

European Liver
Patients Association

ELPA



ELPA Quartal News Report

(October – December 2016)

Word of the President

Dear ELPA Members, ELPA collaborators and sympathizers, another year of dedicated work is behind us. Looking back on past months of 2016, I realize now they served us for strenghtening of our mission and our foundations which were set back in 2005. 2016 has been another amazing year of working with healthcare professionals, patients and decision makers in which we have both experienced and achieved so much. From here we go further, more decisevely and boosted with the positive energy that you so generously transmit to us. For ELPA's executive team that is the best indicator that we are on the right path. In 2017, as the President, it is my duty and honor to grow ELPA even stronger and to protect its procedures, regulations and most important, its mission. I invite you to join me on that journey so we can all together overcome the obstacles which we may encounter and celebrate the fruits of the work which, as we were able to see, comes always.



Second exploratory stakeholders' meeting on viral hepatitis elimination



On October 17th ELPA's President Tatjana Reic chaired a stakeholders' meeting on a consensus initiative to promote hepatitis elimination in Europe. Delegates like Pierre van Damme, VHPB; Luis Mendao, EATG; Jeff Lazarus, University of Copenhagen; Massimo Colombo, University of Milan; Katrin Schiffer, Correlation Network Hepatitis C; Raquel Peck, WHA prompted the discussion which resulted in forming a unique viewpoint: will to support the elimination of viral hepatitis in the WHO Region with a focus on B and C in view of the high impact on morbidity and mortality, to generate political will amongst EU and national decision-makers to eliminate viral hepatitis as a public health threat, as well as relevant stakeholders, focus on surveillance, prevention, testing, access to affordable treatment and many more.

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REGIONAL OFFICE FOR

**World Health
Organization**
Europe



Viral Hepatitis Prevention Board

**World Hepatitis
Alliance**

**Hepatitis B and C
Public Policy Association**



European
**AIDS Treatment
Group**

Meeting in the European Parliament: Call to Action to improve Organ Donation and Transplantation across the EU



On the 18th of October a multi-stakeholder cross-condition meeting was held in the European Parliament to discuss how to improve organ donation and transplantation across the EU. Hosts of the meeting were MEPs Ivan Jakovcic, Alojz Peterle, Romana Tomc and Hilde Vautmans. The purpose of the meeting was to exchange ideas and experiences between institution representatives and transplanted patients. ELPA's representatives were Tatjana Reic, President of ELPA; Angelika Widhalm, Board Member, who has contributed to the meeting with her experience and vision of the organ donation and transplant situation in EU and Lana Crnjac, Office and Communication Manager.



Georgian HCV Elimination program, second TAG meeting



ELPA's President Tatjana Reic chaired the session „*Promote Advocacy, Awareness & Education, Focus on Stigma and Discrimination*“ during the HCV Elimination plan second Technical Advisory Group meeting in Tbilisi, Georgia on October 25th and 26th. The two day meeting began with presentations from Georgian MOH representatives, who provided TAG members with information about a problem of viral hepatitis in that country and was followed by discussion of elimination plan aspects.



Viral Hepatitis Prevention Board: Country Meeting in Albania



On October 27 and 28 Tirana hosted eminent European professionals working on elimination of viral hepatitis on the conference: Prevention & control of Viral Hepatitis in Albania and the neighboring countries: lessons learnt and the way forward. Main objectives of the sessions were to provide an overview of surveillance systems for viral hepatitis and infectious diseases as well as to discuss the further development and the implementation of a National hepatitis plan. ELPA's President Tatjana Reic was one of the chairpersons. Several ELPA members contributed to the meeting agenda as well:

Zdenko Simonovic B18 (Bosnia and Herzegovina), Milan Mishkovikj Hepar Centar Bitola (Macedonia) and Ivana Dragojevic from Hronos (Serbia).



HA-REACT 2nd Advisory Board meeting

On November 4 ELPA, represented by its Board member Milan Mishkovikj, participated in Adviosory Board meeting held in Riga. Adviosory Board is a supporting body for the Steering Committee of the The HA-REACT Joint Action. The Joint Action on HIV and Co-infection Prevention and Harm Reduction (HA-REACT) addresses existing gaps in the prevention of HIV and other co-infections, especially tuberculosis (TB) and **viral hepatitis**, among people who inject drugs (PWID).



Nordic Program - Launch Meeting

10th of November was reserved for Nordic Groups Meeting where ELPA's President Tatjana Reic and Public Affairs director Livia Alimena were invited as speakers. Tatjana Reic held a presentation with the title Time to Deliver Program - The Road to Improved HE care, while Livia Alimena addressed the participants with her presentation on HE Advocacy Tool kit. RHC, ELPA member from Sweden, was represented by Tove Frisch and Michael Mogensen who gave their insights into HE Care in their country as well as participants, i.e. patents representatives, from Denmark.

Meeting with Sirtex



On 5th of November Livia Alimena, ELPA Public Affairs director, Marko Korenjak, ELPA Program Manager and Andrei Baiceanu ELPA Scientific Team Member, met with Sirtex representatives to discuss the HCC survey project during the Sirtex's *European Multidisciplinary Symposium on Liver-Directed Cancer Therapy using 90Y Microspheres* which took place in Rome.



The Liver Meeting 2016



This year's The Liver Meeting organized by AASLD was held in Boston, USA from November 11 to November 15. Among more than 9,500 hepatologists, health professionals, community and patients' representatives and other stakeholders from across the world ELPA had its representatives as well: Tatjana Reic, Livia Alimena and Marko Korenjak. They had the opportunity to hold the meetings with key stakeholders. While the main purpose of the meetings was fundraising they were able to also exchange thoughts on the latest liver diseases research, discuss treatment outcomes, and interact with colleagues at the annual liver meeting which will next year be held in Washington DC.

Robert Mitchell-Thain, ELPA Board Member, represented his organization as well as some other ELPA members like Ingo Van Thiel and Marco Bartoli.



AWARH campaign 2016 and Health Attaché breakfast meeting



Awareness Week on Alcohol-Related Harm (AWARH) was organized from 21 – 25 November 2016. The focus of this year's AWARH was on the ongoing revision of the Audio-visual Media Services Directive (AVMSD) which provides an opportunity to free Europe from health-harmful marketing. During the AWARH several activities were organized, such as health Attaché breakfast meeting which was attended by ELPA's President Tatjana Reic. A thunderclap campaign was also organized with a social reach of 156.419,00 people.



WHA Regional Board Member elections

Two ELPA members were nominated and elected in the WHA Regional Board Member Elections: EURO Regional Board Member: Ivana Dragojević, President of HRONOS and Eastern Mediterranean Regional Board Member: Ammal Metwally, Association of Liver Patient Care (ALPC-Egypt).



Meeting with Commissioner Vytenis Andriukaitis



On November 28th ELPA together with other community representatives met with Health commissioner Vytenis Andriukaitis to lobby & advocate for EU commitment on Viral Hepatitis as well as on TB and HIV. The meeting was dedicated to very much needed integrated plan which would fit the objectives of the EU Health Program. During the meeting ELPA's President Tatjana Reic, representative of Viral hepatitis community, Fanny Voitzwinkler representative of TB Colition and HIV/AIDS representatives Sini Pasanen, Anke van Dam, Luís Mendão and Ann-Isabelle Von Lingen, were informed that on November 22nd, the European Commission has set out a strategic approach for achieving sustainable development in Europe and around the world (including SDG 3.3.).



EMA trainings in London

ELPA Board member Marko Korenjak and ELPA member Andrei Baiceanu attended EMA trainings which took place in London on 29th and 30th of November. During the “Annual training day” they had the opportunity to introduce new patient/consumer representatives to the EMA and to gain experience in the procedures they might encounter in their work. Second day was dedicated to the PCWP meeting.



Interview with Tatjana Reic

In December issue of *Hepatitis B and C Public Policy Association newsletter* it was published an article on Treatment of HCV with Direct Acting Antivirals in Italy written by Prof. Massimo Colombo as well as the interview with ELPA's Tatjana Reic, who shared ELPA's mission, objectives and accomplishments.

The strategy strengthens hepatitis C treatment also in Finland

The Finnish Ministry of Social Affairs and Health has published the hepatitis C strategy for 2017-2019. The hepatitis C strategy aims to improve hepatitis C prevention and to establish guidelines for testing and treatment practices in order to harmonize long-term care for all who have hepatitis C. The initial objective during 2018 is to expand the treatment in replacement therapy to include those with hepatitis C who fulfill the treatment criteria. The long-term goal is treatment for all carriers of hepatitis C, regardless of the degree of liver damage, in order to limit new infections. Finnish Kidney and Liver Association pointed out that, at the moment, awareness raising and preventive work has not been given the sufficient resources however they hope this new strategy will change things as more than half of all new infections occur among people under 30 years of age.



IMPACT program

ELPA University

Year 2

Module 3

The beginning of December was marked by ELPA University IMPACT Program, intended for second year students and held from 5th to 7th December in Warsaw. Students had the opportunity to proceed with work and knowledge gained so far and to participate in Module 3 of the program on liver health and advocacy which combines both theoretical learning and skills based training. As usual, the University IMPACT Program was chaired and managed by Achim Kautz, ELPA's Special Policy Consultant.

Advisory Board Meeting in Warsaw



During 7th and 8th of December, immediately after the completion of ELPA University Module 3, Advisory Board Meeting took place in Polonia Palace Hotel in Warsaw. On this occasion, representatives from Gilead Sciences, Bristol-Myers Squibb, Intercept, AbbVie and Merck & Co., Inc presented their latest scientific developments and replied to ELPA members questions. While meeting was moderated by program Manager Marko Korenjak, all introductions to the industry presentations were made by Ingo Van Thiel, ELPA's Scientific Team Member.



Board Meeting

In parallel with ELPA University Module 3 ELPA's Board members gathered on December 6th and 7th to hold a Board meeting in order to discuss ongoing projects. The board decided to introduce some changes in order to assure faster and easier workflow: the President is now supported by two strong Board members – Vice President for financial matters and Vice President for networking and policy questions. Vice President Marinela Debu takes over for matters concerning finances and Angelika Widhalm as Vice President for matters concerning networking. This decision is coming into force from 1st of January 2017.

ELPA's participation at EATG's Policy Meeting on Access to DAAs in EECA



On 10th and 11th of December Public Affairs Director, Livia Alimena, participated in Policy Meeting on Access to DAAs in EECA in Tbilisi, Georgia organized by European Aids Treatment Group (EATG). While the first day was reserved for meetings with industry (Janssen, MSD and Gilead) second day of the meeting was marked by WHO Global Hepatitis Strategy and WHO regional Action Plan for the European region, presented by WHO's Antons Mozalevskis.

PBC PAN EURO Advisory Board

On December 13th PBC Advisory group meeting was held in Frankfurt. The main purpose of the meeting was to give advice on how Intercept can support the PBC community to meet their current advocacy and education priorities and on the need and rationale for a pan-EU PBC network. ELPA's President Tatjana Reic represented ELPA on this occasion whilst some ELPA members like organizations from Italy, Finland and Germany participated as well. Our Board member Robert Mitchell-Thain presented the work and notable results of his PBC Foundation during this meeting which was moderated by Achim Kautz, our special Policy consultant.



ELPA Stakeholders' meeting



This year's Stakeholders meeting (previously known as Policy meeting) took place in Berlin on 19th of December and has gathered more than 30 professionals – patients, industry representatives and stakeholders. Meeting was opened with ELPA President Tatjana Reic's review on 2016 and its accomplishments and was moderated by Marko Korenjak, ELPA's Program Manager, and Achim Kautz, ELPA's Special Policy Consultant.

Throughout the day and during the presentations held by ELPA team, participants were able to hear about what has been done so far in ELPA from its beginnings.



ELPA team was proud to show results which prove that ELPA's plans and strategies are achieving its goals since the day one. In order to assure further progress, Marko Korenjak informed attendees on planned activities in 2017, explaining them in detail while introducing ELPA Work plan for 2017. Also other ELPA members presented key activities such as: Prof. Dr. Ammal Mokhtar Metwally (Egypt), Julio Bauman (Israel), Livia Alimena (ELPA).

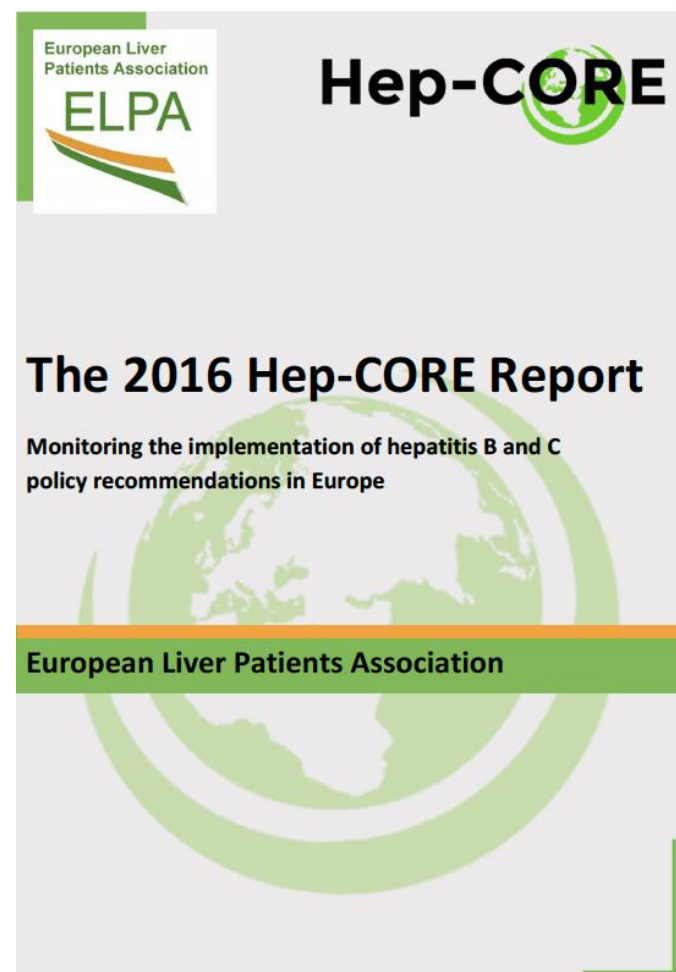


International press conference in Berlin: Hep-CORE Report Launch

On December 20th European Liver Patients' Association published results of the first patient led and unique European Viral Hepatitis Study – Hep-CORE, during an international Press conference organized by ELPA. Results were presented by Prof. Jeffrey V. Lazarus of ISGlobal, University of Barcelona. This report showed some stark findings and worrisome gaps in EU countries policies in coping with viral hepatitis. It shows that 52% of surveyed European (25) and Mediterranean Basin (2) countries lack national strategies to address viral hepatitis B or C, despite the WHO World Health Assembly resolution from May 2016, calling on all countries to have one. On this occasion, Prof. Massimo Colombo, Chairman of the EASL International Liver Foundation and guest at Hep-CORE report launch, emphasized the importance of rigorous HCV surveillance, effective screening programs, increased treatment uptake with high efficacy therapies, and close collaboration between stakeholders. The press conference was opened by a keynote speech of ELPA President, Tatjana Reich and was moderated by ELPA member and Special Policy Consultant, Achim Kautz.

Press conference was extremely successful and was attended by more than 35 journalists (from the press and National broadcasting companies) from various EU countries. The full media coverage report on this topic will be published on ELPA website upon its completion.

International press conference in Berlin: Hep-CORE Report Launch



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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