

ELPA NEWSLETTER n. 2 – 2016

WHO Europe advisory committee for the EU Action Plan for the prevention and control of HIV/AIDS and Viral Hepatitis

Copenhagen – from 3rd to 5th April

President **Tatjana Reic** and ELPA special policy consultant **Achim Kautz** took part to the meeting of the advisory committee for the development of European action plan for the prevention and control of viral hepatitis in the WHO European Region, 2016–2021. Among participants: Antons Mozalevskis (WHO Regional Office for Europe) outlined the action plan on the prevention and control of viral hepatitis in the WHO European Region. Another session focused on overall global vision goals and targets linkages with SDGs and UNAIDS was led by Andy Seale (WHO headquarters).



ELPA Strategy Workshop

Frankfurt – 6th April

ELPA members **Tatjana Reic**, **Marko Korenjak**, **Amal Mokhtar**, **Julio Bauman**, **Sari Hogstrom**, **Achim Kautz**, **José A. Willemse**, **Angelika Widhalm** and **Thomas Szekely** met in Frankfurt to develop and discuss our new 2020 Strategy and deliverables as well as our mission, vision and values.

ILC/EASL – International Liver Congress 2016 of the European Association for the Study of the Liver (EASL). ELPA President Speech during the opening ceremony.

Barcelona – from 11th to 17th April

ELPA President **Tatjana Reic** was honoured to address more than 10.000 congress participants at the Opening session and stressed “...*the fight for political recognition of viral hepatitis and the huge opportunity to eliminate it is not yet won. The European Commission struggles internally to adopt an EU Policy Framework on HIV, Hepatitis and TB, which has been envisaged for quite some time now, but where little progress appears to be made. To me, it is clear that the European Commission needs our help. We need to demonstrate consensus on what is needed to eliminate Hepatitis at European, national and local level. Policymakers, public health experts, healthcare professionals and patients*

need to come together to look at primary and secondary prevention, access and prevention of re-infection, and to develop strategies on how to best approach the different risk groups.

As for the global level, let me reiterate what I said at the Hepatitis C Policy Summit in Brussels in February. We need a UN Declaration on Hepatitis. The fact that there are currently discussions on updating the Dublin Declaration on HIV should makes us think – why not include Hepatitis, as well as TB? Each of these diseases should be included in their own right in an updated Dublin Declaration. Generally, the future is in exploiting synergies wherever possible.

We need to be clever and also investigate how we can exploit synergies between prevention, diagnosis, and management of other diseases to optimize health systems outcomes.

Chronic diseases, including chronic liver diseases, are diagnosed far too late, and primary care is underutilised for both prevention and diagnosis. Non-alcoholic fatty liver disease – NASH - is a case in point here. The problem is that primary care professionals frequently do not have the tight tools available. Health check-up frequently do not include liver enzyme tests, and healthcare professionals are usually not rewarded for an early and correct diagnosis – in fact, just the contrary.

Let me conclude: A lot has been achieved in terms of therapy, but a lot more needs to be done to reduce the burden of liver disease. Let's ensure that we, as the European liver community, have the right arguments in place to convince policymakers and stakeholders that we can win this fight- Hepatitis elimination is the first big opportunity to seize on the way”.



ILC/EASL – International Liver Congress 2016 of the European Association for the Study of the Liver (EASL). ELPA meetings, workshops and AGM.



Barcelona – from 11th to 17th April

ELPA President, Board and all members took part to the International Liver Congress and several activities such as Annual General Meeting, training day, workshops and meetings:

“Transforming HCV Care Together”. “Management of Hepatic Encephalopathy: A serious neuropsychiatric complication of advanced Chronic Liver Disease”. Eliminating hepatitis C – making it real”.

On April 14th Echosens donated ELPA with FibroScan® 530 Compact at its booth. This mobile device is intended to be used for non-profit liver screening campaigns throughout Europe.



Moreover during the congress, ELPA President **Tatjana Reic**, General Manager and Public Affairs Director **Livia Alimena** had several successful stakeholder meetings with EASL governing board, companies, clinicians and nurses as well as International Organisations representatives for European projects such as Galaxy and our project Hep-CORE.

Our board member **Robert Mitchell-Thain**, presented its winning project during the conference *Improve PBC care: Practice to Policy applications and their corresponding PBC initiatives*.

During the conference “*Transforming HCV Care together*”, **Jeffrey Lazarus** (University of Copenhagen) and ELPA special policy consultant, **Achim Kautz**, introduced to the audience the **Hep-CORE project** a study documenting how ELPA member countries are addressing hepatitis B virus (HBV) and hepatitis C virus (HCV) prevention and treatment today. The study is based on a survey which topics include: viral hepatitis policies, disease monitoring, prevention, testing and treatment.

ELPA Symposium: New HCV DAAs: Is Universal Access still a Dream?

Barcelona – from 16th April

During the International Liver Congress (ILC – EASL), ELPA Symposium titled “*New HCV DAAs: Is the universal access still a Dream?*” took place and was co-chaired by ELPA Vice President **Ivan Gardini** (EpaC President) and Charles Gore (WHA). The symposium gathered together international experts (spanning from Europe to USA, from Australia to Africa) and KOLs about Hepatitis who focused on its epidemiology (130 to 150 million people living with chronic hepatitis C), and analyzed the new treatments which can also cure people with advanced cirrhosis, HIV coinfection and other severe comorbidities. On this occasion, we wanted to look at the big picture: how does access work across different continents? What has improved since 2014? Which solutions work, which barriers are still in place? Which are the best practices we could learn from?



During the Symposium, Ms Gjulten Abdullai, a patient from Macedonia, told her story in front of the audience and is now finally granted the treatment thanks to **Ivan Gardini** (EpaC President) together with Professor Antonio **Craxi** MD, Head of Dept. of Internal Medicine and Medical Specialities University of Palermo (Italy).

Regional HCV Launch

Zagreb - from 28th to 30th April

President **Tatjana Reic**, on behalf of ELPA, was invited to attend the AbbVie Regional Launch Event and delivered a speech on ELPA priorities and activities. She also met several partners from Central and Eastern Europe (CEE).



11 NGOs Hepatitis C patients letter to Italian Prime Minister Matteo Renzi

Rome – 10th May

Eleven patient associations gathered together to write a letter to Prime Minister asking to the Government to take action for more than 100.000 patients who don't have access to new Hepatitis treatments. *“So far, only patients in critical and serious conditions are granted new medicines which is against the principle of universal healthcare coverage in our Constitution”* said **Ivan Gardini**, ELPA vice President.

Fibroscan Compact 530 donation to Zagreb Hospital

Zagreb – 12th May

The Viral Hepatitis Department of the Zagreb Hospital for Infectious Diseases "Dr Fran Mihaljevic" received the Fibroscan Compact 530 – the most advanced device for determining the degree of liver damage in patients with acute and chronic viral hepatitis B and C, as a donation from Abbvie.

Tatjana Reic, who attended the conference as a special guest, said: *“elimination of hepatitis C is one of the priority public health challenges in Croatia, but also internationally. Fibroscan, is essential in assessing the level of liver damage in patients with chronic hepatitis C, will enable better diagnosis, monitoring and treatment of this serious disease. Finally this year Croatia should get the draft of the national strategy and action plan for the fight against viral hepatitis”*.



ELPA University

Year 1 and 2, combined Modules 4 and 1 of ELPA University involved a group of 28 enthusiastic patient group representatives from 16 organisations, spanning 13 countries. The aim of the ELPA University programme is to provide patient group representatives from across Europe with the necessary skills and knowledge to advocate for liver health service provisions in their country.

On day one, both Year 1 and Year 2 attendees participated in the joint session run by **Achim Kautz** (ELPA). Following this, Year 2 participants continued with a three day programme where they learned about liver health in different countries, recruiting community group volunteers, community group fundraising and leveraging community collaborations. These training sessions and workshops were given by three trainers from the liver health community; **George Kalamitsis** (PROMETHEUS), **Robert Mitchell-Thain** (PBC Foundation) and **Tara Farrell** (World Hepatitis Alliance).

Some feedback from participants on the programme: *“The best training education given by ELPA”*. *“The training was one of the most professionally run programmes and I use the SMART objectives I learnt on the course everyday”*. *“We will be linking up with other organisations post the course”*



WHO – 69th World Health Assembly

Geneva – 28th May:

President **Tatjana Reic** represented ELPA at the 69th World Health Assembly where 194 Member States government unanimously voted to adopt the first ever **Global Viral Hepatitis Strategy to eliminate viral hepatitis by 2030**. The Strategy sets a goal of eliminating hepatitis B and C by 2030 and includes a set of prevention and treatment targets which, if reached, will reduce annual deaths by 65% and increase treatment to 80%, saving 7.1 million lives globally by 2030.

The ten-year efforts have finally paid off and The Global Health Sector Strategy on Viral Hepatitis whose goal is the elimination of hepatitis B and C by 2030 and includes prevention and treatment targets to reduce annual deaths by 65% and increase treatment by 80%, was unanimously adopted by 194 member states, signalling the greatest global commitment on viral hepatitis ever.

This is definitely an exciting moment for hepatitis community across the globe and a strong commitment for ELPA to continue its' by so far very successful work, but still a lot needs to be done at Country level, said ELPA President.



Moreover, delegates at the World Health Assembly have agreed resolutions and decisions on air pollution, chemicals, the health workforce, childhood obesity and noncommunicable diseases. WE GOT IT!! Finally! First of its kind - GHS on Viral Hepatitis

World Digestive Health Day

UEG (United European Gastroenterology) – 29th May

Ahead of World Digestive Health Day on May 29, UEG, endorsed and supported by ELPA, have launched a new video to highlight the vital importance of healthy early nutrition in helping to reduce the levels of childhood obesity and the burden that this inflicts on healthcare economies.

Hepatitis C Italian national congress on access to treatments promoted by EpaC

Naples – 13th June

The national congress organised by the Italian hepatitis patient organisation (EpaC) goal was to analyze the Italian scenario after two years access of new hepatitis medicines. One of the main focus was on prescription limits which are considered to be related to a phase of contingency which is now

over. So far, only 50.000 patients did have access to new treatments, therefore EpaC called for new guidelines able to set priorities and remove current restrictions.



Governing body and administrative news:

29th April: meeting between ELPA President and ELPA General Manager.

24th May: **ELPA Board Meeting**.

12th - 13th June: meeting between ELPA President, **Tatjana Reic** and ELPA Public Affairs Director, **Livia Alimena**.

28th – 29th June: **ELPA Board Meeting**

We hope that you liked this second issue of ELPA newsletter. In next issue you will find much more and a detailed report on two of our exciting and important July events:

- **Scoping meeting: Exploring a consensus initiative to promote hepatitis elimination in Europe** London - July 13th
- On **World Hepatitis Day 28th July, ELPA presented Hep-CORE** and launched Hep-CORE. press release and blog poster to show the preliminary data from patient groups raise concerns about responses to HBV and HCV in Europe.
- As well as about our promotion throughout **Binspired** – Brussels airlines inflight magazine

Our next newsletter will be issued in December, please send the information regarding the events of your national organization by November to our Public Affairs Director Livia Alimena at

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Our newsletters are always available on our website

www.elpa-info.org