

ELPA NEWSLETTER n. 1/2016

ELPA President Tatjana Reic and ELPA Vice President Ivan Gardini met the European Commissioner for Health Vytenis Andriukaitis

European Parliament - 11 January



The European Commissioner for Health, Vytenis Andriukaitis, met Tatjana Reic and Ivan Gardini to discuss future EU policies regarding hepatitis C and alcohol. The Commissioner recognized the opportunity to eradicate HCV and discussed possible strategies to be taken within the limits of EU competence.

It was a very fruitful meeting planned for 30 minutes but it lasted more than one hour.

The Commissioner invited ELPA to the Chronic Diseases Conference, which will take place on 21st April in Brussels, where there will be the opportunity to further discuss chronic liver disease and hepatitis C.

APASL 2016: Viral Hepatitis Policy Symposium

Tokio – 16th February



This year the **World Health Organization's Strategy on the Elimination of Viral Hepatitis** is likely to be adopting a list of ambitious targets for 2020 and 2030 and the overall goal of the elimination of viral hepatitis as a public health threat by 2030.

Tatjana Reic, on behalf of ELPA, was invited to speak about "What means to Europe the inclusion of hepatitis within the SDGs". Her presentation focused on the broad and deep work ELPA did with other organizations in order to reach the WHO 2014 Resolution on Hepatitis and HCV Summit and Manifesto in Brussels.

WHO workshop: *Better Food for Better Health*

European Parliament – 16th February

ELPA attended the workshop which was organized by the WHO Regional Office for Europe and co-hosted by Mairead McGuinness, Vice-President of the European Parliament, MEP (EPP) and by Biljana Borzan MEP (S&D) and in collaboration with the Netherlands EU Presidency

HCV EU POLICY SUMMIT

Brussels - 17th February



ELPA took an active role during the high level meeting at the HCV EU Policy Summit in Brussels. A key note speech was delivered by **Vytenis Andriukaitis**, Commissioner for Health and Food Safety at the EU Commission. The introductory remarks were also held by ELPA President, reminding on Hepatitis C related healthcare costs such as liver cirrhosis or liver cancer which frequently require a liver transplantation and social costs (like working days, career, and Country’s economy). After she focused on what still needs to be done: make innovative treatments affordable, make concrete plans to

reach out specific risk groups and increase diagnosis rate efficiently and effectively, find new strategies to prevent and avoid infection and re-infection. To conclude, Tatjana Reic asked for a commitment which is still lacking and she proposed a Dublin Declaration for Hepatitis C.



During the first session, another ELPA member, our policy expert, **Achim Kautz**, presented the key elements of a successful elimination strategy from a patient perspective.

This first EU HCV Policy Summit was organised by the Hepatitis B and C Public Policy Association in partnership with European Association for the Study of the Liver (EASL), the European Liver Patient Association (ELPA) and the Correlation Network. During this Summit, the *The Hepatitis C Elimination Manifesto* was presented.

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Elimination Manifesto was presented.

Hepatitis C: The Beginning of the End

Are we ready to think about the elimination of HCV in Croatia?

Zagreb - 19th February



A High level Croatian and regional meeting was held at the Palace Hotel Zagreb with more than 100 participants coming from Croatia and the Balkan Region who gathered together for the first time. The meeting was organized by CATIH "Hepatos" and WHO country office and was hosted by the EU Parliament member Biljana Borzan and included several important international guests.

The meeting aimed to understand the health care situation related to viral hepatitis and estimating the economic burden of the illness for the future, emphasizing the importance of a National Strategy and the adoption of an Action Plan to fight Viral Hepatitis.

Tatjana Reic, Hepatos and ELPA President said: "with this meeting we want to call the attention to the Hepatitis C related social marginalization and to promote all the activities meant to eliminate Hepatitis C, in accordance with basic human rights, non-discrimination, parity and health rights".

HCV 2020 Forum 2016: *accelerating action*

Barcelona - 2nd - 4th March.

The HCV2020 forum gathered together important stakeholders, including policy makers, health care professionals and patient advocates, to share progress being made in addressing hepatitis C. Through the promotion and sharing of best practices and a focus on prevention, early detection, and clinical management of patients, participants contributed towards advancing the control and cure of hepatitis C. Tatjana Reic, representing ELPA, was chairing the plenary session IV: "*Good practices at micro level across the whole HCV pathway: preventing and early detection*", during the forum.



The result of HCV 2020 was *HCV HUB Planning and Implementation* launched by the University of Deusto, as a tool to support knowledge transfer and mutual learning among various countries and stakeholders as well as a support for recommendations any stakeholder can contribute towards advancing the control and cure of HCV.

The first HCV2020 Forum was held on October 2014, 1st and 2nd, in Oxford, UK, hosted by Oxford University.

Viral Hepatitis Prevention Board

Highlight underserved for screening, prevention and treatment of viral hepatitis B and C in Europe.

Ljubljana – 10th -11th March



The Viral Hepatitis Prevention Board (VHPB) comprises a number of advisors, honorary members who are the top stakeholders in the world of Hepatitis. ELPA as member of the VHPB, represented by **Tatjana Reic**, opened the meeting in Ljubljana together with Mojca Maticic.

The board discussed on the following objectives: identify the undertreated groups for screening, prevention and treatment; best practices from other countries related to existing models to reach undertreated groups, improve screening, prevention and treatment; discuss strategies to improve access for hard to reach and undertreated groups towards screening/diagnosis/treatment programs and immunization programs. Finally, identify challenges for research and advocacy for these groups. For more info visit: www.vhpb.org

Enhancing Value in European Health Systems: Improving Outcome

European Parliament - 15th March

ELPA took also an active role in this cross-party initiative which launched a new multi-stakeholder vision document on "*Enhancing Value in European Health Systems: the role of outcomes measurement*". The document focuses on the relationship between the ageing populations and the legacy of economic crisis which are confronting health systems across Europe with unprecedented challenges and a strong focus on health outcomes, to improve quality of care for patients and strengthen public health interventions.

Kangaroo Group

European Parliament - 16th March

ELPA participated to the breakfast panel debate which took place on Wednesday, 16 March in the European Parliament, Restaurant des Députés/ salon privé.

The title of the meeting was: "Transparent prices versus confidential agreements: What's best for patient access and sustainable healthcare?"

European Patient Forum (EPF) - Annual General Assembly

Brussels – 22nd and 23rd March



Tatjana Reic on behalf of ELPA and as a member of EPF, was invited to the annual general meeting, held on 22nd – 23rd of March in Brussels.

The AGM provided members the opportunity to share their experiences and views and reflect on EPF's development and their role therein.

The AGA was divided in the following five parts: Patient Empowerment, Mental health and Partnerships, Governance, Networking and Matchmaking, Building further our capacity as patient leaders.

For further info: www.epf.org.

Recruiting patients for clinical trial

22nd March - Israel

Patient Organizations are the contact point between patients and clinical trials, motivating patients to participate and helping doctors with comprehensive explanations.

Our ELPA member, **Julio Burman** said: “when it comes to evaluate patient feelings and barriers, patients organizations can contribute to this mission, making the balance between risks and benefits”. Burman calls for a “partnership between Doctors, Patient Organizations and Companies for a win-win result”.

ELPA President, General Manager and Public Affairs Director Meeting in Split

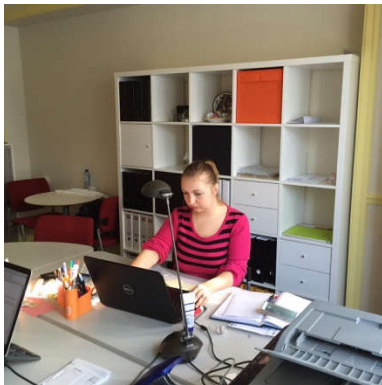
Split 29-31 March

Tatjana Reic (president) and the newly appointed Thomas Szekely (General Manager) and Livia Alimena (Public Affairs Director) met in the office in Split last March to analyse all the important work ELPA has been doing so far and to discuss next priorities and possible strategies.



ELPA NEW OFFICE IN BRUSSELS

We are pleased to announce that ELPA's new office is running and fully operational. The new office is located in Brussels, Rue de la Loi 235, close to the European Commission (few minutes on foot only). **Ivana Malaric** has also joined ELPA as Office manager and is fully operational in Brussels since the 1st of March.



The next ELPA newsletter will be issued in July-August. Please send the information regarding your important events of your National association within July to Livia Alimena (Public Affairs Director) at:

pad@elpa-info.org