

ELPA

Quartal News Report

July - September 2018

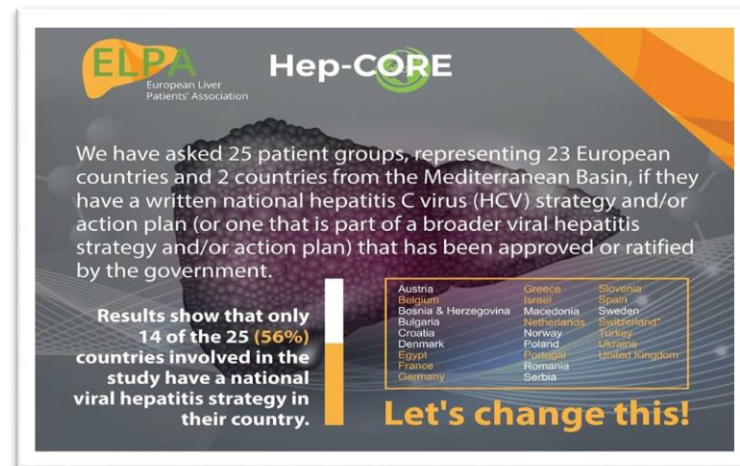
NASH meeting

ELPA Vice president Marko Korenjak was part of NASH meeting. The meeting was held from 6-7 July in Paris. He represented ELPA in a roundtable about the inclusion of patients and patient's organizations in NAFLD/NASH healthcare work. The panel discussed also the importance of transfer of good work from the field of hepatitis to NAFLD/NASH. Prof. Dr. Pawlotsky mentioned, as one of the invited panellists, the importance of the collaboration between ELPA and EASL and the benefits that such collaboration can bring both organizations. Marko Korenjak had also a meeting with prof. Dr. Arun Sanyal about the 2019 Paris NASH meeting and with representatives of Liver Forum from Berkeley School of Public Health regarding research in NASH in the USA and Europe.



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

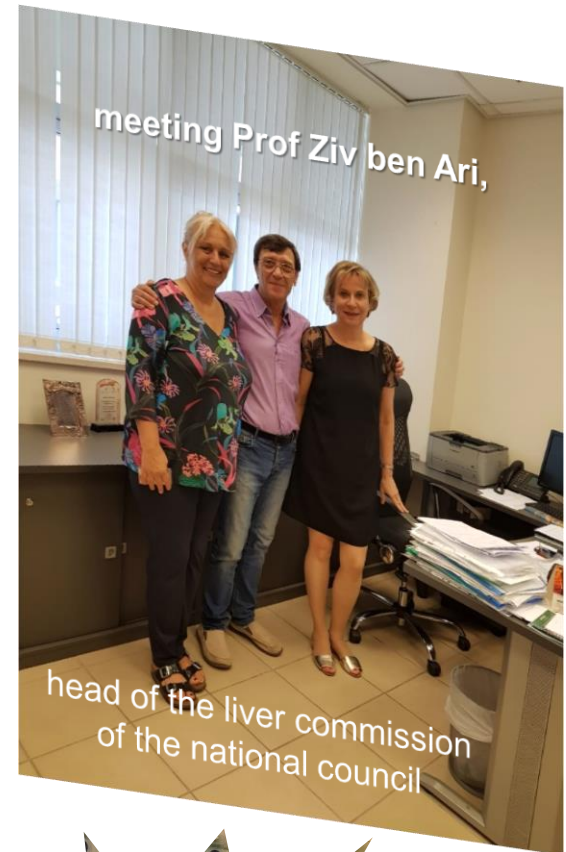
On the occasion of the World Hepatitis Day 2018, European Liver Patients' Association presented the data and findings of the 2018 Hep-CORE micro-elimination survey on HCV micro-elimination in Europe. Twenty-five patient groups, representing 23 European countries and 2 countries from the Mediterranean Basin, were respondents for the study. 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 years' 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. The press release is published on [ELPA website](#) and our social media channels where ELPA recorded 10 Mentions, 5.59K Mention Reach Impressions, 57 Likes, 69 Retweets and 99.9K Retweet Reach Impressions.

Membership support - Hetz

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 – Israeli Association For The Health Of the Liver which 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 **Sindee Weinbaum** and **Amit Halamish**.



Marking PBC day

On September 9th, ELPA members were marking the PBC International Day. Like the previous year, ELPA supported the campaign devised by PBC Network that ELPA is part of.

ELPA President Tatjana Reic, invited all ELPA members via social networks, to symbolically raise their hands in support of patients suffering from PBC, and in this way, to support efforts of raising awareness about PBC all around the world.



Core NASH Delphi online research

Forum for Collaborative Research, Obesity Action Coalition, and Green Park Collaboration organized the specialized program at the beginning and advanced stage of NASH that was researched with the Delphi method. The main goal was to determine a set of clearly defined "core set" of outcomes to measure, demonstrate and differentiate the effectiveness and value of NASH therapies. It is an online programme started in July and it will be finished in 2019. ELPA representative **Marko Korenjak** participated in two online questioners and has had two Skype calls, regarding. ELPA aims to work more in the field of fatty liver which is the future of liver diseases.

The final "core set" will be published in early 2019.

ELPA became part of DEEP programme

Disease Experience Expert Panels (DEEPs) are people living with chronic disease or their relatives, who can provide disease-specific insights and advice based on their experience.

As patients and advocates organization, ELPA becomes a member. The members of Novo Nordisk Disease Experience Expert Panels have expert knowledge as individuals with a chronic disease. We have a unique insight into what it is like to live every day with our condition. As we all working towards developing treatments for chronic diseases it is essential that patients' expertise, knowledge, and experience are included in what DEEP are doing. Patient Relations team follows the methodology of the European Patients' Academy on Therapeutic Innovation (EUPATI) and the Patient Partner project funded by the 7th Framework Programme of the European Commission.



FLAME meeting/Future Leaders in Addiction Medicine

The meeting "Future Leaders in Addiction Medicine" took place in Nice, on September 18th. **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.



HEP-C Community Summit

Summit was held in Lisbon, 18 September. Together with ELPA network partners, we presented the hepatitis advocacy priorities for the coming year by our Interim CEO, **Lana Crnjac**. She presented the results of the Hep-CORE micro-elimination survey at the HCV Community Summit, 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 that highest-risk groups are left behind in the pursuit of HCV elimination in Europe, systematic gaps where high-risk populations which they are ignored if they are difficult to access outside of existing pathways, there is not enough attention is given to hepatitis testing, which is the key to diagnosis and elimination.



7th International Symposium on Hepatitis Care in Substance Users

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 Tatjana Reić, Milan Mishkovikj, Marko Korenjak were invited to participate as the participants at the program and also at workshop done by **Prof. dr Rui Tato Marinho**. Prof Marinho gave a lot of space to **ELPA president Tatjana Reic** to present the work of ELPA. Tatjana presented a patient view on communication between patient and medical professionals. Before the official INHSU meeting, there were three meetings organized for different stakeholders. In National Assembly of Portugal, Mr. Ricardo Baptista Leite - the Member of Parliament, with his organization of parliamentarians from all over the world, organized Joint Action Policy Day where ELPA was represented by **Marko Korenjak**, ELPA's Vice president.



ELPA was invited by the European Association for the Study of the Liver (EASL) to participate in the scientific program at NAFLD Summit 2018, Geneva, Switzerland 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 followed by panel discussion where patients' voice, represented again by ELPA's vice president Marko Korenjak, was well heard. Since session was videotaped it will be available to EASL members that have access to the EASL LiverTree official eLearning Portal of EASL. ELPA also had the booth at the Summit. That was a great way and opportunity for the ELPA team for fundraising activities and presentation of the organization.

NAFLD SUMMIT IN GENEVA



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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