

ELPA

European Liver
Patients' Association

The success of virtual ELPA

ANNUAL REPORT 2020

The success of virtual ELPA

ANNUAL REPORT 2020

ISBN: 978-2-931120-00-2 9782931120002

Authors: **Beatrice Credi, Marko Korenjak, Veronika Všetíčková, Milan Mishkovikj**

Reviewed by: **ELPA Editorial Team - Dr. Hilal Ünalmiş Duda, Dr. Tove Frisch**

Design and layout: **Janja Primožič**

© **European Liver Patients' Association 2020**

'We should fight WITH the patients and not FOR the patients'

Emilia Rodrigues

In memory of Emilia Rodrigues and Muriel Colinet

In 2020, ELPA lost two of its most passionate friends, Emilia Rodrigues and Muriel Colinet.



Emilia Rodrigues

Emilia Rodrigues was the President of *SOS Hepatites Portugal*, ELPA member since 2005; she was also of ELPA Supervisory Committee and later an ELPA Advisor to the ELPA Board. Besides, Emilia collaborated with the most well-known experts in the field of Hepatitis eradication in Europe and beyond.

However, despite the titles, she was, above all, a committed liver disease patients' advocate and a patient herself. She put all her energy into her fight with liver disease. She was always cheery, the best supporter and colleague ever.

SOS Hepatites Portugal, one of the most active associations of support for Hepatitis patients in Portugal, is an association made up of people affected by the Hepatitis virus. It arose from a need to share experiences, strengths, and hope to create a space where patients with viral hepatitis and their families would find a way to help each other concerning common

problems arising from the disease and in a way to improve their quality of life.

Emilia ran the association with the intent to raise awareness around this disease but also to end the marginalization, discrimination, and prejudices these patients are still experiencing. Her tireless commitment and her expertise made Portugal one of the leading countries in Europe and the World regarding Hepatitis elimination.



Muriel Colinet

Muriel Colinet was the President of CHAC (Carrefour Hépatites Aide et Contact) a Belgian founding member of ELPA and the President of ELPA in 2006.

She was a tiredness liver disease patients' advocate who had become a fighter against Hepatitis C together with her husband, who died while waiting for a liver transplant he never received.

Her attitude was always to challenge politicians, experts, and hepatologists relentlessly, but always to listen to patients.

Probably there is no better way to describe her than using the word by Pascal Mélin, President of SOS Hépatites et maladies du foie, French ELPA Member. "My best memory which sums up so well her character and which still makes me laugh was her crazy project to make whoopee cushions with the word hepatitis C written on top to offer to doctors by saying to them

'you can continue not to give a fuck about hepatitis C, but at least it will make some noise!' I had burst into choking laughter, but maybe she was the one who gave us the idea for the "Make some noise against Hepatitis C" campaign."

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

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

EU - European Union

EURODIS - Rare Diseases Europe

HBV - Hepatitis B Virus

HCV - Hepatitis C Virus

HE - Hepatic Encephalopathy

HEP - Hepatitis

HTAI - Health Technology Assessment International

ILC - International Liver Congress

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

Contents

13	Our Mission
13	ELPA Values
14	Foreword of the President
16	ELPA Members in 2020
19	2020 Highlights
21	Three new Memorandum of Understanding
22	The European Vaccines Information Portal (EVIP)
22	DILI meeting @ EASL Digital ILC 2020
22	First online patient events of the MICROB-PREDICT and DECISION projects
25	ELPA's EU medical research projects booklet
25	ELPA welcomed a new ELPA Member
26	Liver Cancer Awareness Month (LCAM) 2020
27	ELPA confirms its collaboration with EMA
29	Policy and advocacy work
31	European Cancer Forum: towards a new era in cancer care
31	Intercept Practice to Policy PBC International Summit
31	Meeting with DG SANTE and the EU Fighting Cancer Plan
33	EASL Conference on HCC
33	Meeting in Denmark to prepare a new Horizon 2020 project
34	Meetings in Brussels and Paris
34	ELPA at the EMA annual meeting PCWP and HCPWP
35	Public Consultation on Europe's Beating Cancer Plan
35	European patients' Forum Annual General Meeting
35	A Call to action in response to COVID-19
36	EU HIV/AIDS, viral hepatitis and tuberculosis Civil Society Forum
36	International Women's and Children's Health and Gender Group, Virtual Conference
36	ELPA joined the EASL Patient Groups Community
36	High-level meetings with representatives from the German region Baden-Württemberg
37	ELPA's collaboration in preparing the HCC Patient Guide for ESMO
37	ELPA representatives in the NASH community in the Patient Advisory Group of IMI EU PEARL project
38	ACHIEVE Coalition's meeting
38	EASL-ILC meeting – The Digital International Liver Congress 2020
39	EPF event on COVID-19 pandemic and the future of HTA collaboration at EU level
39	Rare Disease Day in DIMED Research Projects
39	'The Importance of systemic treatment sequencing in improving survival for patients with HCC' media briefing
40	HBV Cure Workshop by Agence ANRS France
40	The European Drug Report 2020
40	Coalition for Global Hepatitis Elimination's webinar

40 Addressing TB, HIV, and Viral Hepatitis during the COVID-19 Pandemic
41 The 23rd edition of the European Health Forum Gastein
41 The Digital ILC2020
41 ELPA and DiCE meeting on liver cancer. 'Together we are EVEN stronger'
42 Liver Cancer Awareness Month closing event
42 Meeting with the Egyptian Society for the study of Endoscopy and Hepatogastroenterology
43 EMA training day
43 NASH Policy Action
43 European Patient innovation summit 2020
43 EPF Webinar in Telemedicine and E-health
44 ACHIEVE Coalition's meeting
44 High-level Review of Regulatory Frameworks and the way Forward
44 AASLD Meeting 2020
45 PCWP meeting at EMA
45 The 8th Awareness Week on Alcohol-Related Harm
45 International Viral Hepatitis Elimination Meeting (IVHEM) 2020
45 EASL Members' Extraordinary General Assembly
46 Second Meeting of the Regional Collaborating Committee on Accelerated Response to Tuberculosis, HIV and Viral Hepatitis (RCC-THV)
46 EMA's public meeting on COVID-19 vaccines
46 EU Big Data Stakeholders Forum
47 Endorsement to the EKPF's open letter on organ donation and transplantation

49 Empowering our members

51 ELPA President visits Serbia
51 7th Portugal national hepatitis Conference organized by SOS Hepatites
52 Cyprus Liver Patients Association's new President
53 ELPA Director elected Vice President of the "Alliance of Patient Organizations" of Macedonia
53 'RoadMap to Zero, strategies for HCV elimination'

55 Strengthening our association

57 ELPA Educational Training – June/July 2020
59 ELPA Annual General Meeting and Extraordinary General Meetings 2020
59 Nobel Prize for Medicine goes to Hepatitis C discovery
59 ELPA Educational Training – November/December 2020
63 ELPA Stakeholders' Meeting, Europe in 2021
66 The first person belonging to ELPA's family to be given the Covid-19 vaccine

67 ELPA in scientific research projects

69 Medical research project Galaxy, Horizon 2020
69 Medical research project Liverhope, Horizon 2020
70 Medical research project Microb-Predict, Horizon 2020
70 Medical research project Liverscreen, Horizon 2020
70 Medical research project IP Cure B, Horizon 2020

71	Medical research project FiSplat, European Institute for Innovation and Tehnology – EIT Health
71	Medical research project Decision, Horizon 2020
71	Medical research project A-TANGO, Horizon 2020
72	MICROB-PREDICT Meeting
72	IP-cure-B project meeting
73	FiSplat project meeting
73	LiverScreen project meeting
74	ELPA President is a member of the Impact Board of Decision Project
74	IP Cure B Steering Committee meeting
75	Decision project virtual General Assembly Meeting

77 Social media activities

80 ELPA's most successful Social Media Campaigns

80	#EuroTestWeek - Spring and Autumn edition
81	International NASH Day Campaign
82	World Hepatitis Day
82	International PBC Day 2020
83	World Patient Safety Day 2020
83	PSC Day 2020
84	AWARH
84	ELPA's support to its members, stakeholders, supporters and friends' campaigns
85	A website entirely dedicated to Liver Cancer

87 ELPA Structure

89 ELPA structure 2018-2022

91 ELPA Working groups

93	ELPA Working Group on Rare Liver Diseases
93	ELPA Working Group on Primary Liver Cancer
94	ELPA Working Group on Clinical Trials
94	ELPA Working Group on Harm reduction
95	ELPA Working Group on MAFLD/NASH
95	ELPA Working Group on Prevention
96	ELPA Working Group on Hepatitis B elimination

97 Financial accounting and transparency

102	Publishing financial reports
102	Statutory audit for 2018, 2019 and 2020

103 Acknowledgments

Our Mission

ELPA emerged from a desire amongst European liver patient groups to share their experiences of the often very different approaches adopted in different countries. In June 2004, 13 patient groups from 10 European and Mediterranean basin countries met to create the association. ELPA was formally launched in Paris on April 10th, 2005, during the annual conference of the European Association for the Study of the Liver (EASL) and in 2020 had 32 members from 25 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 as compared to other areas of medicine such as heart disease, and to share the experience of successful initiatives. ELPA and its members are dedicated to multi-level lobbying initiatives involving European Union and national policymakers, liver specialists, associations, and public health experts. ELPA's vision is that all liver patients are diagnosed in time, treated with respect, and have equal access to the best medical care standard – regardless of origin, lifestyle, and type of liver disease.

Our ultimate goal is a world without liver diseases.

ELPA Values



Equality



Respect for
diversity



Patient
driven



Commitment



Transparency

Foreword of the President



Marko Korenjak

Dear ELPA Friends,

Due to the COVID-19 pandemic, 2020 has been studied with shocking changes in our professional and personal lives. However, we cannot underestimate the outstanding results achieved by ELPA together with all of you. In times of crisis, and despite the social distancing, ELPA did not give up, proved that it is possible to be ever closer and more vital. The fact that ELPA's 15th Anniversary occurs during these challenging times should not discourage us from joining forces even more than before. In all of the areas, the results are all proudly shown in this overview of our activities throughout 2020. I firmly believe that it should inspire you to support our work and comprehend the importance of an association like ELPA.

I would like to thank ELPA Members for being part of ELPA's family. Without you and your tireless commitment, ELPA would not exist. You are the beating heart of our association, and ELPA is working hard, primarily to support you in your invaluable day-to-day work.

Yet, I would also like to thank ELPA Stakeholders and Supporters for being by our side fighting liver diseases. If, after 15 years, we are growing bigger and stronger than ever, it is also thanks to your support and the trust you have placed

in us and our work. However, ELPA wants to continue on the same fruitful path, but we are also determined to be more ambitious for our Members and all liver patients. That is the reason why we still need you.

I should also thank the ELPA Governing Board, the ELPA Scientific Committee, and the ELPA Office for their tireless efforts to push patients' needs on top of the scientific and political agenda. ELPA team has several ideas and projects that will be done in the near future to establish higher-quality management processes in the association.

This may sound strange, but I also have to dedicate a line to Information Technologies. Without the possibility to connect virtually, our advocacy work would be heavily undermined in 2020. We had the opportunity instead to reach many people and spread our message worldwide. The section of this report dedicated to Social Media is clear evidence of the importance of ITs.

I like to think of ELPA as an orchestra made of various instruments that only together play a beautiful symphony. Thank you all for being part of this colourful and diverse family. Nothing would happen without you and your specialness.

I also want to make a wish. I wish the following year were a rebirth for all of us but preserving the same stubborn willingness we showed in making ELPA growing and thriving, continually working to improve liver patients' lives in Europe and beyond.

Our ultimate goal is a world without liver diseases.

Together we are stronger!

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



ELPA Members in 2020



BELGIUM

- Vlaams Hepatitis Contactpunt - VHC



FINLAND

- The Finnish Kidney and Liver Association



BOSNIA & HERZEGOVINA

- The Chronic Viral Hepatitis Patients Association, "B18"



FRANCE

- SOS Hépatites Fédération



CROATIA

- Croatian association for liver diseases, "Hepatos"
- HUHIV - Croatian Association for HIV and viral hepatitis



GEORGIA

- Hepatitis C Cured Patient Association



CYPRUS

- Cyprus Liver Patients Association, "Promitheas"



HUNGARY

- Hungarian Association of Chronic Hepatitis Patients, "VIMOR"



DENMARK

- Leverforeningen



IRELAND

- Hepatitis C Partnership



EGYPT

- Association of Liver Patients' Care – ALPC



ISRAEL

- Israeli Association For The Health Of the Liver, "Hetz"

**MACEDONIA**

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

**NORWAY**

- proLAR

**POLAND**

- Star of Hope Foundation

**PORTUGAL**

- SOS Hépatites Portugal

**ROMANIA**

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

**RUSSIA**

- Humanitarian Action
- United Against Hepatitis

**SERBIA**

- Association for helping patients with chronic viral hepatitis, "HRONOS"

**SLOVAKIA**

- HEP HELP KLUB
- Šanca pre pečeň

**SLOVENIA**

- Slovenian Association for patients with viral hepatitis - Slovenia HEP

**SPAIN**

- Catalan Association of Hepatitis Patients - ASSCAT
- National Federation of Liver Patients and Transplanted - FNETH

**SWEDEN**

- Riksföreningen Hepatit C – RHC

**TURKEY**

- Living with Hepatitis Association - HEPYAŞAM

**UNITED KINGDOM**

- British Liver Trust
- Hep C Positive
- Liver4Life



2020 Highlights

Three new Memorandum of Understanding

In 2020 the European Liver Patients Association (ELPA) signed two new Memorandum of Understanding (MoU). The first with **Digestive Cancers Europe (DiCE)** and The agreement brought about a formidable and active patient advocacy partnership that allows the two organizations to put their joint efforts behind bettering the outcomes and quality of life of liver patients across Europe. The two organizations started working hand-in-hand, focusing their collaborative projects on the following three key areas: raising awareness on prevention, early detection, proper treatment, and rehabilitation; bringing liver cancer onto the political radar and agenda; providing liver cancer expert and peer-to-peer patient support. The second MoU was signed with the **European Kidney Patients' Federation (EKPF)**. This new MoU had the objective to formalize the cooperation between EKPF and ELPA to improve patients' well-being and provide support to the patient population. The two associations are both parts of the European Patients' Forum (EPF). Working together and being part of a more significant umbrella patients' association is the key to successfully influencing decision-makers and putting patients in the spotlight. The third MoU is about rare liver disease. It has been signed between ELPA and the **PBC Foundation**, the only UK-based organization that deals explicitly with Primary Biliary Cholangitis, a long-term, auto-immune condition that affects the liver. ELPA strongly wanted this collaboration to work even harder in the field of rare liver disease through the Working Group dedicated to this field.



Marko Korenjak, ELPA President - Stefan Gijssels, CEO of Digestive Cancers Europe (DiCE)



Marko Korenjak, ELPA President - Daniel Gallego Zurro, EKPF President



Marko Korenjak, ELPA President - Robert Mitchell-Thain, PBC Foundation Development Officer

The European Vaccines Information Portal (EVIP)

ELPA was proud to be one of the partners who collaborated in the new European Vaccines Information Portal (EVIP). Developed by ECDC in close collaboration with EMA and the European Commission, EVIP is now publicly available. It was created following a Council Recommendation on “strengthened cooperation against vaccine-preventable diseases.” The portal is available in all EU languages, and the information is provided in an easily accessible language, enriched with many visuals. Besides, EVIP provides reliable and evidence-based information on vaccines and vaccination, including national vaccination schedules. This includes how vaccines are developed, authorized, and monitored in the EU and general information on the benefits of immunization and five disease factsheets (HPV, Flu, Measles, Pertussis, and Rubella – more will be added in due course). The portal currently contains no information related to COVID-19 as work is ongoing in this area. Updated information in this area will be published once available.

DILI meeting @ EASL Digital ILC 2020

On August 29, 2020, in the framework of the EASL Digital ILC meeting, Dr. Teresa Casanovas Taltavull, ELPA Director and ELPA Scientific Committee leader and ELPA President Marko Korenjak, presented about Drug-Induced Liver Injury (DILI). It is a disorder whereby drugs (including pharmacological therapies, traditional medicines, and herbal or dietary supplements) cause liver damage. ELPA President focused more on the relevance of a patient perspective in DILI. He stressed that it is imperative to inform that the use of so-called “natural products” is not without risks. The role of liver patients’ associations is critical in this area since nobody would be better than another patient to inform his peers. Also, he pointed out the importance of social media to expand medical information. Dr. Teresa Casanovas Taltavull, instead, presented a case report of probable autoimmune hepatitis caused by dietary and herbal supplements (DHS). She underlined that one effective way to draw attention to the problem of DILI is by telling a patient’s individual story because knowledge can help prevent harm.

First online patient events of the MICROB-PREDICT and DECISION projects

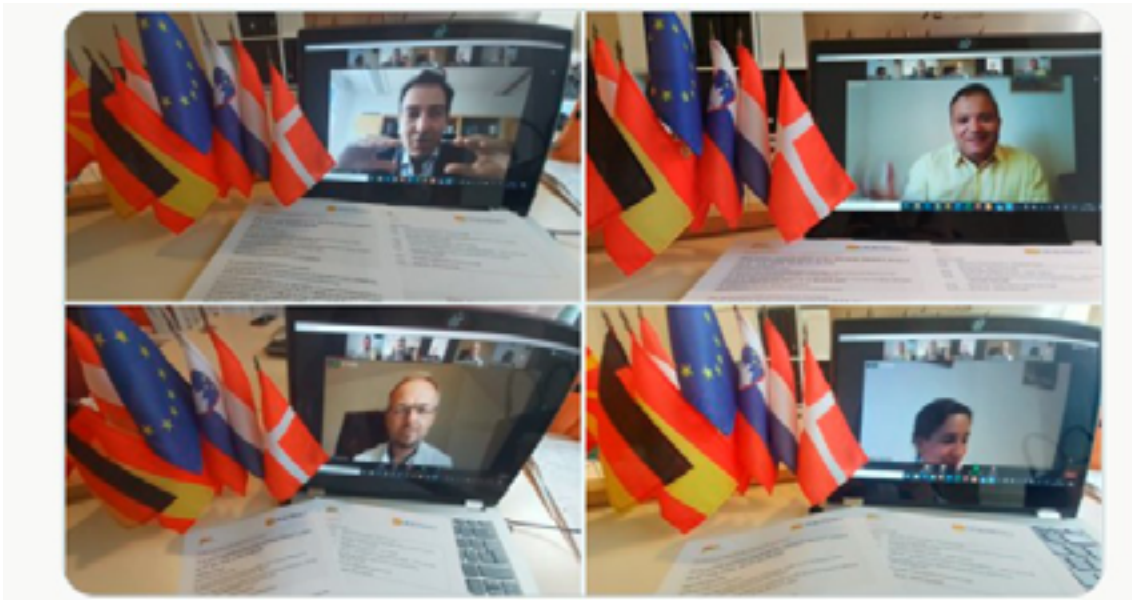
‘Medical research project and patients’ Perspective & discussion’ was a virtual workshop held on July 8, 2020, in the framework of the **EU medical research project MICROB-PREDICT**, where ELPA’s main objective is the dissemination of the project’s information and results. In the MICROB-PREDICT project, 22 European institutions join forces to improve the prevention and treatment of cirrhosis.

The meeting started with a brief introduction by the organizing committee followed by the first presentation delivered by Marko Korenjak. He shared with the audience information about decompensated cirrhosis / acute-on-chronic liver failure (ACLF) from a patient perspective. He focused on the fact that there are more than 13 distinct definitions of ACLF. He gave an overview of a healthy liver’s progression to decompensated cirrhosis, stressing that other organs are implicated. He concluded by saying that the acceptance of ACLF as a new syndrome has stimulated widespread research across the world, MICROB-PREDICT included, leading to two main benefits. Firstly, more accurate personalized risk stratification. Secondly, the improvement of the personalized treatment of decompensated cirrhosis and ACLF.

Introduced by Marko Korenjak, the second speaker took the floor just after ELPA President's presentation. As a principal investigator in the MICROB-PREDICT project, Prof. Dr. Jonel Trebicka's presentation and the entire project revolved around the microbiome's importance. The project will investigate the human microbiome to identify predictors and mechanisms associated with the development of decompensation and progression to ACLF and death. This will result in better stratification of cirrhotic patients enabling microbiome-based intelligent and personalized allocation to treatment, and ultimately prevent ACLF and reduce mortality.

Prof. Dr. Aleksander Krag, Head of Hepatology Department Odense University Hospital, started his presentation. Being the head of the clinical trial in the MICROB-PREDICT (WP7) project, he explained this part of the project. Alb-Trial - the clinical trial of MICROB-PREDICT- will be a state-of-the-art clinical trial aiming at validating the microbiome-based biomarker developed within the framework of MICROB-PREDICT. The short time from biomarker development to validation in a clinical setting will be unprecedented in the field of liver diseases. This will allow researchers to quickly implement personalized treatment guidelines to benefit patients, relatives, and the community.

At the end of Prof. Krag's presentation, Marko Korenjak gave the floor to the fourth panelist, Dr. Minneke Coenraad, dissemination manager in the MICROB-PREDICT project. She highlighted the importance of informing the patients' community, the scientific community, and the general public on the results of scientific projects such as MICROB-PREDICT. After a general introduction, she described 4 dissemination tools related to MICROB-PREDICT: the website, with a part dedicated to patients in 3 languages with also some background information, a brochure with a summary of basic facts about the project, the Twitter account, and videos with an interview of people part of MICROB-PREDICT consortium.

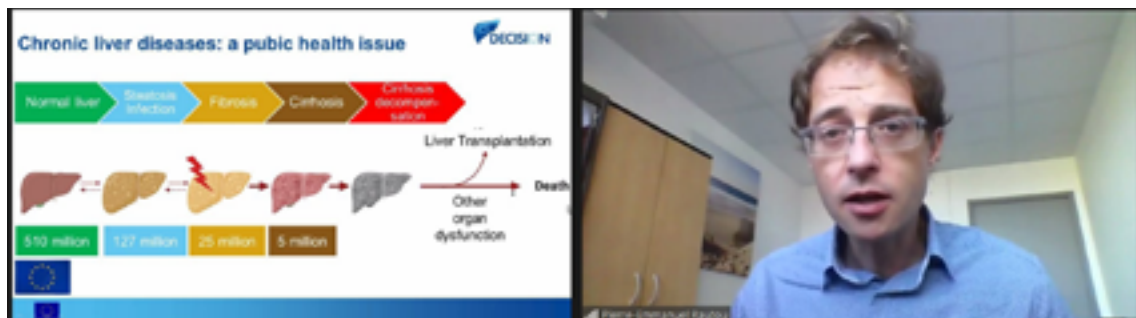


Prof. Dr. Jonel Trebicka, principal investigator in MICROB-PREDICT project - Marko Korenjak, ELPA President - Prof. Dr. Aleksander Krag, head of the clinical trial in MICROB-PREDICT - Dr. Minneke Coenraad, dissemination manager in MICROB-PREDICT project

The first online patient event of the **EU medical research project DECISION** took virtually place on August 31, 2020. In the DECISION project, 21 European institutions join forces to tackle end-stage liver disease and liver failure with a systems medicine approach. Over the next 5.5 years, the DECISION research

consortium will analyze and integrate data from existing clinical cohorts and biological samples to identify novel combinatorial therapies, validate them in animal models, and test the most promising combinatorial therapy in a clinical trial. The DECISION project's overall aim is to prevent acute-on-chronic liver failure (ACLF) and significantly reduce the mortality rate amongst patients with decompensated cirrhosis.

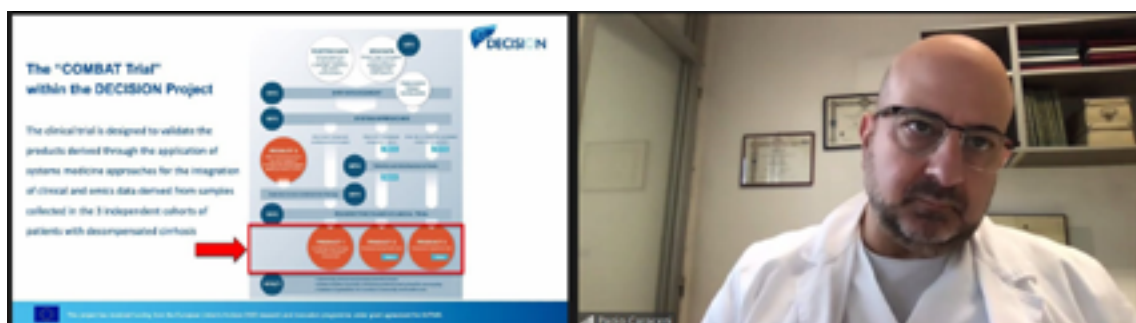
The webinar started with a brief introduction by Marko Korenjak. He thanked all the people attending the meeting; he stressed the importance for patients to be part of scientific projects, such as DECISION, and he shortly presented the panelists. Introduced by Marko Korenjak, the first speaker took the floor just after ELPA President's presentation. As coordinator and principal investigator in the DECISION project, Prof. Dr. Pierre-Emmanuel Rautou gave an overview of the project.



Prof. Dr. Pierre-Emmanuel Rautou, coordinator and principal investigator in the DECISION project

After a short introduction by Marko Korenjak, Prof. Dr. Paolo Caraceni, Professor of Internal Medicine, Alma Mater Studiorum University of Bologna-Italy, started his presentation. Being the head of the clinical trial in the DECISION project (WP5), he explained COMBAT-trial, the clinical trial nested in DECISION, designed to validate the combinatorial therapies and the novel biomarkers identified during the first year of the project. His presentation was composed of two parts. In the first part, Prof. Caraceni explained why the COMBAT-trial addresses a critical clinical need related to managing these very sick patients. In the second part, he gave specific details about the trial.

At the end of Prof. Caraceni's presentation, Marko Korenjak gave the floor to the third panelist, Prof. Dr. Sara Montagnese, Professor of Medicine and Honorary Consultant Physician Padova University Hospital, Italy, and involved in the dissemination activities of the DECISION project. She listed all the possible doubts and



Prof. Dr. Paolo Caraceni - head of the clinical trial in the DECISION project

questions a patient with cirrhosis could have and stressed that mostly the answers are 'we do not know,' the scientific community is still not very good at working out who will develop complications. However, according to Prof. Montagnese, to make progress in these fields, a project like DECISION is crucial. Prof.

Montagnese finished her presentation stressing the importance of disseminating DECISION's activities and results among the scientific community and reaching a larger audience, patients included. She also emphasized that the patients' associations' participation in projects like DECISION is essential to drive scientific research forward.

ELPA's EU medical research projects booklet

In June 2020, ELPA published a booklet describing all the EU medical research projects ELPA is involved in. This overview is an occasion to look at all ELPA's partners and show how ELPA's collaboration in scientific and medical frameworks is crucial. On the one hand, ELPA's participation in scientific projects is part of this tireless advocacy work. Being part of them enriches the research field with the unique views of patients' organizations. On the other hand, ELPA, with its exclusive way of communicating and disseminating scientific results, acts like a translator making complex contents accessible to a broader public. To this day, we are proud that ELPA is included in science research projects that explore the possibilities to improve liver patients' lives – in total, around 75 million EUR spend for top liver research in Europe at more than 50 leading research laboratories and hospitals in Europe.



ELPA welcomed a new ELPA Member

In 2020, several associations wanted to join ELPA, but only two fulfilled the proper requirements. ELPA Board of Directors checked all the applications. It was decided that an association from Croatia and one from Montenegro would have presented themselves during the ELPA Annual General Meeting 2020 that took place on August 31. The decision to be part of ELPA as associate members was submitted to the assembly during AGM, and ELPA members gave the green light to the Croatian association CAHIV that, for the next year, will be an associate member of ELPA. Congratulations!

Liver Cancer Awareness Month (LCAM) 2020

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. 2020 ELPA's social media campaign revolved around the idea that Liver Patients' Associations' role is crucial, and it is based on the dissemination of updated and scientific information mainly focused on prevention since nobody is better than patients to inform other patients. This year, in particular, ELPA focused deeper on the importance of the correlation between liver cancer and NASH, alcohol consumption, cirrhosis, and hepatitis. Besides, ELPA did not forget the massive impact the COVID-19 crisis has on liver patients, cancer patients included. ELPA received several endorsements and encouragement messages from other associations, supporters, and stakeholders. ELPA reached 35 million impressions and almost 20.000 visits on the webpage www.livercancermonth.eu in just 30 days. On this topic, ELPA also organized two side events: a workshop in collaboration with Digestive Cancers Europe (DiCE) and a roundtable as a closing campaign event. However, ELPA's cooperation during the LCAM did not stop with Patients' organizations. This year, Ipsen and the "The Organ Family" supported ELPA's campaign.



As part of the campaign, Ipsen launched an animated series following “The Organ Family.” These character representations of various body organs detailed the effects of lifestyle factors on the central character, Liv the Liver. The videos were subtitled in many ELPA members’ languages to improve their dissemination.

ELPA confirms its collaboration with EMA

Following ELPA’s annual renewal form assessment, the European Medicine Agency (EMA) confirmed our organization remains compliant with the criteria required to be an EMA eligible organization, as defined by EMA Management Board. EMA engages with a network of over thirty-five eligible organizations, ensuring that the needs and concerns of a wide range of patients and consumers are represented via direct contact with the Agency. In most cases, these organizations are not-for-profit, have a European Union-wide mandate, and include umbrella organizations and organizations focusing on a specific area. ELPA will continue to work together with the Agency and all the eligible organizations to improve liver patients’ lives.



Policy and advocacy work

European Cancer Forum: towards a new era in cancer care

On January 28, 2020, ELPA attended the European Cancer Forum in Brussels. This year's edition was dedicated to exploring the future of treating and living with cancer and the future of innovation access. The forum was organized just a week before the launch of the "Europe's Beating Cancer Plan" by the European Commission. Stella Kyriakides - European Commissioner for Health and Food Safety - invited all the stakeholders to fill in the European Commission's public consultation.

Intercept Practice to Policy PBC International Summit

This Summit took place on January 31, 2020, in London, UK. Attendees were representatives from Finland, Macedonia, Germany, Italy, Austria, Sweden, U.S.A, and the United Kingdom. ELPA was represented by Sindee Weinbaum, who also represented the Israeli association - Hetz. The summit was composed of several sessions about Practice to Policy projects included a workshop where each participant worked out a possible plan for future implementation. Each plan was presented to all the attendees, and they are supposed to be distributed to all of them. Sindee Weinbaum also had a meeting with Parisa Sanandaji, Patient Advocacy Director at Intercept, about the PSC trials that have been stopped and the possibility of future trials. She also met with Lisa Bright about possible programs for NASH and Policy to Practice in 2021. They also discussed the possibility of translating the PBC APP into many different languages.



Sindee Weinbaum, Leader of ELPA Working Group on Rare Liver Disease

Meeting with DG SANTE and the EU Fighting Cancer Plan

ELPA President Marko Korenjak's trip to Brussels on February 3 and 4, 2020, has been characterized by two significant events. At the European Commission, the first was a meeting with Anne Bucher, the Director-General of DG SANTE. Here, together with ELPA Board representative Milan Mishkovikj, Marko Korenjak discussed ELPA's activities over the next 5 years. However, the discussion focused on two main issues. Firstly, Milan Mishkovikj described the plans for working with WHO Europe. Also, Marko Korenjak presented the White Paper on HCC ELPA will launch in the European Parliament in 2020. At the European Parliament, the second was the attendance to the 'EU Beating Cancer Plan' launch by the Commissioner for Health and

Food Safety, Stella Kyriakides. The plan was presented by Ms. Kyriakides and endorsed by the President of the European Commission, Ursula von der Leyen, and two Vice-Presidents of the European Parliament and by some MEPs. This event was also the occasion for meeting and networking with many people, such as GLI representatives and the EPF Director. At the European Parliament, Marko Korenjak also recorded a video message saying how ELPA is proud to be part of the discussions about the 'EU Beating Cancer Plan.'



Milan Mishkovikj, ELPA Director – Anne Bucher, Director General of DG SANTE – Marko Korenjak, ELPA President



Milan Mishkovikj, ELPA Director – Veronika Všetickova, Head of Brussels office and EU Affairs Marko Korenjak, ELPA President



Milan Mishkovikj, ELPA Director – Veronika Všetickova, Head of Brussels office and EU Affairs Marko Korenjak, ELPA President

EASL Conference on HCC

ELPA President Marko Korenjak participated in EASL Conference on HCC in Prague, the Czech Republic, on February 6 and 7, 2020. During the first day, he had a meeting with EASL CEO Ben Hainsworth and the EASL scientific community's representative, Prof. Maria Reig. She is a very well-known specialist on HCC working in Barcelona, in Hospital Clinic in the Jordi Bruix team. She has been involved in all clinical trials on HCC, and as a clinician, she visits patients directly. They discussed all the open questions between ELPA and EASL, and they made a plan regarding the following steps to take in 2020. The conversation was mainly focused on the liver cancer event ELPA would like to organize, the ELPA round table discussion in Dublin before the EASL-NASH meeting, and other issues connected to EASL-ILC in London. Later the same day, Marko Korenjak got in contact with two new companies that were present at the congress, Boston Scientific and Eisai, a Japanese company. He also reached Dr. Pooja from Bayer, with whom we were already in contact, to ask her to provide ELPA with Bayer's representative's name attending the congress in Prague to arrange a meeting accordingly. During the second day, the President had a meeting with representatives from Boston Scientific. Everybody agreed that there is a common interest in collaborating, and Boston Scientific said yes to support us in 2020 regarding some small activities. Before leaving, the last meeting with a medical representative from Bayer was the opportunity to discuss the support ELPA needs regarding ELPA educational days in Frankfurt and the White Paper's launch on HCC in the European Parliament in 2020.



Marko Korenjak, ELPA President - Ben Hainsworth, EASL Managing Director

Meeting in Denmark to prepare a new Horizon 2020 project

The meeting took place on February 18-20, 2020, in a remote location close to Stenstrup, Denmark. The consortium members, ELPA included, gathered together to discuss the next steps that should be done shortly. Though ELPA President Marko Korenjak did not have the time to present on the work package dedicated to the communication and dissemination activities, this meeting was an extraordinary occasion

to join forces to push forward ELPA's goals. Indeed, he had the chance to present ELPA's activities, stressing some details about the role we would like to have in the project that had been proposed.

Meetings in Brussels and Paris

ELPA President's trip to Brussels from March 8 to 12, 2020, created occasions to gather with several EU representatives to discuss the position of liver patient association in the emerging COVID19 situation. ELPA President also went to Paris to discuss with leaders of the project ELPAs engagement in an upcoming new EU Horizon 2020 project for liver-transplanted patients in Europe. ELPA President successfully managed to involve ELPA not only to work on patients' perspectives but also to participate in the dissemination of the project results actively. ELPA is, therefore, looking forward to the approval of another EU Horizon 2020 Project in which we will proudly participate in the preparation of the necessary documents.



Marko Korenjak, ELPA President – Dr. Vincent Karam - Prof. Dr. René Adam - Prof. Dr. Christophe Duvoux

ELPA at the EMA annual meeting PCWP and HCPWP

On March 3 and 4, 2020, ELPA participated at the EMA annual meeting "Patients and Consumers Working Party (PCWP) and the Healthcare Professionals Working Party (HCPWP)" in Amsterdam. ELPA representative was Teresa Casanovas, ELPA Director and leader of the ELPA Scientific Committee. This meeting was crucial for ELPA because representing liver patients in Europe, ELPA should be updated regarding EMA work. Indeed, EMA joined 44 associations and members representing patients' associations and healthcare professionals. EMA received exciting information about clinical trials, big data use and its protection, analysis of shortages of medicines across Europe, and information about treatments in rare diseases and special populations. EMA is trying to evolve and introduce innovations in various fields.



EMA annual meeting PCWP and HCPWP – Group Picture

Public Consultation on Europe’s Beating Cancer Plan

In March 2020, ELPA gave its opinion in the EU-wide public consultation on Europe’s Beating Cancer Plan. The consultation will help shape the Plan, identify critical areas, and explore future action. The public consultation aimed to allow EU citizens and stakeholders to contribute and voice their opinion on the best ways to address this issue in the EU. The consultation results will feed into the outline of Europe’s Beating Cancer Plan and help identify the areas and the scope of future action.

European patients’ Forum Annual General Meeting

ELPA - represented by Vice-President Julio Burman - took part in the European patients’ Forum Annual General Meeting. On April 25, 2020, EPF Members gathered online for the 17th Annual General Meeting. This was the first-ever virtual AGM for EPF, adapting to the current COVID-19 circumstances while upholding fundamental governance standards for EPF and its members. During the event, members of EPF’s Board and Secretariat reported 2019 activities and gave an overview of our current and upcoming work for 2020-2021. The event also saw the election of new board members, the approval of three new full-member organizations, and the first-ever election of members for the newly created EPF Ethics Committee.

A Call to action in response to COVID-19

ELPA President Marko Korenjak and ELPA Director and ELPA Treasurer Ivana Dragojevic worked on drafting a Call to action in response to COVID-19 in the framework of the Regional Collaborating Committee on Accelerated Response to Tuberculosis, HIV and Viral Hepatitis (RCC-THV) Hosted by the WHO Regional Office for Europe. The Committee called on national governments, development partners, United Nations agencies, and civil society to increase their efforts to ensure rights and equity-based approaches in providing information, care, and social support to the most vulnerable communities and key populations affected by the three diseases.

EU HIV/AIDS, viral hepatitis and tuberculosis Civil Society Forum

In May 2020, ELPA applied to be part of the EU HIV/AIDS, viral hepatitis, and tuberculosis Civil Society Forum. The application was successful, so ELPA is officially one of the new member organizations, and it will represent liver patients in the CSF along with 61 organizations plus two partner organizations. Due to the current situation related to Covid-19, the first introductory meeting will be held online on the 3rd of July 2020. ELPA is very much looking forward to the collaboration in the upcoming almost three years.

International Women's and Children's Health and Gender Group, Virtual Conference

On June 19, 2020, ELPA Director and ELPA Treasurer Ivana Dragojevic participated in the 'International Women's and Children's Health and Gender Group Conference.' The International Women's and Children's Health and Gender (InWomen's) Group, chaired by Dr. Wendee Wechsberg of RTI International, is a multidisciplinary forum addressing all aspects of substance use among women, children, and youth. Ms. Dragojevic attended sessions I and II regarding the topic: 'Prevention of HIV risk and intimate partner violence among adolescents in South Africa' and 'Preventing violence and HIV among women and girls in South Africa: merging components from successful intervention.' From her perspective, addressing issues such as HIV, prostitution, sexual abuse without even mention hepatitis is unacceptable. In her conclusion, her participation in this meeting showed that liver patients' associations have much work to do.

ELPA joined the EASL Patient Groups Community

ELPA is proud to announce that it became part of the EASL Patient Groups Community. ELPA's successful application is just the latest step of a long and fruitful collaboration started many years ago. However, it is also a fresh start to strengthen ELPA's partnership with EASL even more than before. In addition, ELPA's participation in the EASL Patient Groups Community will allow ELPA to build new synergies and to create new opportunities with EU leading hepatology associations and share best practices with other patient groups on the ILC Patient Forum. ELPA is looking forward to being an active member of this community and together support liver patients to promote a better knowledge of their needs.

High-level meetings with representatives from the German region Baden-Württemberg

ELPA President Marko Korenjak was personally invited by Theresia Bauer, the Minister of Science, Research and Arts of the State of Baden-Württemberg, Germany, to the online-event: "No one size fits all: Artificial Intelligence as Key Technology for Personalised Medicine." On July 3, as ELPA representative, he could discuss with high-level distinguished panellists the interfaces between AI and medicine, the cooperation between science and industry, and the future funding instruments for health and AI planned by the European Commission. After an introduction by Bodo Lehmann, Head of the Representation of the State of Baden-Württemberg to the European Union and Dr. Julia Stamm, Founder and Director, Science Leads, Berlin, the keynote speech was delivered by Minister Theresia Bauer and Prof. Dr. Bernhard Schölkopf, Director, Max Planck Institute for Intelligent Systems. Dr. Karim Berkouk, Deputy Head of Unit Combatting

Diseases, DG Research and Innovation, European Commission, underlined the link between AI and health. Artificial intelligence is one of the technologies that are key to Europe's future, as stressed during the debate by Dr. Nuria Oliver, Chief Data Scientist, Data-Pop Alliance, Member of the Board of ELLIS Society (European Laboratory for Learning and Intelligent Systems), and by Dr. Oliver Stegle, Head of Division, Computational Genomics and Systems Genetics, German Cancer Research Center Heidelberg and European Molecular Biology Laboratory Heidelberg. Besides, personalized medicine is one out of many key applications of this modern data-driven approach to healthcare. Cross-disciplinary collaboration and a strong European network of AI hubs are needed to leverage AI's full potential. During the final session of the meeting, Michael Vorländer, Head of Unit Education and Research, Permanent Representation of Germany to the European Union, focused on research and innovation priorities under the German EU Council Presidency.

On the occasion of the 100th anniversary of Anthroposophic Medicine, the International Federation of Anthroposophic Medical Associations (IVAA) is organizing a symposium presenting the contribution of Anthroposophical Medicine to Integrative Oncology. The event is hosted by the Representation of the State of Baden-Württemberg to the European Union and takes place online on October 26, 2020. ELPA President Marko Korenjak was personally invited to participate in the meeting. In the context of the preparation of Europe's Beating Cancer Plan, the symposium focused on Integrative Oncology as a patient-centered, evidence-informed field of cancer care. Integrative oncology utilizes practices from different traditions alongside conventional cancer treatments to optimize health, quality of life, and clinical outcomes. Multiple studies have demonstrated the benefit and the potential of integrative cancer care in reducing patient suffering and improving long-term prospects.

ELPA's collaboration in preparing the HCC Patient Guide for ESMO

ELPA President Marko Korenjak and ELPA Director and ELPA Scientific Committee leader Dr. Teresa Casanovas Taltavull joined forces with the European Society for Medical Oncology (ESMO), publishing the HCC Patient Guide. ESMO Guides for Patients are designed to assist patients, their relatives, and caregivers in better understanding the nature of different types of cancer and evaluating the best available treatment choices. In particular, this guide has been prepared to help patients, friends, families, and caregivers better understand the nature of hepatocellular carcinoma and the available treatments. The medical information described in this document is based on ESMO clinical practice guidelines for managing hepatocellular carcinoma.

ELPA representatives in the NASH community in the Patient Advisory Group of IMI EU PEARL project

Dr. Teresa Casanovas Taltavull, ELPA Director and ELPA Scientific Committee leader, and Mrs. Yiannoyla Koylla, President of the Cyprus Liver Patients Association and leader of the ELPA Working Group on NASH/MAFLD, were chosen as representatives of the NASH community in the Patient Advisory Group of IMI EU PEARL project. It aims to revolutionize the way we do clinical trials by making them more efficient and patient-friendly. The project team will do this by setting up adaptive clinical trial platforms, which allow multiple companies to test their candidate drugs simultaneously against a shared placebo group. EU-PEARL will build the platform on several pillars. A clinical network of hospitals will provide the clinical trials environment and a place where different stakeholders can come together and interact. Patients are

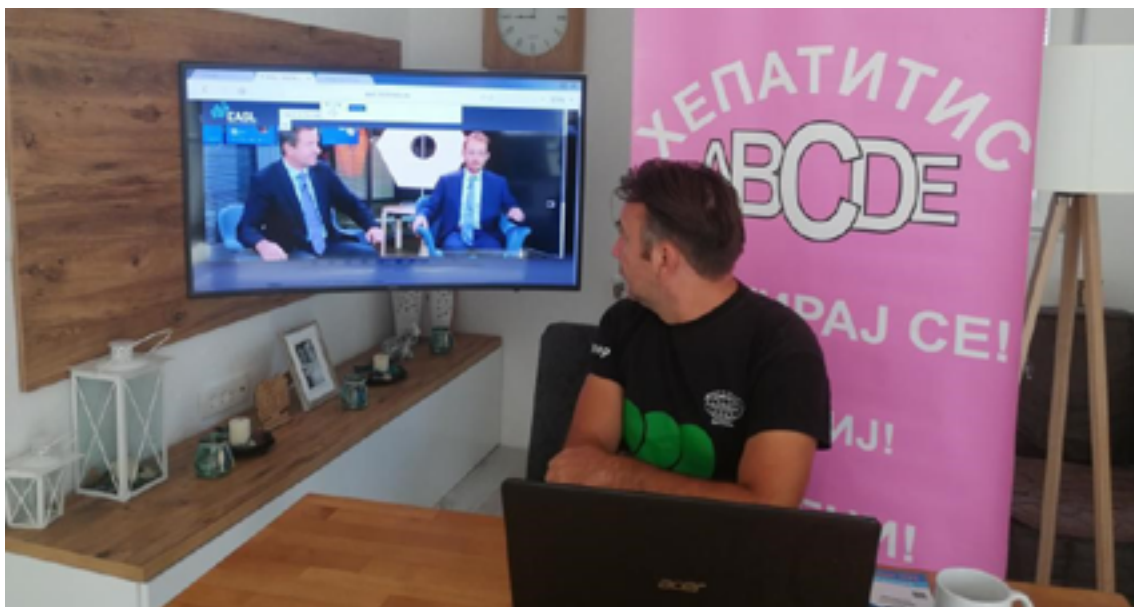
partners in the project, and they will contribute to the design of the platforms. EU-PEARL will also develop a comprehensive set of tools and methods for the planning, implementation, and analysis of the trials. Finally, it will address regulatory issues as well as data governance. EU-PEARL will focus its efforts on four disease areas: major depressive disorder, tuberculosis, liver disease, non-alcoholic steatohepatitis (NASH), and neurofibromatosis. However, the project outputs will make it possible to set up similar trial platforms in other disease areas in the future.

ACHIEVE Coalition's meeting

On August 26, ELPA Director and ELPA Treasurer Ivana Dragojević participated in an ACHIEVE Coalition's meeting. ACHIEVE is a multi-stakeholder coalition united in the fight against viral Hepatitis B and C, and Ms. Dragojević is ELPA's Representative in the Coalition. The primary purpose of the meeting was to plan a second meeting with the German Health Minister and obtain support from the German EU Council Presidency regarding the European Reference Network on communicable diseases, including Hepatitis, ahead of the Trilogue negotiations with the European Parliament and Commission on EU4Health to help driving forward Hepatitis elimination. Given Germany's long-standing Presidency focus on integrating data into healthcare, ACHIEVE wants to highlight the importance of better data regarding Hepatitis.

EASL-ILC meeting – The Digital International Liver Congress 2020

During the first EASL Digital ILC meeting held on 27th-29th August 2020, as EASL is forging synergies between itself and umbrella patient organizations to fight liver disease together, ELPA's participation did not go unnoticed. ELPA was part of the patient synergies booth. Still, it also participated in the booths of three medical research projects in which ELPA also participate: EU Medical Research Project Microb-Predict, Decision, and LiverScreen.



Milan Mishkovikj, ELPA Director following the EASL-ILC Congress

Also, During EASL-ILC Congress, ELPA was working hard disseminating the content of the event. ELPA is very proud of all the positive feedback it received, likes, comments, posts, and support. That shows that our community is strong than ever, and despite the current crisis, we all stand together fighting for a better and healthier future.

EPF event on COVID-19 pandemic and the future of HTA collaboration at EU level

On September 9, 2020, the European Patients' Forum (EPF), EURORDIS, and MEP Tiemo Wölken co-hosted the online event "Lessons learned from the COVID-19 pandemic and future of HTA collaboration at EU level". ELPA Representative was ELPA Director Milan Mishkovikj. The congress was organized to relaunch a constructive debate and boost the cooperation in Health Technology Assessment (HTA) at the European level to effectively respond to the needs of national health systems and patients across Europe, in the context of COVID-19 response and beyond. As we are approaching a new phase in the COVID-19 crisis, the European Union is considering a more ambitious health policy than previously foreseen for the upcoming Multiannual Financial Framework (MFF) through the EU4Health program and other initiatives. In this context, the Proposal for a Regulation on European Cooperation in Health Technology Assessment (HTA) is very timely: European patients and citizens count on a transparent, high quality, and practical EU cooperation. In that sense, we consider that an agreement on the HTA regulation is not just only urgent but also possible.

Rare Disease Day in DIMED Research Projects

On September 4, 2020, ELPA President Marko Korenjak participated in the Webinar organized by the University of Padova dedicated to rare diseases. DIMED, the Medical Faculty of the University of Padova, deals with many rare diseases that can be divided into four main groups: rheumatological diseases, hemato-oncological and coagulation diseases, endocrine-metabolic diseases, and liver and kidney diseases. Precisely for this, the event constituted the beginning of an information and training path project to expand knowledge, integrate skills, generate synergies, and encourage meeting and exchange moments among doctors, researchers, administrators, politicians, and patients interested in rare diseases. The President had the occasion to present ELPA and its activities during the first day of the Webinar.

'The Importance of systemic treatment sequencing in improving survival for patients with HCC' media briefing

ELPA President Marko Korenjak attended the virtual media briefing on the Bayer publication 'The Importance of systemic treatment sequencing in improving survival for patients with hepatocellular carcinoma (HCC)' on September 10, 2020. On behalf of the European Liver Patients' Association, Marko Korenjak, Dr. Teresa Casanovas Taltavull, ELPA Director and leader of ELPA Scientific Committee and Veronika Všetickova are the Patient Advocacy Group reviewers. During the meeting, the experts outlined the current challenges of managing patients with HCC. They aimed to provide clear, straightforward guidance on implementing a robust clinical approach to systemic treatment sequencing to help drive a universal improvement in overall survival among patients with HCC.

HBV Cure Workshop by Agence ANRS France

On September 16, 2020, ELPA participated in the “7th ANRS HBV Cure Workshop”. ELPA Director Milan Mishkovikj had the opportunity to interact with all the participants discussing the state of the art of this field for which knowledge evolves rapidly. The program included plenary sessions with renowned speakers and a panel discussion to address the most relevant questions, such as new therapies and clinical trials. The roundtable discussion was focused on the gaps in the field of HBV treatment.

The European Drug Report 2020

ELPA Vice-President Julio Burman took part in the launch of the European Drug Report 2020 organized by The European Monitoring Centre for Drugs and Drug Addiction (EMCDDA) on September 22, 2020. In this latest annual review — marking 25 years of monitoring — the EMCDDA describes the drug situation at the end of 2019, along with recent changes brought by the COVID-19 pandemic in early 2020. The report provides a comprehensive analysis of patterns emerging across the EU, Turkey, and Norway in the areas of drug supply, illicit drug use, and associated public health problems. National data sets are also provided across these themes and on critical harm-reduction interventions. In a new format, chapters are organized primarily by drug type and by related harms. The publication is an essential resource for developing evidence-based policy and action and provides a valuable baseline against which future changes in the drug field can be measured.

Coalition for Global Hepatitis Elimination’s webinar

ELPA Vice-President Julio Burman and ELPA Director Milan Mishkovikj were part of the webinar “Scaling-up Hepatitis Testing to Achieve the SDGs: Challenges and Opportunities from the COVID-19 Response” organized by the Coalition for Global Hepatitis Elimination on September 28, 2020. It was a UN General Assembly Virtual Side Event that brought together leading diagnostic organizations, country representatives, and public health institutions to discuss both the challenges and opportunities in hepatitis testing presented by COVID-19 to pursue WHO elimination targets and SDG goals. Key discussion areas included: capacity building for diagnostic testing in response to COVID-19, the impact of COVID-19 on the national capacity for hepatitis B and C testing, and the opportunities for leveraging COVID-19 testing capacity to strengthen testing for hepatitis B and hepatitis C.

Addressing TB, HIV, and Viral Hepatitis during the COVID-19 Pandemic

On September 23, 2020, ELPA President Marko Korenjak participated in the National TB, HIV, and Viral Hepatitis Programme Managers and Partners Meeting by the World Health Organization (WHO). The meeting had the title ‘Addressing TB, HIV and Viral Hepatitis during the COVID-19 Pandemic’. It had the main objectives of discussing country and partner experiences in ensuring access to and continuity of quality and timely TB, HIV, and viral hepatitis services during the COVID-19 pandemic and exchanging experiences and opportunities on monitoring TB, HIV, and viral hepatitis. Also, panelists and attendees exchanged experiences and opportunities on monitoring the impact of the COVID-19 pandemic on the TB,

HIV, and viral hepatitis epidemics and shared the latest WHO policy guidance and recommendations on TB, HIV, viral hepatitis and comorbidities, and European Centre for Disease Prevention and Control (ECDC) guidance documents on TB, HIV and viral hepatitis.

The 23rd edition of the European Health Forum Gastein

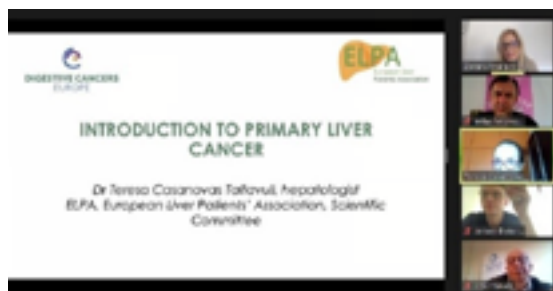
On September 30, 2020, ELPA President, some ELPA Directors, and some ELPA Members attended the first day of the 23rd edition of the European Health Forum Gastein. The day was a mix of live sessions and on-demand content, interactive participation, and meaningful networking with fellow delegates. At a time when the COVID-19 pandemic has stretched health care systems to the limit and beyond and turned our social, economic, and political lives upside down, that edition of the European Health Forum Gastein set out to explore new partnership's models to advance health for all.

The Digital ILC2020

ELPA President Marko Korenjak participated in the Digital ILC2020 Takeaway. As part of EASL's groundbreaking Digital ILC 2020, the EASL Takeaways look back on key topics from the congress, with leading experts discussing the most impactful science and putting it into perspective. ELPA President took part in the two-part episode summarizing the most relevant sessions for patients and patients' advocates. In particular, the meeting focused on monitoring HCV patients after SVR and the burden of chronic liver disease. ELPA gave its unique point of view as a patients' association.

ELPA and DiCE meeting on liver cancer. 'Together we are EVEN stronger'

On October 21, 2020, on Liver Cancer Awareness Month, the European Liver Patients' Association joined forces with Digestive Cancers Europe (DiCE), organizing, in the framework of the DiCE Masterclass series, the webinar 'Deep Dive into Liver Cancer.' This session delved into liver cancer's intricacies and how best to support people affected by it on their personal journeys. During the first part, all the attendees had the occasion to listen to three medical doctors' presentations. Dr. Teresa Casanovas Taltavull, hepatologist ELPA Director and leader of ELPA Scientific Committee, Prof. Jeroen Dekervel member of the Digestive Oncology team at the University Hospitals Leuven, and Prof. Thierry de Baere, head of the Interventional Radiology Unit at Gustave Roussy Cancer Centre, and University Paris-Saclay, delivered three presentations



'Deep Dive into Liver Cancer' - slides



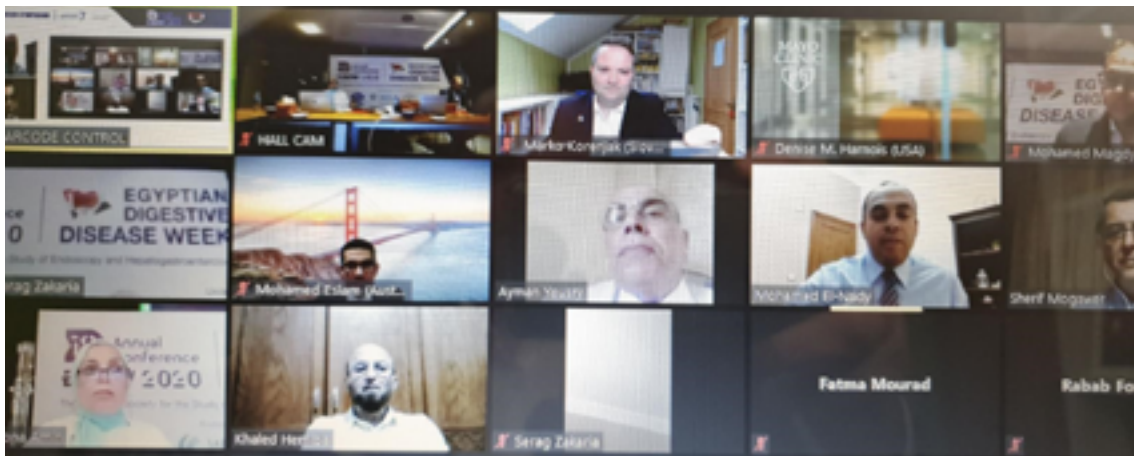
about liver cancer. They stressed the importance of multidisciplinary medical teams to tackle the disease at best, presented new available systemic (combination) therapies and the role of interventional radiology in treating liver cancer. After a short coffee break, it was time to listen to a moving testimony from a liver cancer patient followed by an oncologist. The last hour of the meeting was exclusively dedicated to ELPA and DiCE members. The day's conclusion could be sum up in a new version of ELPA's motto, 'Together we are stronger.' In light of the fruitful meeting, Marko Korenjak, ELPA President, and Stefan Gijssels, DiCE Chief Executive Officer, stressed that 'Together we are EVEN stronger.'

Liver Cancer Awareness Month closing event

The virtual roundtable "Patients call for increasing the awareness of liver cancer, during the COVID19" was organized by ELPA and Digestive Cancers Europe (DiCE) on October 30, 2020, as a conclusive LCAM event. Dr. Masoud Dara, Coordinator Communicable Diseases, WHO Regional Office for Europe, gave a keynote speech regarding World Health in pandemic and beyond. ELPA President Marko Korenjak and ELPA Director Milan Mishkovikj presented ELPA's activities and results of Liver Cancer Awareness Month 2020. They stressed the impact of COVID19 and the power of networking and social media activities. Their presentations were followed by one from our partner. Giulia Berenghi, DiCE Policy Manager, informed the participants regarding DiCE's involvement in EU Beating Cancer Plan and the collaboration with ELPA. The last part of the roundtable was dedicated to some scientific data and achievements. Dr. Teresa Casanovas Taltavull, ELPA Director and leader of ELPA Scientific Committee, illustrated the scientific work of ELPA with a focus on HCC white paper and ESMO guidelines. Then she left the floor to ELPA Director Prof. Gamal Shiha. He gave more details on the article 'GES: A validated simple score to predict risk of HCC in patients with HCV-GT4 associated advanced liver fibrosis after oral antivirals'. The meeting was successfully live-streamed on ELPA's Facebook page.

Meeting with the Egyptian Society for the study of Endoscopy and Hepatogastroenterology

On October 23, 2020, the Egyptian Society for the study of Endoscopy and Hepatogastroenterology organized their annual conference. ELPA President Marko Korenjak participated in the International Webinar on (NAFLD Vs MAFLD Update). He delivered a presentation regarding the patient perspective



Egyptian Society for the study of Endoscopy and Hepatogastroenterology – Group Picture

of redefining fatty liver disease. ELPA President had the opportunity to stress some of the content of the article 'Redefining fatty liver disease: an international patient perspective' (see news above). He also presented ELPA, its characteristics, values, and scope to the audience during his speech.

EMA training day

The European Medicines Agency (EMA) annual Training Day was reinstated as a virtual training on October 23, 2020. ELPA participated in the meeting representing liver patients. The session provided an overview of the EMA and the centralized procedure and continued with one breakout session where the focus is on reviewing documents. The sessions offered an overview of medicines evaluation, emphasizing when and how to get involved. Using a hands-on, interactive approach, participants learned how to contribute to scientific advice procedures, scientific-advisory-group meetings, and reviewing information for patients.

NASH Policy Action

On October 29, 2020, ELPA Director Milan Mishkovikj participated in the NASH Policy Action organized by Intercept. The meeting aimed to inspire change in how patient care pathways are designed and implemented for NAFLD and NASH. As collaboration is vital to improving patient care pathways in NAFLD and NASH, the session was the occasion for a call to action to enhance international pathways. ELPA stressed that during 2021 there would be many initiatives to raise awareness and advocate for a better understanding and better outcomes of this disease.

European Patient innovation summit 2020

In 2020 the European Patient innovation summit (EPIS) was a fully online event held in November and preceded by two webinars in October. On October 22, 2020, ELPA took part in the first pre-summit webinar. On November 5, 2020, some ELPA representatives could debate the role of patients in a digital world and how to make the latest opportunities for engagement arising from COVID-19. Established in 2016, the European Patient Innovation Summit (EPIS) is a platform for patient advocates from across Europe to discuss all aspects of digital health and achieve consensus on the patients' position on different digital world issues and health. EPIS includes an annual event and is organized and funded by Novartis. Content is developed together with a Steering Committee of representatives from patient organizations who advocate for the patient community. Each year, the Summit provides a unique opportunity for European patient advocates to come together, breaking down linguistic barriers to discuss common problems and identify solutions.

EPF Webinar in Telemedicine and E-health

On October 23, 2020, EPF hosted the fourth webinar for members of their series focusing on Digital Health, with the topic 'E-health and Telemedicine – What are we really talking about?'. Representatives from ELPA, ELPA Director Milan Mishkovikj, and ELPA Vice Director Julio Burman had the pleasure to hear firstly from Dr. Nick Guldemon, who is currently Associate Professor Integrated Care and Technology at Erasmus School of Health Policy & Management. Following Dr. Nick Guldemon, the meeting focused on

a case study on telemedicine presented by Jessie Cunnett, Associate Director, Head of Health and Social at Traverse, a consultancy focusing on people development. Last but not least, Marcin Rodzinka, Mental Health Europe Advocacy and Policy Officer, presented his community's view on e-health and telemedicine.

ACHIEVE Coalition's meeting

On November 3, 2020, ELPA Director and ELPA Treasurer Ivana Dragojević participated in an ACHIEVE Coalition's meeting. ACHIEVE is a multi-stakeholder coalition united in the fight against viral Hepatitis B and C, and Ms. Dragojević is ELPA's Representative in the Coalition. The meeting's main purpose was to plan ACHIEVE's activities in 2021 and ensure that relevant calls were put together early in the EU4Health program, working on submitting a proposal in 2021. The participants also discussed a way to more vigorously advocate in the field of cancer prevention involving and collaborating with some potential stakeholders.

High-level Review of Regulatory Frameworks and the way Forward

On November 10, 2020, ELPA President Marko Korenjak was part of the meeting 'High-level Review of Regulatory Frameworks and the way Forward' organized by the Forum for Collaborative Research and Berkeley University Public Health School. The Forum HIV Prevention Trial Design Project convened a series of public meetings. It wanted to offer the community a powerful opportunity to review and discuss strategies with all the stakeholders to allow for less resource-intensive clinical trial options for new PrEP interventions' approval maintaining scientific rigor. These meetings/webinars focused on issues regulators, particularly the U.S. Food and Drug Administration (FDA), European Medicines Agency (EMA), and African Regulatory agency. The second webinar on November 10 discussed the potential path forward, continuing to review the regulatory framework for clinical trial innovation relevant for PrEP. Experts from the U.S. and South Africa provided a high-level overview.

AASLD Meeting 2020

Some ELPA representatives participated in The Liver Meeting Digital Experience™ (TLMdX), organized by AASLD, a leading organization of scientists and healthcare professionals committed to preventing and curing liver disease on November 13-16, 2020. Due to the current situation, the 2020 conference was structure as a new immersive digital setting to access ground-breaking science, exchange ideas with leading hepatology professionals, clinicians, and researchers, and network with peers. TLMdX™ brought together clinicians, associates, and scientists worldwide to exchange information on the latest research, discuss recent developments in liver treatment and transplantation, and network with leading experts in the field of hepatology.

PCWP meeting at EMA

On November 16, 2020, ELPA president Marko Korenjak participated, in the framework of the European Medicine Agency (EMA), in the meeting organized by Patients' and Consumers' Working Party (PCWP) and Healthcare Professionals' Working Party (HCPWP) related to COVID-19 pandemic update. This meeting brought together all eligible patient and consumer and healthcare professionals organizations and members of PCWP and HCPWP to discuss updates on Agency's response to the COVID-19 pandemic, patient / HCP participation in EMA Covid-19 Taskforce (ETF), pharmacovigilance aspects on COVID therapeutics & vaccines, and information materials on COVID-19 vaccines.

The 8th Awareness Week on Alcohol-Related Harm

ELPA took part in the 8th Awareness Week on Alcohol-Related Harm (AWARH) held from November 16 to 20, 2020. Not only did ELPA contributed to a vast online campaign, but also it was involved in one of the webinars organized during the awareness week. ELPA President Marko Korenjak presented at the webinar 'Alcohol and Health Policies in Europe and UN Sustainable Development Goals (SDGs)' on Wednesday, 18 November 2020. He stressed the link between alcohol and cancer, which was one of this year's themes, with an overview of liver cancer damage, and then he suggested some actions that can be taken in this field. Around 12% of cancer cases worldwide are linked to alcohol consumption, and regarding the liver, people who drink more than 3 drinks per day increase their risk of liver cancer by 16%. Alcohol is responsible for one-third of all liver cancers, being the first cause in Central and Western Europe and the second cause globally.

International Viral Hepatitis Elimination Meeting (IVHEM) 2020

Some ELPA representatives participated in the annual edition of the International Viral Hepatitis Elimination Meeting (IVHEM) on December 4-5, 2020. IVHEM is a global forum for the exchange of practical experiences and challenges faced in the effort to eliminate viral hepatitis as a public health threat by 2030. The 2020 program of IVHEM included key practical examples of innovative intervention studies, country elimination programs, and novel funding mechanisms for testing and treatment, all focusing on meeting the 2030 elimination targets set by the World Health Organization (WHO). The meeting objectives were: to provide a forum for knowledge exchange and discussion of practical experiences of advances in the clinical management of viral hepatitis; to provide a toolbox for practical application of research & development for evidence-based policymaking; to facilitate cross-disciplinary discussion on barriers and challenges to the elimination of viral hepatitis.

EASL Members' Extraordinary General Assembly

ELPA President Marko Korenjak was part of the EASL Members' Extraordinary General Assembly held on December 10, 2020. An extraordinary year, such as 2020, called for increased connection with and accountability to our community. EASL wanted to hear from its members what they want and need from EASL as a professional association. The Extraordinary General Assembly was a key opportunity for EASL members and the Governing Board to discuss the challenges and accomplishments of the association. EASL members were invited to take part and have their say. Every contribution helped to drive hepatology

forwards. EASL thanked its members for believing in EASL and for their continued dedication to the liver community.

Second Meeting of the Regional Collaborating Committee on Accelerated Response to Tuberculosis, HIV and Viral Hepatitis (RCC-THV)

On December 10, 2020, ELPA President Marko Korenjak was part of the Second Meeting of the Regional Collaborating Committee on Accelerated Response to Tuberculosis, HIV, and Viral Hepatitis (RCC-THV). The 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. 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, social mobilization, and facilitating an accelerated response to TB (including M/XDR-TB), HIV and viral hepatitis prevention, diagnosis, treatment, and care.

EMA's public meeting on COVID-19 vaccines

ELPA was part of the European Medicine Agency's public meeting on COVID-19 vaccines on December 11, 2020. EMA wanted to inform European citizens about the EU regulatory processes to approve COVID-19 vaccines and the Agency's role in their development, evaluation, approval, and safety monitoring. The public meeting informed citizens about EMA's role in the pandemic and of EU regulatory procedures. It also allowed the public and stakeholder groups to speak and share their needs, expectations, and any concerns that will be considered by EMA and the European medicines regulatory network in the decision-making process. Together with the European medicines regulatory network, EMA supports the development of COVID-19 vaccines and has taken steps to speed up the evaluation processes for these vaccines. The Agency and its partners are doing so while ensuring that the same high regulatory standards for quality, safety, and efficacy are being applied to COVID-19 vaccines.

EU Big Data Stakeholders Forum

On December 15, 2020, ELPA took part in the EU big data stakeholder virtual forum organized by the European Medicine Agency (EMA). This meeting's objectives were to inform on implementation of the HMA-EMA Big Data Task Force; priority recommendations; understand stakeholders' perspectives; discuss opportunities for stakeholder collaboration and priorities. The European Medicines Agency (EMA) and Heads of Medicines Agencies (HMA) set up a joint task force to describe the extensive data landscape from a regulatory perspective and identify practical steps for the European medicines regulatory network to make the best use of big data in support of the innovation and public health in the European Union (EU).

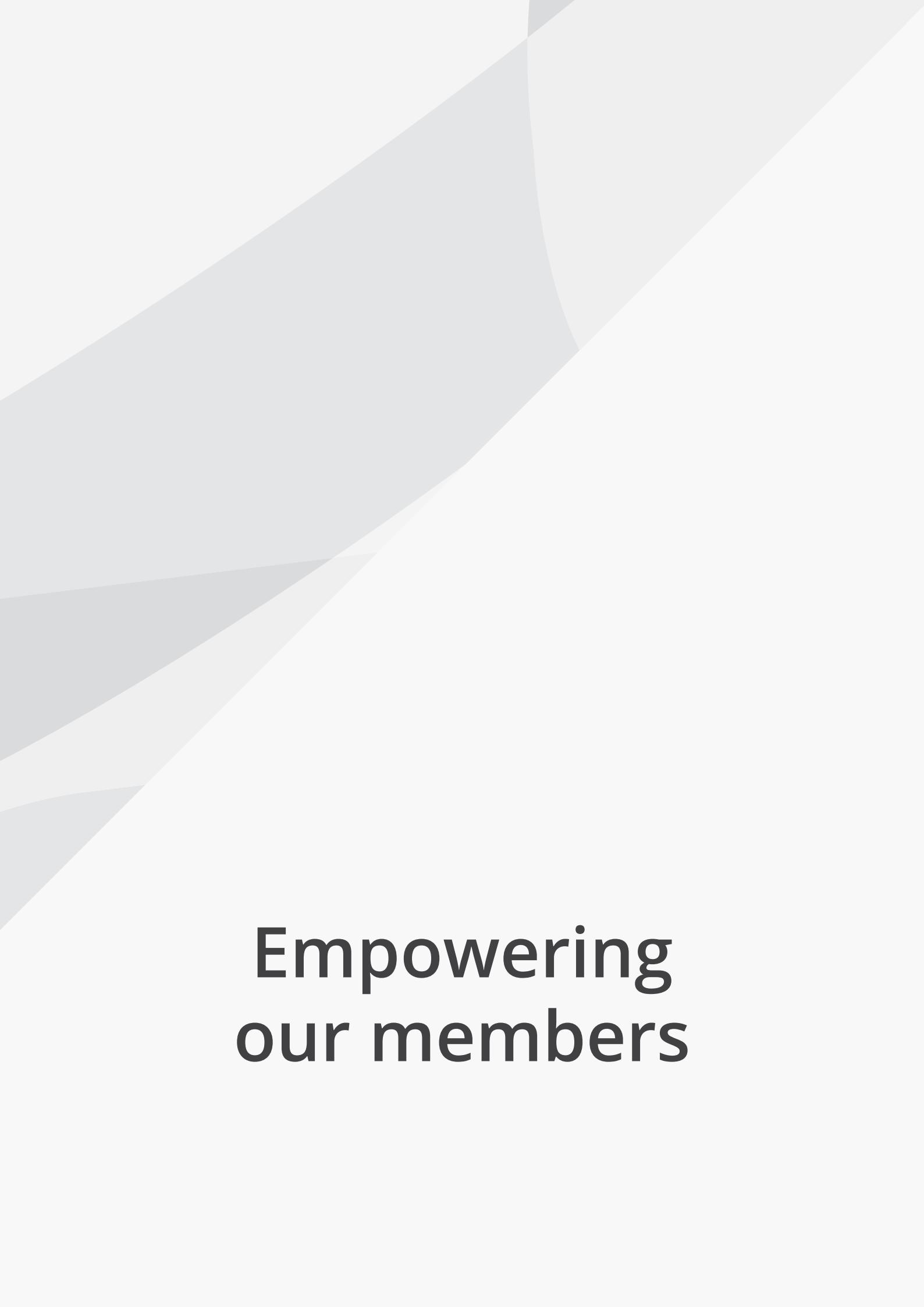
Endorsement to the EKPF's open letter on organ donation and transplantation

ELPA endorsed the open letter on organ donation and transplantation written by the European Kidney Patients' Federation (EKPF), with which ELPA signed a Memorandum of Understanding in 2020.

The endorsement has been confirmed by:

- 20 Members of the European Parliament supporting the MEP for Kidney Health
- 12 National Competent Authorities for Organs
- 59 stakeholder organizations

This was a great occasion to promote organ donation and transplantation in Europe.



**Empowering
our members**

ELPA President visits Serbia

The meeting took place at the National Institute for Public Health in Belgrade, Serbia, on January 24, 2020. Here, along with the director and a medical doctor, ELPA President Marko Korenjak discussed all the necessary national legislation restrictions or conditions needed to use the FibroScan in Serbia. They agreed that this device's use will be beneficial to all the Serbian patients and that the device should be moved around the country. There are three clinics in Serbia, and they planned to use the FibroScan in at least three of them. Some insurance company representatives agreed to propose to insure the device from Belgium to Serbia and once it will be used in Serbia. At the National Institute for Public Health in Belgrade, the same day was also the occasion to discuss the educational project for Serbia's beauty salons. ELPA Director and ELPA Treasurer Ivana Dragojevic - Serbian NGO representative - and her colleague presented the first educational day that reached 30 beauty salons and focused on sterilization process and virus issues, especially hepatitis. At the end of the day, ELPA President and Ivana Dragojevic had a meeting with MSD industry representatives regarding the general situation of hepatitis elimination in Serbia. They agreed to support several ideas presented by Ivana Dragojevic.

7th Portugal national hepatitis Conference organized by SOS Hepatites

The Conference took place in Lisbon, Portugal, on February 15, 2020. The day before, ELPA President Marko Korenjak arrived in town, and he met with Emilia Rodriguez and some other representatives of the Portuguese NGO SOS Hepatites, ELPA's member. They discussed the current and future activities of the association. Besides, the name of the NGO will change because the focus of the association will be on liver diseases and not only on hepatitis. Before it started, ELPA President met with some representatives of



*Marko Korenjak, ELPA President – Emilia Rodrigues
President of SOS Hepatites Portugal*

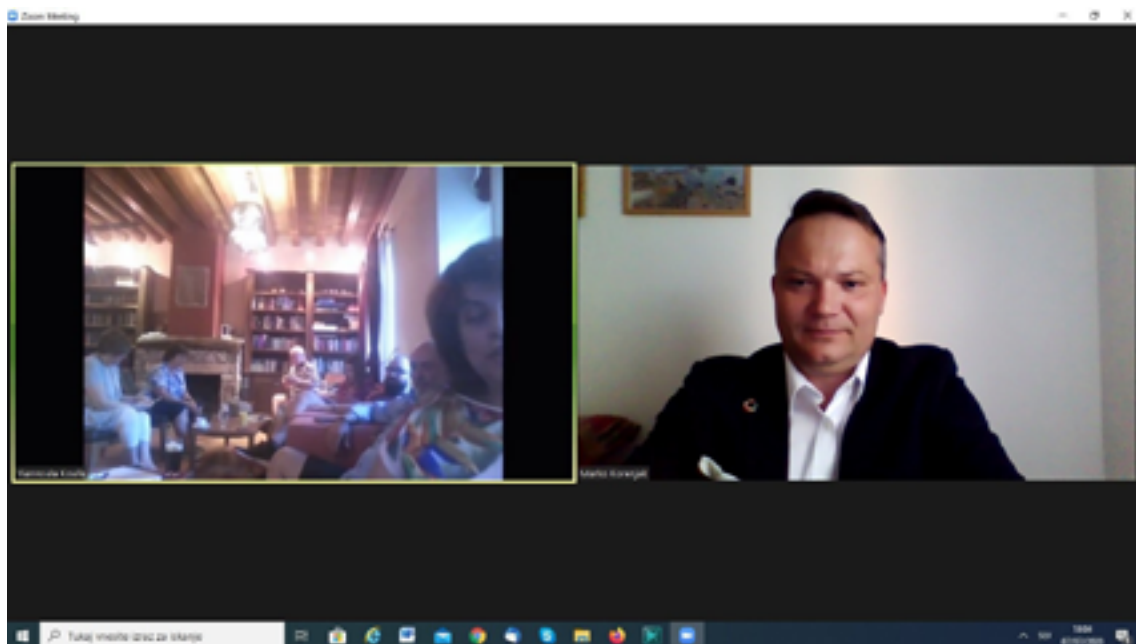


Marko Korenjak, ELPA President

pharma companies that supported the meeting in Lisbon during the Conference's day. He also exchanged views on the status of hepatitis patients in Portugal with Prof. Rui Tato Marinho. The ELPA president's presentation addressed the current situation on viral hepatitis elimination in Europe from a patient association perspective and possible barriers we see now in Portugal. Portugal was off to a great start, but now the activities are scaling down, so we need an active approach that will solve current possible problems like the difference in viral hepatitis elimination in small towns Vs big cities with advanced hospitals, number of small administration solutions that can be easily implemented to help the medical professionals and more. ELPA congratulated Portugal on the work that has been done, and, as a patient association, it expects the good practice to continue also in the future.

Cyprus Liver Patients Association's new President

On July 7, ELPA President Marko Korenjak participated in the first Cyprus Liver Patients Association meeting chaired by the newly elected President Yiannoula Koulla. He expressed gratitude to all board members that decided to spend time helping other patients. Cyprus Liver Patient Association was deeply involved in ELPA work in the past. ELPA organized a press conference in Cyprus, ELPA University module, and participated in expert work as part of the program ELPA@home led by Julio Burman. In all its activities, ELPA was supported by Yiannoula Koulla, and she proved to be a vital and essential part of Cyprus care for liver patients.



Yiannoula Koulla President of the Cyprus Liver Patients Association – Representatives from the Cyprus Liver Patients Association - Marko Korenjak, ELPA President

ELPA Director elected Vice President of the “Alliance of Patient Organizations” of Macedonia

Milan Mishkovikj, ELPA Director, was elected Vice President of the “Alliance of Patient Organizations” of Macedonia. The “Alliance of Patient Organisations” is an organization gathering patient organizations from FYROM – North Macedonia (Created in 2016). The organization’s objectives are: to provide access to treatment, improve the conditions of treatment and enhance the patients’ quality of life; to develop health policies at the national level to protect patients’ rights; to foster the cooperation between state bodies, health organizations and healthcare professionals in the design and implementation of strategies, criteria, standards, best practices in the health care of Macedonia. The participation of an ELPA Director in the governing board of the Alliance is a significant sign of how Patients’ associations should work together at the national and international levels because only together we are stronger.

‘RoadMap to Zero, strategies for HCV elimination’

On December 3, 2020, ELPA Member Hepatitis C Partnership organized the webinar ‘RoadMap to Zero, strategies for HCV elimination.’ ELPA endorsed the meeting, and some of its representatives participated in it. They could discover how barriers can be broken down and professions united with one goal to get on with treating people living with Hepatitis C. To watch the inspiring kick-off conference led by Professor John Dillon, Dr. Stephen Barclay, and Professor Diarmaid Houlihan surf the association’s website.



**Strengthening
our association**

ELPA Educational Training – June/July 2020

The very first virtual ELPA Educational Training started on 17th June 2020 with greetings by ELPA President Marko Korenjak. After a short tour of presentations by all the attendees, the floor has been taken by Dr. Teresa Casanovas-Taltavull, ELPA Director and leader of ELPA Scientific Committee. She broke the ice by presenting the impact of liver disease on Health-Related Quality of Life (HRQL). Her presentation was a fantastic example of translating complex medical contents into something beneficial for all liver patients' communities. A quick Q&A session led the participants to the coffee break, followed by the second presentation. Ms. Nadine Aknin from Sirtex, together with her colleague Ms. Claudia Pyfer, gave an overview of selective Internal Radiation Therapy in liver tumors. A presentation full of details but easy to understand for the general public and a short but comprehensive video pushed the attendees to ask many questions. The first day of the ELPA Educational Training was wrapped up by Dr. Teresa Casanovas-Taltavull's presentation about the COVID-19 and its effects on liver patients' management. Thanks to the fact that this is a hot topic, many participants asked questions to Dr. Casanovas-Taltavull regarding her point of view about the pandemic's evolution and the situation related to hospitals and health care.



ELPA Educational Training – Group Picture

The second day of the virtual ELPA Educational training was held on June 24, 2020. After a short introduction by ELPA President Marko Korenjak, Dr. Teresa Casanovas Taltavull, ELPA Director and leader of ELPA Scientific Committee took the floor.

During her presentation, all the attendees had the possibility to listen to a detailed overview about optimizing outcomes in patients with Hepatic Encephalopathy (HE), a complication of cirrhosis. HE is a

reversible syndrome of impaired brain function occurring in patients with advanced liver diseases. As usual, Dr. Casanovas Taltavull was able to translate extremely complex medical contents into something very clear and valid for the entire liver patients' communities. A quick Q&A session led the participants to the coffee break, followed by a workshop on HCC by Achim Kautz. His presentation was composed of two parts. The first one was focused on HCC medical aspects and the second one on HCC policy aspects. An animated debate followed, especially because Mr. Kautz gave the audience many stimulating insights and a lot of food for thought. One of the most exciting characteristics of this session was the attendees' involvement, who could discuss the situation in their own countries, make examples, share good practices, and complain about the lack of services or their quality.

On July 1, 2020, ELPA organized its **third day** of Educational training exceptionally in a virtual form. All the ELPA members' representatives attending the meeting had a short conversation about the role of patients' organizations, and they exchanged updates about ELPA's activities.

After an introduction by ELPA President Marko Korenjak, Julio Burman took the floor and broke the ice with a first, important question: why should I participate in a clinical trial?

During his presentation, all the attendees had the possibility to listen to a detailed overview about patients' involvement in a clinical trial, risks and benefits, the importance of that, and many details about how to help patients understand clinical trials. He mainly focused on the Informed Consent Form as a process and not only as a document but also on the importance of giving patients more knowledge.

After his brilliant lecture, attendees asked many questions, and a lively debate started. Before the coffee break, the President, wrapping up the session, also added some comments stressing that the leading role of patients' associations in this field is information and education. They have to be able to answer all the questions coming from patients. This is the reason why they have to put more effort into patients' participation in clinical trials. Everybody agreed on organizing more training about this topic.

A workshop on NASH by Achim Kautz followed the coffee break. As it happened last week after his presentation on HCC, an animated debate followed, especially because Mr. Kautz gave the audience many stimulating insights and a lot of food for thought, stressing the important and delicate role of patients' associations that are in between patients and doctors.

One of the most interesting characteristics of this session was the attendees' involvement, who discussed this topic from their points of view.

The **last day** of the ELPA Educational training on July 8, 2020 – exceptionally in a virtual form – was extremely dense with information, debates, and exchanges among ELPA members, attendees, and a remarkable variety of panelists.

After an introduction by ELPA President Marko Korenjak, the floor was taken by the first company, Novartis. Monia Steenackers, Global IHD Patient Advocacy Head, and Nico Jansses, Global Medical Director, presented the Novartis Commitment to hepatology. After a first more general part, they focused more on clinical trials, which triggered many questions by attendees.

After the coffee break, Dr. Teresa Casanovas Taltavull, ELPA Director and leader of ELPA Scientific Committee, shared some updating information for liver patients about Hepatocellular Carcinoma (HCC). Her detailed presentation focused on a multidisciplinary approach the liver patients can benefit from. As always, Dr. Casanovas Taltavull gave the audience many stimulating insights and a lot of food for thought, stressing the important and delicate role of patients' associations between patients and doctors.

After the lunch break, the second company of the day took the floor. From Bayer Medical affair Oncology, Pooja Merchant and Kirhan Ozgur dal presented how Bayer engaged with patients and gave an overview of liver cancer treatment. Questions from attendees mainly regarded late diagnosis complications, updates on therapies, dissemination of new information to raise more awareness, especially at a high level, liver cancer, and representatives' involvement at the national level.

ELPA Annual General Meeting and Extraordinary General Meetings 2020

ELPA Annual General Meeting 2020 took place on August 31, 2020. For the first time, ELPA members gathered on a virtual platform to discuss and approve vital topics for the association. Additional changes to ELPA Statutes were approved together with the new ELPA Internal Rules. The assembly composed of the majority of ELPA members also agreed on approving and adopting accounts 2019, work plan 2020, the proposal of ELPA budget 2020, and the revised ELPA budget 2020 because of COVID19. Several issues come up related to the work of Ms. Tatjana Reić as ELPA Director. The ELPA Governing Board decided to organize an Extraordinary General Meeting (EGM) in September 2020 to discuss with all ELPA members the role of Ms. Tatjana Reić as Director. The General Assembly decided for her suspension for 3 months. During the next EGM in December 2020, the majority of ELPA members agreed to remove Ms. Tatjana Reić from her mandate as ELPA Director until the next election.

Nobel Prize for Medicine goes to Hepatitis C discovery

ELPA celebrated the three scientists who discovered the virus Hepatitis C as the winners of the 2020 Nobel Prize in Medicine or Physiology. British scientist Michael Houghton and US researchers Harvey Alter and Charles Rice realized that even though the viruses Hepatitis A and Hepatitis B had been already discovered, there was another mystery, infection at work. Patients were still getting sick after receiving donated blood. After the trio had managed to isolate the virus's genetic sequence in 1989, it was named Hepatitis C. The World Health Organization estimates that more than 70 million people are infected with hepatitis C, with 400,000 dying each year from related conditions such as cirrhosis and liver cancer. The Nobel Laureates' discovery of the Hepatitis C virus is a landmark achievement in the ongoing battle against this viral disease and raised hopes of eradicating the Hepatitis C virus from the world population.

ELPA Educational Training – November/December 2020

The first day of ELPA Educational Training on November 4, 2020, started with ELPA President Marko Korenjak, stressing why that first day was entirely dedicated to members. He explained that ELPA's activities' structure is changing because the workgroups put together members that want to be active in the field. For this reason, they needed a dedicated moment to present their work.

The first presentation was delivered by Julio Burman, ELPA Vice President and leader of the Clinical Trial workgroup. He underlined the importance of Patients' association in this field. According to him, patients' associations can inform patients, translate complex medical contents for them, and encourage them to

participate in clinical trials. Patients' associations create, together with patients, companies, and health professionals, a sort of coalition.

Yiannoula Koulla, leader of the MAFLD/NASH workgroup, followed Julio Burman, first presenting all the participants in the group and then introducing the disease, stressing the importance of using the new name MAFLD. She continued her presentation listing all the activities, including developing a new App, the group had scheduled for the upcoming year for the younger and adults. Part of the presentation was dedicated to the importance of prevention, a healthy lifestyle, and awareness of these topics.

ELPA Director and ELPA Treasurer Ivana Dragojevic, leader of the workgroup on prevention, took the floor and detailed two new 2021 projects in this field. The first is called 'HepFreeBudge' and aims at tackling Hepatitis involving professionals in the beauty parlors. The second one is the HBV and women project. It focuses on different 12 areas to raise awareness and understand all the women's concerns about their lives and HBV.

Before the coffee break was the turn of Sindee Weinbaum, leader of the rare diseases workgroup. She stated that rare diseases are a vast topic and a large area to cover. However, they managed to work on many rare liver diseases as the fruitful collaboration with new partners had shown in the two most recent awareness campaigns on PBC and PSC.

After the coffee break, ELPA President Marko Korenjak gave an overview regarding ELPA's involvement in medical scientific projects. He started stressing how ELPA's participation boosted the reputation of the association. Then, he sketched why patients should be involved in medical, scientific projects. Moreover, he presented the new EU program Horizon Europe 2021-2027 with a specific focus on cancer. He also updated the members regarding the number of projects ELPA is currently involved in. They increased from 7 to 8 as ELPA is participating in a new project in the field of Acute-on-chronic liver failure (ACLF).

The floor was given back to ELPA Vice President and fundraiser leader Julio Burman, who make the participants aware of some tips to keep in mind when they approach donors. He stressed the importance of considering that NGOs' voice is unique as well as their activities. Donors need to collaborate with them. He also gave some insights about the correct jargon and approach to use in communicating with donors. Then, he presented what donors like to support the most and some recent trends. The last part of his presentation was dedicated to awareness campaigns' relevance and how to plan a successful project to present to donors. His conclusion was focused on the importance of measuring and showing numbers as a first step to be fruitful in fundraising.

Unlike day one, **the second day of ELPA Educational Training** on November 11, 2020, was entirely dedicated to Pharma Companies' presentations. The meeting started with ELPA President Marko Korenjak welcoming everybody.

Dr. Elliot Norry, the representative of Adaptimmune, delivered the first presentation. He went deep into the work the company is doing concerning liver cancer. He presented a complex and personalized therapy and the related stage of clinical trials. He also tried to sketch what would come next, and he stressed the importance for patients to understand how a treatment works. However, it is complicated to translate complex medical procedures into more straightforward content. Yet, the company has social media channels with materials that patients and advocates can use. One of the most exciting characteristics of this session was the attendees' involvement. They were able to ask many questions and discuss this topic from their points of view.

After the break, some representatives from Mirum took the floor. Dr. Ed Tucker presented how Mirum engaged with patients and gave an overview of the ongoing clinical trial and treatments. ELPA was delighted to hear from such a young but engaged company. They are mainly focused on rare liver diseases both in children and in adults. Too many liver disease patients still fall victim to the unknown. For many liver diseases, their causes and effective diagnostics, treatments, and cures remain unclear and motivate the audience to ask many questions, especially pediatric clinical trials.

This ELPA Educational Training never ceased to surprise its attendees. **The third day on November 18, 2020**, was divided into two distinct parts. Before presentations from Pharma Companies, ELPA went sporty.

Yianoulla Koulla and Veronika Všetickova, ELPA working group on MAFLD and NASH, animated a session entirely dedicated to practical steps to become more physically active. The first theoretical part, where participants also could share their experience regarding being physically active, was followed by a live training session composed of some stretching exercises and some aerobic ones. Many participants asked questions and asked for advice related to physical activities and how to train as better and successfully as possible.



Veronika Všetickova - ELPA working group on MAFLD and NASH

Straight after this first part, it was time for Pharma Companies to join the Educational Training. Dr. Judith Ertle, the representative of Boehringer Ingelheim, delivered her presentation giving an update on BI's NASH strategy. Focusing on patients' high-unmet needs, she started presenting the liver as a central organ for the metabolism and providing multiple essential functions. Then, after an overview of NASH disease, she showed different approaches to improve cirrhosis in NASH patients. She concluded her speech by giving some details about clinical trials coming up in 2021. At the end of the presentation, questions went in both directions. Participants were curious about BI's commitment to NASH, but also BI's representatives were interested in ELPA's point of view on the topic.

After the break, some representatives from Norgine took the floor. Kym Jacks-Bryant, Head of Digital Centre of Excellence at Norgine, presented LiverSync, an App for empowering patients living with Hepatic encephalopathy (HE) to take an active role monitoring their condition. She went deep into the App's features and its safety in terms of personal data protection. This new branch of technology applied to health care fascinated the participants, who asked many questions and stressed the importance of these tools, especially in the current times when the COVID-19 crisis makes access to treatment and hospitals more and more difficult.

The fourth day of ELPA Educational Training on November 25, 2020, was entirely dedicated to presentations from Pharma Companies. The meeting started with ELPA President Marko Korenjak welcoming everybody.

Dr. McWherter, the representative of CymaBay, delivered the first presentation. He went deep into the work the company is doing concerning Primary Biliary Cholangitis (PBC). He stressed that unmet needs remain despite existing treatments. Then, he presented a new promising therapy and the related stage of clinical trials and results. The last part of his presentation was dedicated to this new drug's safety in patients with PBC. This session was characterized by the attendees' involvement. They were able to ask many questions and discuss this topic with both of the representatives of CymaBay who were participating in ELPA training. Their attention was brought by some participants to the importance of extending clinical trials involving as many countries as possible.



ELPA Educational Training – Group Picture

After the break, some representatives from Gilead took the floor. This presentation was composed of 3 parts. The introduction by Mr. Bowman gave an overview of Gilead's involvement in liver diseases. Dr. Salehi followed with an insight of Primary Sclerosing Cholangitis (PSC), and he added more details regarding the evaluation of an investigational therapy by Gilead. Dr. Vanstraelen shifted the attention to Hepatitis C, presenting some elimination programs supported by Gilead. The Q&A session was the occasion to ask the speakers about Gilead's work in other liver diseases such as NASH.

The fifth and last day of ELPA Educational Training on December 2, 2020, was composed of a mix of presentations from Pharma Companies and representatives from the medical-scientific field. The meeting started with ELPA President Marko Korenjak welcoming everybody.

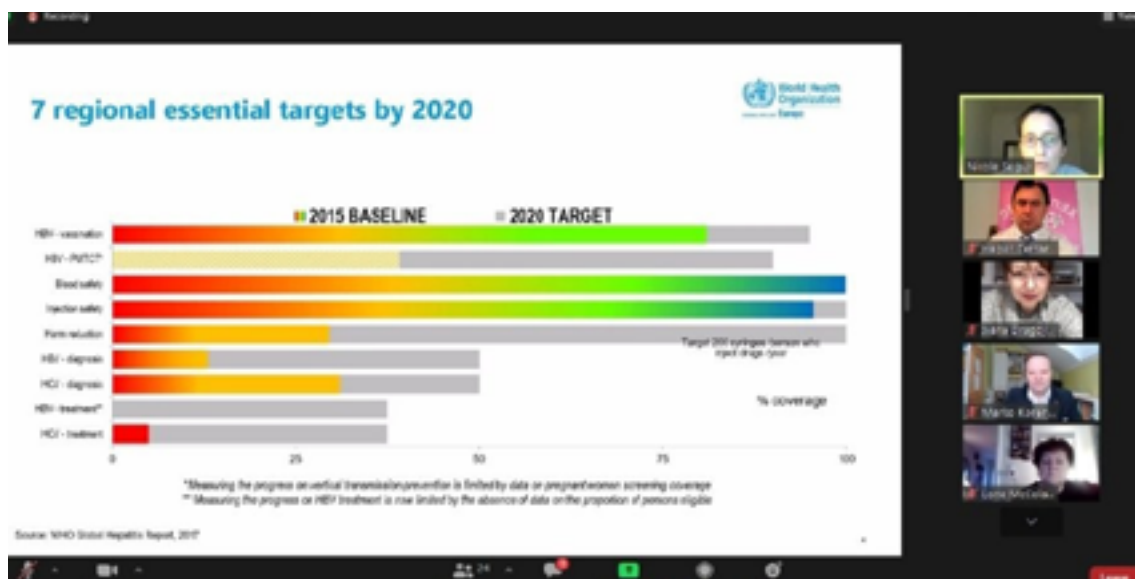
Representatives from AstraZeneca delivered a two-part presentation. Ms. Marchione, Global Oncology Patient Affairs, gave an overview of the company, its engagement towards patients, especially in oncology. She stressed that liver cancer for them is a very new field, and they are excited to work on it. Regarding liver cancer, Mr. Moren, Global Oncology Medical Affairs, presented the disease, gave details about immunology therapies, and described AstraZeneca clinical trial portfolio. During the Q&A session, attendees stressed that all these new therapies provide hope to liver patients and motivate patients' associations to continue their work.

After the break, Dr. Teresa Casanovas Taltavull, hepatologist, ELPA Director and leader of ELPA Scientific Committee, took the floor. Her presentation was focused on the pediatric side of liver diseases. She started giving an overview of the elimination of Viral Hepatitis C (HCV) in children and adolescents. She gave details about diagnosis and treatments stressed the importance of a target like reproductive-aged women. Then, she shifted the audience's attention to two rare liver diseases in children: the Lysosomal Acid Lipase Deficiency (LALD) and the Progressive Familial Intrahepatic Cholestasis (PFIC). Dr. Casanovas Taltavull ended her presentation by giving some information regarding the ELPA Liver Cancer Working Group. She presented some facts and figures about Hepatocellular carcinoma (HCC) and Cholangiocarcinoma (CCA) and some future projects and goals the Working Group would like to achieve in 2021.

The last part of the webinar hosted a presentation by Prof. Christoph Roderburg from the Universitätsmedizin in Berlin. He delivered a detailed and exhaustive overview of HCC treatments and combinations of drugs explaining the current standard and some different combinations that gave an idea about the future in this field. He concluded his presentation stressing that the rise of novel combinations has improved the prognosis of patients with advanced HCC and that individualized treatment of HCC patients is possible.

ELPA Stakeholders' Meeting, Europe in 2021

ELPA Stakeholders' Meeting, organized on 2nd December 2020, was the occasion to gather with some representatives of the most prominent associations in the field of liver diseases and patients' advocacy.



Dr. Nicole Seguy - Unit lead HIV, Hepatitis and STI, WHO Europe

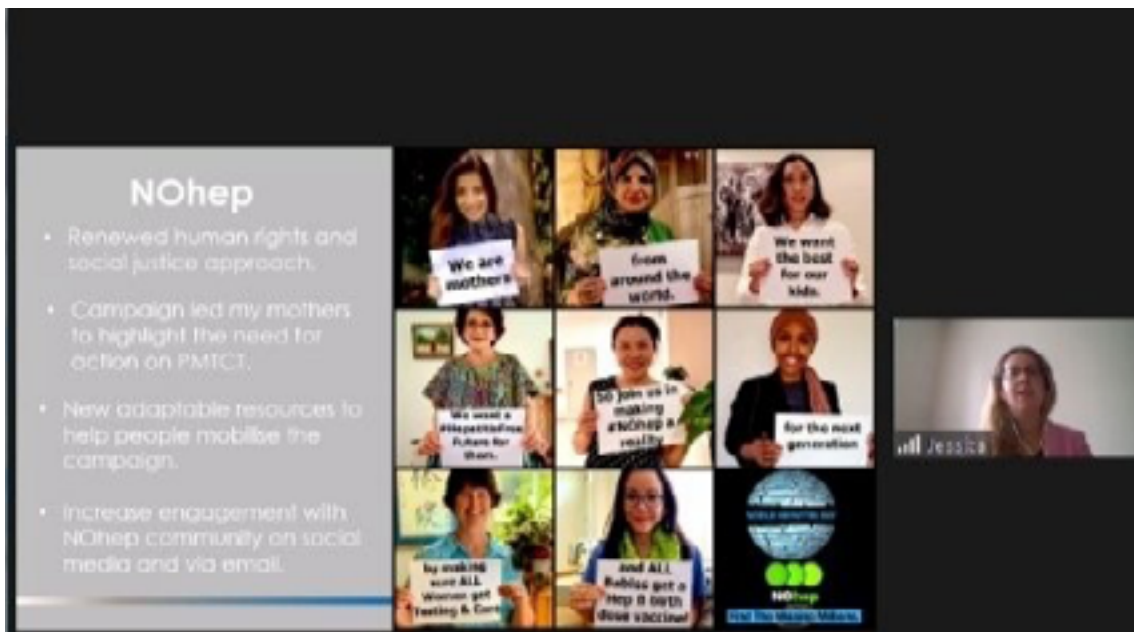
After a short introduction by ELPA President Marko Korenjak, the first speaker took the floor.

Dr. Nicole Seguy, Unit lead HIV, Hepatitis and STI, WHO Europe, gave an overview of the updates in the field of Hepatitis elimination, challenges, and responses in the WHO European Region. She described the regional targets, the cascade of cure for Viral Hepatitis C (HCV), and she stressed that WHO is striving to have better data. Therefore it would work on patients' registries. She concluded by presenting the WHO guidance on maintaining essential health services in the COVID-19 context.

Dr. Seguy's presentation was followed by Greet Hendrickx's presentation from the Viral Hepatitis Prevention Board. After a short description of her association's structure, Ms. Hendrickx presented the Viral Hepatitis Prevention Board's activities in 2020, stressing the fact that everything had been turned into virtual except some countries' meetings that were impossible to organize virtually. She finished her presentation with the future planned activities in the upcoming year.

During his presentation, Eberhard Schatz, representative of the Correlation Network, stressed the importance of collaboration and partnership. After introducing the Correlation Network, he presented one of its significant activities related to good practice examples of Hepatitis C interventions and their related outcomes. He also dedicated some word to the Monitoring Report on Harm Reduction and the Briefing Paper on Harm Reduction response in the Europe region during the COVID-19 pandemic. He finished his presentation by giving an overview of his association's advocacy goals for 2021.

Before the coffee break was the turn of Katharina Ossenberg from the ACHIEVE Coalition Secretariat. She listed all the ACHIEVE's strands of action, such as the EU4Health funding program, advocacy on the EU Beating Cancer Plan, and advocacy on the EU health Data space. All of these fields represent both opportunities and challenges in 2021.

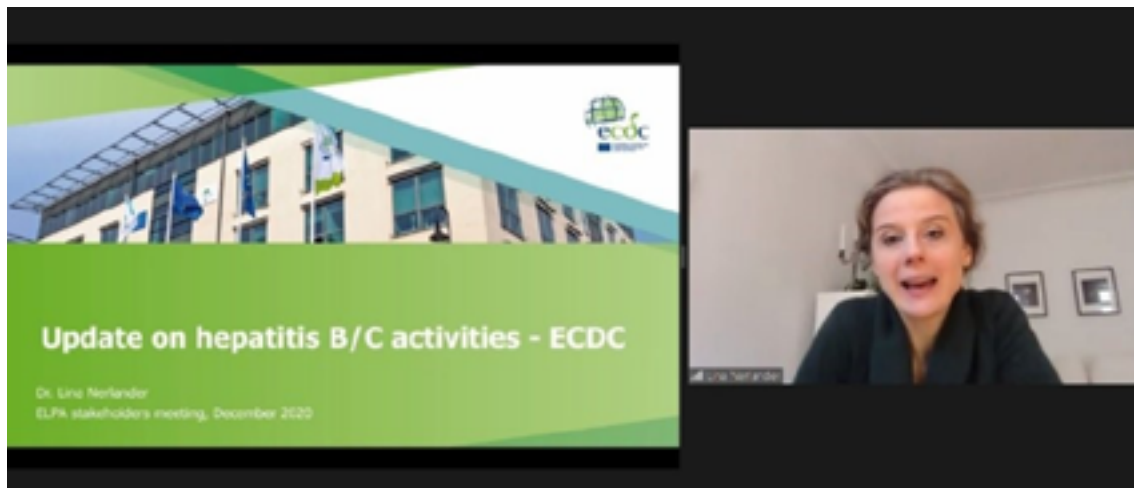


Jessica Hicks - World Hepatitis Alliance

After the coffee break, the floor was taken by Jessica Hicks from the World Hepatitis Alliance. She presented the Alliance in detail. Then, she stressed three unifying themes related to Hepatitis elimination. She also suggested some ideas regarding World hepatitis Day 2021, a new capacity building program, and the World

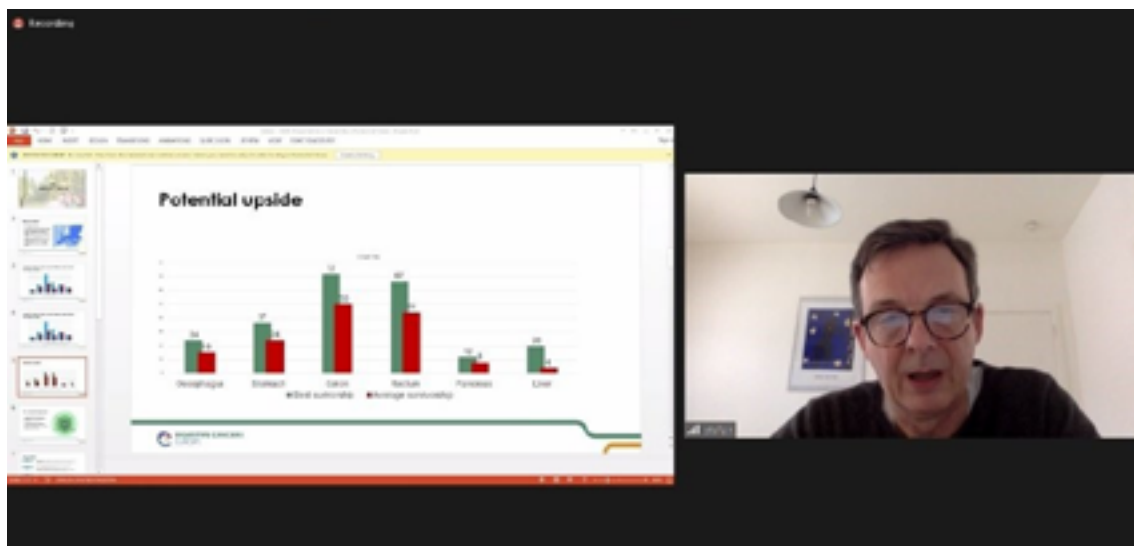
Hepatitis Summit in Bangkok, Thailand, in late 2021. She concluded her presentation by stressing that one of the Alliance's priorities is also addressing the lack of resources in the field of Hepatitis elimination.

Dr. Lina Nerlander from the European Centre for Disease Prevention and Control (ECDC) presented some updates on ECDC's activities related to Hepatitis B and C. She gave insights regarding surveillance, monitoring, how to get better estimates of prevalence, new PWID guidance, country support and the work with civil society. She concluded by informing the audience of the expansion of the ECDC mandate by the European Commission and the opportunities that this represents.



Dr. Lina Nerlander - European Centre for Disease Prevention and Control (ECDC)

Then, it was the turn of Stefan Gijssels, CEO of Digestive Cancers Europe (DiCE). After some data about Digestive Cancers in Europe, he presented the association's future vision and opportunities and its strategic framework. He also gave an interesting explanation of what patients' organizations do at the individual and collective levels.



Stefan Gijssels, CEO of Digestive Cancers Europe (DiCE)

Presentations delivered by some ELPA representatives characterized a second session of the webinar.

Marko Korenjak, ELPA President, listed all the ELPA achievements in 2020, included ELPA's involvement in 9 European medical research projects. Then, he sketched ELPA's strategic focus in 2021 in the field of members' empowerment, policy and advocacy activities, and building a more assertive European association.

After ELPA President's presentation, Milan Mishkovikj, ELPA Director, explained the importance and power of social media in disseminating and communicating for patients' organizations. According to him, social media give patients' organizations visibility and, consequently, a stronger voice. He also stressed that this way of communicating was crucial during the COVID-19 pandemic. After this introduction, Mr. Mishkovikj gave an example of an extremely successful ELPA campaign. He presented ELPA's online engagement during the October Liver Cancer Awareness Month.


The first person belonging to ELPA's family to be given the Covid-19 vaccine

ELPA reached Ms. Sindee Weinbaum, representative of the ELPA Member Hetz, the Israeli Association For The Health Of The Liver, and the ELPA Working Group leader on Rare Liver Diseases. She is the first person belonging to ELPA's family to be given the Covid-19 jab on December 27, 2020, in Tel Aviv as part of a mass vaccination program.

The interview is available on ELPA website.



Sindee Weinbaum, Leader of ELPA Working Group on Rare Liver Disease



ELPA in scientific research projects

Funding



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



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



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



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



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



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



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



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



ELPA continued joining and participating in numerous EU projects, mainly in disseminating and “translating” medical and scientific objectives and results to the general public, patients, and relatives. Since January 2020, ELPA is 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 2020 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 2021.



Medical research project Galaxy, Horizon 2020

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



Medical research project Liverhope, Horizon 2020

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

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



Medical research project Microb-Predict, Horizon 2020

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



Medical research project Liverscreen, Horizon 2020

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

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



Medical research project IP Cure B, Horizon 2020

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



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

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



Medical research project Decision, Horizon 2020

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



Medical research project A-TANGO, Horizon 2020

In Europe, about 30,000 people die every year from alcohol related cirrhosis, a form of chronic, non-communicable disease. The patients that are at highest risk of death are those with superimposed alcoholic hepatitis (AH) who do not respond to therapy and develop acute on chronic liver failure (ACLF), a newly described syndrome characterised by multiorgan failure. Treatment of ACLF is an unmet need. Based upon their clinical and pre-clinical studies, the A-TANGO consortium aims to perform Phase 2 clinical trials of a novel, patented and innovative therapeutic strategy by repurposing a toll-like 4 receptor antagonist (TAK242, Technology Readiness Level (TRL) 8), which targets inflammation, and combining it with granulocyte colony-stimulating factor (G-CSF, TRL9) that improves hepatocyte proliferation (G-TAK, TRL4). A successful trial will advance G-TAK to TRL8. Additionally, A-TANGO aims to discover novel biomarkers for patient selection and defining prognosis, building health economics models and reimbursement strategies to allow maximal dissemination and exploitation.

Being part of many medical research projects, ELPA representatives participated in many meetings related to implementing and monitoring them.

MICROB-PREDICT Meeting

From January 20 to 22, 2020, ELPA President Marko Korenjak participated at MICROB-PREDICT Meeting in Frankfurt, Germany. During the first day at the University hospital, the masterclass venue for young investigators, ELPA President met Prof. Trebicka discussing the activities of ELPA in 2020. The masterclass was followed by a keynote lecture - representing the formal start of the yearly meeting of the consortium partners of the MICROB-PREDICT project - given by Prof. Dimmeler, one of the most cited and well know professors working at University. The second day was characterized by a meeting with Prof. Jalan regarding ELPA involvement in his latest project called A-TANGO. The participation in this meeting was also the occasion to discuss both with Prof. Jalan and Prof. Arroyo about the lack of treatment or medical possibilities to end-stage liver disease patients in some European countries.



A presentation about MICROB-PREDICT Project

IP-cure-B project meeting

On January 27 to 29, 2020, ELPA President Marko Korenjak participated at the IP-cure-B kick-off meeting in Lyon, France. The purpose of the meeting was the presentation of all the WP leaders and related workload. Besides, the conference was organized to arrange in-person and online sessions over the next year. Marko Korenjak presented on workload WP8 - communication and dissemination strategies - with all the activities ELPA needs to do. Altogether, the WP leaders also discussed the next steps regarding the implementation of this project.



Marko Korenjak, ELPA President

FiSPlat project meeting

On February 4 and 5, 2020, ELPA President Marko Korenjak participated in the FiSPlat project kick-off meeting in Barcelona, Spain. FiSPlat is a cheap, fast, and non-invasive method to diagnose liver cirrhosis in primary care. The two significant patients' benefits of the project are the development of equipment that will be used for liver screening and will be simpler to manage. The lower cost will give the possibility of scaling up liver screening processes to detect liver diseases. Marko Korenjak also took the opportunity to meet with nurses from Hospital Clinic Marta Carol and Nuria Fabrellas discussing ELPA's participation in Stigma research for the LiverHope project. They set up a detailed action plan and agreed on an in-person meeting after the LiverScreen kick-off meeting in Barcelona on February 17, 2020.



Marko Korenjak, ELPA President with FiSPlat consortium's representatives

LiverScreen project meeting

On February 17, 2020, ELPA President Marko Korenjak participated in the LiverScreen project kick-off meeting in Barcelona, Spain. After a short discussion with all the partners part of the work package (WP7) dedicated to the communication and dissemination activities for which ELPA has the leading role, he attended the formal kick-off meeting with Dr. Teresa Casanovas Taltavull, ELPA Director and leader of ELPA Scientific Committee. Of course, a session was dedicated to WP7 and the President, together with the other partners, presented on it. The LiverScreen project will be the largest liver screening project with FibroScan in the European Union in the next 5 years. It is estimated that 30,000 people will have been



Prof. Pere Ginès

screened for the early detection of liver diseases at the end of the project. Marko Korenjak also had a separate talk respectively with Prof. Maja Thiele regarding a new Horizon 2020 project, Prof. Salvatore from Hospital Val de Hebron in Barcelona about the communication between EASL and ELPA, Ms. Walker on ELPA's fundraising activities, and Prof. Pere Ginès about what he expects, as the leader of the LiverScreen project, from patients organizations and ELPA's collaboration. After these meetings, Marko Korenjak joined Marta Carol and Nuria Fabrellas at the Hospital Clinic to exchange views on the Stigma research ELPA will be involved in for the LiverHope project.



Dr. Teresa Casanovas, ELPA Director and ELPA Scientific Committee Leader - Marko Korenjak, ELPA President

ELPA President is a member of the Impact Board of Decision Project

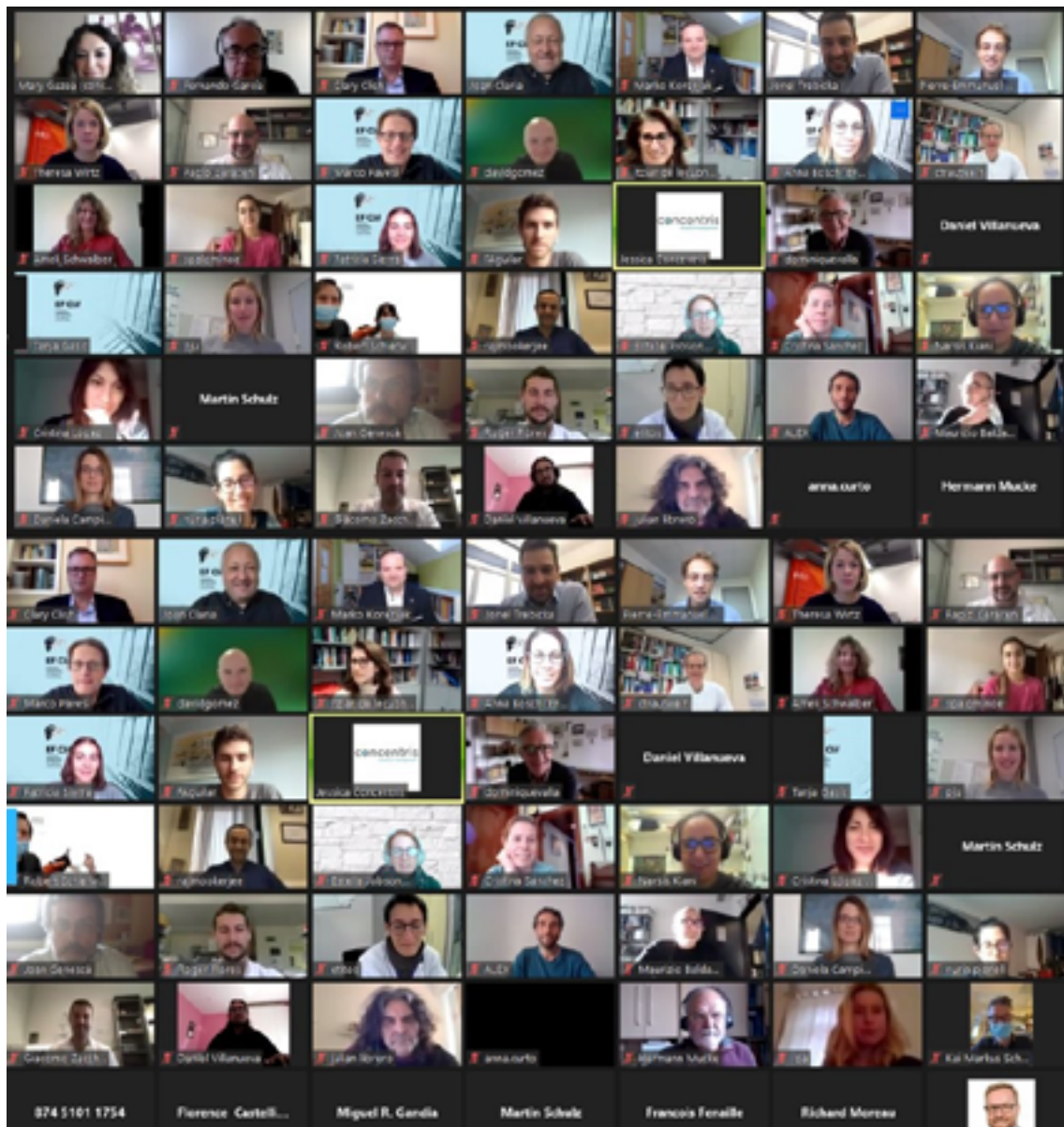
ELPA President Marko Korenjak has been elected as a member of the Impact Board of the medical research project Decision. This project, of which ELPA is part, is focused on the end-stage chronic liver disease (cirrhosis) that is a significant cause of morbidity and mortality and has an enormous socioeconomic impact because of high health care costs and the patients' inability to work or seek employment. The presence of ELPA in the Impact Board is excellent news because it represents a step further to strengthen patients' participation in medical research projects. Being part of them enriches the research field with the unique views of patients' organizations. ELPA acts like a translator making complex contents accessible to its members and the broader public with its exclusive way of communicating and disseminating scientific results.

IP Cure B Steering Committee meeting

On July 7, ELPA President Marko Korenjak, part of the Steering Committee of the EU medical research project IP Cure B, of which ELPA is a partner, participated in a meeting during which the Committee discussed the impact of COVID19 on the project. Several partners have experienced problems regarding the COVID crisis and the obligations that need to be fulfilled in the project. ELPA delivered all agreed tasks as many of them were prepared in late 2019 and realized at the beginning of 2020. During the meeting, ELPA presented all the communication and dissemination activities done by our experts. Also, ELPA actively participated in developing a new clinical design process and lowering the invasive procedures to the optimum level for research to produce reliable and usable results, with clear benefits for the involved patients.

Decision project virtual General Assembly Meeting

On November 24-25, 2020, 51 members of the DECISION consortium and 4 members of the Scientific and Ethical Advisory Board met online to discuss the progress made during the first 8 months and important next steps. Despite the COVID-19 pandemic, the project is mostly on track, and important first results have been delivered. ELPA participates in the project, funded by the European Commission through the program Horizon 2020, to disseminate and communicate the results. DECISION strives to understand better the pathophysiology of decompensated cirrhosis leading to acute-on-chronic liver failure (ACLF) at the systems level by taking advantage of already existing large and clinically well-characterized patient cohorts. The ultimate goal is to significantly reduce mortality through combinatorial therapies tailored to the specific needs of individual patients.



DECISION Project – Group Picture

In 2020 ELPA was also involved in the drafting of prestigious scientific articles.

'Nursing care of patients with cirrhosis'

ELPA, as a partner of the LiverHope project, was proud to announce the publication on *Hepatology* - the journal with the higher impact factor in the field - of the article "Nursing care of patients with cirrhosis." Written by the group of nurses of the LiverHope led by Núria Fabrellas, Hospital Clinic in Barcelona along with some nurses from the Mayo Clinic (Rochester MN) and with the collaboration of ELPA, the article stresses the importance of nurses with specific knowledge on liver diseases to be incorporated in multidisciplinary teams managing patients with cirrhosis.

'GES: A validated simple score to predict risk of HCC in patients with HCV-GT4 associated advanced liver fibrosis after oral antivirals'

ELPA is proud to announce the publication on *Liver International* of the article 'GES: A validated simple score to predict risk of HCC in patients with HCV-GT4 associated advanced liver fibrosis after oral antivirals' written by Prof. Gamal Shiha, Director of the European Liver Patients' Association and CEO of the Egyptian Liver Research Institute and Hospital (ELRIAH), Mansoura, Egypt. Hepatocellular carcinoma (HCC) risk persists after hepatitis C virus (HCV) eradication with direct-acting antivirals (DAAs), particularly in patients with liver cirrhosis. Identifying those who are likely to develop HCC is a critical unmet medical need. In three large cohorts of HCV patients with liver cirrhosis and advanced fibrosis with a sustained virologic response (SVR) after DAA, Prof. Shiha and his team developed and validated a simple General Evaluation Score (GES). This score can accurately stratify patients according to HCC risk and help identify patients who will not benefit from continued HCC surveillance based on a patient's estimated risk, enabling a personalized surveillance strategy targeting those at high HCC risk. GES score needs to be further replicated in further independent large cohorts of different origins before it can be additionally recommended for use for HCC surveillance in clinical practice. This kind of score can offer individualized patient HCC risk prediction.

'Redefining fatty liver disease: an international patient perspective'

Despite its increased recognition as a significant health threat, fatty liver disease associated with metabolic dysfunction remains mostly underdiagnosed and undertreated. In recent research published in *THE LANCET Gastroenterology and Hepatology*, an international team of researchers, together with some representative from ELPA and ELPA Members, has called for the disease to be renamed from non-alcoholic fatty liver disease (NAFLD) to metabolic-associated fatty liver disease (MAFLD) and has suggested how the disease should be diagnosed. The call to reframe the condition will ultimately positively affect patient care and quality of life and, through this effect, will reduce the burden on health-care systems. For patients, policymakers, health planners, donors, and non-hepatologists, the new acronym MAFLD is clear, squarely placing the disease as a manifestation of metabolic dysfunction and improving understanding at a public health and patient level. Also, the new acronym is meaningful to all citizens as well as governments and policymakers, and, above all, it is devoid of any stigma.



Social media activities

SOCIAL MEDIA ACTIVITIES Report by Milan Mishkovicj

Many supporters from all over the world

 **ELPA Website - 2020**

TOTAL VISITS:
181,758

 **Twitter**

FOLLOWERS

6,571

NEW FOLLOWERS

+1073

MENTIONS

942

 **Facebook**

LIKES

2,236

  **Twitter, Facebook & Others**

IMPRESSIONS

150 M



Circle 1 Circle 2 Circle 3

- | | | |
|----------------------------------|---------------------------------|---------------------------------|
| @EvoCFactorable | @DecisionUnit | @GeneThema |
| @bcsr_center | @baso_klypn | @AASLDtweets |
| @PSChefcom | @StemCellChao | @CLSpasta |
| @oncologistforum | @StevenGrove | @AASLFoundation |
| @EASLnews | @MasoudDas | @AASLDPresident |
| @dpc_europe | @LiverGiant | @IQ_Step |
| @GLOBOCAN_GCO | @JSGiacca | @MicrobPredict |
| @ascascrform | @EU_Health | @intercancer |
| | @EuroCancerCare | @CDC_Cancer |
| | @StemCellsEU | @EuroTestDesk |
| | @StemCellPilot | @CANPharmacogen |
| | @MyriadEurope1 | @EBICostion |
| | @Evelyn_Lay | @ACHDYL_hes |
| | @JN_Apaya | @CF_JustCancer |
| | @anderson2 | @WHO_Europe |
| | | @epimeteoportal |
| | | @europe1 |
| | | @OrionGen_Lives |
| | | @european1 |
| | | @Hes_Alliance |
| | | @european2 |
| | | @BumblebeeFound |
| | | @EUROGATEBESUDL |
| | | @ELCAnews |
| | | @PerseusMission |
| | | @OrionMedical |



ELPA's most successful Social Media Campaigns

#EuroTestWeek - Spring and Autumn edition

As 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 1 week, twice a year, to scale up voluntary testing. It promotes awareness of the benefits of earlier diagnosis of HIV and viral hepatitis infections and effective links to treatment and care while respecting the principle of confidentiality. As the world continues to respond to the COVID-19 pandemic, many communities, especially those most marginalized, continue to struggle with closed, restricted, and/or overloaded services. The European Testing Week 2020 showcased the resilience of many testing services during the COVID-19 pandemic. Services kept safely running thanks to innovations such as teleservices for counseling and other support services, appointment-only-based services, and the expansion of self-testing and/or self-sampling services. ELPA called on members and stakeholders to join and support the campaign to advocate and raise awareness about HIV, viral hepatitis, and STI during the COVID-19 pandemic. Thanks to its engagement, ELPA was among the first 10 influencers on Twitter at the end of the virtual campaign from its social media channels.



International NASH Day Campaign

ELPA has been honored to celebrate the International NASH Day on 12th June 2020 in partnership with the Global Liver Institute. ELPA's two-week social media campaign has been a great occasion to raise awareness on NASH-NAFLD among the decision-makers and engage patients, clinicians, and policymakers, push forward the discussion about these diseases and promote better a more comprehensive communication on this topic. The campaign focused on prevention and explored the solutions that contribute 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. The campaign also reminded patients, partners, experts, policy decisions makers, stakeholders, and the general audience that NASH/NAFLD is our next biggest challenge in Europe as its rate among populations increases.



World Hepatitis Day

ELPA has been honored to celebrate World Hepatitis Day on 28th July 2020 in partnership with its friends and stakeholders. ELPA's two-week social media campaign has been a great occasion to raise awareness and engage patients, clinicians, and policymakers to discuss Hepatitis and promote better and more comprehensive communication on this topic. In particular, the campaign focused on access to treatments, screening programs, immunization, and, above all, the achievable goal to eliminate hepatitis infection as a public health threat in Europe by 2030.



Kristy Maclean Hayes, The Hepatitis C Partnership, Ireland - ELPA Member

International PBC Day 2020

ELPA was honored to celebrate International PBC Day on September 13, 2020. 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 the fact that 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).



World Patient Safety Day 2020

ELPA joined the World Patient Safety day 2020 campaign on September 17. No one should be harmed in health care. Yet, thousands of patients worldwide suffer avoidable harm or are put at risk of injury while receiving health care every day. COVID-19 pandemic has unveiled the vast challenges that especially health workers are facing globally. 'Health Worker Safety: A Priority for Patient Safety' had, therefore, been selected by the World Health Organization as the theme for World Patient Safety Day 2020, which focused on the interrelationship between health worker safety and patient safety, summarized in the slogan 'Safe health workers, Safe patients.' This emphasized the need for a safe working environment for health workers as a prerequisite for ensuring patient safety.



PSC Day 2020

October 29, 2020, was PSC Awareness Day. Primary Sclerosis Cholangitis (PSC) is a rare, immune-mediated liver disease that affects the bile ducts and liver. In PSC, the bile does not flow properly in the bile ducts inside and/or outside the liver. Also, PSC is a complex and varied condition with different ways of presenting itself. With a weeklong social media campaign, ELPA put a face on this liver disease so that we may work to recognize how to diagnose better, treat, and cure it. Too many liver disease patients fall victim to the unknown. For many liver diseases, their causes and effective diagnostics, treatments, and cures remain unclear. Moreover, this adds pain and difficulties in dealing with the disease. ELPA continually works to push forward and to perfect its activities for all of these liver patients.



AWARH

ELPA took part in the 8th Awareness Week on Alcohol-Related Harm (AWARH), held November 16 to 20, 2020, with a vast online campaign. Around 12% of cancer cases worldwide are linked to alcohol consumption, and regarding the liver, people who drink more than 3 drinks per day increase their risk of liver cancer by 16%. Alcohol is responsible for one-third of all liver cancers, being the first cause in Central and Western Europe and the second cause globally.



A website entirely dedicated to Liver Cancer

In October 2020, ELPA, to make its engagement deeper and broader, launches a website entirely dedicated to liver cancer: <https://livercancermonth.eu/>

2020 VISITS:
33,817

ENDORSED BY:
DIGESTIVE CANCERS EUROPE



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


















ELPA Structure

ELPA structure 2018-2022

ELPA Board of Directors

President	Marko Korenjak, M.A., M.A.		Slovenia
Vice-President	Julio Burman		Israel
Vice-President	Dr. Tove Frisch		Sweden
ELPA Treasurer	Ivana Dragojević		Serbia
ELPA Director	MSc. Milan Mishkovikj		Macedonia
ELPA Director	Prof. Dr. Gamal Shiha M.D.		Egypt
ELPA Director & Scientific Committee leader	Dr. Teresa Casanovas Taltavull M.D.		Spain

ELPA Scientific Committee

Scientific Committee leader	Dr. Teresa Casanovas Taltavull M.D.		Spain
	Dr. Helena Glasová M.D.		Slovakia
	Dr. Reham Soliman M.D.		Egypt
	Dr. Salvatore Piano M.D.		Italy
	Dr. Vesna Lučić- Samardžija M.D.		Bosnia & Herzegovina
	Dr. Sabela Lens M.D.		Spain



ELPA Advisor


Richard Hall		UK
--------------	---------------------------------------------------------------------------------------	----

Editorial Team

Leader	Dr. Hilal Ünalmiş Duda		Turkey
--------	------------------------	---------------------------------------------------------------------------------------	--------

ELPA Brussels office





Head of Brussels office and EU Affairs	Veronika Všetíčková		Belgium
Administrator and Content creator	Beatrice Credi		Belgium



ELPA Working groups






In 2020, ELPA officially had seven Working Groups.

ELPA Working Group on Rare Liver Diseases

LEADER	Sindee Weinbaum		Israel
MEMBERS	Richard Hall		UK
	Lone McColaugh		Denmark
	Tarja Teitto-Tuckett		Finland

The Group coordinated the PBC Awareness Day in conjunction with PBC Foundation, PFIC Awareness Day, and it was part of the Global Awareness Day. It also participated in the PSC International Awareness Day with PSC Partners Seeking a Cure. After the leader of ELPA Rare Diseases Working Group, Ms. Sindee Weinbaum, had a meeting with Ms. Emily Ventura from the PFIC (Progressive Familial Intrahepatic Cholestasis) Advocacy and Resource Network, Inc and organized together with it an awareness day campaign on October 5, they discussed how moving along within Europe with ELPA members. The ELPA Rare Diseases Working Group met with the PFIC group leader from Poland and connected with Star of Hope, the ELPA Member from Poland. They will become part of the PFIC organization and get support from it with connection to the Ministry of Health, hospitals, and doctors. This is the start of having members working on rare diseases (PSC, PBC, AIH, LALD, and PFIC), and this is also one of the goals of the ELPA Rare Diseases Working Group. The Group also helped to form a support group with parents in Italy




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. Hepatocellular carcinoma (HCC) is considered one of the leading causes of cancer-related deaths worldwide. Cholangio Carcinoma (CCA) is regarded as rare cancer. Being aware of all of this, the Group considered that When HCC is diagnosed, approximately 30% of patients are eligible for potentially curative therapies. Recently more treatments are available for intermediate and advanced stages, improving survival and quality of life. Early screening with detection and link to care to HCC in specialized centers are very much needed. Considering CCA, much work needs to be done on diagnosis and therapies. Patient prognosis has not improved substantially in the past decade, with 5- year survival (7–20%) and tumor recurrence rates after resection disappointing. Among the most remarkable 2020 Group's



achievements, it should be listed: the October Liver Cancer Awareness Month, the Educational Training Program For ELPA members that included Liver Cancer among its topics, and the preparation of the White Paper (with DiCE Association) on Liver Cancer to be presented to Members of the European Parliament and other EU stakeholders in 2021.

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 2021. 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 found 9 clinical trials in Israel and listed them on the ELPA website for all who wish to consider participating in them. They would like to see all ELPA members follow this example and list Clinical-Trials on their website. Boehringer Ingeleim contacted the Leader and three patients from different countries. They met virtually and together provided constructive comments on the "Informed Consent" and Protocol. These comments helped simplify and clarify information made available to those who wish to participate in clinical trials. The Leader's experience gained through Boehringer Ingeleim helped the Workgroup do the same for the Hep-B trial. The Group is constantly in touch with Pharma companies to keep the 2021 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 has just started working on the harm reduction topic. Harm reduction refers to policies, programs, and practices that aim to minimize 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 MAFLD/NASH

LEADER	Yiannoula Koulla		Cyprus
MEMBERS	Lone McColaugh		Denmark
	Sindee Weinbaum		Israel
	Manuel Weiss Perez		Spain
	Tarja Teitto-Tuckett		Finland
	Veronika Všetíčková		Slovenia



The driving force behind the decision to form this ELPA group was the rapid increase of the disease and the decision to do something about it. Knowing this, the team has set up objectives for Education, Awareness activities, and a Problem-based design. In 2020 each member of the group started from their own country to inform or learn existing programs (like the nurse program for NAFLD/NASH in Finland) or found out how the situation is in our own country. They also presented the group to all ELPA Members to increase awareness and education among them. Knowing that there are no drugs available, they suggested other alternatives and raise awareness of the importance of good nutrition and a healthy lifestyle. They also prepared a survey to disseminate in 5 languages. This small survey, besides the information which it could provide, it will also serve as a Registry within ELPA –a center of data. It would gather an overview of unique experiences and information, which will help us evaluate the problem and raise awareness on MAFLD/ NASH.

ELPA Working Group on Prevention

LEADER	Ivana Dragojevic,		Serbia
MEMBERS	Julio Burman		Israel
	Marko Korenjak		Slovenia

A Working Group on prevention was formed in 2020 to respond to the need for a deeper understanding of prevention as a key for decreasing diseases, in this case-liver diseases. The group leader is Ivana Dragojevic, ELPA Director and ELPA Treasurer, who has twenty years of practice in education and members are Marko Korenjak and Julio Burman, who have extensive experience in the field of prevention through the ELPA@ Home project, which they have successfully implemented over the years. The goal of the prevention group is to educate also the general population and not just patients. In 2020, we made a work plan for the next year in which we propose two projects. "Women and HBV" in which we will engage a team of experts and mainstream media to reach a whole new pool of people, "ordinary" women, and "HepFreeBadge," which is intended for the education of professionals in the cosmetics industry/beauty parlor -sterilization protocols and measures to protect clients and employees from Viral Hepatitis.

ELPA Working Group on Hepatitis B elimination

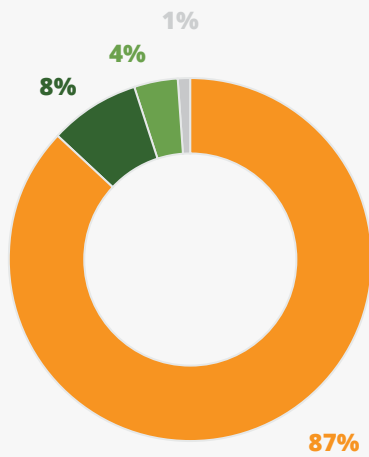
Leader:	Marinela Debu		Romania
Members:	Ivana Dragojevic		Serbia

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 particular Group aims to provide tools for chronic HBV patients to live their lives as safely as possible.

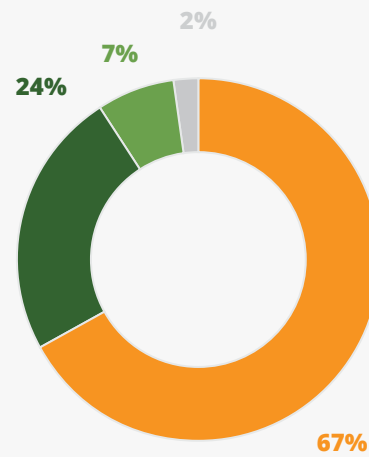


Financial accounting and transparency

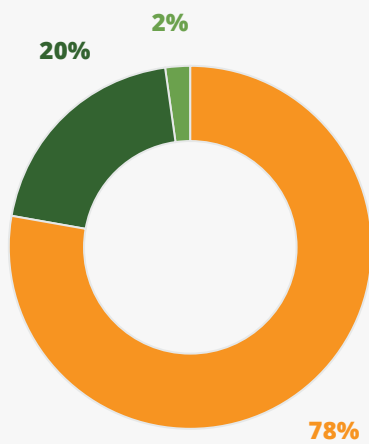
2019 - INCOME



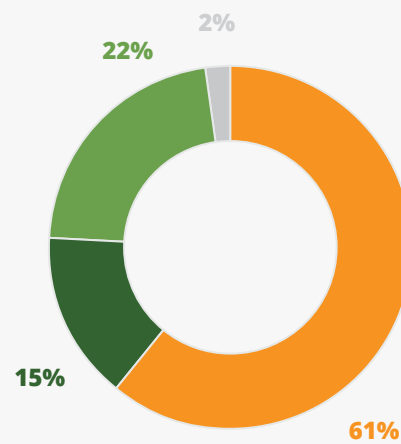
2019 - EXPENDITURES



2020 - INCOME



2020 - EXPENDITURES



- Membership fee
- Sponsors and donors
- EU Projects
- Other

- ELPA work
- Operational expenses
- Wages and fees
- Depreciation



European Liver Patients Association Aibl
Internal year statement

		2020
		01-01-2020 - 31-12-2020
ASSETS		
FIXED ASSETS		57 523,08
Financial fixed assets		57 523,08
	230000 - Plant, machinery and equipment (D)	66 940,00
	230009 - Amortisations of plant, machinery and equipment (D)	-13 387,96
	240200 - Software and hardware (D)	7 777,46
	240209 - Amortisations of software and hardware (D)	-7 206,42
	288009 - Miscellaneous guarantees (D)	3 400,00
CURRENT ASSETS		821 884,99
Amounts receivable within one year		2 968,42
	Trade debtors	2 968,42
	400300 - Suppliers with debit balance (D)	2 968,42
Cash at bank and in hand		791 425,71
	550200 - KBC Bank R/C BE51 7360 6502 8662 (D)	4 429,29
	550201 - KBC Bank R/C BE87 7360 5607 8794 (D)	445 052,36
	550202 - KBC Bank R/C USD BE87 7360 5607 8794 (D)	225 567,00
	550203 - KBC Bank R/C GBP BE87 7360 5607 8794 (D)	33,34
	550204 - KBC Bank R/C CHF BE87 7360 5607 8794 (D)	43 303,52
	550205 - KBC Bank R/C DKK BE87 7360 5607 8794 (D)	19 678,00
	550210 - KBC Bank Spaar BE22 7490 1856 2347 (D)	51 098,30
	550211 - KBC Deposit BE72 7430 7791 0616 (D)	2 259,16
	570000 - Treasury (D)	4,74
Deferred charges and accrued income		27 490,86
	490000 - Costs to be carried forward (D)	240,86
	491000 - Accrued revenue (D)	27 250,00
TOTAL ASSETS		879 408,07
EQUITY AND LIABILITIES		
CAPITAL AND RESERVES		773 719,15
Allocated funds		103 552,00
	131000 - Funds allocated for covering social liabilities (C)	50 000,00
	131001 - Other unavailable reserves (C)	53 552,00
Accumulated profits (losses)		670 167,15
	140000 - Profit carried forward (C)	670 167,15
PROVISIONS		
AMOUNTS PAYABLE		105 688,92
Amounts payable within one year		19 226,42
	Trade debts	1 177,42
	Suppliers	1 177,42
	440000 - Suppliers (C)	-1 791,00
	440200 - Suppliers with debit balance (C)	2 968,42
	Taxes, remuneration and social security	18 049,00
	Taxes	4 151,48
	4514000 - VAT payable Intracommunity (PI) (C)	2 598,95
	453000 - Withholding taxes payable (C)	1 552,53
	Remuneration and social security	13 897,52
	454000 - NSSO contributions payable (C)	-1 050,79
	455000 - Wages (C)	4 564,93
	456010 - Provision for holiday pay employees (C)	10 383,38
Accruals and deferred income		86 462,50
	493000 - Revenue to be carried forward (C)	61 000,00
	493100 - Settlement funding (C)	25 462,50
TOTAL LIABILITIES		879 408,07




European Liver Patients Association Aibl
Internal year statement

INCOME STATEMENT

Income and charges

Turnover		478 731,30
702001 - Core funding (C)		230 284,77
702002 - Reimbursements (C)		1 028,16
702003 - EU Project (C)		98 000,00
702004 - Sci.work & Advisory Board (C)		42 450,00
702005 - HCC (C)		79 500,00
702006 - Various revenue (C)		475,00
702007 - NASH (C)		24 993,37
702008 - Rare Liver Diseases (C)		2 000,00
Operating income		72,00
743000 - Recovery of staff costs (C)		72,00
Raw materials, consumables, services and other goods		217 021,88
602020 - Project -Accommodation (D)		2 175,29
602030 - Project - Communication (D)		11 503,36
602040 - Project -Admin supply & other (D)		41 190,21
602060 - Project -Badges (D)		2 808,00
602090 - Project -Booth Furniture (D)		2 929,66
602100 - Project -Compensation (D)		18 000,00
602120 - Project -Contributinal compensation (D)		3 675,00
602130 - Project -EASL (D)		400,00
602150 - Project -EPF (D)		250,00
602160 - Project -EU Institutions (D)		2 167,02
602190 - Project -Fees (D)		14 253,98
602220 - Project -Hotel (D)		396,00
602280 - Project -Others (D)		7 396,28
602290 - Project -Printed Material (D)		7 889,20
602310 - Project -Representation (D)		7 990,83
602320 - Project -Rest costs last year (D)		15 663,24
602340 - Project -Scientific support (D)		8 400,00
602350 - Project -Subsistence (D)		1 532,26
602360 - Project -Subsistence - Contributinal (D)		1 500,00
602380 - Project -Travel & transfer costs (D)		10 854,89
602430 - Project -Support Treasurer (D)		7 600,00
606400 - Insurance (D)		199,10
610102 - Rental costs of buildings (D)		10 422,00
610201 - Rental costs of plant, machinery and equipment (D)		2 184,05
611000 - Office supplies and printed material (D)		301,37
611001 - Hardware, software and software licences (D)		2 760,00
612000 - Social secretariat fees (D)		2 344,60
612007 - Administrator (D)		2 945,96
612008 - Office manager (D)		3 607,22
613200 - Insurance against business risk (D)		413,12
615200 - Accountants' and bookkeepers' fees (D)		8 772,74
615201 - Auditors' fees (D)		5 687,00
615204 - Lawyers' fees (D)		4 961,73
616201 - Communication (D)		3 691,68
616531 - Costs of seminars and training (D)		156,09
Remuneration, social security costs and pensions	(+)/(-)	70 615,38
620200 - Employees (D)		59 240,34
620203 - Employees - other benefits (D)		72,00
620204 - Employees - provision for holiday pay (D)		8 972,15
621000 - Employer's social security contributions (D)		201,68
621006 - Additional social security contributions (D)		1 188,56
623006 - External medical service (D)		352,65
623025 - Other staff costs (D)		588,00
Depreciation of and other amounts written off formation expenses, intangible and tangible fixed assets		7 264,92
630220 - Amortisations of machinery and equipment (D)		6 693,96
630232 - Amortisations of software and hardware (D)		570,96
Operating profit (loss)	(+)/(-)	183 901,12

		European Liver Patients Association Aibl Internal year statement	
Financial income			3 957,33
	751000 - Interest rate of banks (C)		0,22
	754000 - Favourable exchange differences (C)		3 908,72
	755000 - Favourable rounding differences (C)		48,38
	758000 - Payment differences in your advantage (C)		0,01
Financial charges			<u>26 747,07</u>
	654000 - Adverse exchange differences (D)		23 568,49
	657100 - Bank costs (D)		3 087,38
	658000 - Payment differences (negative) (D)		0,88
	659100 - Late-payment interest (D)		90,32
Gain (loss) on ordinary activities before taxes		(+)(-)	<u>161 111,38</u>
Transfer to tax free reserves			<u>6 694,00</u>
	789000 - Transfers to tax-free reserves (C)		6 694,00
Gain (loss) of the period		(+)(-)	<u>167 805,38</u>

Publishing financial reports

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

Statutory audit for 2018, 2019 and 2020

ELPA is currently under external statutory auditing processes that need to be done for a minimum of 3 years. The audit is done by an external, independent, certified auditor for Belgium and Nederland from Alerte Bernard Advies en Interim. Audit reports are published every year at the ELPA web page and can be found here: <https://elpa.eu/statutory-audit/>.



Acknowledgments

ELPA is thankful to all its members and numerous volunteers that have helped us accomplished our goals in 2020. We are also grateful to all our supporters and stakeholders. They have been backing our endeavors to fight liver disease over the years.

In 2020, ELPA received grants as well as, in some cases, in-kind support from the following companies:



The Hep-cast



**The real-life stories behind
the fight to eliminate
viral hepatitis.**

Gilead Sciences Europe Limited and the World Hepatitis Alliance have collaborated to create a podcast series that goes beyond the statistics to explore the human impact of the hepatitis C (HCV) crisis, as we hear from people whose lives have been changed forever by the virus.

Hosted by Dr Sarah Jarvis, the Hep-cast profiles leading advocates, doctors, public health experts and decision makers working towards HCV elimination around the globe, as well as those with lived experience. Some of our guests include:

Homie Razavi

CDA Foundation, USA

Manal El-Sayed

Ain Shams University, Cairo and Egyptian
National Committee for Control of Viral Hepatitis

Su Wang

World Hepatitis Alliance

Heidi Fridriksdottir

TrapHepC, Iceland

Prof Graham Foster

Queen Mary University of London, UK

Sonjelle Shilton

Foundation for Innovative New
Diagnostics (FIND)

Maka Gogia

Georgian Harm Reduction Network

If you're interested in infectious diseases, public health, social justice and improving the lives of people who are often overlooked by society – this is the podcast for you!



**Listen, share and subscribe
by searching for The Hep-cast
on the platforms below:**





**AbbVie
Here.
Now.**

Helping millions
find a new day.
Right here.
Right now.


At AbbVie, our goal is to help people live their best lives today and tomorrow.

That's why we'll never give up on discovering the next medical breakthrough, while continuing to support patients in the here and now.

Read how we help patients like Don: herenow.abbvie

Don,
Hepatitis C patient

abbvie



Bristol Myers Squibb™

Transforming
patients' lives
through science™

We are in the business of breakthroughs—the kind that transform patients' lives. Dedicated to our mission of discovering, developing and delivering life-saving innovations that help patients prevail over serious diseases, we'll never give up our search for more hope, for more people, around the world.

Visit bms.com to see how we're bringing a human touch to everything we do.



We are leading
a revolution in oncology
to redefine cancer care



*Tackling liver disease,
a collective journey
of discovery*

Thank you! to ELPA and all the member organisations and partners for your collaboration during an unprecedented year. Liver disease doesn't stop due to a pandemic and neither have we. We remain committed to stopping chronic liver disease and look forward to working with all of you as we head into 2021.





Boehringer Ingelheim

Making new and better medicines for humans and animals is at the heart of what we do. Our mission is to create breakthrough therapies that change lives. Since its founding in 1885, Boehringer Ingelheim has remained an independent, family-owned company. We have the freedom to pursue our long-term vision, looking ahead to identify the health challenges of the future and targeting those areas of need in which we can make a real difference.

As a world-leading, research-driven pharmaceutical company, more than 51,000 employees create value through innovation daily for our three business areas: Human Pharma, Animal Health, and Biopharmaceutical Contract Manufacturing. Our investment in R&D drives innovation to create the next generation of medicines that save lives and improve quality of life.

We realize more scientific opportunities by embracing the power of partnership and diversity of experts across the life-science community. By working together, we accelerate the delivery of future next medical breakthroughs that will transform the lives of patients now, and in generations to come.

More information about Boehringer Ingelheim can be found at www.boehringer-ingelheim.com.

...SO JOSEP CAN CONTINUE **TO DANCE** WITH HIS WIFE.

Josep
Living with liver cancer
Barcelona, Spain

We are dedicated to improving patients' lives through innovative medicines in Oncology, Neuroscience and Rare Disease. Because patients can't wait.
www.ipsem.com

IPSEN
Innovation for patient care

Date of preparation: February 2021
ALL RIGHTS RESERVED

LIVERSYNC®

Spotting the early signs of brain function decline in advanced liver disease.



This app was developed and produced by the Norgine group of companies as a service to medicine.

LIVERSYNC, NORGINE and the sail logo are registered trademarks of the Norgine group of companies. All other trademarks mentioned in this advertisement are the property of their respective owners.



Feb 2021
GL-HEP-LVS-2100001

European Liver Patients' Association

Schuman Roundabout 2-4, Level 6, 1040 Brussels, Belgium

office@elpa.eu

T: +32 (0) 478 155 224

www.elpa.eu

Facebook

@European Liver Patients' Association

Twitter

@EuropeLiver

LinkedIn

European Liver Patients' Association

