

European Liver
Patients Association

ELPA



ELPA Quartal News Report

(July – September 2016)

Word of the President

During July, August and September, ELPA has been proactively participating in various projects and actions which support our endeavours in assuring further healthcare improvements for all liver patients. I am very proud to say that our diligent team has contributed in many initiatives during these months, having in mind all the time that only by mutual cooperation we can achieve our goals. That is why I would like to dedicate this opening letter to invite all ELPA members to work proactively, to use all your knowledge and experience and share it with others. So far we have built a strong network that can achieve important things in the field of viral hepatitis and other liver diseases, but only if we support each other, if we exchange the experience we have gained and if we continue, without ceasing, to acquire new knowledge.

Exploratory meeting on a joint stakeholder initiative on HCV



On July 13th ELPA's President **Tatjana Reic** attended an exploratory discussion in London about creating an EU high level stakeholder platform which would serve to work towards effective and appropriate prevention and management of Chronic Viral Hepatitis, in particular the elimination of Hepatitis C. Besides ELPA, the meeting was also attended by Jeffrey Lazarus and David Goldberg, as well as other prominent representatives of VHPB, EASL HepB&CPPA, EATG and WHA. It was also suggested that in future this platform should be co-chaired by Tatjana Reic and Pierre van Damme.



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World Hepatitis Day 2016



On July 28th, people throughout the world have celebrated the World Hepatitis day. On this occasion, a press conference was held in Moscow promoting a world without liver disease. ELPA's President **Tatjana Reic** and Board member **Robert Mitchell - Thain** participated in this event in order to support patients in Russia who are subjected to even greater discrimination. World Hepatitis day is an important tool in raising awareness of this *silent* disease and fighting for appropriate treatment standards for all the patients. On that occasion ELPA presented preliminary results of the **HepCORE** study which was launched to assess national responses to viral hepatitis in the region.

The data, which was obtained by surveying ELPA member groups, suggest that some European countries are falling behind in terms of the policies and practices that public health experts and the World Health Organization recommend as the basis for an effective response to the hepatitis B virus (HBV) and hepatitis C virus (HCV) epidemics. Survey topics include viral hepatitis policies, disease monitoring, prevention, testing and treatment. Researcher [Jeff Lazarus](#), a longtime friend of ELPA, worked closely with us and with an esteemed international study group to develop this very comprehensive survey.

World Hepatitis Day 2016



ELPA Board meeting



ELPA Board meeting was held in Brussels on August 27th. On this occasion ELPA's Board members have discussed ongoing projects and their current results. We would like to highlight that one of the major decisions taken during the meeting was to undertake further steps towards the better communication with ELPA members as well as to advance the internal communication and to increase the transparency within ELPA. Our team is working hard on providing relevant information not only to our members, but to all of those who are somehow related to our cause. Also, we would like to invite you to follow our Facebook and Twitter pages which have achieved a big notice from the public, as well as to share your news with us.

Women in High Places: Leading the Global Challenge of Hepatitis and Liver Cancer Control



Caring ambassadors organized a *Women in high places* meeting in New York to address the link between hepatitis and liver cancer. Our President **Tatjana Reic** was recognised and attended this event as well as other representatives from many influential organizations in the field of Hepatitis and Liver Cancer. The meeting took place from September 6th to September 8th in New York City and has, once again, confirmed that women leaders can be of great value in supporting the fight against hepatitis. This meeting was one example of how women can come together and develop unique and thriving set of tools and visions to enrich and enhance our collective efforts in hepatitis elimination.



Project *PBC Educational day*



As a part of the PBC International day, which was marked on September 11th, ELPA made its contribution holding the **PBC Educational day** on September 4th. Project leader **Robert Mitchell -Thain** gave a lecture about PBC, PSC and AIH aiming to educate gathered participants on rare liver diseases. PBC Educational day was created and implemented by ELPA team who work hard in drawing attention to the liver diseases and was granted by winning the Practice to Policy Program by Intercept. PBC International day is marked with a goal to raise the awareness and to increase public understanding on PBC.



IMPACT programme module 2 for 2nd Year ELPA University students

ELPA University constantly continues to work on educating and informing its students. Therefore, Module 2 for ELPA University second year students was held in Lisbon from September 5th-7th. On this occasion students had the opportunity to listen and learn about developing effective patients materials and working with media in order to enhance the advocacy for better treatment and care for people living with liver conditions. They were also taught about clinical trials, reimbursement process and policies in EU, as well as how to tackle the stigma which, unfortunately, liver patients often face.

Impact programme



RC66 meeting of WHO EURO region

The WHO Regional Office for Europe, as one of WHO's six regional offices around the world, organized the RC66 meeting which took place in Copenhagen on 12th – 16th of September and was a sequel of conclusions adopted in Geneva. In May 2016 the Global Hepatitis Strategy was adopted in Geneva and now it was the time to devise the European Action Plan. The plan was endorsed in Copenhagen on September 15th and ELPA's **Tatjana Reic**, as one of the attendees, has provided ELPA community with all the impressions and key points from that session.



RC66 meeting of WHO EURO region



EASL Special Conference

Our Public Affairs Director Livia Alimena presented **The roadmap for cure – The patients' perspective** at AASLD – EASL special conference in Paris between the 23rd - 25th of September. The fact that Livia Alimena received the highest number of questions by the audience prove that both the topic and the presentation were received with great interest. ELPA was represented by our member Andrei Baiceanu as well. As a participant he has devised and sent out an interesting report with conference's highlights and insights. The European Association for the Study of the Liver (EASL) hosted a Special Conference regarding Hepatitis C Virus (HCV) infection called "Roadmap to Cure"

and brought together many Hepatologists, Virologists, Researchers and Health Professionals to discuss the EASL Treatment Recommendations Guidelines and outline the goals in order to increase patients' access to treatment. EASL Treatment Guidelines for HCV presented some great achievements in hepatitis research reached in the last two decades. It is the first time in EASL history that the HCV Guidelines do not have Interferon-based treatments. Also, another crucial point discussed during the meeting was the need to increase screening for HCV to be able to diagnose and treat more patients as well as to decrease the rates of HCV infection worldwide.

EASL Special Conference



WHO Regional Technical Consultation in Minsk



Regional Technical Consultation on dissemination of the WHO guidelines on HIV and Viral Hepatitis for 12 Eastern European and Central Asian countries, took place from September 26-29 in Minsk, Belarus. Main goals and expectations of the meeting, among other, were to explain technical elements of the new 2014/15 WHO's consolidated guidelines for HIV and Hepatitis, to provide an opportunity for well-informed WHO and MOH staff to discuss new policy recommendations.

ELPA was represented by President Tatjana Reic who co-chaired a session on WHO guidelines on Viral Hepatitis, surveillance and testing. In her introduction speech she addressed the participants to show to Eastern European and Central Asian countries that the efforts patients organizations have been making in ELPA countries so far, are visible and showing results.



HepCORE launch preparations



On September 28th ELPA representatives met with Hanover agency team in order to elaborate a plan for HepCORE report launch. In order to mark the importance of this first ever study assessing how hepatitis B and C are being addressed by governments and public in 27 ELPA member countries, an international press conference is going to be organized on 20th of December in Berlin. The international press conference will be opened by President Tatjana Reic and will have remarkable speakers: Prof. Jeffrey Lazarus, Achim Kautz, Erika Duffel and Prof. Massimo Colombo (world leading expert on Hepatitis and President of EASL Foundation).

Besides the launch, they have also discussed a 2017 plan regarding the dissemination of the results and other important advocacy work to be done in 2017. The meeting took place in Brussels and was attended by General Manager of Hanover Agency and his team, Jeffrey Lazarus from Copenhagen University, the scientific lead of HEP-Core project, Livia Alimena, Marko Korenjak and Milan Mishkovikj on behalf of ELPA.



11 years of Advocating for Liver Health



*ELPA's mission is to secure that all liver patients are diagnosed on time, treated with respect and have equal access to the best standard of medical care – regardless of their origin, lifestyle or type of liver disease. Our ultimate goal is a **world without liver disease.***

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