

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

January – March 2017

A large, abstract orange geometric shape, composed of several overlapping triangles and polygons, located in the bottom-right corner of the slide.

Launch of Liverhope project

LIVERHOPE IS EU FUNDED PROJECT AIMING TO INTRODUCE SIMVASTATIN AND RIFAXIMIN AS NEW THERAPY FOR PATIENTS WITH DECOMPENSATED CIRRHOSIS.

Liver cirrhosis represents the end-stage of a chronic disorder which results in severe and permanent damage of a vital organ. In recent years, liver cirrhosis was one of the leading causes of death in adults worldwide, both in males and females. The number of deaths due to cirrhosis in Europe has been estimated to be around 170,000 annually, with varying mortality rates in different European countries.

On January 12th we took part in **Liverhope** kick-off meeting in Barcelona, during which Marko Korenjak, ELPA Board member, presented ELPA and patients' view on the project, receiving a very good feedback from all the assembled professionals working on **Liverhope** project. Essential topics discussed during the meeting include: project overview, economic reporting, monitoring issues and dissemination of the results.

Furthermore, for the next five years, which is the whole duration of the project, ELPA will act as a key point in dissemination of results and all other information regarding the project.

Call to action: Organ donation and transplantation Across the EU

As a continuation of to the meeting held in November 2016, a second meeting on Organ donation and transplantation Across the EU was held on January 17, as a part of the PHA's Call to action campaign. The meeting was chaired by **Pisana Ferrari** from **Pulmonary Hypertension Association Europe** and was attended by ELPA's **Vice President Angelika Widhalm** and **Policy Officer Lana Crnjac**. Besides **ELPA**, the meeting was also attended by **European kidney Health Alliance, European Kidney Patients' Association, European Federation of Allergy and Airways Diseases Patients' Associations, European COPD Coalition, Donor and Transplantation Institute and Marking Public Affairs**. The meeting served as a great opportunity to exchange thoughts on most salient issues in the field of ODT and was enriched by **Melania Istrate** from **IDT Foundation** who gave a presentation *Training and social awareness for increasing organ donation in the European Union and neighbouring countries*.

*To remind you, PHA Europe decided to develop **Call to Action** to address issues such as shortage of organs, long waiting lists, high mortality, lack of awareness, understanding in the general population and, in some countries, lack of surgery facilities. Call to action is a cross-condition transversal campaign where organizations with the same problems could advocate for change together.*



ELPA@Home and Hep-CORE study
presentations

In the very beginning of February, ELPA has launched its new advocacy program **ELPA@Home**, created and coordinated by our member **Julio Burman** and kindly sponsored by **AbbVie**. The project's launch was accompanied by press conference proudly attended by ELPA's **Vice President Marinela Debu**, **Public Affairs Director Livia Alimena**, **Special Policy Consultant Achim Kautz**, **Scientific Team Member Andrei Baiceanu** and ELPA's associate and friend **Homie Razavie**.



This visit to Romania, not only that it has showed a great response to ELPA@Home program, but it has also served as a good opportunity to meet several key stakeholders in order to advocate for the Romanian Hepatitis strategy, about to be developed in coming years. ELPA's team has also held a fruitful meeting with the **Romanian Minister of Health, Mr. Vlad Voiculescu.**



Only one month after launching our Hep-CORE project, we took the opportunity being in Romania and presented their National results and findings on implementation of Hepatitis B and C policy recommendations in Europe.



Presentation of ELPA@Home and Hep-CORE survey in Lithuania

Mid of February was reserved for the “**Baltic Countries National Strategies towards the elimination of Hepatitis C**” conference, held on February 14th. On that occasion **Julio Burman, CEO and Founder at HETZ** (The Israeli Association for the Health of the Liver) gave a presentation on two significant ELPA deliverables: **ELPA@Home project** and **Hep-CORE survey**. The conference aimed to show the current situation in countries like Lithuania, Latvia, Poland, Hungary and Estonia, among which, unfortunately, only Latvia has a hepatitis patients' association. Besides the presentations, conference was marked by a fruitful round table discussion where ELPA's Julio Burman participated as well.

ELPA's President Tatjana Reic participated in **EU Presidency Conference** hosted by the Government of Malta in collaboration with the ECDC, held from 30 January – 2 February. On Wednesday, February 1st, she moderated the first plenary session **"Surveillance and monitoring and evaluation of testing"** and afterwards participated as a panellist in a Round table discussion: **"Hepatitis C and unequal access to treatment in Europe"**.

The conference in Malta gathered a great number of stakeholders which resulted with numerous meetings like the one with Charmaine Gauci, Superintendent of Public Health for Maltese Presidency with whom our President, together with several members of ACHIVE initiative (Charles Gore, Pierre van Damme, Jeffrey Lazarus, Eberhard Schatz), discussed Hepatitis priorities in the upcoming Maltese Presidency and further.

ELPA at HepHIV
conference in
Malta

NGO Forum at APASL

ELPA's Program Manager Marko Korenjak participated at NGO Forum organized by The Asian Pacific Association for the Study of the Liver APASL. The conference whose participants had a possibility to engage in numerous workshops and debates, took place in Shanghai, China from February 15 – 18. During his attendance at the Forum, Marko gave a presentation on ELPA's activities, results and projects such as Hep-CORE study, Liverhope project, ELPA at home Program and many more. Besides holding the presentation he has also met the Slovenian Ambassador in Shanghai Mr. Boris Škoda, and dr. Paolo Ascoli, Liverhope project Stakeholder. The conference was closed on 18th after the briefing on the forum's results for all the participants.

PBC advocacy network meeting

With the first one held in December in Frankfurt, PBC network held the second PAN-EU PBC advocacy meeting on March 2nd in Amsterdam where several ELPA members were present (HAA, EpaC, The Finish Kidney and Liver Association, PBC Foundation, as well as candidate member Leverforeningen Denmark). ELPA itself was represented by President **Tatjana Reic**. The purpose of the meeting was to agree on the goals and smart objectives of the network, learn more about the experience of the stakeholders included, discuss how the network can be managed and, finally, prepare for the meeting/s during 52nd EASL ILC in Amsterdam. Like the first one, this meeting was also funded by Intercept pharmaceuticals, organized by Four Health Communications agency and facilitated by Achim Kautz from Leberhilfe project.



ELPA University Year 2 – closing session



Closing session of ELPA University Impact programme for Year 2 students was held in Sarajevo from 13-15 March. Module 4 was attended by ELPA University students who, on this occasion, acquired knowledge about social media campaigns and its implementation in fighting liver diseases as patients' associations.

Also, first 2017's Board meeting was held in Sarajevo in parallel with ELPA University closing session. That simultaneity offered a great possibility for Board members to meet with ELPA University students and their trainers. Board meeting was marked by discussions with regards to ELPA projects and forthcoming ELPA AGM and Symposium.

Hep-CORE preparatory meetings in Copenhagen

Just upon completion of events held in Sarajevo, ELPA representatives travelled to Copenhagen where they have held Hep-CORE preparatory meeting with the representatives from Danish Liver Patients' Association, soon to be new ELPA members at that time.

Meeting was enriched with discussion about Hep-CORE programme related activities in Denmark, as well as with the presentation of Hep-CORE. ELPA was represented by President **Tatjana Reic** and **Julio Burman**, while the meeting was also attended by ELPA's friend and collaborator **prof. Jeffrey V. Lazarus**. Several meetings with local shareholders and pharma industry representatives were held as well.

MEP Friends of Liver group event in European Parliament

On March 22nd, MEP Friends of Liver Group in European Parliament organized “The Challenge of Hepatitis C in Central and South Eastern Europe: Who is at risk and how can patients gain access to effective screening, diagnosis and treatment?” meeting, hosted by Dr. Cristian Busoi MEP, who also chaired the meeting, and co hosted by Dr. Biljana Borzan MEP and Dr. Andrey Kovatchev MEP.

On that occasion **ELPA presented 2016's ground-breaking study Hep-CORE**, covering the situation on the ground. The study was presented by **Livia Alimena, ELPA Public Affairs Director**. Meeting was attended by numerous prominent professionals coming from medical, political and patients' sector.



These are some of the key messages carried out by ELPA representatives during the meeting:

We have the unique opportunity to eliminate viral hepatitis B and C in Europe, two viruses which have caused tremendous harm, personal and financial, over the past decades. However, endeavors towards elimination still lack of political support which could encourage a revision of the Dublin Declaration to include all three diseases: viral hepatitis B and C, tuberculosis and HIV. Such a new Declaration would show a political commitment by Member States to implement the WHO hepatitis elimination goal by 2030. – **Tatjana Reic, President of ELPA.**

Elimination of viral hepatitis is possible only with collaboration between medical workers, politicians, and patients. Medical workers should be concerned with offering excellent health services and products, politicians are responsible for making real and concrete systematic changes and, finally, patients' organizations for devising activities which would offer dissemination and communication services to all patients or future patients. - **Marko Korenjak, ELPA Governing Board Member.**



The Hep-CORE Report is the only survey in the European Union that evaluates to which extent key international recommendations on viral hepatitis B and C have been addressed in 27 ELPA member countries. The report analyses various aspects relating to HBV and HCV: overall national response, public awareness and engagement, disease monitoring and data collection, prevention, testing and diagnosis, clinical assessment, and treatment. Therefore, Hep-CORE offers an overall picture on hepatitis policies in 27 European and Mediterranean countries and it is a great tool to support advocacy. – **Livia Alimena, ELPA Public Affairs Director**

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

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