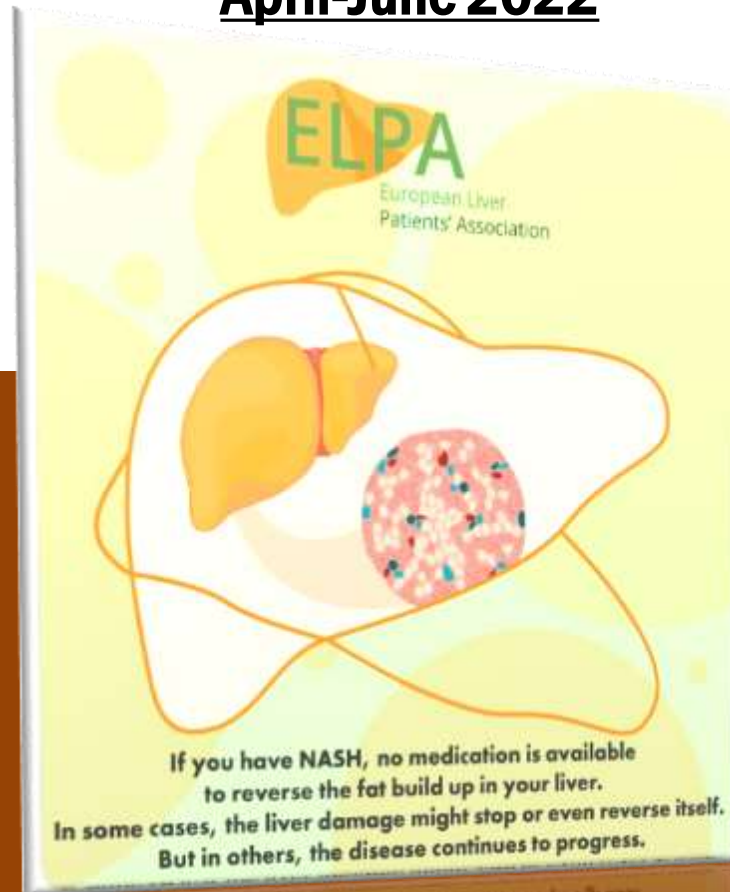


Quartal News Report

April-June 2022



ELPA Directors gathering in Cyprus



ELPA Directors met in Cyprus from April 6 to 11, 2022.

During ELPA Directors' first meeting in person after the pandemic, they had the possibility to discuss current topics and the development of the association in the 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 also had the occasion to attend a sports event organized by the Cyprus Archery Federation during which they had the opportunity to promote a healthy and active lifestyle.

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.

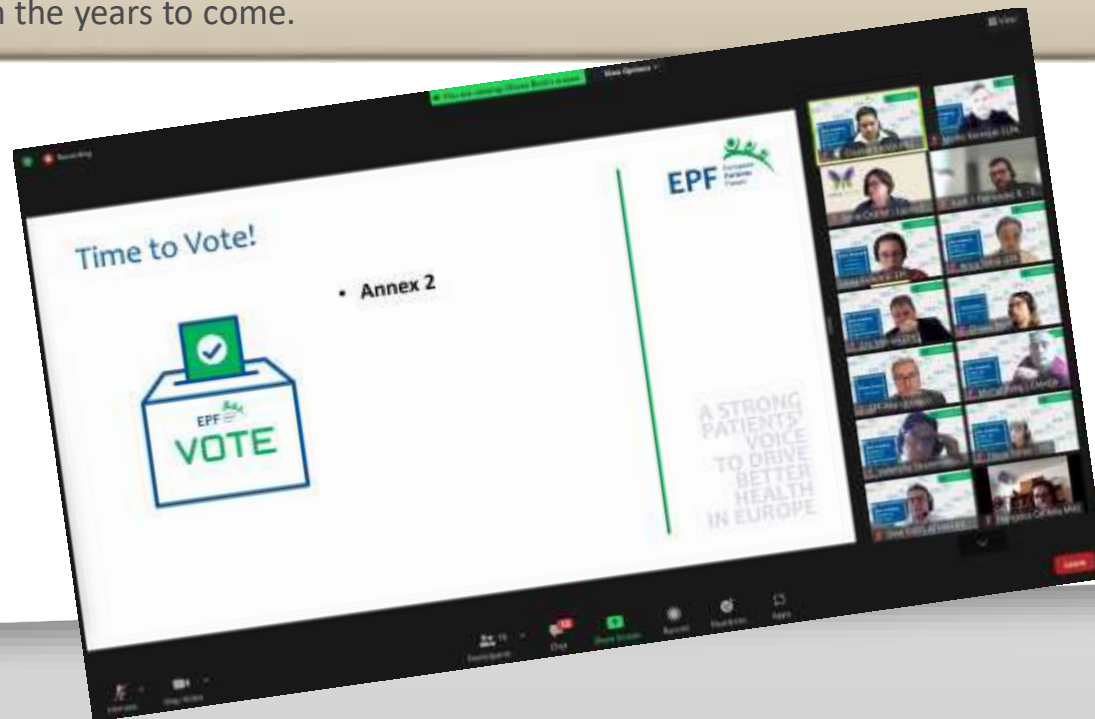
During this event learners engaged in practical exercises led by representatives from the multi-stakeholder EUPATI Faculty. Also, the event was a great opportunity for participants to meet each other, to interact, network and share experiences and learnings within the group. Graduates of the EUPATI Fellow 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.



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 reflect 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 collective accomplishments of the past year in the view of further developing 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.



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 took part in the European celebration of the **XVI European Patients' Rights Day** (EPRD) organized 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 into 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 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 organized 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 a national level.





Multistakeholder workshop on EMA extended mandate and Data Quality Framework multi-stakeholder workshop

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.

On April 7, 2022, the **European Medicine Agency (EMA)** hosted a 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 on an in-depth analysis.

EASL Policy and Public Health Committee meeting

Marko Korenjak, ELPA President, being part of the EASL Policy and Public Health Committee as a patient representative, 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

The first patient recruited in the IP-cure-B clinical trial

The first patient has been recruited in the ANRS HB07 IP-cure-B clinical trial, sponsored by ANRS | Emerging Infectious Diseases and run by the Hospices Civils de Lyon – Hepatology Department, in Lyon, France, in the framework of the [IP-cure-B](#) 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 at improving 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.

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 of 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 patients

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.

The first patient recruited in the IP-cure-B clinical trial

The Hospices Civils de Lyon in Lyon, France, is not the only partner running a clinical trial in the framework of the IP-cure-B project, **other centers are:**



HOSPITAL	DEPARTMENT
Hospices Civils de Lyon in Lyon (France)	Hepatology Department
Universitat Klinikum in Freiburg (Germany)	Department of Internal Medicine Clinic for Internal Medicine II – Gastroenterology, Hepatology, Endocrinology and Infectiology
Hôpital Saint-Joseph in Marseille (France)	Hepato-gastroenterology department
Fondazione IRCCS Ca' Granda Ospedale Maggiore Policlinico in Milan (Italy)	Gastroenterology and Hepatology Division
University Hospital of Parma in Parma (Italy)	Department of General and Specialized Medical
Vall d'Hebron University Hospital in Barcelona (Spain)	Internal Medicine and Hepatology
Hôpital Pitié Salpêtrière in Paris AP-HP (France)	Department of Hepato-Gastroenterology
Hôpital de Brabois in Vandoeuvre les Nancy (France)	Department of Hepato-Gastroenterology

High level symposium for decision makers **ELPA and Liver White Paper**

Marko Korenjak

President – European Liver Patients' Association
May 10, 2022



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, and 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.



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), an 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 last years within the National Framework were the prevention 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.

Meetings in North Macedonia



From May 4 to 6, 2022, ELPA President Marko Korenjak visited North Macedonia.

ELPA member from North Macedonia HEPAR CENTAR-Bitola organised many meetings and it was an occasion to present ELPA activities, assess the progress of the country in fields such as hepatitis elimination and talk about the future of liver disease and liver patient advocacy. A crucial topic was also the presentation of the National Declaration and a talk on a National Cancer Plan and hepatitis elimination.



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.

EUPATI 10th Anniversary

Two ELPA Directors, Julio Burman and 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-day 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".



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 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 representatives 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.





ELPA representative participated in the 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 organizations, 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'.**

ECPC Conference 2022

IP-cure-B Steering Committee meeting

On May 10, 2022, ELPA took part in the meetings of the [IP-cure-B](#) project 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.



IP- 
cure-B



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 between May 15 and 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. 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.

A new ELPA member!

In June 2022 ELPA welcomed a new member to its family.
A warm welcome to the

Asociación Española Déficit de Lipasa Ácida Lisosomal (AELALD)
Spanish Patient Organisation Lysosomal Acid Lipase Deficiency (AELALD)



ELPA Annual General Meeting 2022

On June 24, 2022, 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, presented during the meeting, and also greeted a new ELPA member. Welcome on board *Asociación Española Déficit de Lipasa Ácida Lisosomal (AELALD)* - Spanish Patient Organisation Lysosomal Acid Lipase Deficiency (AELALD)!



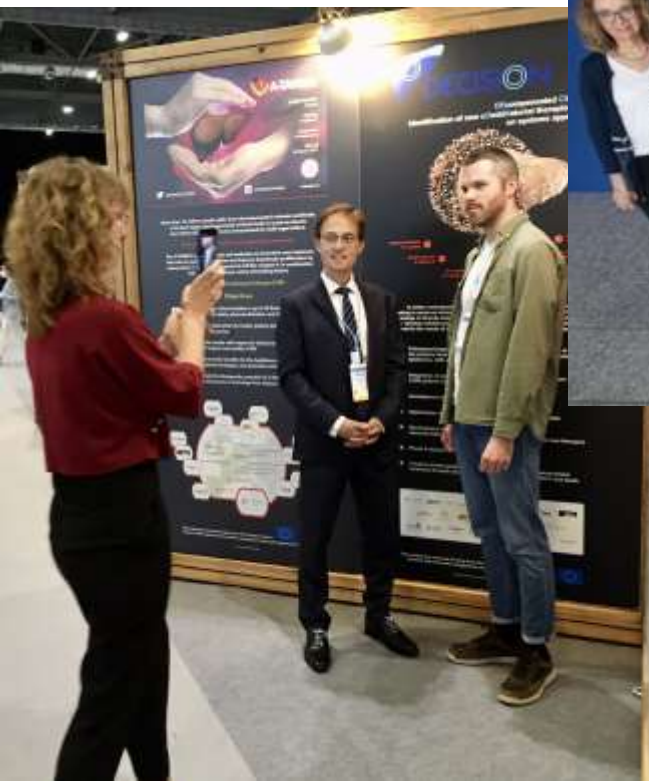




EASL-ILC 2022

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 also had the opportunity to exchange views with some partners from the EU projects ELPA is involved in A-TANGO, DECISION and Microb-Predict. In addition, Dr Teresa Casanovas presented DILI from a 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 McColaugh, president of Leverforeningen, Danish ELPA member.



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 Croatia 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.



WILSON DISEASE: A STORY OF COPPER OVERLOAD

- Defective *ATP7B* gene function leads to reduced or absent activity of the *ATP7B* protein, which is primarily expressed in hepatocytes. This results in decreased:
 - Copper incorporation into caeruloplasmin in hepatocytes¹
 - Copper excretion into bile²
- Consequently:
 - Copper: accumulates in the liver, leading to tissue damage²
 - Free copper (non-caeruloplasmin-bound copper) is released into the bloodstream and deposits in other organs (eg, cornea, brain, kidneys, heart)^{1,2}

1. https://www.ncbi.nlm.nih.gov/pmc/articles/PMC6111111/ 2. https://www.ncbi.nlm.nih.gov/pmc/articles/PMC6111111/



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 topics 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 zero alcohol or not and how to manage this from a hepatologist point of view. 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 Hepatites, 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.

Fatty liver, let's talk about it!
 ¡Hablaremos sobre el hígado graso!

Αιτωδες Ηπαρ. Ας το κουβεντιασουμε!
 Замастен црн дроб, ајде да зборуваме за тоа!

ROUNDTABLE DISCUSSION

JUNE 9, 2022

Fatty liver, lad os snakke om det!
 La maladie du foie gras, parlons-en!

Puhetta rasvamaksasta!
 POGOVARJAJMO SE O ZAMAŠCENOSTI JETER!

Steatoza hepatica, hai sa vorbim despre astal

مرض الكبد الدهني، دعونا نتكلم عنه!



Manuel Romero-Gómez @mromerogomez · 8 Jun
 June 9th ELPA organizes the NASH International day with a Roundtable:
Fatty liver, let's talk about it. Alcohol zero for patients at risk NASH or advanced fibrosis. Do not miss it. Be connected with life and healthy liver.
 @AEEHLiver @HospitalUVRocio @EuropeLiver @fneth_org

14:00 - 14:30	Executive summary by webinar anchors led by gastroenterologist https://www.gastrojournal.com	Dr. Janna Almirante, Hepatology, Israel
14:30 - 15:00	Prevention of transplanted liver failure	Dr. Pascal Mallat, President of SOE Hepatology, France
15:00 - 15:30	Alcohol zero for transplanted liver patients	Dr. Elena Moreno Armendariz, Federación Nacional de Enfermos y Trasplantados Hepáticos (FNETH), Spain
15:30 - 16:00	Let's talk about it...	Dr. Yaelitza Kivitz, group leader of ELPA FNETH NASH group interested in All Transplanted, Israel

Alcohol zero or not? Manage it from the point of view of the patient

Hospital Universitario Virgen del Rocío, Avda. Dr. Fedriani, 2, 41013 Sevilla, Spain

Prof. M. Romero-Gómez, Digestive Diseases department, Virgen del Rocío Institute of Biomedicine of Seville. University of Seville

#FATTYLIVERMONTHEUROPE
 Fatty liver, let's talk about it
 ROUNDTABLE DISCUSSION
 Join us! JUNE 9, 2022

ELPA @EuropeLiver · 9 Jun
 Prevention of #NAFLD in children and adults Prof @SagiZelber, 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 #NASHday

Prevention of NAFLD in children and adults

Shira Zelber Sagi R.D., Ph.D. Dept. of Gastroenterology, Tel Aviv Medical Center School of Public Health, ELPA, And I help prevent today every day

Sugar-containing beverage intake in infancy increases risk for NAFLD in school-aged children

3 times increased risk to develop NAFLD at age of 20 year old!

High Fructose consumption

3.5 times greater risk to develop advanced liver disease (NASH) (including cirrhosis) in 2020

Ultra processed food and drinks
 Major source of added sugar, high energy dense foods & low nutritional value

- Ultra-processed food (UPF) consumption has increased drastically worldwide
- 50%-60% of total daily energy intake in several high-income countries

A human & planetary healthy plate

Estimated deaths prevented among adults by global adoption of this diet

28% of global deaths = 11 million each decade (year)

Mediterranean style diet, it is what I eat & I recommend it to all!

WHO Commission on Nutrition

Swiss NASH Foundation and 9 others

8 11

ELPA @EuropeLiver · 9 Jun
 Interview with transplanted #NASH patient Ms Elena Moreno Armendariz, Federación Nacional de Enfermos y Trasplantados Hepáticos (@fneth_org), Spain #NASHDay #fattyLivermonth #LiverTwitter #LiverCancer #ILC2022 @Marko_Korenjak @surfing_NASH @intNASHday @swissnash @GlobalLiver

#fattyLivermonth

I've never had any toxic habits. I've never drunk, I've never smoked. Obviously I've never taken drugs either but there was a problem with transaminases and my digestion was very complicated and I was quite upset...

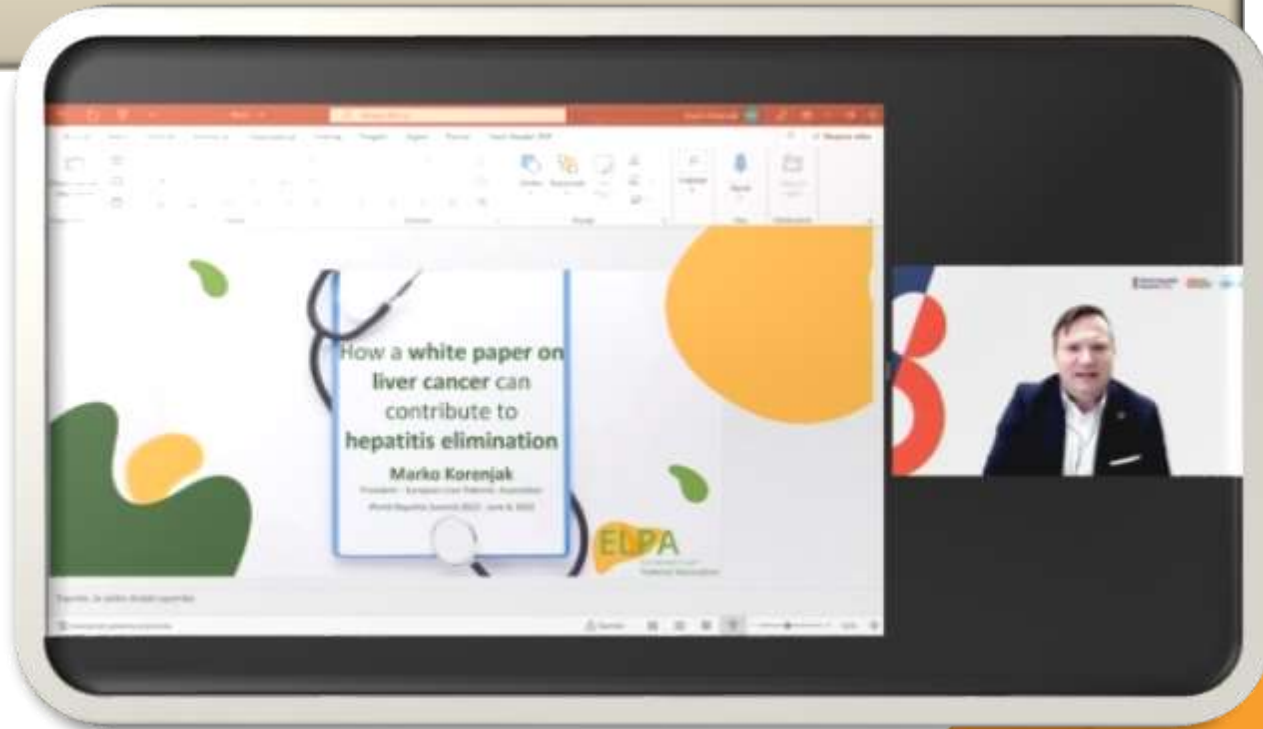
zoom

EASL Education and 6 others

12 20

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.



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 hepatitis D from patients' perspectives. The purpose of the conference was to bring together the academic, regulatory, pharmaceutical communities 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 bringing 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.

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.



SPONSORED BY

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.



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 at having a targeted, population-based screening intervention program for chronic liver diseases in Europe, ready for implementation.



LIVER
SCREEN



We can proudly say that ELPA created a culture of continual improvement. It is a future-proof association able to navigate the present and foresee what is yet to come.

ELPA President, ELPA Directors,
ELPA Secretariat, ELPA Quality Manager



ISO 9001:2015

ELPA confirmed its quality standard to better communicate with supporters and stakeholders for 2022. **ELPA is the 1st patients' association in Europe with a quality management system. We will continue to improve ourselves to support liver patients.**

Health Emergency Preparedness and Response Authority

HERA

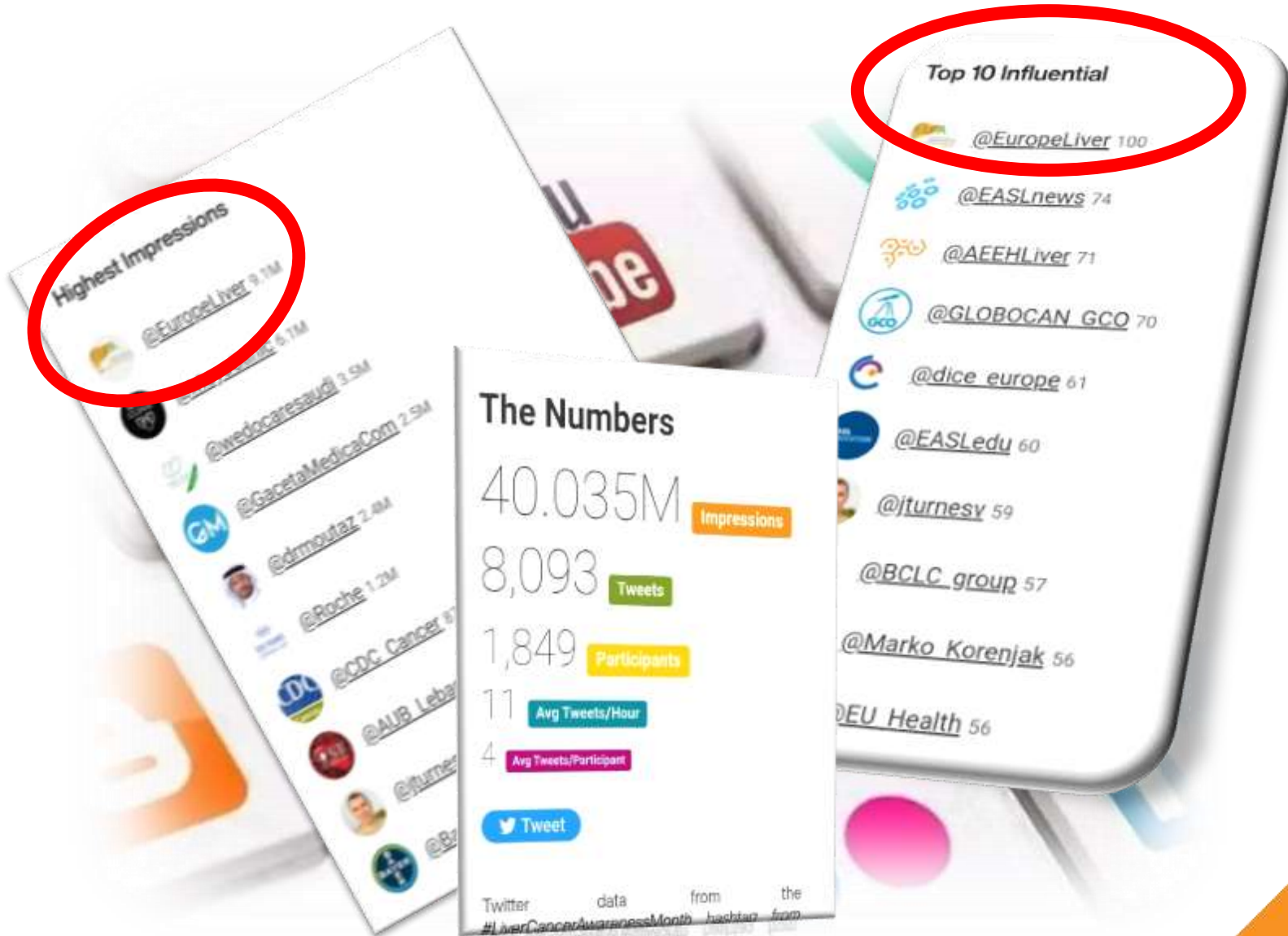
HERA Civil Society Advisory Forum

ELPA is happy to announce that it was appointed as a member of the **HERA Civil Society Advisory Forum**.

The Health Emergency Preparedness and Response (HERA) department's mission is to prevent, detect, and rapidly respond to health emergencies.

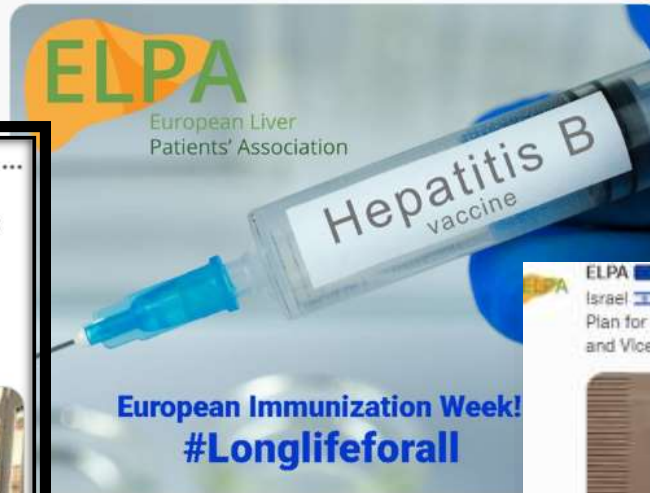
HERA, created in the aftermath of the COVID-19 pandemic, will anticipate threats and potential health crises, through intelligence gathering and building the necessary response capacities.

ELPA on social Media





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 #ivertwitter #HBV



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](#)

8 16

ELPA @EuropeLiver · 10 Jun
Israel parliament: Discussion about the implementation of the National Plan for elimination of #hepatitis by 2030 Julio Burman, CEO of Hetziliver and Vice-President of ELPA [@Hep_Alliance](#)

10 15

ELPA supports its members, stakeholders, supporters and friends' campaigns

ELPA @EuropeLiver · 24 May

Addressing viral #hepatitis B and C to reduce the incidence of liver cancer should be considered in all the cancer prevention initiatives mentioned in the Europe Beating Cancer Plan. @EuroTestWeek #EuroTestWeek #TestTreatPrevent #ILC2022 #Alcoholfree #NASHday #FattyLiverMonth

WORLDWIDE, INFECTIONS WITH HEPATITIS C AND B VIRUSES CAUSE AN ESTIMATED 57% OF CASES OF LIVER CIRRHOSIS 78% OF CASES OF PRIMARY LIVER CANCER.



Tackling viral hepatitis B and C is essential to prevent cancer and reduce its burden significantly.

GET TESTED!

EASLnews and 9 others

17 22



After a long period of disruptions of testing services caused by the pandemic

it's time to catch up on testing and regain focus on viral hepatitis elimination.

TEST. TREAT. PREVENT.



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.'*

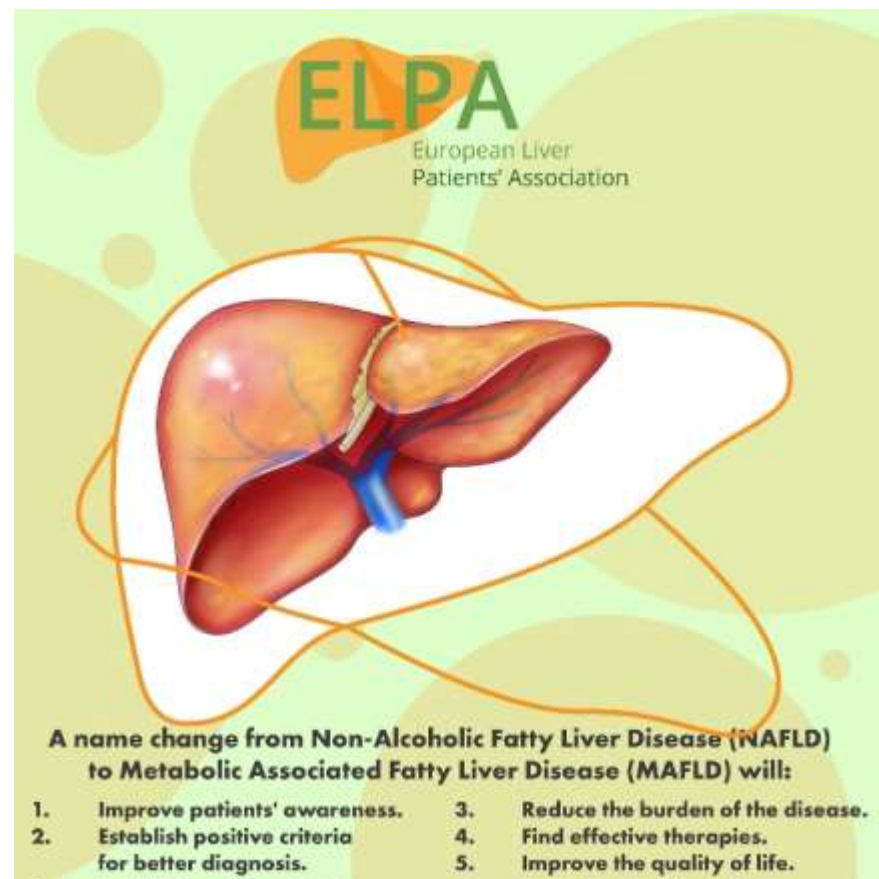
The campaign revolved around different messages. Some informed about the diseases.

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 NAFLD and NASH. 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 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.

**Fatty Liver Month,
ELPA Campaign - 2022**




Fatty Liver Month, ELPA Campaign - 2022

ELPA @EuropeLiver · 8 Jun

Did you know? #NASHday #ILC2022 #MAFLD #NAFLD #FattyLiverMonth #LiverCancer #LiverTwitter #Obesity

Join us Tomorrow morning 🗨️ Topic Roundtable discussion on "Fatty Liver, let's talk about that"



ELPA
European Liver
Patients' Association

If you have NASH, no medication is available to reverse the fat build up in your liver. In some cases, the liver damage might stop or even reverse itself. But in others, the disease continues to progress.

Marko and 9 others

ELPA @EuropeLiver · 14 Jun

The growing prevalence of #NAFLD and #NASH in children and young people is particularly concerning. #FattyLiverMonth #Nashday #ILC2022 #LiverTwitter #LiverCancer @EU_Commission @EU_Health @Marko_Korenjak @AleksanderKrag @EASLnews @EASLedu @EASObesity



ELPA
European Liver
Patients' Association

With obesity shifting towards an early onset in life, NAFLD/NASH prevalence began to increase in the younger populations. In the Western countries, 3%-10% of children are estimated to be affected by NAFLD. However, the rate is underestimated, and in contrast with that in adults, the disease in children has been ignored by healthcare providers.

Ahmed Elshankawy and 9 others

ELPA @EuropeLiver · 9 Jun

#NAFLD is more common in people with certain health conditions, including obesity or obesity-related complications, such as type 2 diabetes. #NASHday #ILC2022 #FattyLiverMonth #LiverTwitter @Marko_Korenjak @Nashday_NASH @wiscnash @intNASHday @schattenberg @RGreenSw @NASH



ELPA
European Liver
Patients' Association

Doctors have found NAFLD in 40 - 80 % of people who have diabetes and in 30 - 90 % of people who are obese.

and 8 others

Alcohol awareness campaign 2022



Only 10 out of 27 EU member states have an action plan to implement alcohol policy (labelling, taxes, advertisement). Moreover, there is not a single country in the world that has health information messages on alcoholic beverages or advertisements, differently from cigarettes.





ELPA

European Liver
Patients' Association

TOGETHER
We are
STRONGER

ELPA's aim is 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 as compared to other areas of medicine such as heart disease; to share experience of successful initiatives; to work with professional bodies such as EASL and with the EU to ensure that treatment and care are harmonized across Europe to the highest standards.



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