), ELPA member, stressed that there is an acute need for funding for the National Framework for the Control of Viral Hepatitis in Romania, which was launched in 2019 and must be implemented until 2030. The representatives believe that due to the COVID-19 pandemic, the only impactful actions that were carried out in the least years within the National Framework were the prevention



Marinela Debu - Chairman of the Health Commission Dr Adrian Streinu-Cercel, Romanian Senate meeting

programs, screening, and the diagnosis of the patients with chronic hepatitis diseases secondary to the viral infections of hepatitis B/D and C viruses – a project that was co-financed by European funds.

Timely treatment of liver disease and liver cancer

On May 11, 2022, the Finnish Kidney and Liver Association, ELPA member, organised a seminar ‘Timely treatment of liver disease and liver cancer’. The number of liver diseases is rising alarmingly in Europe and in Finland. Attention needs to be paid to the prevention, identification, and timely treatment of liver disease. The seminar was opened by Sari Tanus, Member of Parliament, Specialist, Member of the Parliamentary Support Group for Kidney, Liver and Transplant Patients. Then ELPA President, Marko Korenjak, presented the recent White Paper on Liver Cancer published by ELPA, which sets out recommendations for raising awareness, prevention and early detection of liver cancer. Professor Perttu Arkkila talked about the situation of liver diseases in Finland. The seminar also presented the results of a study commissioned by the Finnish Kidney and Liver Association. Maria Guzenina, Member of Parliament, is considering organizing the prevention of liver disease in new welfare areas.



Marko Korenjak, ELPA President, in Finland

ELPA is back to school

On May 10, 2022, ELPA President Marko Korenjak had the occasion to talk about health and healthy lifestyle style in front of pupils in a school in Slovenia. These activities were part of the EU Project PaCo, “Participation in Society through Classroom Activities and Cooperation” in which ELPA is involved. The project, financed in the framework of the Erasmus+ programme, involves 6 countries: Finland, Estonia, Spain, Hungary, the Czech Republic, and Slovenia. It aims to develop students’ participation and citizenship education to provide the background knowledge necessary to maintain a civilized society. It also promotes associational activities with NGOs, decision-makers, and local experts in the schools.



Marko Korenjak, ELPA President, visiting a school

Meetings in North Macedonia

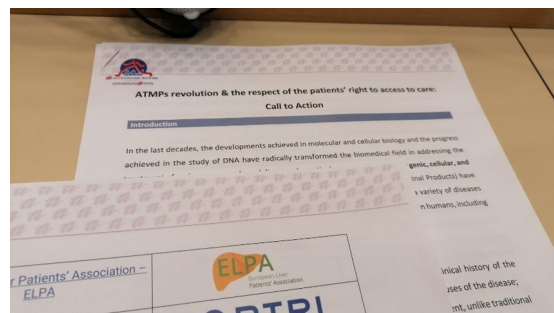
From May 4 to 6, 2022, ELPA President Marko Korenjak visited North Macedonia. He met with representatives from the 2 associations part of ELPA and with many political and national health authorities. It was an occasion to present ELPA activities, assess the country's progress in fields such as hepatitis elimination and talk about the future of liver disease and liver patient advocacy.



Marko Korenjak, ELPA President - Milan Mishkovikj, ELPA Director - N. Macedonia Health Minister Dr Bekim Sali - N. Macedonia Director of Health Insurance Fund - Special Adviser for Health N. Macedonia Health Minister cabinet

Advanced Therapies Medicinal Products, call to action

ELPA endorsed the 'Advanced Therapies Medicinal Products revolution & the respect of the patients' right to access to care' call to action by Active Citizenship Network (ACN) in collaboration with many other associations. Across Europe, a patient who wants to access an ATMPs (a reality of cure for patients suffering from serious diseases who have not yet found a concrete therapeutic answer) may face various obstacles of a social nature: lack of scientific knowledge, lack of regulatory uniformity and transparency, regional inequalities of access, and lack of public funds for this type of therapy. For this reason, some organisations have decided to launch



this Call to Action which is aimed at national and European Institutions first, but also at the whole health ecosystem including civic & patient associations, and citizens.

ELPA endorsed the Oslo Declaration - a call for policy action to curb alcohol harm

Together with international organisations representing doctors, cancer patients, young people, researchers, public health and development advocates across Europe, ELPA endorsed the Oslo Declaration - a call for policy action to curb alcohol harm.

Europe is the heaviest alcohol-consuming region in the world. The burden of alcohol-related harm to individuals, families, communities, and society is enormous. Half of the deaths due to liver disease are a result of alcohol.

Many individuals who develop life-threatening harm are largely unaware of the risks of alcohol consumption. The time has come for concerted action across Europe to reduce these harms.



Elimination of Viral Hepatitis in the Balkan countries: lessons learnt and the way forward

Organised by the Viral Hepatitis Prevention Board and opened by Dr. Bekim Sali Minister of Health, North Macedonia, the meeting had the following objectives:

- Provide an overview of the current viral hepatitis situation in the countries: surveillance systems, epidemiology, screening, burden, prevention, treatment and the cascade of care.
- Discuss achievements and challenges in the prevention and control of viral hepatitis, the possible implementation of new prevention strategies, control measures and monitoring system in the countries.
- Discuss the development and the implementation of a national hepatitis plans.
- Assess the needs to achieve the goal of eliminating viral hepatitis as a major public health threat by 2030 as set out in the renewed WHO Global Strategy and WHO Europe Action Plan, building

on the UN Sustainable Development Goals' (SDG) commitments.

- Discuss successes, issues and barriers to overcome and the way forward.

Among all other outstanding speakers, ELPA President Marko Korenjak and ELPA Director Milan Mishkovikj presented the role of patient organisations in the Balkan region.



Marko Korenjak, ELPA President - Milan Mishkovikj, ELPA Director - N. Macedonia Health Minister Dr Bekim Sali, Elimination of Viral Hepatitis in the Balkan countries

IV meeting of experts and families affected by Lysosomal Acid Lipase Deficiency

On November 26, 2022, ELPA Vice-President Julio Burman presented ELPA's activities during the IV meeting of experts and families affected by Lysosomal Acid Lipase Deficiency (LAL-D). He was invited by the Spanish Patient Organization Lysosomal Acid Lipase Deficiency (AELALD) ELPA member. LAL-D is a rare, chronic, progressive inherited disorder. It affects the body's ability to produce an enzyme called lysosomal acid lipase (LAL). This enzyme is needed for the breakdown of fats (lipids) and cholesterol in your cells. When the LAL enzyme is missing or deficient, fats accumulate in organs and tissues throughout the body, primarily leading to liver disease and high "bad cholesterol," which is linked to cardiovascular disease. LAL-D is an ultra-rare disease, which is defined as a disease that affects fewer than 20 people per one million of the general population. The disease affects individuals of all ages from infancy through adulthood; however, manifestations of the disease vary across the lifespan. Infants with LAL-D begin to show severe symptoms about one month of age that rapidly progress to life-threatening complications, with death typically occurring before six months of age. Historically, LAL-D in infants was called Wolman disease.



Julio Burman, ELPA Vice-President, IV meeting of experts and families affected by LAL-D



**STRENGTHENING
OUR ASSOCIATION**

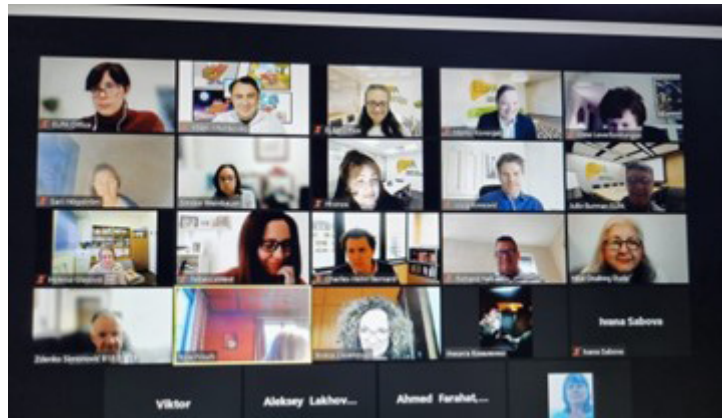
Members unanimously approved updates of ELPA Statutes, Codes of Conduct, and Internal Rules

On February 24, 2022, ELPA held an Extraordinary General Meeting to discuss ELPA Statutes, Codes of Conduct, and Internal Rules changes. The revision of the three documents was necessary to update them to the Belgian Law.

ELPA members from Bosnia and Herzegovina, Cyprus, Croatia, Denmark, Egypt, Finland, Israel, North Macedonia, Poland, Romania, Russia, Serbia, Slovakia, Slovenia, Spain, Sweden, Turkey and the United Kingdom unanimously approved the new ELPA Statutes, Codes of Conduct, and Internal Rules.

The assembly has adopted the new documents in line with the comments and questions from one auditor, three ELPA members (6 questions) and a lively and proficuous discussion among members.

A special thank goes to Mr Charles-Henri Bernard, Senior Associate, Hogal Lovells company, for his commitment to helping ELPA become a future-proof association.



ELPA Extraordinary General Meeting, Group Picture



ELPA Annual General Meeting, Group Picture

ELPA Annual General Meeting 2022

On June 24, 2022m in London, during the attendance of the EASL-ILC 2022, ELPA organised its Annual General Meeting in person. After a welcome and a brief introduction by the ELPA President, Mr. Marko Korenjak, the assembly adopted the AGM 2021 minutes, the Annual and Financial Reports 2021 the work plan and budget for 2022.



Marko Korenjak, ELPA President - Dr Teresa Casanovas, ELPA Scientific Committee Leader and ELPA Director, ELPA Annual General Meeting



ELPA Annual General Meeting, Group Picture

A new ELPA Member

ELPA members gathered in the General Assembly during the Annual General Meeting, greeted a new ELPA member. Welcome on board Asociación Española Déficit de Lipasa Ácida Lisosomal (AELALD) - Spanish Patient Organization Lysosomal Acid Lipase Deficiency (AELALD)!



Eduardo López, President AELALD



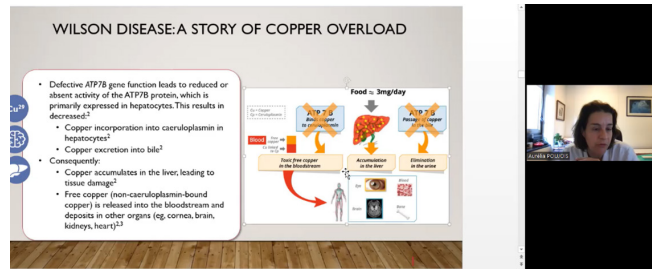
ELPA Educational Training, Group Picture

ELPA Educational Training

On June 23, 2022, ELPA organised its first day of Educational Training in person in London during the attendance of the EASL-ILC 2022. The first part was dedicated to two presentations by ELPA members' representatives from Croatian and Finland. They presented some activities organised by their associations as good

practice. In the second part, representatives from Siemens Health gave an overview of their activities. Then, representatives from Mirum presented the company's work in the rare liver diseases field. The second day was dedicated to rare liver disease, the Wilson disease. On June 29, 2022, Prof Dr Peter Ott and Dr Aurélia Poujois gave a complete overview of this condition, starting with its history, epidemiology, and genetics. Then, they explained the different clinical presentations, the neurologic and the hepatological diseases. They concluded by illustrating the current and upcoming treatments.

The Fall edition of the ELPA Educational Training took place on November 9, 19 and 23, 2022. ELPA members had the possibility to listen to presentation by industries and stakeholders this year focused on updates about rare liver diseases, liver cancer, NASH and Hepatitis D.



Dr Aurélia Poujois, ELPA Educational Training

ELPA Stakeholders' Meeting 2022



ELPA Stakeholders' Meeting, Group Picture

As every year ELPA organized a meeting inviting its major partners and stakeholders in the field of patients' advocacy in liver diseases. The ELPA Stakeholders' Meeting 2022 took place on November 18, and it was a great moment of exchange and networking among ELPA members and representatives from many different associations and international organisations.

Speakers:

- Prof Dr **Aleksander Krag**, Vice-Secretary EASL.
- Prof **Tim Meyer** MD PhD, ILCA President-Elect, Chair of the ILCA Systemic Therapy Guideline Committee.
- Dr **Nicole Seguy**, Unit lead HIV, Hepatitis and STI, WHO Europe.
- Dr **Erika Duffell**, Principal Expert Hepatitis, ECDC.
- Prof Dr **Rui Tato Marinho**, President of the Portuguese Society of Gastroenterology, Director of the National Program for Viral Hepatitis, Ministry of Health.
- Prof Dr **Patrizia Burra**, Chair of UEG Public Affairs Committee.
- Mrs **Katarina Ossenberg**, ACHIEVE Coalition Secretariat.
- Ms **Greet Hendrickx**, Viral Hepatitis Prevention Board.
- Mr **Roberto Pérez Gayo**, C-EHRN.

- Ms **Jessica Hicks**, World Hepatitis Alliance.
- Mr **Marko Korenjak**, ELPA President.
- Dr **Teresa Casanovas Taltavul**, Coordinator of ELPA Scientific Committee, ELPA Director, President of ASSCAT (Asociación Catalana de pacientes hepáticos).
- Ms **Yannoual Koulla**, President of Cyprus Liver Patients' Association, Leader of ELPA NAFLD / NASH group, Republic of Cyprus.
- Dr **Sabela Lens MD**, Hospital Clínic de Barcelona, Liver Unit, Barcelona, Spain.
- Mr **Marco Greco**, President of the European Patient Forum (EPF).

ELPA Elections 2022

November 18, 2022, was an exceptional, meaningful, and emotional day. The members of the European Liver Patients' Association recognised the work that was done in the association in the last years under Marko Korenjak's leadership.



ELPA Elections, Group Picture

Twenty countries (from ELPA members) that were part of the General Assembly in Barcelona voted unanimously for Marko's Korenjak position as ELPA President for another term, from 2022 to 2026. Also, the Board of Directors was renewed for 4 years time.



ELPA IN SCIENTIFIC RESEARCH PROJECTS

ELPA continued to join and participate in numerous EU projects, mainly in disseminating and “translating” medical and scientific objectives and results to the general public, patients, and relatives. Since January 2022, ELPA has been part of the consortium of the following EU projects funded by Horizon 2020: Liverscreen, LiverHope, Decision, Galaxy, MICROB-PREDICT, IPCureB, A-Tango, and FisPlat (EITHealth). In addition, it is part of ESCALON, COBALT and FACILITATE. In 2022 ELPA was waiting for the evaluation and approval of more projects. It worked with many partners on new collaborations in the framework of the new EU Horizon Programme.



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:

- 3) identification of groups from the general population at high risk of having chronic liver disease,
- 4) screening their liver stiffness with the innovative transient elastography (TE) technology (until now only validated in patients with known liver disease) for diagnosis, and
- 5) 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

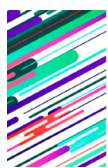
In Europe, about 30,000 people die every year from alcohol related cirrhosis, a form of chronic, non-communicable disease. The patients that are at highest risk of death are those with superimposed alcoholic hepatitis (AH) who do not respond to therapy and develop acute on chronic liver failure (ACLF), 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).



COvid-19
vaccination and
Biomarkers in
cirrhosis And
post-Liver
Transplantation
(**COBALT**)

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.

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

IP-cure-B's 2nd General Annual Meeting

On January 20 and 21, 2022, ELPA participated in the 2nd IP-cure-B General Annual Meeting as a partner of the project.

The expected results of IP-cure-B are fivefold:

- 1) Improve the functional cure rate in Chronic Hepatitis B (CHB) and provide opportunities for finite duration curing therapies.
- 2) Provide the rationale for combining new innate immune modulators with novel DREP or DC-targeting HBV vaccines and their combination in order to achieve the functional cure of HBV through reshaping of intrahepatic innate immunity and stimulating the expansion of HBV specific immune responses.
- 3) Develop novel HBV therapeutic vaccine strategies to be evaluated in combination in clinical trials;
- 4) Identify and validate immunological and virological correlates of cure.
- 5) Establish a pharmaco-economic model comparing multi-step add-on therapies and new curative regimens in order to estimate the clinical benefit of HBV functional cure and to provide the basis for uptake by national health systems.

LiverScreen executive meeting INN-ACTA

On February 14, 2022, ELPA, as partner in the project, participated in the LiverScreen meeting. LiverScreen project will screen a total of 30.000 people recruited from different European countries. By analysing the results from the 30.000 subjects 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, the consortium aims to have a targeted, population-based screening intervention program for chronic liver diseases in Europe, ready for implementation.

FiSPlat Consortium Meeting

On February 21, 2022, ELPA, as partner in the project, participated in the meeting of the FiSPlat Consortium. Liver cirrhosis is one of the most important causes of death, resulting in an economic burden of 17B€ in Europe/year. Its progression is silent, becoming one of the most difficult areas for early detection of patients. The lack of methods to diagnose it at early stages prevents stopping this dangerous killer. The partner of this project introduced FiSPlat (FibroScan Screening Platform): a cheap, fast, non-invasive method to diagnose early-stage cirrhosis, based on Transient Elastography, without the need for medical specialists. FiSPlat is based on a new version of FibroScan, developed to be used in Primary Care. It enables primary healthcare to screen populations at risk, improving early patient stratification and preventing progressive cirrhosis.



Dr Teresa Casanovas, ELPA Scientific Committee Leader and ELPA Director with the FiSPlat team, FiSPlat Consortium Meeting



MICROB-PREDICT 4th General Assembly Meeting

MICROB-PREDICT 4th GA meeting, taking place from 15-18 March 2022 in Mallorca has been successfully completed. The first 1.5 days were reserved for the first MICROB-PREDICT paper-writing workshop. 35 scientists from all over Europe discussed 12 papers about ACLF and microbiome in four different places face-to-face and virtual at the same time. The other days were dedicated to hearing further updates and results from our different work packages. ELPA President, Marko Korenjak, presented the results of the dissemination activities within the project. With 54 participants joining on-site and almost 20 participants remotely the meeting was a great success.



Marko Korenjak, ELPA President - Prof Dr Dr med JoneI Trebicka, MICROB-PREDICT 4th General Assembly Meeting



Marko Korenjak, ELPA President - Prof Dr Pere Ginès M. D., MICROB-PREDICT 4th General Assembly Meeting

A-TANGO Steering Committee meeting

On March 30, 2022, ELPA participated in the A-Tango Steering Committee meeting. Twice per year, the Steering Committee (SC) of the A-TANGO consortium convenes to present the progress of all work packages, discuss potential issues, and outline the next steps. More than 10 million people worldwide suffer from decompensated cirrhosis, often as a result of severe alcoholic hepatitis (sAH) or other chronic liver diseases. In its final stages, decompensated cirrhosis leads to acute-on-chronic liver failure (ACLF), a syndrome characterized by multi-organ failure. Effective treatment of ACLF is an urgent and unmet need. The A-TANGO consortium performs Phase 2 clinical studies of an innovative therapeutic strategy that targets inflammation and improves hepatocyte proliferation. This novel combinatorial therapy is called G-TAK. In addition, A-TANGO strives to identify reliable biomarkers for better patient stratification and an increased survival rate.

IP-cure-B Steering Committee meeting

On May 10, July 12, October 24 and, November 23, 2022, ELPA took part in the meetings of the IPCureB 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 understandable by patients. The process of dissemination and communication involves all ELPA's communication channels, and we actively participate in all events organized 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.

A-TANGO, 2nd GA Meeting

Once a year, the entire A-TANGO consortium (including PhD students, postdocs, and senior scientists working on the A-TANGO project) congregates at the project's General Assembly (GA) Meeting. This year the GA took place in Barcelona from May 15 to 17, 2022. ELPA presented its activities related to the WP7 about dissemination, communication, and training efforts of the project. A-TANGO will achieve the expected impacts of producing meaningful advances in clinical practice by reducing the mortality and improving the quality of life of patients with acute-on-chronic liver failure (ACLF) whilst reducing the disease burden of individual patients and health care systems following validation in these late-stage clinical trials.



Veronika Všetickova, ELPA Head of EU Affairs, A-TANGO, 2nd GA Meeting

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 the highest risk of death are those with superimposed or severe alcoholic hepatitis (SAH) who do not respond to therapy and develop acute-on-chronic liver failure (ACLF), a syndrome characterised by multiorgan failure.

LiverScreen - Executive Committee meeting

On June 9, 2022, ELPA as a partner in the project, participated in the LiverScreen Executive Committee meeting. LiverScreen project will screen a total of 30,000 people recruited from different European countries. By analysing the results from the 30,000 subjects 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, the consortium aims to have a targeted, population-based screening intervention program for chronic liver diseases in Europe, ready for implementation.

IP-cure-B - Scientific workshop

On June 14, 2022, all the IP-cure-B partners met to share updates regarding the project. Each principal investigator responsible for each WP presented the state of the art of tasks related to the specific objectives they are responsible for. ELPA, in charge of communication and dissemination, showed the activities already done and some ideas to put in place in the upcoming future. The objective of the EU-funded IP-cure-B project is to develop novel curative concepts for chronic hepatitis B (CHB). The project aims 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 will also identify immune and viral biomarkers for monitoring patient stratification and treatment response. Integration of biological and clinical data will enable models for the best combination treatment and effectiveness of novel curative therapies concerning 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 will be obtained in a clinical trial of a combination of novel compounds stimulating innate immunity.



Veronika Všetickova, ELPA Head of EU Affairs, LiverScreen General Assembly

LiverScreen General Assembly

On September 19, 2022, some ELPA representatives participated in the LiverScreen General Assembly. They presented ELPA's activities related to the WP7 about dissemination, communication, and training efforts of the project. LiverScreen project will screen a total of 30,000 people recruited from different European countries. By analysing the results from the 30,000 subjects 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, the aim is to have a targeted, population-based screening intervention program for chronic liver diseases in Europe ready for implementation.

DECISION, 4th General Assembly

On October 19-21, 2022, ELPA was part of the 4th General Assembly meeting of the DECISION project. The meeting was a great success with the first day devoted to paper writing: on that day, 12 meetings took place to discuss and progress on 7 different papers with more than 20 people. On the second day, participants extensively discussed the specifics of the upcoming COMBAT-Trial as well as the brand new and



Marko Korenjak, ELPA President - Dr. Ameli Schwalber, DECISION, 4th General Assembly

refined animal models of ACLF. The third day was devoted to multi-omics analyses, bioinformatics and machine learning as well as an update on the newly developed tools and checklists for ethics and data protection and the health economics studies planned in DECISION. ELPA President Marko Korenjak, being our association a partner of the project, presented the impact of the communication and dissemination activities during the last year.

IP-cure-B, 1st laymen event

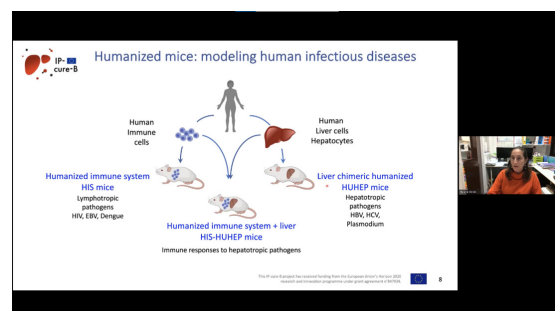
The first IP-cure-B project laymen event took place on November 23, 2022. On the occasion of the ELPA educational training, some Principal Investigators of the project described to ELPA members the scope of IP-cure-B and some aspects of the medical research in its framework.

Prof Dr **Fabien Zoulim** started the round of presentations by giving a brief but exhaustive overview of the project, its scope, structure and goals.

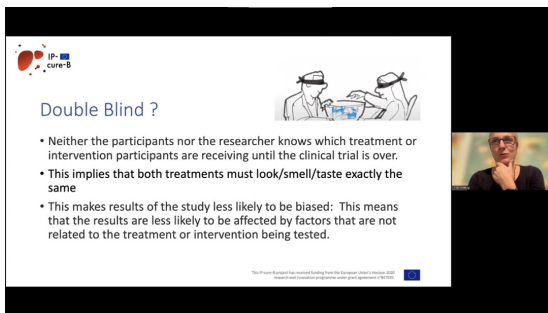
Prof Dr **Carlo Ferrari** explained immune responses to control or clear HBV infection and the therapeutic strategy of IP-Cure-B. Prof Dr **Massimo Levrero** presented the development of novel immunotherapeutic concepts in the framework of the project. Prof Dr **Hélène Strick-Marchand** described how animal models for investigating novel immune therapies work.



Prof Dr Fabien Zoulim, IP-cure-B, 1st laymen event



Prof Dr Hélène Strick-Marchand, IP-cure-B, 1st laymen event



Prof Dr Linda Wittkop, IP-cure-B, 1st laymen event

Prof Dr **Linda Wittkop** ended the workshop by focusing on the importance of clinical trials and their methodology for demonstrating a drug activity.

IP-cure-B clinical trial

There is a clinical trial going on in the framework of the IP-cure-B project.

The ANRS HB07 clinical trial is sponsored by ANRS | Emerging Infectious Diseases and takes place in different centres across Europe involved in the project.

The objective of the EU-funded IP-cure-B project is to develop novel curative concepts for chronic hepatitis B (CHB). The project aims 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 will also identify immune and viral biomarkers for monitoring patient stratification and treatment response. Integrating biological and clinical data will enable models for the best combination of treatment and effectiveness of novel curative therapies concerning 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 will be obtained in a clinical trial of a combination of novel compounds stimulating innate immunity.

Outcomes for medical experts

The project aims at proposing a treatment paradigm shift with the development of novel combination therapies for CHB with improved cure rates and a better appraisal of novel biomarkers to improve patient selection for treatment and monitoring treatment response.

Outcomes for community

The development of such curative therapies with a finite duration of administration will pave the way towards a universal treatment of all individuals that suffer from chronic HBV infection. It is thus expected to result in a long-term reduction in cost and global burden of CHB (short-term therapy, increased treatment uptake in the infected population, decreased rate of liver complications and mortality).

Outcomes for patient

The project aims at designing and developing novel treatment strategies towards the cure of infection with a shorter duration of treatment. It is expected to result in improved quality of life and decreased social stigma.

LIST OF CLINICAL TRIAL SITES

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SOCIAL MEDIA ACTIVITIES

SOCIAL MEDIA ACTIVITIES Report by Milan Mishkovikj

Many supporters from all over the world

 **ELPA Website**

TOTAL VISITS:
928,310

 **Twitter**

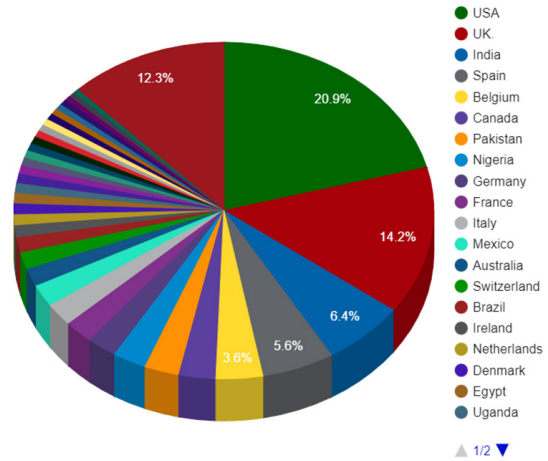
FOLLOWERS
9,265
NEW FOLLOWERS
+1,014

 **Facebook**

LIKES
2,649

 **Twitter, Facebook & Others**

IMPRESSIONS
1 Billion



Analysis of @EuropeLiver FOLLOWERS

Show Percentage/Absolute

Analysis Export	
Location	Followers
USA	20.86%
UK.	14.2%
India	6.38%
Spain	5.58%
Belgium	3.56%
Canada	2.84%
Pakistan	2.67%
Nigeria	2.6%
Germany	2.29%
France	2.24%
Italy	2.22%
Mexico	2.11%

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:

#EuroTestWeek

- 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).



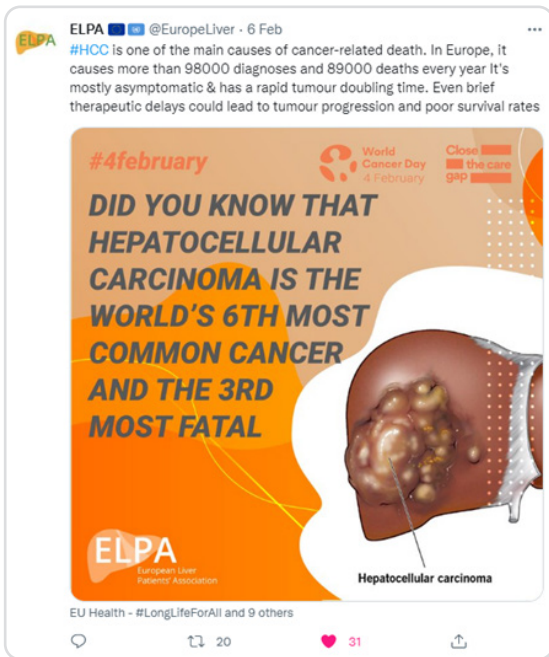
#EuroTestWeek



- 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

In 2022 ELPA celebrated, as every year, World Cancer Day on February 4. However, ELPA decided to go beyond World Day and run a two-week campaign. It started with a message from the ELPA President on February 4, 2022. Then, it continued



World cancer day

tackling a different facet of the issue every day with a constant connection between the general topic and the specificity of liver cancer. 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, and cancer in children, as the International Childhood Cancer Day took place on February 15, 2022. This assured a complete coverage of the topic.

World Obesity Day

On March 4, 2022, ELPA President and some representatives from the MAFLD/NASH Working Group of ELPA endorsed World Obesity Day.



World Obesity Day

Alcohol awareness campaign

In May 2022, ELPA crafted a specific campaign to raise awareness about alcohol-related ham.



Alcohol awareness campaign

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

ELPA @EuropeLiver · 28 Jan

Once patients are cured, they should go back to their normal lives. However, only 5 EU countries apply art. 17 #GDPR, recognising the right to be forgotten for people who have beaten cancer, while only 3 include HCV.

#InternationalDataProtectionDay

@EU_Health @Marko_Korenjak

Source: gdpr.eu

EASLnews and 6 others

ELPA @EuropeLiver · 10 Mar

Dr.Teresa Casanovas president of @asscatinforma and leader of scientific committee of ELPA was invited from Association Colombianas de hepatologia as liver patients representative to present the process of #hepatitis elimination in Spain (from patient point of view)

ELPA @EuropeLiver · 27 Apr

Topic In 2019, #hepatitis B resulted in an estimated 820 000 deaths, mostly from #cirrhosis and #hepatocellular #carcinoma (primary liver cancer). Hepatitis B can be prevented by vaccines that are safe, available and effective #EUCancerPlan #LiverCancer #livertwitter #HBV

European Immunization Week!
#Longlifeforall

Marko and 9 others

ELPA @EuropeLiver · 12 May

12th May is the International Nurses Day. A big thank goes to our expert nurses who work so fantastically hard for LIVERHOPE and LIVERSCREEN projects

@liverunitclinic @hospitalclinic
@Liver_Screen @LiverHope_h2020
@EU_HaDE #H2020 @EU_Health #internationalnursesday
@Marko_Korenjak

ELPA @EuropeLiver · 12 Nov 2022

ELPA member #PROMITHEAS #NASH #Transplant #Liver

Cyprus Patients' Association 'PROMITHEAS' join forces as NASH is the no.1 for Liver transplantation

The event aims to enlighten and raise awareness of citizens about the benefits of blood donation, the role and importance of a compatible bone marrow donor, as well as organ donation for transplantation, as supreme acts of humanity and solidarity for our fellow man. Life values necessary for the cultivation and consolidation of a society, where small and everyday actions can make a difference and be transformed into great acts of high social responsibility











ELPA STRUCTURE






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Head of ELPA office	Beatrice Credi	 Belgium



ELPA WORKING GROUPS

In 2022, ELPA officially had eight Working Groups. Headed by a leader, each Group can count up to 5 members. 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 2022 the Group coordinated many campaigns on ELPA channels: Facebook, Twitter, Instagram, and Youtube.






- PBC Awareness day – September 11 - Social media campaign.
- PFIC Awareness Day – October 5 – Social media campaign.
- Global PSC Awareness Day – October 29 - Social media campaign and Pre-recorded Webinar with leading physicians from all over the world.
- Rare Disease Week – February 28 – March 7 – Social Media Campaign and series of webinars.

The 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 the Wilson's Disease Steering Committee and the collaboration with the GLI – Pediatric Rare Disease Council.

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.

The Group also started working on rare liver diseases such as LALD, Biliary Atresia, and Autoimmune Hepatitis.

ELPA Working Group on Primary Liver Cancer

LEADER	Dr. Teresa Casanovas Taltavull M.D.		Spain
MEMBERS	Lone McColaugh		Denmark
	Sindee Weinbaum		Israel
	Marko Korenjak		Slovenia
	Milan Mishkovikj		North Macedonia

Liver cancer is a significant health problem worldwide, and its incidence is increasing. Hepatocellular carcinoma (HCC) represents 80-90% of primary liver cancer and is considered one of the leading causes

of cancer-related deaths worldwide. Cholangiocarcinoma (CCA) is also a primary liver cancer; however, it is considered rare.

Many cases of liver cancer develop in a liver with advanced liver disease, fibrosis/cirrhosis, and the origin of this liver disease is viruses, alcohol, fatty liver, potentially prevented with vaccination (hepatitis B), anti-viral treatment (hepatitis C) and appropriate lifestyle with a healthy diet, physical exercise and avoiding toxins such as alcohol.




Moreover, liver diseases are not well known, and in addition, they are asymptomatic for many years. Being aware of all of this, the Group considers that when HCC is diagnosed, only approximately 30% or less of patients are diagnosed at an early stage and eligible for potentially curative therapies thereafter; liver cancer is a diagnosis with a very bad prognosis. ELPA and other groups are working to support and inform patients and families about new clinical research.

Recently more treatments have been available for intermediate and advanced stages, improving survival and quality of life. However, in ELPA, we consider crucial information about liver cancer prevention and early screening in patients who we know are at risk. The early detection and link to care for liver cancer in specialised centres for diagnosed patients are very much needed by European citizens. Considering CCA, which is a rare tumour, much work needs to be done on diagnosis and therapies, considering that it is a tumour of heterogeneous origin. The patient's prognosis has not improved substantially in the past decade.

Among the most remarkable 2022 Group achievements, it should be listed:



- Roundtable discussion - LIVER CANCER AND SUPPORT FOR PATIENTS, FAMILIES AND CAREGIVERS
- October Liver Cancer Awareness Month.
- Liver Cancer: No Patient Left Behind, Optimising the European Response in collaboration with Digestive Cancers Europe (DiCE).
- Participation in the presentation of the Liver Lancet Commission with EASL.
- The Educational Training Program for ELPA members that included Liver Cancer as a topic.
- The White Paper, launched with DiCE in 2021, has also been translated into many ELPA member national languages to help patients and stakeholders worldwide.
- Participation in the hybrid European Conference about Cholangiocarcinoma (CCA) organised by the AMMF (the Cholangiocarcinoma charity in the UK).
- ELPA participated as a panellist giving the patient's voice in the meeting 'The BCLC 2022 update. Tackling the complexity of liver cancer management' in Barcelona. Title of the talk: 'The multidisciplinary board for an optimal patient journey.'
- Participation in the Patient Advocates Track Sessions during the ESMO congress.
- ELPA Working Group in liver cancer is also building advocacy actions revolving around NASH, alcohol, obesity, and rare liver diseases.
- It should also not be forgotten the synergies with pharma companies, such as Terumo and Ipsen, and with other companies in the field.

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 2022. The Group was also in contact with Pharma companies. It was responsible for collecting and researching clinical trials in various countries to help ELPA members with up-to-date information. They would like to list Clinical-Trials on ELPA members' websites. They participated in many meetings and webinars about this topic, and two members of the Group, after enrolling in the EUPATI Fellow Programme 2021, graduated as EUPATI Fellow in 2022. The Group is constantly in touch with Pharma companies to keep the Clinical Trial list updated for all ELPA members.

ELPA Working Group on Harm reduction

LEADER	Aleksey Lakhov		Russia
MEMBERS	Philip Spalding		UK

This is a brand new Group that started working on the harm reduction topic in 2020. 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.

ELPA Working Group on Fatty Liver / MAFLD & NASH Disease

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

The work of the Group focuses on the following areas.

Research & development

- ELPA NAFLD/NASH small survey. The results were announced internationally.
- The Group supported the movement to change the name of the disease.

Awareness & Education

- Let's talk about fatty liver! Roundtable discussion (June 9)
- ELPA Patient Summit NAFLD, improving patient's knowledge (October 6)
- ELPA Clinical Trials Programme 2022
- NAFLD/NASH Social Media Campaign




Coalitions among stakeholders

With the help and support of ELPA, the Group came in contact with various stakeholders and Associations.

Knowledge brings strength

The members of this group have participated in many international and national seminars and ELPA educational meetings to be updated about the disease and advocate at their best for these patients.

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. Modernization and increasing the level of service in beauty parlours.
- Extension of statutory regulations regarding additional controls that include sterilization 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, 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 elimination

LEADER	Marinela Debu		Romania
MEMBERS	Ivana Dragojević		Serbia

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 elimination since its creation. However, this Working Group, formally established in 2019, 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.

ELPA Working Group on Cirrhosis

LEADER	Marko Korenjak		Slovenia
MEMBERS	Julio Burman		Israel

The working group on cirrhosis continues to monitor the development in this field closely. The members of the working group collaborate actively with other ELPA working groups on issues connected with cirrhosis. In the year 2022, the working group on cirrhosis increased the level of work of the members. The group is especially proud of ELPA's participation in Awareness Week on Alcohol-Related Harm (AWARH). However, considering the importance of this topic, in December 2022, ELPA developed a separate social media campaign to inform about alcohol-related harm publishing short videos featuring Dr Salvatore Piano, M.D., busting some common perceptions about alcohol and liver.



FINANCIAL ACCOUNTING AND TRANSPARENCY

Word from ELPA Treasurer

The financial position of the European Liver Patients' Association remained strong in the fiscal year 2022 despite tremendous challenges resulting from the COVID-19 global pandemic consequences. ELPA achieved this through wise expense management combined with a successful fundraising performance.

The fundraising activities conducted during 2022 made the association less dependent on pharmaceutical companies' contributions expanding the proportion of funding coming from different sources.

Ivana Dragojević, ELPA Vice-President and Treasurer

Conclusion from the external auditor

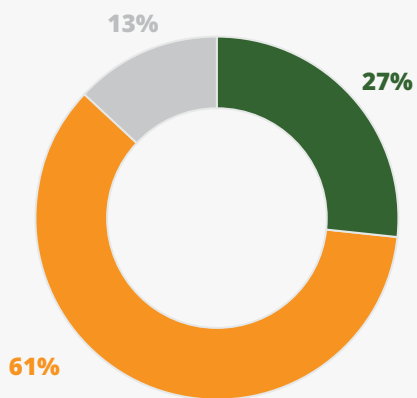
We report to you on the performance of our mandate as contractual auditor of THE EUROPEAN LIVER PATIENTS' ASSOCIATIONS (ELPA). As contractual auditor, we have to report to the Board of Directors of the Association. We have reviewed the financial statements of ELPA, with a balance sheet total of EUR 1.076.171,77 and an income statement with a profit of EUR 6.886,70.

Based on our review, nothing has come to our attention that causes us to believe that these financial statements do not present fairly, in all material respects, the financial position of the European Liver Patients' Associations as at December 31, 2022, and the results of its operations for the year then ended, in accordance with the financial-reporting framework applicable in Belgium.

Publishing financial reports

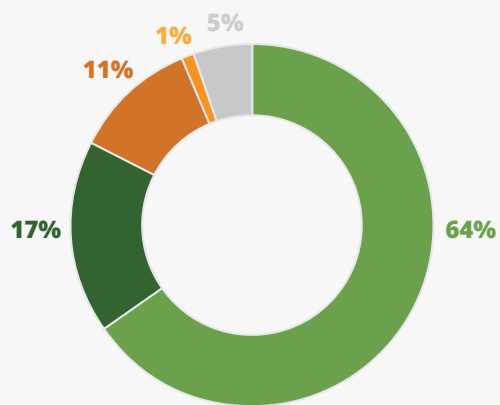
All financial reports of ELPA from 2007 are published every year and can be found on our webpage: www.elpa.eu

Revenue 2022



- Core funding
- ELPA's projects
- EU project

Expenditure 2022



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



European Liver Patients Association

(EUR)	31/12/2022	31/12/2021
Assets		
Fixed assets	44 372,47	51 026,11
III. Tangible fixed assets	40 672,47	47 626,11
B. Plant, machinery and equipment	40 164,12	46 858,08
C. Furniture and vehicles	508,35	768,03
IV. Financial fixed assets	3 700,00	3 400,00
C. Other financial fixed assets	3 700,00	3 400,00
2. Amounts receivable and cash guarantees	3 700,00	3 400,00
Current assets	1 031 799,30	1 016 884,64
VII. Amounts receivable within one year	7 041,26	0,00
A. Other receivables	7 041,26	0,00
IX. Cash at bank and in hand	1 024 758,04	1 006 730,93
X. Accruals and deferred income	10 153,71	10 153,71
Total assets	1 076 171,77	1 067 910,75
Equity and liabilities		
Equity	831 232,10	824 345,40
III. Reserves	103 552,00	103 552,00
A. Reserves not available	103 552,00	103 552,00
4. Other	103 552,00	103 552,00
IV. Accumulated profits (+)/ losses (-)	727 680,10	720 793,40
Amounts payable	244 939,67	243 565,35
IX. Amounts payable within one year	34 273,00	18 456,09
C. Trade debts	4 818,12	3 969,94
1. Suppliers	4 818,12	3 969,94
E. Taxes, remuneration and social security	29 454,88	14 486,15
1. Taxes	18 415,19	5 372,02





2. Remuneration and social security	11 039,69	9 114,13
X. Accruals and deferred income	210 666,67	225 109,26
Total Equity and liabilities	1 076 171,77	1 067 910,75
Profit and loss account		
I. Operating income	577 527,86	403 947,35
A. Turnover	577 527,86	403 947,35
D. Other operating income	0,00	0,00
II. Operating charges	584 182,05	365 384,43
A. Goods for resale, raw materials and consumables	397 722,01	201 899,00
1. Purchases	397 722,01	201 899,00
B. Services and other goods	114 764,08	82 260,17
C. Remunerations, social security costs and pensions	64 489,49	72 896,68
D. Amortisations of and other amounts written down on formation expenses, intangible and tangible fixed assets	6 953,64	7 275,97
G. Other operating charges	252,83	1 052,61
III. Operating profit/loss	-6 654,19	38 562,92
IV. Financial income	16 278,71	18 587,10
B. Income from current assets	0,00	0,00
C. Other financial income	16 278,71	18 587,10
V. Financial charges	2 737,82	6 523,77
C. Other financial charges	2 737,82	6 523,77
VI. Profit/loss of the period before taxes	6 886,70	50 626,25
IX. Profit/loss of the period	6 886,70	50 626,25



X. Transfer from/to untaxed reserves	0,00	0,00
A. Transfer from untaxed reserves	0,00	0,00
XI. Profit/loss of the period available for appropriation	6 886,70	50 626,25
Appropriation account	0,00	0,00
A. Profit/loss to be appropriated	727 680,10	720 793,40
1. Profit/Loss of the period available for appropriation	6 886,70	50 626,25
2. Profits/loss of the preceding period brought forward	720 793,40	670 167,15
D. Profit/loss to be carried forward	727 680,10	720 793,40
1. Profit to be carried forward	-727 680,10	-720 793,40



ACKNOWLEDGMENTS

ELPA is thankful to all its members and numerous volunteers that have helped us accomplish our goals in 2022. We are also grateful to all our supporters and stakeholders. They have been backing our endeavours to fight liver disease over the years.

In 2022, ELPA received grants as well as, in some cases, in-kind support from the following companies:



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WE WORK WITH MORE THAN **241** PATIENT ORGANIZATIONS WORLDWIDE ACROSS OUR **THREE** THERAPEUTIC AREAS

48



RARE DISEASES

130



ONCOLOGY

63



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Together, let's stop chronic liver disease

Today, millions of people are silently progressing from chronic liver disease to liver cancer.^{1,2} **This needs to change.**

Our OneLiver mission is to partner with the healthcare community to break this cycle, to help stop, or even reverse the disease. Our core expertise will continue to focus on cutting-edge diagnostics and treatment.

We look forward to our continued collaboration in 2023 and beyond with ELPA, the member organisations and partners, to make our mission a reality.

1. Cheemerla S. and Balakrishnan M. *Clin Liver Dis* (Hoboken) 2021;17:365-370;
2. McGlynn KA, et al. *Hepatology* 2021;73(Suppl 1):4-13.





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Mirum is propelled by a passion for patients and their loved ones to transform scientific discoveries into therapies that are poised to change the trajectory of rare liver diseases for generations to come.

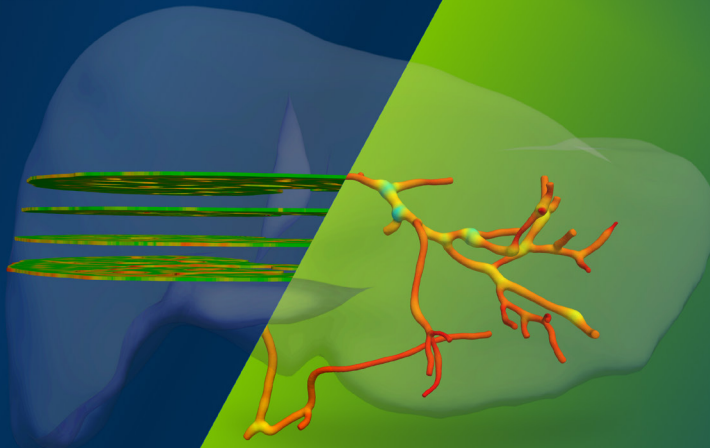
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