

The logo for ELPA, consisting of the letters 'ELPA' in a white, bold, sans-serif font. The text is positioned within an orange, abstract, organic shape that resembles a stylized leaf or a drop with a textured, layered appearance. This shape is located in the top-left corner of the slide.

ELPA

Quartal news report

July – September 2017

A decorative orange geometric shape, composed of several overlapping triangles, located in the bottom-right corner of the slide.

Resolution on the EU's response to HIV/AIDS, Tuberculosis and HCV

MEPs of European Parliament have adopted the Resolution on the EU's response to HIV/AIDS, Tuberculosis and Hepatitis C in their plenary session on 5 July. This resolution aims to point out the opportunity of eliminating viral hepatitis as a public health threat by 2030, referring to the WHO Global Health Sector Strategy and the UN SDGs. With this Resolution Members called on the Commission and the Member States to develop a comprehensive EU Policy Framework addressing HIV/AIDS, tuberculosis and viral hepatitis, while taking into account the varying circumstances and specific challenges faced by the Member States.

The Commission, Council and Member States are called upon to put in place harmonised surveillance programmes across the Union, which enable timely detection of outbreaks of viral hepatitis, Tuberculosis and HIV. As proven to be successful in fighting HIV/AIDS, the Resolution also suggests to expand the Dublin Declaration on Partnership on fighting HIV/ AIDS in Europe and Central Asia, by including viral hepatitis.



ELPA@Home workshops in Croatia



During Croatian Hepatitis Days, on July 5th and 6th, one of the most important ELPA's 2017 projects was held in Zagreb. ELPA@Home workshops, under the name of *How to Influence Policy and Public Perception*, took place at Zagreb Palace hotel just prior to Regional Hepatitis Round Table/Meeting where some of ELPA members were present as well. Attendees were able to learn more during workshops held by **Marko Korenjak** and **Julio Burman**, who talked about how to change public perception, how to influence policy, the most efficient way to cooperate and about patients' problems in Croatia.

Report on Alcohol and Digestive Cancers across Europe: Time for a change

ELPA is continuing working on alcohol related policy issues and in that light has supported UEG's *Report on Alcohol and Digestive Cancers across Europe: Time for a change*. The report highlights the alarming scale of alcohol consumption across Europe and its direct and indirect impact on digestive cancers. It canvasses the opinions of leading European digestive cancer specialists, stakeholder organizations and patient groups, as well as endorsement from the Estonian Presidency of the Council of the EU. You can read the full report [here](#).

5th Board meeting

ELPA Board members have held Board meeting in Zagreb on 8th of July. Among other topics, members have mainly discussed the position of possible new Board member, one to replace Robert Mitchell-Thain. This meeting served as a good opportunity to make an overview and to think on further steps to be done in September. Once the Board reaches the decision, all ELPA members will be in a timely manner.

Hep-CORE at Croatian Hepatitis Days

ELPA's Vice President **Marko Korenjak** presented Hep-CORE results for Croatia during Croatian Hepatitis Days. As mentioned above, on that occasion our member Hepatos organized Regional Meeting and Round Table named *No Excuse for No Hep* and gathered eminent experts in the field of hepatitis in the region – Croatia, Slovenia, Bosnia & Hercegovina, Montenegro, Serbia, Macedonia, Kosovo, Albania, Romania, Bulgaria, Hungary.

ELPA in European Parliament magazine

In the article *MEPs call for strong EU political commitment on eliminating viral hepatitis*, **MEP Karin Kadenbach** has put a strong emphasis on the importance of viral hepatitis elimination. Earlier in June she has co-chaired Achieve coalition launch in EP, along with **ELPA President Tatjana Reic**, chair of ACHIEVE coalition. Throwing spotlight on the need of stronger political will, MEP Kadenbach quoted Tatjana Reic: “We have a cure for hepatitis C and hepatitis B can be effectively controlled through immunization and treatment. What is needed is a concerted effort by all member states in favor of prevention, screening and access to treatment and care.” Full article can be read [here](#).

Mobile InfoHepCenter in Serbia

Upon appeal from Hronos, ELPA's Serbian member, Croatian colleagues from Hepatos, brought to Serbia mobile InfoHepCenter, a screening van through which valuable activities were performed in two major Serbia's cities Novi Sad and Belgrade; activities badly needed in Serbia to support hepatitis patients in Serbia who are lacking of not only DAA's but also diagnostics. Approximately 150 patients were screened for their liver fibrosis status with a devastating results: over 30% results show saviour liver damage and majority of patients were not aware of it.



Public debate on hepatitis in Serbia

In order to promote the World Hepatitis day in Serbia, ELPA member **Hronos** invited ELPA President **Tatjana Reić** to participate in a Public debate organized at Belgrade's Medical University as well as in several media interviews. Bringing EU level experience and inputs, she has helped to point out the severity of problems in Serbia such as no introduction of new DAA treatments, lack of diagnostic, stigma and general patient problems.



World Hepatitis Day 2017

Moscow conference

Russian team from *United against Hepatitis* organized a press conference on 25th of July, to mark this year's World Hepatitis Day. ELPA President Tatjana Reic was asked to participate and support this raising awareness conference via Skype, joining so Antons Mozalevskis from WHO and Charles Gore from WHA. The goals and objectives of the conference were to draw attention to the situation with hepatitis, to discuss issues related to hepatitis as well as their solutions, to highlight the importance of raising awareness of transmission and many more.

Hepatitis community around the world marked 10th World Hepatitis Day, in order to raise awareness and bring attention to the burden of the disease and its effect on the population. This year ELPA canalized its activities to social media where we have promoted several achievements in 2017, accomplished together with other hepatitis community stakeholders.


PBC is a rare disease that affects

1 person in 100,000¹



Treatments are available to **slow disease progression** and manage symptoms

Liver transplantation is used for those with end-stage liver disease¹



Feelings of **isolation and loneliness** are common side effects of the condition³



Sharing experiences and connecting with others can help³

#PBCandMe

SUNDAY 10 SEPTEMBER



#PBCandMe

PBC International Day 2017

This year's PBC International Day 2017 was marked by a joint campaign, carried out by PBC network, informal group of several European advocacy organizations working in the field of rare diseases, liver disease or PBC. The aim of this campaign, was to raise awareness and bring attention to this autoimmune disease.

Thanks to NLV's huge efforts in campaign preparation, this year it was implemented and carried out worldwide, especially Europe where ELPA plays a major role in patients advocacy.

ELPA managed to reach more than 100 000 Twitter users

ELPA would like to thank to all of you who were working on dissemination of information during PBC Day campaign by engaging on ELPA Twitter account.

Follow [this](#) link to read more.

PBC Day goes global

Hepatitis Hilfe Österreich
Hepatitis Hilfe Österreich shared three GIFs on their Facebook page

The Finnish Kidney and Liver Association
Infographic translated to Finnish and shared on The Finnish Kidney and Liver Association's Facebook page

Rarissimas Portugal
Rarissimas translated all the infographics into Portuguese and shared on their Facebook page

NLV (Nederlandse Leverpatiënten Vereniging)
NLV posted 15 tweets with a reach of 17.3K including four GIFs in the run up to PBC day

ELPA
ELPA posted 26 tweets reaching over 100,000 followers. On PBC Day a video of ELPA's President, Tatjana Reic discussing PBC was shared and re-shared by key opinion leader Jeffrey V. Lazarus who has 4,802 followers

PBC Sverige
PBC Sverige translated one of the infographics into Swedish and posted it on their Facebook page

Liver4Life
Liver4Life shared two tweets with reaching over 3,000 liver experts and advocates in the UK

American Liver Foundation
American Liver Foundation set up a fundraising page on their Facebook. So far they have raised \$361 beating their target of \$200

Canadian PBC Society
The Canadian PBC Society posted a series of five 'letters' on Facebook raising the awareness of PBC and its symptoms

Canadian Liver Foundation
The Canadian Liver Foundation shared two GIFs on Twitter and invited individuals to share their stories using #PBCandMe

SLAP - Save Liver Association for Patients
Save Liver Association for Patients shared the PBC day logo on their Facebook page

PBCers
The PBCers hosted a lunch with patients and patient organisations and shared a photo using the hashtag PBCandMe on Twitter

Forening for autoimmune leversykdommer (FAL)
Forening for autoimmune leversykdommer translated the factsheet into Norwegian

EPAC Italia
EPAC translated the press release and shared with journalists in Italy and it was published in a local newspaper PharmaStar

Leberhilfe Projekt gUG
Leberhilfe Projekt completed a survey around PBC QoL and management and presented the results at the national congress of gastroenterologists. They also developed an online platform for people living with PBC in Germany

SUNDAY 10 SEPTEMBER
international PBC day 2017

ELPA

ELPA posted 26 tweets reaching over 100,000 followers. On PBC Day a video of ELPA's President, Tatjana Reic discussing PBC was shared and re-shared by key opinion leader Jeffrey V. Lazarus who has 4,802 followers

international PBC day 2017

Launch of INTEGRATE: EU-funded Joint Action

On 19th of September ELPA has participated in the afternoon a policy session and debate on how to move towards integration of HIV, hepatitis, TB & STIs was arranged with the official launch of the EU-co –financed Joint Action on integrating prevention, testing and link to care strategies across HIV, viral hepatitis, TB and STIs in Europe (INTEGRATE), which brings together 29 partners from 15 countries. INTEGRATE is funded by the 3rd EU Health Programme and will run over three years (September 2017-August 2020). 29 partners have been nominated by their Ministry of Health, representing 15 EU countries plus Serbia. Partners are Public Health institutions, Hospitals (infectious disease and research departments), NGOs and Universities.

Furthermore, ELPA was asked to be **part of Advisory Board**, which President Tatjana Reic kindly accepted.

Launch was followed by series of workshops, held on 20th in the premises of DG Sante, where Commissioner Andriukaitis addressed all the participants. During this event ELPA was represented by **ELPA President Tatjana Reic** and **Policy Officer Lana Crnjac**.



Commissioner Andriukaitis addressing all the participants



HCV Mini Policy Summit Romania

On 27th of November Tatjana Reic, **as ACHEIVE chair and ELPA President**, took part in Mini Policy Summit “**Eliminating HCV in Romania**”, organized by

Hepatitis B and C Public Policy Association and hosted by **MEP Cristian Silviu Buşoi**. This event aimed to bring together policy makers, patient representatives, academics, clinicians and industry from Romania and EU level, who will later leave the Summit with a stronger commitment to work jointly towards the elimination of HCV and a clearer understanding what could and should be done to eliminate HCV in Romania and how the EU could support this effort.

Tatjana Reic concluded her intervention by asking how Romania can support Europe in eliminating viral hepatitis? It is clear that the European Parliament needs support of a future EU Council Presidency to give political prominence and importance to the issue. She expressed her hope Romania will pick up the political baton and make the fight against viral hepatitis a political priority during its Presidency in the first half of 2019. This way, it can be ensured that Member States throughout Europe will commit to eliminating viral hepatitis.

Follow [this](#) link to hear the full speech of ELPA President at HCV Elimination Mini Policy Summit.



ELPA's most successful programme goes on

ELPA University Year 3 Module 1



Module 1 of the third year of ELPA University IMPACT Programme commenced in Budapest from 27 – 30 September

ELPA University is a year-long training programme that has been set up by ELPA to provide knowledge and skills based training to community organisations from countries in Europe that have less developed liver healthcare systems and patient support. The programme focuses on improving attendees' knowledge of liver conditions and their treatment and management. Practical skills training is also provided to support attendees to advocate for improved services and care within their country.

Follow [this](#) link to hear welcome words to ELPA University students 2017/2018.



Alcohol labelling meeting



Public health advocates, including ELPA, have participated in a meeting on Alcohol labelling, held in European Parliament on 28th of September, and called for the alignment of alcoholic beverages with other food products. Bringing a strong message how people have a right to know what is really in the products they buy, this meeting gathered respectable participants such as **Commissioner Vytenis Andriukaitis** and **Gauden Galea, Director of the Division of Noncommunicable Diseases and in WHO/Europe**. On this occasion ELPA was represented by **Policy Officer Lana Crnjac**. The meeting was organized by **Eurocare – European Alcohol Policy Alliance**.

Hiring new administrator

As we have written in previous ELPA weekly activities issues, ELPA was hiring a new administrator during June and July. After prolonging the call for one additional week, ELPA Board has chosen a candidate who proved to suit the best a role of administrator. Mrs. Veronika Vsetickova will start her work as of 1st of September, until then all procedures remain the same and all invoices and reimbursement forms are to be sent to office@elpa.eu. You will be informed of the changes in a timely manner.

To remind you, this motion was set in place after January's decision that ELPA will be hiring new administrator after EASL's ILC, upon which ELPA Board shared a call with the membership in wish to fill the missing seat.

Launch of ELPA's Hepatitis B working group

After forming first ELPA working group on Rare diseases, lead by Richard Hall from Liver4Life, ELPA has launched second group: Hepatitis B group

To remind you, as envisaged by ELPA strategy, working groups will gather ELPA members and other experts in realm of liver diseases, who will work together and help ELPA Board in implementation of activities and to discern gaps in policy.

The group will be lead by **Silvana Lesidrenska** from ELPA member association Hepactive, with ELPA Board Partner **Marinela Debu**.

Janssen and MSD discontinue research for the treatment of HCV

During September two pharma companies, MSD and Janssen, announced their strategic decision to discontinue developing an experimental drug combination for chronic hepatitis C, explaining they have stopped after Phase 2 since there are already good pan-genotypic treatments offered on the market.

ELPA's aim is to promote the interests of people with liver disease and in particular: to highlight the size of the problem; to promote awareness and prevention; to address the low profile of liver disease as compared to other areas of medicine such as heart disease; to share experience of successful initiatives; to work with professional bodies such as EASL and with the EU to ensure that treatment and care are harmonized across Europe to the highest standards.

www.elpa.eu

office@elpa.eu

+32 (0)2 880 4349

