

ASPIRE TO INSPIRE



ANNUAL REPORT 2018
European Liver Patients' Association



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 14th 2005 during the annual conference of the European Association for the Study of the Liver (EASL) and now has 34 members from 27 countries. ELPA's aim is to promote the interests of people with liver disease and in particular: to highlight the size of the problem; to promote awareness and prevention; to address the low profile of liver disease as compared to other areas of medicine such as heart disease and to share experience of successful initiatives. ELPA and its members are dedicated to multi-level lobbying initiatives involving European Union and national policymakers, liver specialist, 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 standard of medical care - 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

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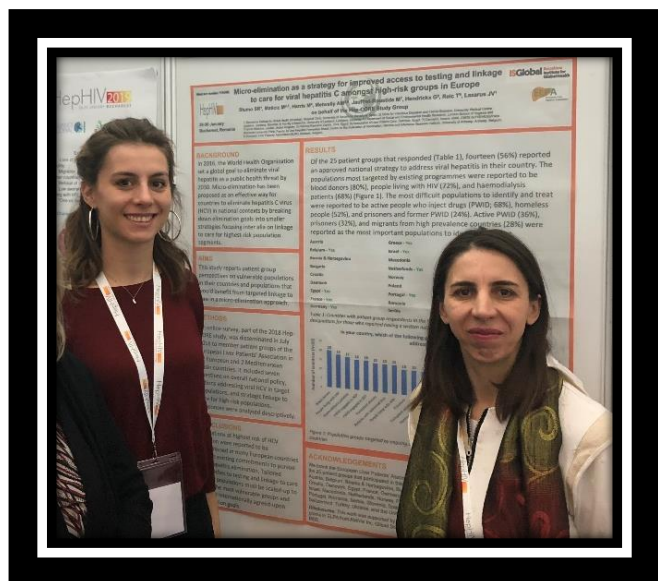
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For Samya Stumo, in memoriam

This report is dedicated to our collaborator Samya Stumo, who recently passed away. Samya was a member of the IS Global team working on ELPA's Hep-CORE study since 2016 and has immensely contributed to the evolvement of the study that continues to change the lives of the hepatitis patients. Samya's dedication to the project and its cause will always be remembered by all ELPA members.

"I am still pretty shocked. I cannot find appropriate words to express my feelings; when I think about Samya I cannot stop the tears. Why bad things always happen to good persons? Always smiling, always being so polite, so kind, so tolerant, so helpful...." said ELPA President when learned the sad news.

HepHIV conference in Bucharest, Romania – last photo with Marinela Debu, ELPA Board member taken on 30th January when late Samya presented Hep-CORE results on Micro elimination in high risk groups



FOREWORD OF THE PRESIDENT

Dear Stakeholder,



to represent the liver patients across Europe and advocate for a change is not an easy task. It is a journey often marked with postponed decisions and failure to put the patients in the center of the system. Such hurdles sometimes make our goals seem unattainable and might result in discouragement, but never with giving-up. And rightly so, given that our role of the patients is to make our voice loudly heard and our needs communicated. To be able to do so, we in ELPA have dedicated our professional lives to the cause of bringing the change into the life of the liver patients – to ease their struggles and to bring deserved attention to the burden of the liver disease in Europe. For more than 14 years now we have been aspiring to grow even bigger, stronger and to being recognized globally, all to assure that all liver patients are diagnosed in time, treated with respect, and have equal access to the best standard of medical care - regardless of origin, lifestyle, and type of liver disease. We aspire to inspire others to share with us the abundance of hope that one day all liver patients

will have equal access to treatment and that we will no longer be stigmatized, as we often are.

My last year's foreword envisaged changes in 2018. In ELPA that referred both to the changes in our Governance and regulations. Introducing these changes and implementing them until November 2018 when I passed on the baton to the new ELPA President, Marko Korenjak, I have witnessed maturing of our organization and strengthening the connections between our members. Unfortunately, end of the 2018 we have faced several patients' groups leaving ELPA. However, I am immensely proud of the work that ELPA has done so far and I am happy to announce that we have entered the 2019 with new Governance and plethora of refreshing ideas for continuing doing the good work and saving lives across Europe. I hope that this overview of our activities throughout the 2018 will inspire you to support our work and to comprehend the importance of the patient's voice.

A handwritten signature in black ink, appearing to read 'Tatjana Reic'.

MSc Tatjana Reic, President of the European Liver Patients' Association

ELPA MEMBERS IN 2018



AUSTRIA	Hepatitis Aid Austria (HAA)
BELGIUM	Vlaams Hepatitis Contactpunt (VHC)
BOSNIA & HERZEGOVINA	The Chronic Viral Hepatitis Patients Association “B18”
BULGARIA	HepActive National Association for Fighting Hepatitis „Hepasist“
CROATIA	Croatian Association For The Liver Diseases (HEPATOS)
CYPRUS	Cyprus Liver Patients Association „Promitheas“
DENMARK	Leverforeningen
EGYPT	Association of Liver Patients’ Care (ALPC)
FINLAND	The Finnish Kidney and Liver Association
FRANCE	SOS Hépatites Fédération
GERMANY	Deutsche Leberhilfe e.V
GREECE	Hellenic Liver Patient Association „Prometheus“
HUNGARY	Hungarian Association of Chronic Hepatitis Patients „Vimor“
ISRAEL	Israeli Association For The Health Of the Liver “Hetz”
ITALY	Associazione EpaC Onlus
MACEDONIA	Hepar Centar – Bitola Association for health education, prevention and better treatment (HEPTA)
NETHERLANDS	Dutch Liver Patients' Association
NORWAY	proLAR
POLAND	Star of Hope Foundation
PORTUGAL	SOS Hepatites Portugal
ROMANIA	Patients with hepatic impairment Association of Romania (APAH–RO) Association Sano–Hep
SERBIA	Liver patients' association „Hronos“
SLOVAKIA	Hep Help Klub
SLOVENIA	Slovenian Association of patients suffering from hepatitis Slovenia HEP
SPAIN	Catalan Association of Hepatitis Patients (ASSCAT), National Federation of Sick and Transplanted Liver (FNETH)
SWITZERLAND	Swiss Hepatitis C Association
SWEDEN	Riksföreningen Hepatit C (RHC)
TURKEY	Living with Hepatitis Association “HEPYAŞAM”
UNITED KINGDOM	British Liver Trust Hepatitis C Trust Liver4Life
UKRAINE	PBC Foundation Stop Hepatitis

2018 HIGHLIGHTS

ELPA activities at International Liver Congress™
11-14 APRIL 2018, PARIS

EASL opening ceremony

As every year, ELPA has had an opportunity to be presented by ELPA President, at the EASL opening ceremony. During this year's address MSc Tatjana Reic reiterated the importance of the patient community and once again **reminded us of the steps that need to be done in order to achieve the WHO goal of the hepatitis elimination by 2030, but also of the challenged remaining around NAFLD and NASH, HCC, HE and PBC.**

MSc Tatjana Reic, ELPA President



Annual General Meeting

Another successful AGM during which ELPA members had the opportunity to exchange the ideas and opinions took place. ELPA's aim as an umbrella association is to merge different cultures and nations so that all of us together achieve the common goal which we are fighting for, the elimination of hepatitis and the world without the liver disease. Prior to the AGM almost 80% of ELPA members have answered to a survey whose results showed a satisfaction with the direction in which ELPA is developing.

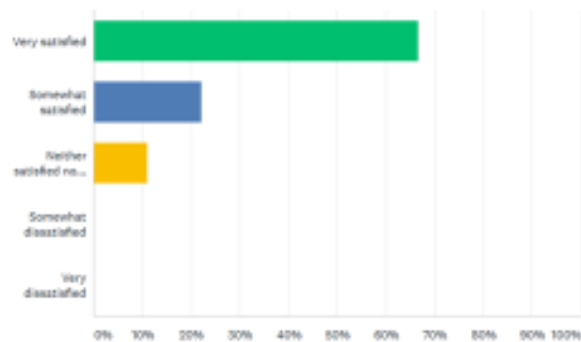
27 out of 34 (79,41 %) members took part in the survey



As you might know, in recent years, ELPA is putting significant efforts in order to apply changes in its development to better serve its members and patients (e.g. formation of work groups, stronger inclusion of our members in day to day work...). How satisfied or dissatisfied are you with the direction in which ELPA is going/developing?

Answered: 27 Skipped: 0

Q8:



ANSWER CHOICES	RESPONSES
Very satisfied	66.67% 18
Somewhat satisfied	22.22% 6
Neither satisfied nor dissatisfied	11.11% 3
Somewhat dissatisfied	0.00% 0
Very dissatisfied	0.00% 0
TOTAL	27

24 out of 27 (88,89%) has recognized ELPA's current government's significant efforts in order to apply changes in its development to better serve its members by answering that they were satisfied with the direction in which ELPA is going/developing.

In particular:

- 18 out of 27 (66,67%) members who participated in survey answered they were very satisfied, which de facto, translated into numbers, presenting membership as whole, presents that **52,94% (18 out of 34) of all ELPA members were very satisfied**
- 6 out of 27 (22,22%) answered they were somehow satisfied i.e. 17,65% of ELPA membership
- 3 out of 27 (11,11%) answered they were neither satisfied nor dissatisfied i.e. 8,82% of ELPA membership

In conclusion: survey findings showed that 70,59% (24 out of 27 out of 34) members were satisfied with the direction in which ELPA is going/developing, which certainly pointed us that we were going in the right direction.



Please specify one area in which, in your opinion, ELPA needs most improvement? Please comment/explain your answer in the comment box.



Q9:

ANSWER CHOICES	RESPONSES
Internal communication	7.41% 2
External communication	14.81% 4
Networking (Connecting member organizations to each other)	22.22% 6
Website content	3.70% 1
Social media	3.70% 1
Member inclusion in day to day activities	14.81% 4
Improvement in scientific area	7.41% 2
Policy work/advocacy & lobbying at EU/International level	7.41% 2
Policy work/advocacy & lobbying at national level/s (in country support)	18.52% 5
TOTAL	27

Top 3 findings:

- 22,22% (6 out of 27) answers showed us that *Networking*, in terms of connecting member organization to each other, has been recognized as the area that most members ask for improvement,
- followed by *in country support* (18,52% i.e. 5 out of 27) and
- *Member inclusion in day to day work* as well as *External communication* (14,81% i.e. 4 out of 27, each).

Comments:

"Somewhere in between workshops and peers we do need guidance on how to maintain day to day workflow of the organization regardless of projects and specific approach to fundraising to our countries."

"More transparency needed internally with the members and externally with partners, stakeholders and sponsors."

"Improving the clarity of the structure and accountability of the senior management to external (nonmember organizations)."

Taking into account survey findings and additional comments, ELPA governance has planned and scheduled for January-April 2019 period to update and/or introduce missing procedures and updates of all ELPA bylaws, before regular 2019 elections were scheduled. Yet, later events and November snap elections have interrupted this governance from finalizing work plans scheduled to close out current mandate in the proper way.

During this AGM ELPA accepted three new member organizations: Cyprus Liver Patients Association „Promitheas“ from Cyprus, proLAR from Norway and Swiss Hepatitis C Association from Switzerland.

ELPA Symposium

Symptom management across liver diseases: Is there a big picture?

Marko Korenjak and MSc Tatjana Reic, ELPA

The symposium chaired by MSc Tatjana Reic and Marko Korenjak took place on 12th April 2018 during the annual EASL International Liver Congress in Paris. The aim of the session was to address the symptoms such as fatigue, pruritus, sexual problems or mental health issues - an overarching problem in liver disease. Similar complaints may be heard from many patients with different diagnoses, such as viral hepatitis, toxic, metabolic, autoimmune or advanced liver disease.



Improved symptom management is an urgent unmet need and very high up on the wish list of people living with chronic liver disease. With this annual symposium, ELPA wanted to take a new approach to symptom management: Rather than look at one particular liver disease and its symptoms, we would like to look at frequent symptoms, and compare their causes and management options across a variety of liver diseases.



ELPA Symposium audience – extra seats were requested so additional room was provided

Workshop Driving Collective Impact for HCV Elimination

What a symbolic way to kick-off our activities at the International Liver Congress with organizing a joint workshop *Driving Collective Impact for HCV Elimination* together with the **European Association for the Study of the Liver**, on the margins of the ILC 2018. The objective of the workshop was to gather patients and clinicians to exchange views on the current situation in their home countries with regards to HCV elimination. For this occasion ELPA members from Italy (EpaC) and Romania (APAH-Ro) showcased their best practice examples, while the other participants had the task to elaborate which case study was most relevant to their geographic area of influence and have discussed the key solutions from the case studies.



Prof. Dr. Mojca Maticic



Spring European Testing Week – Pilot

In collaboration with the INTEGRATE Joint Action, we have launched a pilot project Spring European Hepatitis-HIV Testing Week 2018, which took place on 18- 25 May 2018. This pilot aimed to promote wide-scale testing and related activities and sought to complement the November campaign. This pilot focused on identifying barriers that ETW participants experience in implementing integrated testing in different settings across Europe. 104 organizations have pledged their support for Spring European Hepatitis - HIV Testing Week, among which a number of ELPA's members from Austria, Bulgaria, Croatia, Macedonia and Romania, who carried out very successful testing activities in their respective countries, while many others participated through the media and social networks.

The week also came as a result of the hepatitis community's request to introduce additional testing week that would have integrated approach, but would be focused on hepatitis. Seeing the best practice from European Testing Week, hepatitis community has been repeatedly requesting for an additional testing week where hepatitis would get more attention than so far.



[#SpringTestingWeek](#) at Austria, Croatia, Romania and Macedonia

World Hepatitis Day 2018 and launch of the Hep-CORE 2018 micro-elimination survey

On the occasion of the World Hepatitis Day 2018, European Liver Patients' Association presented the data and findings of the 2018 Hep-CORE micro-elimination survey on HCV micro-elimination in Europe. Twenty-five patient groups, representing 23 European countries and 2 countries from the Mediterranean Basin, were respondents to the survey. ELPA has noted that many countries find the idea of viral hepatitis elimination to be daunting, complex and one of many competing challenges for their health system. Therefore, part one of this year's Hep-CORE survey focuses on micro-elimination, which breaks down national elimination goals into smaller goals focusing on individual population segments. Two previous reports, from studies in 2016 and 2017, showed an overall picture of the viral hepatitis policy in Europe and the gaps between national policy and WHO European Region recommendations for addressing the HCV epidemic. The 2018 survey results, shared on World Hepatitis Day on 28 July, provide a measure of whether the viral hepatitis response is equitable in Europe.

ELPA Hep-CORE
European Liver Patients' Association

We have asked 25 patient groups, representing 23 European countries and 2 countries from the Mediterranean Basin, if they have a written national hepatitis C virus (HCV) strategy and/or action plan (or one that is part of a broader viral hepatitis strategy and/or action plan) that has been approved or ratified by the government.

Results show that only 14 of the 25 (56%) countries involved in the study have a national viral hepatitis strategy in their country.

Austria	Greece	Slovenia
Belgium	Bosnia & Herzegovina	Spain
Bulgaria	Macedonia	Sweden
Croatia	Netherlands	Switzerland
Denmark	Norway	Turkey
Cyprus	Poland	Ukraine
France	Romania	United Kingdom
Germany	Serbia	

Let's change this!

ELPA Hep-CORE
European Liver Patients' Association

WORLD HEPATITIS DAY 2018

ELPA is presenting Hep-CORE micro-elimination survey on Friday, 27 July at 10:00 CET

On the occasion of the World Hepatitis Day 2018, ELPA will launch online a part one of the Hep-CORE 2018 study results. Hep-CORE survey, created especially for World Hepatitis Day 2018, focuses on micro-elimination, which breaks down national elimination goals into smaller goals focusing on individual population segments.

ELPA Hep-CORE
European Liver Patients' Association

25 patient groups were asked to select which of the micro-elimination target populations would be the easiest to target in their country.

Their responses were:

blood donors	haemodialysis patients	haemophilia patients
40%	40%	36%

ELPA Hep-CORE
European Liver Patients' Association

25 patient groups were asked to select which of the micro-elimination target populations would be the most difficult to identify and treat.

Their responses were:

PWID (active) not engaged in harm reduction programmes like NSP or OST	Homeless people	Prisoners
68%	52%	26%

Changes in ELPA Governance

At the elections held on 25 November 2018, ELPA has elected new President and new Board members. Every four years, ELPA members among themselves choose those to represent them in ELPA Governing Board and to advocate for the better of liver patients at the international level. Since 2005 they had the opportunity to do it five times, most recently on 25 November 2018 when ELPA elections for the new president and board members were held. At an Extraordinary General Meeting, organized back to back with our annual Stakeholders' and Advisory Board meeting, they have elected Marko Korenjak to succeed MSc Tatjana Reic after her almost 8 years on this position.



ELPA members at the Extraordinary General meeting

At the democratic elections ELPA members had opportunity to choose new President among three candidates: 1) George Kalamitsis representing Greek association Prometheus, 2) Marko Korenjak, representing Slovenian association SLOVENIJA HEP and 3) Robert Mitchel-Thain, representing UK based PBC Foundation.

After the Assembly had voted by the secret ballot, three members' committee, appointed by the Assembly to supervise the voice counting procedure, have announced that Marko Korenjak is elected as the new ELPA President.



Marko Korenjak, newly elected ELPA President

I am truly honored to be given this opportunity by my colleagues and friends – ELPA members. Their recognizing my work in raising awareness on liver diseases and promoting the rights of liver patients, tells me that we are going in the right direction. – said Marko Korenjak, newly elected ELPA President.

The same procedure was held to choose the size of the Board (according to the ELPA Statute), as well as new Board members. Newly elected Board counted twice more members than previous one:

- Julio Burman (Hetz - Israeli Association For The Health Of the Liver),*
- Teresa Casanovas (Catalan Association of Hepatitis Patients – ASSCAT),*
- Marinela Debu (APAH-RO Romania),*
- Ivana Dragojevic (Association for helping patients with chronic viral hepatitis – HRONOS),*
- Tove Frisch (Riksföreningen Hepatit C – RHC),*
- Milan Mishkovikj (Hepar Centar – Bitola),*
- Madalina Mezei (Sano-Hep),*
- Robert Mitchell-Thain (PBC Foundation),*
- Tatjana Reic (Croatian Association for Liver Diseases „Hepatos“),*
- Gamal Shiha (Association of Liver Patients' Care – ALPC),*
- Jose Willemes (Dutch Liver Patient Association - NLV)*

MSc Tatjana Reic, former hepatitis patient, who devoted majority of her professional life to fight against viral hepatitis, and former ELPA President, wished all the best to the new President and the new Board highlighting that ELPA's mission is still not finished, but on contrary, renewed and broadened with the liver related public health threats that we are facing:

I have been with ELPA since its beginnings and many of the people that were here today at the EGM I know since our early days. I have to say I am both happy to see that these patients and patients' representatives never lost a sight of our ultimate goal - a world without liver diseases. I am also proud that our joint endeavors in reaching that goal have been recognized by European institutions such as European Commission, European Parliament, ECDC and many others.

In their four-year mandate the Governing board members will, together with their new chair, represent ELPA members across different stakeholders' groups such as expert groups, other patients' groups/initiatives and European institutions, putting the patient in the center of the system. Day after the democratic elections at the EGM, members from nine countries have decided to leave ELPA as of 31st of December 2018 and few days later a member from one additional country joined them. Listed on p29*

EMPOWERING OUR MEMBERS

strategic goal II

ELPA@Home, Cyprus

A very successful ELPA@Home project continued in 2018 with Cyprus, where two days of ELPA@home workshop were organized and led by Marko Korenjak and Julio Burman. On the first day they held a workshop with NGOs who are working on Thalassemia, liver transplantation and PWIDs. Although they are all committed to the elimination of viral hepatitis, it was first time ever they were sitting together at the same table. The second day was organized to hear about specific problems from governmental and clinicians' perspectives. The workshop was closed by MSc Tatjana Reic, President of ELPA, who addressed the participants and expressed satisfaction with the successfully conducted meetings, followed by Press conference



ELPA@Home trainers Julio Burman and Marko Korenjak with the representatives of Cyprus' patients' group members

IMPACT programme / ELPA University - Year 3 Module 2

ELPA University Year 3 Module 2 was held in Nicosia, Cyprus from 11th to 14th of February. The module consisted of two and a half days of training, with nine theory sessions and two practical workshops. The training was led by six expert speakers including Jeffrey Lazarus, IS Global and Bridie Taylor, World Hepatitis Alliance. A total of 13 participants from nine different countries attended ELPA University Module 2. The attendees were very enthusiastic and engaged during the sessions and found the training valuable and informative. The feedback so far has been very positive.



ELPA University participants in Nicosia, Cyprus

POLICY AND ADVOCACY WORK

and crossover activities

HCV elimination Advisory Board

On the 1st of February ELPA's Marko Korenjak participated in the HCV elimination Advisory Board meeting. In his interventions he has stressed repeatedly that elimination of HCV is not possible without collaboration with patient groups who are responsible for raising awareness, having strong patient voice, connecting health care providers, politicians and other important stakeholders. It is thus critically important for elimination of HCV to form new patient groups in countries without patient activities and to educate them on the role and the scope of impact of patient organizations.

dr. Jordan Feld, Marko Korenjak and dr. Lisa Barrett



Hep-CORE Study group

Hep-CORE Study group met on the 1st of February in Berlin. That was a good idea for ELPA representatives to discuss the 2018 Hep-CORE methodology with the Study group, which will be strengthened based on the feedback of experts in the field. In short, it will be based on data extraction from official documents, followed by a survey to assess the implementation of policies in practice.

EASL monothematic conference on HCV:

Striving towards the elimination of HCV infection

The aim of this two day Conference was to bring together major stakeholders in the field of HCV and combine their expertise to better understand the burden of HCV, strategies to enhance prevention, testing, linkage to care and treatment, and current progress and future directions for working towards the WHO goal of eliminating HCV by 2030. As an invited speaker in the session "How far are we from reaching the WHO targets of HCV elimination?" ELPA President Msc Tatjana Reic gave a lecture about the Role of patients Organizations.

MSc Tatjana Reic, ELPA President



ECDC expert panel meeting on HBV, HCV and HIV testing

MSc Tatjana Reic attended *high level expert panel meeting* organized by ECDC from 5th - 7th February in Stockholm. The scope of this 2.5 days meeting was to review the body of evidence on HBV, HCV and HIV testing in the EU/EEA resulting from the systematic reviews and the complementary evidence gathering activities, as well as to formulate evidence-based options for implementation based on a consensus-building approach.

Hot Topics in prevention and control of Viral Hepatitis - VHPB

Technical meeting

On March 14 VHPB Advisory meeting took place in Lisbon, Portugal and was followed by a Technical meeting *Hot Topics in prevention and control of Viral Hepatitis*, on 15-16 March 2018. Together with prof. dr. Mojca Maticic ELPA President, MSc Tatjana Reic chaired a panel discussion session *Investigate the public health needs to implement hepatitis B treatment protocols in the European countries and the impact they will have on the WHO's hepatitis elimination goals*.

Meeting of Minds

A number of patients' representatives associations have met in London on 15th of March for a meeting focused on people aging with HIV and possible complications that can follow. Vice President Marko Korenjak attended this meeting speaking about the problem of people aging with HIV as they develop liver damage because of the treatments prescribed, as well as the about the aging co-infected patients. The group containing cancer, kidney, mental health and many other disease focuses explored the possibilities of joint actions to support the activities of HIV community.

WHO and civil society meeting on HIV, TB, Hepatitis, STIs and

Universal Health Coverage

ELPA participated at the WHO and civil society meeting on HIV, TB, Hepatitis, STIs and UHC, held in Geneva on 22-23 March. At this two day meeting the participants underlined that "universal health coverage and communicable diseases" is not an either or agenda or an end to vertical programming, but that universal health coverage suggests we should be collaborating closely to rethink how disease programs are designed and delivered in the future.

During the meeting participants worked on the draft discussion paper, which will be finalized by the end of April and made available for sessions at key events later this year including the World Health Assembly, the AIDS 2018 Conference in Amsterdam and the United Nations High Level Meeting on Tuberculosis.

HepHIV 2019 Conference planning meeting

ELPA President MSc Tatjana Reic participated in the first planning meeting of HepHIV 2019 Conference, held in Frankfurt on 16th of April. The conference will take place on 28-30 January 2019 in Bucharest, Romania, under the Romanian EU presidency (January-July 2019). The conference is organized by the HIV in Europe Initiative jointly with the EU funded Joint Action on integrating prevention, testing and linkage to care strategies across HIV, viral hepatitis, TB and STIs in Europe - INTEGRATE - which runs

from 2017-2020. The overall aim of the HepHIV2019 conference will be to further improve integration of HIV, viral hepatitis, STI and TB testing by engaging stakeholders within the fields and to stimulate exchange of experiences and best practice as well as presenting the latest evidence within the field of testing and linkage to care for all 4 conditions.

EASL-LANCET Commission on Liver Disease in Europe

EASL-LANCET Commission kicked-off with the first meeting, held in Geneva from 30 April – 1 May 2018. Participants, among which ELPA President MSc Tatjana Reic was there to present ELPA, set about to provide answers to the questions such as: *What is the true prevalence of liver disease across different countries in Europe? What are the current and future challenges, and opportunities, facing hepatology? What are the needs and standards of care for patients with liver disease, in different areas of the healthcare system?* and many more.

INTEGRATE Joint Action meeting in Croatia

INTEGRATE Joint Action work packages meeting was held from 2nd to 4th of May 2018 in Zagreb, Croatia. This three day meeting vastly covered the topics of European Testing Week and patient survey, for which ELPA has been explicitly invited to provide input and expertise. Sessions have also served as the final step in ELPA's preparations of Spring European Testing Week, held in May from 18-25. ELPA was represented by ELPA President MSc Tatjana Reic and Interim CEO Lana Crnjac during Integrate JA meeting.

CSF meeting of the EU HIV/AIDS, VIRAL HEPATITIS AND TB

ELPA's Civil Society Forum representative MSc Tatjana Reic, attended the CSF meeting held in Geneva 13 -15 May in Luxemburg. After the initial review of the current situation and report on what has been done so far, CSF members have worked/discussed World Hepatitis Day, EMCDDA initiative on promoting HCV testing in drug treatment settings, UNAIDS activities for 2018, actions in responding to the expanding epidemics among men who have sex with men and access to PrEP, actions in relation to the upcoming High-Level Meeting on TB, ECDC-WHO surveillance and monitoring report and new ECDC TB tools and many more.

Press conference and ACHIEVE-VHPB event in Romania

A successful press conference was held on 15 May, Bucharest, Romania, organized by Marinela Debu, ELPA's Vice President and President of APAH RO. The event was attended by patients from all over Europe, including ELPA President, MSc Tatjana Reic, and took place prior to the ACHIEVE-VHPB event in Bucharest. Organized with the support of the Romanian Ministry of Health, this event had the



two-fold aim of: helping Romania reach the 2030 elimination goal of viral hepatitis by identifying good practice and bringing in external expertise based on the successful VHPB approach as well as to encourage Romania to make viral hepatitis monitoring a priority during the Romanian EU Council Presidency in H1 2019. Also, ELPA President was honored to hear about the request of The

Secretary of State in the Ministry of Health, Dr. Corina Pop, who has specifically requested ELPA's participation at the meeting.

World Hepatitis Alliance Global Stakeholder Meeting

WHA's two-day consultations were held on 17-18 May 2018 in London, with the aim to validate the data from the WHA global survey and to participate in a workshop under the scope of the Find the Missing Millions campaign. ELPA was represented by Interim CEO Lana Crnjac where she represented the voice of the European Liver patients, while Ammal Mokhtar, ELPA Member from Association of liver patient care (ALPC-EGYPT) represented WHA as Executive Board Member for the Eastern Mediterranean Region.

The 2nd EU HCV Summit

ELPA President MSc Tatjana Reic participated in the 2nd EU HCV Policy Summit, "Securing sustainable funding for Hepatitis C Virus elimination plans", held on 6th of June in Brussel, where she had presented ELPA's work. This half-day conference hosted by the Hepatitis B&C Public Policy Association gathered together 100 + experts, stakeholders, and policymakers from across Europe, including ELPA Board members Marinela Debu, Marko Korenjak and Milan Mishkovikj. Teresa Casanovas and Angelika Widhalm were present there as national representatives, as well as other ELPA members from Italy, Bulgaria, and Portugal.



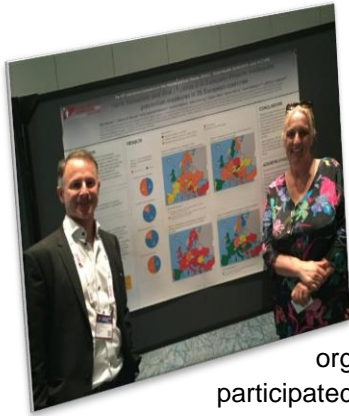
MSc Tatjana Reic, ELPA President



ELPA members Marko Korenjak, Emilia dos Santos Rodriges, Marinela Debu and Teresa Casanovas-Taltavull

International Symposium on Viral Hepatitis and Liver Disease

(ISVHLD) - Global Hepatitis summit 2018



One of the most established global liver meetings was held in Toronto, Canada from 14th - 16th of June. The Global Hepatitis Summit brings together top clinicians and researchers from around the world to shine an important focus on global public health. ELPA's representatives had an opportunity to meet with Jeffery Lazarus, WHA Board members, and other various stakeholders as well as Gail Wright, President of Canadian PBC Society and some representatives of the industry. ELPA participated in the NOhep Village Advocacy Day. ELPA's President, MSc Tatjana Reic met representatives of Russia's patients' organizations for an update on the situation in their country. ELPA has also participated in ICE-HBV meeting.

Prof. Jeffrey Lazarus and MSc Tatjana Reic

Share Now Exchange meeting

A meeting focused on the CEE region took place on Friday 28 – 30 June in Ljubljana, Slovenia.

This meeting was organized by Gilead Sciences Europe Ltd. Exchange was an inspiring opportunity for delegates by offering individuals the opportunity to have helped to address key management and care of Central and Eastern ELPA members from Macedonia, Slovenia, and Serbia were one of the attendees.



and financed by The Share Now opportunity to groups and share initiatives that challenges in the HCV and HIV in the European region. Bulgaria, Croatia,

Marking the PBC day

On September 9th, ELPA members were marking the PBC International Day. Like in the previous years, ELPA supported the campaign devised by PBC Network that ELPA is a part of. ELPA President MSc Tatjana Reic, invited all ELPA members to symbolically raise their hands in support of patients suffering from PBC, and in this way, to support efforts of raising awareness on PBC.



Core NASH program

Forum for Collaborative Research, Obesity Action Coalition, and Green Park Collaboration organized the specialized program of the beginning and advanced stage of NASH, using the Delphi method. The main goal was to determine a "core set" of outcomes to measure, demonstrate and differentiate the effectiveness and value of NASH therapies. It is an online program started in July and it will be finished in 2019. The final "core set" will be published in early 2019.

HEP-C Community Summit

The summit was held in Lisbon on the 18th of September. ELPA Interim CEO Lana Crnjac presented the ELPA's hepatitis advocacy priorities for the coming year highlighting the need for prioritized and strategic testing in hard to reach populations and measuring whether access to HCV services is fair across all population groups. ELPA pointed out that highest-risk groups are left behind in the pursuit of HCV elimination in Europe, that there are systematic gaps and that the high-risk populations are ignored if they are difficult to access outside of existing pathway.

FLAME meeting/Future Leaders in Addiction Medicine



MSc Tatjana Reic, President of ELPA

The meeting "Future Leaders in Addiction Medicine" took place in Nice, on September 18th. MSc Tatjana Reic, ELPA President co-chaired a panel with Annemarie Ward. On the meeting titled "Harnessing the capability of patient organization groups (PAGs)" she had presented ELPA's work and goals ELPA have for the future. The most important objectives of the meeting were, supporting the education and development of future leaders in addiction medicine by providing leading insights in OUD with plenary sessions on the latest scientific evidence, giving delegates the opportunity to collaborate and share ideas with their peers on the key challenges and limitations in OUD management. To identify potential strategies/solutions to address current challenges and limitations in OUD management and advocating for better treatment of patients. The most important objectives of the meeting were, supporting the education and development of future leaders in addiction medicine by providing leading insights in OUD with plenary sessions on the latest scientific evidence, giving delegates the opportunity to collaborate and share ideas with their peers on the key challenges and limitations in OUD management. To identify potential strategies/solutions to address current challenges and limitations in OUD management and advocating for better treatment of patients.

International Symposium on Hepatitis Care in Substance Users

The 7th International Network on Hepatitis in Substance Users (INHSU) meeting 2018 was organized in Cascais, Portugal from 19 - 21 September 2018. This Symposium is the leading International conference focused on the management of hepatitis among substance users.

ELPA representatives MSc Tatjana Reic, Milan Mishkovikj, Marko Korenjak were invited to participate as the participants at the program and also at the workshop led by Prof. dr Rui Tato Marinho. MSc Tatjana Reic presented a patients' view on communication between patients and medical professionals. Before the official INHSU meeting, ELPA participated also in the meeting that was held in National Assembly of Portugal, organized by Ricardo Baptista Leite, the Member of Parliament.



Prof. dr. Rui Tato Marinho

EASL NAFLD Summit

ELPA was invited by the European Association for the Study of the Liver (EASL) to participate at NAFLD SUMMIT 2018 in Geneva, from 20 to 22 September. The program was focused on scientific and industry partners in NAFLD and NASH. ELPA was able to present the patient view on the research and patient problems in the field of NAFLD and NASH. The presentation was done on the second day of the scientific conference and presented by ELPA vice president Marko Korenjak. The presentation was videotaped and available to EASL members that have access to the EASL LiverTree official eLearning Portal of EASL. ELPA also had the booth at the Summit.

Liver cancer awareness campaign

Along with the policy research on liver cancer that commenced in the Q3 of 2018, ELPA took a leading role in bringing the HCC higher on the agenda. Therefore, this October we have launched a digital

**Information can reverse
the HCC odds**

ELPA
European Liver
Patients' Association

campaign "Information can reverse the HCC odds", which could have been followed on ELPA's official Twitter and Facebook account. We encourage all the members to join us in raising awareness on HCC and to share and retweet information on our social media channels in 2019.

VHPB country meeting: Russia

ELPA participated at a VHPB's country meeting which was held in Moscow, Russia, from 25th – 26th October 2018. ELPA was represented by President MSc Tatjana Reic. She contributed to a press conference during the VHPB meeting and she chaired, together with Yury Zhulev a session titled "The Role of Civil Society in the Response to Viral Hepatitis in Russia". ELPA was also present at a VHPB advisory meeting On Wednesday, October 24. During the advisory meeting, various topics were discussed such as composition and structure of the Viral Hepatitis Prevention Board and the future meetings for planning 2019 -2020.



The European Civil Society Involvement in Drug Policy Conference

The CSIDP Conference was held on 5 November in Brussels. The conference brought together civil society organizations, national and European policymakers, and other stakeholders to discuss for the very first time the importance of civil society involvement in drug policy. Gathered participants discussed the level of involvement in the European Member States, provided models of good practice and gave an opportunity to critically discuss potential bottlenecks and shortcomings.

Civil Society Forum Meetings

After the 1st meeting held in May in Luxembourg, regular 2nd yearly CSF meeting on HIV/AIDS, Viral Hepatitis and Tuberculosis took place at Albert Borschette Congress Centre in Brussels on 6 of November 2018. During the event a time slot for key developments at country/key population level was reserved, where ELPA President Tatjana Reic gave a brief report on Hep-CORE project and the latest results. A day after, ELPA also took part in a joint meeting of the two Civil Society Forums – the one on HIV, Viral Hepatitis and Tuberculosis and the one on Drugs. During the event, each Forum presented their activities on European and international level.

Fundraising during AASLD LM® and surrounding meetings



The Liver Meeting® organized by AASLD was held on 8-13 November in San Francisco where ELPA was represented by MSc Tatjana Reic, Marko Korenjak and Lana Crnjac. ELPA President, MSc Tatjana Reic and ELPA Vice President Marko Korenjak were invited to present ELPA's success story at the AASLD patients' session. During the event, they shared ELPA's know-how with US-based patients groups. ELPA representatives also held a meeting with EASL governing board meeting and met with Greg Bologna, AASLD Vice President to discuss further cooperation. Seven meetings were arranged to secure funding for the 2019.

Patient Centricity Advisory Board

MSc Tatjana Reic participated at Ipsen's Advisory board meeting on 22-23 November 2018 in Les Ulis, France, where she shared patients' perspectives. Due to this advice, Ipsen has decided to embed our feedback in Ipsen Patient centricity strategy, include recommended action items and key performance indicators they need to focus on and check internal feasibility so that they can build a realistic Roadmap for their 2019-2022 journey.

4th Hepatitis C Technical Advisory Group Meeting

ELPA President, as a TAG member, participated in the 4th Hepatitis C Technical Advisory Group Meeting held on November 28-30, 2018 in Tbilisi, Georgia. During the meeting the following topics were discussed: Immediate and long-term clinical outcomes of DAA treatment, evaluation of diagnostics and treatment delivery models both at specialized and non-specialized HCV care settings, Improving Access to care and treatment, surveillance and economic evaluation. Together with Dr. Margaret Hellard from Burnet Institute MSc Tatjana Reic chaired the session "Promote Advocacy, awareness, education, and partnerships for HCV-Associated Resource Mobilization".

11th European Public Health Conference: From micro to macro

11th European Public Health Conference – From Micro to macro: how to achieve our Hepatitis C elimination targets by 2033 was held on November 29 in Ljubljana, Slovenia. ELPA newly elected President Marko Korenjak chaired the session together with Prof. Lazarus. Prof. dr. Maticic presented the Slovenian success story regarding hepatitis. John Dillon from the United Kingdom and Eli Zuckerman from Israel presented-HCV elimination in practice: case studies from the field.

ACHIEVE coalition expert panel at European Parliament

On 4th of December ACHIEVE, a multi-stakeholder coalition chaired by ELPA Board member and former President MSc Reic held an expert panel at European Parliament. Hosted by EP's Friends of the Liver group co-chair MEPs Cristian-Silviu Busoi and Karin Kadenbach the discussion „How can we support Viral Hepatitis elimination in the line with the Global Strategy and UN SDGs“ focused on a review of the work that was done until now and the main focus for the next years. In her welcome speech MSc Tatjana Reic



called EU – Council, Commission and Parliament, to help patients and implement the WHO Global Strategy and the Europe Action Plan to achieve elimination by 2030". After the two panel discussions Ricardo Baptista Leite, President of UNITE – Global Parliamentarians Network to End HIV/AIDS, Viral Hepatitis and Other Infectious Diseases concluded the meeting with pointed out that given the progress already made, the EU should aim at achieving the UN goals much earlier than other world regions.

ELIMINATING HEPATITIS C

I want to thank Professor Jeffrey Lazarus, ISGlobal University of Barcelona, for his invaluable input to this article.



EU policymakers, be they representatives of Council, Commission or Parliament, owe it to Europe's citizens to take the action so that hepatitis will be a thing of the past by 2030 as set out by WHO.

A unique opportunity that shouldn't be missed

EU policymakers owe it to Europe's citizens to make hepatitis a thing of the past, argues **Tatjana Reic**



Tatjana Reic is President of the European Liver Patients' Association (ELPA) and Chair of the ACHIEVE coalition

Hepatitis C (HCV) is an urgent public health problem for the European Union, where an estimated 3.2 million people are chronically infected with HCV. However, this is a problem that can be solved, thanks to the availability of highly effective treatment that cures almost all cases. In 2016, the World Health Organization (WHO) issued its first global health sector strategy on viral hepatitis, calling for its elimination as a public health threat by 2030. Building on

the United Nations' Sustainable Development Goals, this strategy established ambitious but feasible targets for 2030 including achieving a 90 percent reduction in HCV incidence and a 65 percent reduction in HCV mortality, as well as increasing the average number of sterile needles and syringes available to people who inject drugs receive each year to 300.

EU Member States committed to these targets at the 2016 World Health Assembly. However, only six are on track to meet the 2030 elimination goal: France, Iceland, Italy, the Netherlands, Spain and the United Kingdom. To remedy this poor showing, EU countries must stop restricting access to treatment to only those with advanced liver disease, since reduced access contributes to the spread of HCV. Most Europeans are also unaware of their infection and there is little systematic effort to identify patients. Promising approaches such as micro-elimination

need to be more fully explored. Micro-elimination seeks to eliminate HCV in particular target populations, permitting rapid, focused action. It can also address inequities in service delivery by concentrating health system attention on stigmatised groups. Initiatives aimed at specific risk groups, such as men who have sex with men, migrants and drug users, already exist for HIV

"Most Europeans are also unaware of their infection and there is little systematic effort to identify patients"

in so-called 'Fast-Track' cities, such as Amsterdam and Madrid and need to be adapted to include hepatitis.

Furthermore, greater efforts need to be made to locate those infected by untested blood donations, par-

Ahead of ACHIEVE event in the EU Parliament a political version of the article, drafted by Prof. Jeffrey Lazarus for a scientific publication, was published in the Parliament Magazine authored by MSc Tatjana Reic, ELPA past President and ACHIEVE coalition chair, in order to react to the Commission Staff Working Document and to complement and promote the advocacy event taking place in the European Parliament on 4th December 2018.

STRENGTHENING ASSOCIATION

and in country support

ELPA members presenting their posters during EASL ILC at the Gilead poster session



Shining a light on the great work of community organizations to engage hard-to-reach populations, this event was an opportunity for us to share our experience with the wider HCV community, learn from each other and spark new ideas for future projects. With even 25% of poster presentations coming from ELPA members, the presentations were attended by all ELPA membership who came to support other colleagues. Among 13 posters presented at the session, 4 posters were made by ELPA members from Croatia, Egypt, Norway and Slovenia. The association from Slovenia presented by Marko Korenjak won the judges award while the audience award went to the project "Towards a Village Free from Hepatitis" from Egypt. Congratulations to both

associations for their hard and innovative work!

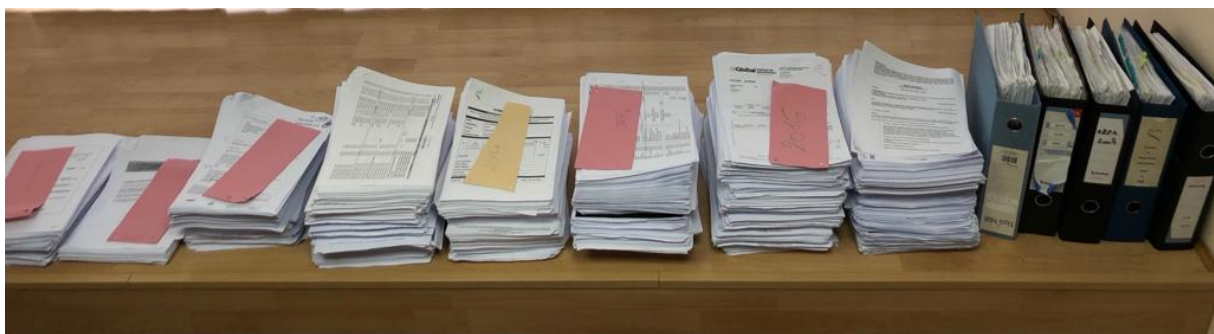
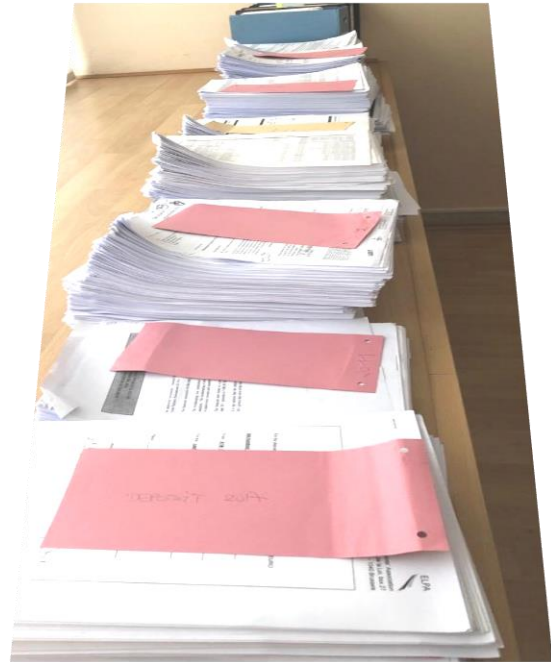
ELPA Stakeholders and the Advisory Board Meeting

This year's Stakeholders' meeting was held on 26 November back to back to our EGM and Advisory Board meetings in Ljubljana. Attended by ELPA members and our partners in the field, we have used the opportunity to present our highlights in 2018, as well as the plans for 2019. Traditionally, ELPA has always included its most important stakeholders in the discussion in order to align on activities where possible and detect the possibilities for new collaborations. This year our agenda included: Prof. dr. Mojca Maticic, MD, Head of the Viral Hepatitis Unit at the Clinic for Infectious Diseases and Febrile Illnesses, University Medical Centre Ljubljana, and Head of the Outpatient STI Service at the same University Medical Centre, who gave the presentation of Slovenian model for hepatitis C elimination; Ddr. Klemen Jaklic, Judge at the Slovenian Constitutional Court, professor of law at Harvard University, who spoke about the Health as a Fundamental Human Right; Prof. dr. Rui Tato Marinho, International Symposium on Hepatitis Care in Substance Users (INHSU); Luis Mendao, European AIDS Treatment Group (EATG); Antons Mozalevskis, WHO Europe; Greet Hendrix, Viral Hepatitis Prevention Board (VHPB); Peter Rice, Eurocare; Neil Causey, ACHIEVE Coalition and Ekaterina Gorbunova, Global Parliamentarians Network to End HIV/AIDS, Viral hepatitis.

After the Stakeholders' meeting, a two day advisory board meeting took place on 27th and 28th of November. During these two days companies presented their plans for next years, focusing mainly on NASH, NAFLD, hepatitis and liver cancer. ELPA members gave an excellent feedback to the topics discussed.

Extraordinary General Meeting

A 13 hours long Extraordinary General Meeting was held on 25 November in Ljubljana. Out of 37 member associations, 26 sent their representatives to participate in the meeting, while 10 organizations provided their power of attorneys. The meeting was organized in order to discuss requests from several ELPA members, mainly regarding the finances and transparency. For the sake of discussion ELPA Office was temporary transferred to Ljubljana, where copies of all ELPA financial documents from 2007 to 2017 were brought to ELPA members. This was greeted by many members and rated as the highest level of transparency in carrying out the work at the international level. The meeting was also a great opportunity for the members to get an overview not only about ELPA's past but also of the plans for future, given that the candidates for the President, at the elections held as a part of the EGM, presented themselves and their vision of ELPA in the years to come. A vivid discussion among patients' groups' representatives showed once again that the liver patients' movement has come a long way, but that there is still some room for improvement. That is why ELPA members greeted the ongoing process of revising all ELPA governing documents and rebuilding them.



As already above mentioned a day after the EGM, on 26th November, association from nine countries announced they would leave ELPA as of the end of calendar year 2018 since they were not satisfied with results of the elections. *Namely: EPAC (Italy). Austria - Die Hepatitis Hilfe Österreich – Plattform Gesunde Leber (HHÖ), Bulgaria - Hepactive Patients' Association, Bulgaria – Hepasist – National Association for Fighting Hepatitis, Germany - Deutsche Leberhilfe e.V., Greece - Hellenic Liver Patient Association “Prometheus”, Nederland - Nederlandse Leverpatiënten Vereniging (NLV), Romania - Asociația SanoHep România, Swiss - Die Schweizerische Hepatitis C Vereinigung (SHCV), UK – The Hepatitis C Trust, UK - The PBC Foundation (UK) Ltd, Ukraine – Stop Hepatitis NGO later joined by Italy – Associazione EpaC Onlus.

Technical Consultation on development of National Action plan for Viral Hepatitis

Upon the invitation from patients' organization Hepar - Centar, Bitola, World Health Organization held *Technical Consultation on the development of National Action plan for Viral Hepatitis* held in Skopje, on 23-24th March 2018. The overall purpose of this National technical consultation was to identify national strategic directions as a basis towards a national action plan for viral hepatitis prevention, control and management in Macedonia.

The meeting aimed to gather National Experts and other international Key participants in order to contribute to an overall assessment of the Hepatitis situation and to define the problem in the country through sharing of available data and information about the magnitude, scope, characteristics and consequences of viral hepatitis. Also, to identify the challenges and opportunities, to develop a national action plan for elimination of viral hepatitis, to define strategic priorities (goals, objectives, targets, activities) for achievable interventions in the next 4 years, to agree on further steps to advocate, to initiate and roll out the 4-year national, to make a plan of action for elimination of viral Hepatitis based on the WHO regional and global action plans with aim to draft the Outline of National Action plan with identified priorities for the next four years and to form a national technical working group to support MOH oversees the development of an operational plan and the roll out implementation.

During the meeting ELPA's President MSc Tatjana Reic moderated the session *Reducing costs – access to affordable medicines and diagnostics* and Ivana Dragojevic from Hronos, moderated the Session 8 with Prof. dr. Viktorija Calovska.

After the Technical Consultation on development of National Action plan for Viral Hepatitis meetings, to reiterate the ELPA in country support, ELPA President traveled to Macedonia in April and met WHO representative for Macedonia, Dr. Jihane Tawilah, as well as Clinic's director and newly appointed Focal point for Hepatitis in Macedonia. On the April 20th, MSc Tatjana Reic has also had a TV interview on "Good Morning Macedonia".



*Antons Mozalevskis, WHO and
Milan Mishkovikj, ELPA*

"Countdown HCV" - eliminating hepatitis C in Spain

ELPA Vice president Milan Mishkovikj was part of a meeting held on 15th of June in Madrid. The Alliance for the Elimination of Viral Hepatitis in Spain (AEHVE) has aimed at the development of screening programs that will make cases of hepatitis C patients unfamiliar, and the improvement of continuity and care coordination mechanisms as the keys so that Spain eradicates this disease within the objective set by the World Health Organization (WHO), before the year 2030. ELPA represented the role of Patients Organizations in the process.

Membership support

One of ELPA's important activity is to support work of its members at national levels. In order to support work and efforts in viral hepatitis strategy implementation, early September ELPA President has visited Israel to support member Hetz Health of the Liver which



– Israeli Association for the supports liver patients since 2000. President of Hetz Association, **Julio Burman** met with ELPA President and organized meetings with officials and experts in the Ministry of health with the Head of epidemiology who is

also responsible for the national plan and with the Head of the department of

drug rehabilitation as well as an unofficial dinner with Hetz members Sinee Weinbaum and Amit Halamish.

Screening and prevention for viral hepatitis and HIV in CEE- Common challenges-joint solutions

ELPA's representatives participated in the regional conference “Screening and prevention for viral hepatitis and HIV in CEE - Common challenges, joint solutions”, held in Sofia Bulgaria 28.-29 June. Gathering representatives of national authorities, health institutions, health professionals, patient organizations, industry and media from Central and Eastern Europe, the main objective of the conference was to identify the key challenges faced by stakeholders and policymakers in terms of screening and prevention for viral hepatitis and HIV, as well as to exchange best practices from the region and beyond. President Reic's role was to deliver a keynote speech in the opening session on the patient perspective on early diagnosis and screening as well as the expected forthcoming activities related to the topic during the upcoming Romanian Presidency of the Council of EU. ELPA Board member Marinela Debu delivered Hep-CORE presentation and the other members of the Board made sure that the patients' voice was heard. The meeting was organized by ELPA member Hepasist from Bulgaria, while our members from Bosnia and Herzegovina, Greece and Macedonia attended the meeting as national representatives.

Romanian national conference

ELPA President MSc Tatjana Reic presented ELPA's success story at Romanian national conference held on 2-3 November in Brasov, Romania. The conference was organized by APAH-RO and their President Marinela Debu. ELPA Board attended the conference upon Marinela Debu's invitation and took the opportunity to hold a Board meeting and to discuss the tasks for the upcoming EGM.

ELPA IN RESEARCH PROJECTS

EU funded / supported

LiverScreen

In 2018 ELPA was honored to participate as a partner in the LiverScreen research project, funded by the European Institute for Innovation and Technology - section for Health. As the project partner, we have actively participated in kick-off meeting held on 26th of February in Barcelona. On that occasion Marko Korenjak presented the "Role of ELPA in the dissemination of LiverScreen information". In its first phase, the project includes screening for early detection of liver diseases in general population in Spain (Barcelona) and in France (Paris). In the next phases, it will include more centers in several EU countries including also the screening of 40.000 people in Europe with Fibroscan. This is going to be the biggest screening project for early detection of liver diseases in general public in Europe. ELPA is responsible for dissemination and communication part of the project. Second partner's meeting took place on 21 November in Barcelona, attended again by ELPA Vice President Marko Korenjak. Last year's LiverScreen activities were the first milestone to the biggest screening initiative in Europe in regards to early detection of liver diseases. The next step is an application for Horizon2020 funding for that will in next few years secure a screening of the liver of 40.000 patients in the European Union. ELPA was not only part of EIT Health project, but will also be an active consortium partner in the next Horizon2020 project. We are looking forward to changing the future for all liver patients.



www.eithealth.eu



EIT Health is supported by the EIT,
a body of the European Union



Impact of the project

- For patients: Identification of patients at risk of developing liver disease can mean early and more cost-effective treatment – and therapy to prevent further development.
- For society: Improved forecasting permits better allocation of resources and healthcare policy to address the problem of liver disease in both primary care and hospital settings.
- For healthcare professionals: Education and training of staff with specialist skill sets needed for the future in the health care systems

LIVERHOPE - "Simvastatin and Rifaximin as new therapy for patients with decompensated cirrhosis"

The objective of the LIVERHOPE project 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. As a part of the planning activities, ELPA Vice President Marko Korenjak participated in the project meetings held in May and June, with the aim to establish a clear protocol for activities for the patient organization and to discuss the possibilities of ELPAs collaboration with LIVERHOPE Nurses Forum.

LIVERHOPE



This project is supported through Societal Challenges (Health, demographic change and well-being) of the European Community's H2020. Grant agreement number 731875

Marko Korenjak with prof. Pere Gines, Project leader

SOCIAL MEDIA ACTIVITIES

2018 report by Milan Mishkovikj

ELPA is among top 3 social media influencers 2018 regarding:

The #SpringTestingWeek Influencers

Top 10 by Mentions

- @HepatitisEurope 896
- @IntegrateJA 892
- @EU_Health 872
- @ECDC_HIVAIDS 837
- @HIVheptestweek 776
- @EASLnews 737
- @Hep_Alliance 736
- @JVLazarus 678
- @rixwolff 656
- @EASLedu 621

The #ILC2018 Influencers

Top 10 by Mentions

- @EASLnews 4,209
- @EASLedu 3,306
- @HepatitisEurope 1,322
- @JVLazarus 1,104
- @aelsarkawy75 973
- @JMPawlotsky 819
- @EASLEUAffairs 703
- @Hep_Alliance 593
- @NO_hep 528
- @tomhemmingk 504

The influencers of #INHSU18

Top 10 by Mentions

- @INHepSU 287
- @jasongrebely 77
- @HepatitisEurope 74
- @JVLazarus 70
- @RBaptistaLeite 62
- @INPUD 60
- @HRInews 58
- @iasociety 55
- @GregDore2 54
- @stephentbarclay 52

The influencers of #NAFLDsummit

Top 10 by Mentions

- @EASLedu 396
- @EASLnews 136
- @HepatitisEurope 90
- @easleuaffairs 77
- @Zucmanrossi 58
- @genfit_pharma 43
- @JHepatology 24
- @fabiomarra_dr 18
- @QAnstee 17
- @phil_newsome7 13

The Numbers



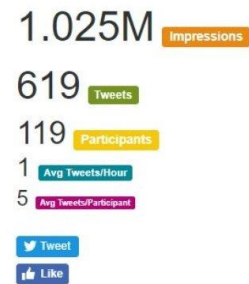
The Numbers



The Numbers



The Numbers



over 15.000.000 impressions



2.001 followers, 1.938 likes



4.889 followers, 10.300 likes



#NAFLDsummit
October Liver Cancer Awareness
Month 2018.
#INHSU18
HEP-C Community Summit
2018 PBC Awareness day
#HandsUP4PBC
World Hepatitis Day 2018
#SpringTestingWeek 2018
#ilc2018 EASL2018

Some of our biggest fans in 2018 were: EU commissioners
[@V_Andriukaitis](#), [@Moedas](#), [@EU_Health](#),
followed by: [@JVLazarus](#), [@Resoundant](#),
[@mromerogomez](#), [@NASH_Education](#), [@hepar_centar](#),
[@AASLDtweets](#), [@hepatitisihelpc](#), [@NO_hep](#),
[@EASLedu](#), [@GHirnschall](#), [@HepatosZagreb](#), [@NO_hep](#),
[@hcvresearchnews](#), [@LiverCancerConn](#), [@TbHivActivist](#),
[@JHepatology](#), [@stephenpalmer](#), [@HCSMnews](#),
[@Hep_Alliance](#), [@HepBFoundation](#), [@ECDC_HIVAIDS](#),
[@EMJReviews](#), [@EASLnews](#), [@eupatientsforum](#)

ELPA Governing Board 2018

The European Liver Patients' Association (ELPA) is a not-for-profit association for viral hepatitis and other liver diseases. ELPA is directed by a Governing Board, which is elected by its members at the Annual General Meeting.

Before the elections that took place on the 25th of November 2018

Tatjana Reic, President
Marinela Debu, Vice President/Treasurer
Angelika Widhalm, Vice President
Milan Mishkovikj, Vice President
Marko Korenjak, Vice President
Teresa Casanovas-Taltavull, Vice President
Robert Mitchell-Thain, Vice President

After the elections that took place on the 25th of November 2018

Marko Korenjak, President
Julio Burman
Teresa Casanovas-Taltavull
Marinela Debu
Ivana Dragojevic
Tove Frisch
Madalina Mezei (resigned immediately next day)
Robert Mitchell-Thain (no more member as of 31 December 2018)
Milan Mishkovikj
Tatjana Reic
Gamal Shiha
Jose Wilemse (resigned immediately next day)

Scientific Committee

Before the elections that took place on the 25th of November 2018

Ingo van Thiel, Scientific Committee Leader
Teresa Casanovas-Taltavull
Marco Bartoli
Robert Mitchell-Thain

After the elections that took place on the 25th of November 2018

Teresa Casanovas-Taltavull, Scientific Committee Leader
Nominated and will be determined on AGM in April 2019
Nominated and will be determined on AGM in April 2019

ELPA Secretariat

Lana Crnjac
Veronika Vsetickova

FINANCIAL ACCOUNTING AND TRANSPARENCY

ELPA accounts are finalized in time for approval at the Annual General Meeting. The 2018 final accounts will be available in April 2018 and are therefore not included in this report. Full information will be posted online at www.elpa.eu.

ACKNOWLEDGEMENTS

ELPA is thankful to all its members and numerous volunteers that have helped us accomplish our goals in 2018. We are also thankful to all our stakeholders who have been supporting our endeavors in fighting the liver diseases over the years.

In 2018 ELPA received grants as well as, in some cases, in-kind support, from the following companies:



abbvie



STATUTORY AUDITOR'S REPORT TO THE GENERAL MEETING OF MEMBERS OF THE EUROPEAN LIVER PATIENTS' ASSOCIATION (ELPA) FOR THE YEAR ENDED 31 DECEMBER 2018

In the context of the statutory audit of the annual accounts of ELPA (the Organisation), we hereby present our statutory auditor's report. It includes our opinion on the audit of the annual accounts as well as our report on the other legal and regulatory requirements. These reports form part of an integrated whole and are indivisible.

We will be appointed as statutory auditor by the general meeting of members of 12 April 2019, following the proposal by the board of directors issued upon presentation by the works' council of 07 February 2019. Our statutory auditor's mandate will expire on the date of the general meeting of members which will deliberate on the annual accounts closed on 31 December 2020. We have performed the review of the annual accounts of ELPA for 11 consecutive years.

Report on the audit of the annual accounts

Unqualified opinion

We have audited the annual accounts of the Organisation, which comprise the balance sheet as at 31 December 2018, the profit and loss account for the year then ended and the notes to the annual accounts, characterised by a balance sheet total of € 910.028,16 and a profit and loss account showing a profit for the year of € 8.660,76.

In our opinion, the annual accounts give a true and fair view of the Organisation's net equity and financial position as at 31 December 2018, as well as of its results for the year then ended, in accordance with the financial reporting framework applicable in Belgium.

Basis for unqualified opinion

We conducted our audit in accordance with International Standards on Auditing (ISAs) as applicable in Belgium. Our responsibilities under those standards are further described in the '*Statutory auditor's responsibilities for the audit of the annual accounts*' section in this report. We have complied with all the ethical requirements that are relevant to the audit of annual accounts in Belgium, including those concerning independence.

We have obtained from the board of directors and the officials of the Organisation the explanations and information necessary for performing our audit.

We believe that the audit evidence we have obtained is sufficient and appropriate to provide a basis for our opinion.

Responsibilities of the board of directors for the annual accounts

The board of directors is responsible for the preparation of annual accounts that give a true and fair view in accordance with the financial reporting framework applicable in Belgium, and for such internal control as the board of directors determines is necessary to enable the preparation of annual accounts that are free from material misstatement, whether due to fraud or error.

In preparing the annual accounts, the board of directors is responsible for assessing the Organisation's ability to continue as a going concern, disclosing, as applicable, matters related to going concern and using the going concern basis of accounting unless the board of directors either intends to liquidate the Organisation or to cease operations, or has no realistic alternative but to do so.

Statutory auditor's responsibilities for the audit of the annual accounts

Our objectives are to obtain reasonable assurance about whether the annual accounts as a whole are free from material misstatement, whether due to fraud or error, and to issue a statutory auditor's report that includes our opinion. Reasonable assurance is a high level of assurance, but is not a guarantee that an audit conducted in accordance with ISAs will always detect a material misstatement when it exists. Misstatements can arise from fraud or error and are considered material if, individually or in the aggregate, they could reasonably be expected to influence the economic decisions of users taken on the basis of these annual accounts.

As part of an audit in accordance with ISAs, we exercise professional judgment and maintain professional skepticism throughout the audit. We also:

- Identify and assess the risks of material misstatement of the annual accounts, whether due to fraud or error, design and perform audit procedures responsive to those risks, and obtain audit evidence that is sufficient and appropriate to provide a basis for our opinion. The risk of not detecting a material misstatement resulting from fraud is higher than for one resulting from error, as fraud may involve collusion, forgery, intentional omissions, misrepresentations, or the override of internal control;
- Obtain an understanding of internal control relevant to the audit in order to design audit procedures that are appropriate in the circumstances, but not for the purpose of expressing an opinion on the effectiveness of the Organisation's internal control;
- Evaluate the appropriateness of accounting policies used and the reasonableness of accounting estimates and related disclosures made by the board of directors;
- Conclude on the appropriateness of the board of directors' use of the going concern basis of accounting and, based on the audit evidence obtained, whether a material uncertainty exists related to events or conditions that may cast significant doubt on the Organisation's ability to continue as a going concern. If we conclude that a material uncertainty exists, we are required to draw attention in our statutory auditor's report to the related disclosures in the annual accounts or, if such disclosures are inadequate, to modify our opinion. Our conclusions are based on the audit evidence obtained up to the date of our statutory auditor's report. However, future events or conditions may cause the Organisation to cease to continue as a going concern;
- Evaluate the overall presentation, structure and content of the annual accounts and whether the annual accounts represent the underlying transactions and events in a manner that achieves fair presentation.

We communicate with the board of directors regarding, among other matters, the planned scope and timing of the audit and significant audit findings, including any significant deficiencies in internal control that we identified during our audit.

Report on other legal and regulatory requirements

Responsibilities of the board of directors

The board of directors is responsible for the presentation and the content of the other information included in the annual accounts and for the compliance with the legal and regulatory requirements regarding bookkeeping, as well as for compliance with the Law of 27 June 1921 on non-profit organisations, foundations, European political parties and European political foundations, and with the Organisation's by-laws.

Responsibilities of the statutory auditor

In the context of our mandate and in accordance with the Belgian standard (Revised in 2018) which is complementary to the International Standards on Auditing (ISAs) as applicable in Belgium, it is our responsibility to verify, in all material aspects, the other information included in the annual accounts and, compliance with certain provisions of the Law of 27 June 1921 on non-profit organisations, foundations, European political parties and European political foundations and with the by-laws, as well as to report on these elements.

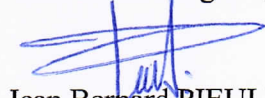
Statement related to independence

- Our audit firm did not provide services which are incompatible with the statutory audit of annual accounts, and we remained independent of the Organisation throughout the course of our mandate.
- No additional work services which implicated fees and which are compatible with the statutory audit of annual accounts as referred to in article 17 of the Law of 27 June 1921 on non-profit organisations, foundations, European political parties and European political foundations, which refers to article 134 of the Company Code, has been carried out.

Other statements

- Without prejudice to certain formal aspects of minor importance, the accounting records are maintained in accordance with the legal and regulatory requirements applicable in Belgium.
- There are no transactions undertaken or decisions taken in breach of the by-laws or of the Law of 27 June 1921 on non-profit organisations, foundations, European political parties and European political foundations that we have to report to you.

Londerzeel-Belgium, April 9, 2019



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