

ELPA

Quartal News Report

January-March 2018

ELPA team planning activities, projects and collaborations for 2018

Every new year means new beginnings so January was spent in adding final touches to reports for the past year and preparation for smooth implementation of the 2018 projects.



•**Annual General Meeting (AGM)**
2018 at the EASL's International
Liver Congress (ILC) 2018 in Paris



•**ELPA Symposium** on Symptom
management across liver diseases:
Is there a big picture?



•**Hep-CORE training** /workshop,
led by prof. Jeffery Lazarus



•Development and planning of the
most successful projects: **Hep-
CORE, ELPA@home**



Hep-CORE

Unique patient-led monitoring tool

Hep-CORE study is carried out by a research team led by **Prof. Jeffrey V. Lazarus**, on ELPA's behalf.

This study's results were presented in three scientific journals and presented at fifteen conferences last year. **Hep - Core** has been used for EU data frame strategic action plan development by ECDC and we aim to achieve much more.

The 2018 **Hep-CORE** methodology will be strengthened based on the feedback of experts in the field. In short, it will be based on data extraction from official documents, followed by a survey to assess the implementation of policies in practice. Study findings will again be published as a scientific article and presented at scientific conferences, national meetings and other relevant events.



ELPA@home

One of the most important strategic goals of European Liver Patients' Association is member empowerment. We are constantly searching for ways to improve the impact of our members also at national levels.

ELPA has recognized the extreme value of the **ELPA@home** structure for our members because the setting of the program is unique to each country we visit. We have some basic structure which is being replicated, but every time we try to develop the program that is up-to-date with the latest information's in the country and the problems we identify together with ELPA member of the country we visit.

ELPA@Home is a service provided to the members in which ELPA experts visit different countries and work with various stakeholders (NGOs, patients, physicians and media) to improve their activities and to build a broader coalition.



HCV elimination Advisory Board meeting

On the 1st of February Gilead has held **HCV elimination Advisory Board meeting** where ELPA was represented by **Marko Korenjak**.

He has stressed that elimination of HCV is not possible without collaboration with patient groups who are responsible for raising awareness, having strong patient voice, connecting health care providers, politicians and other important stakeholders.

It is thus critically important for elimination of HCV to form new patient groups in countries without patient activities and to educate them on the role and the scope of impact of patient organizations.



EASL monothematic conference

“Striving towards the elimination of HCV infection”

Berlin 02-03 February, 2018

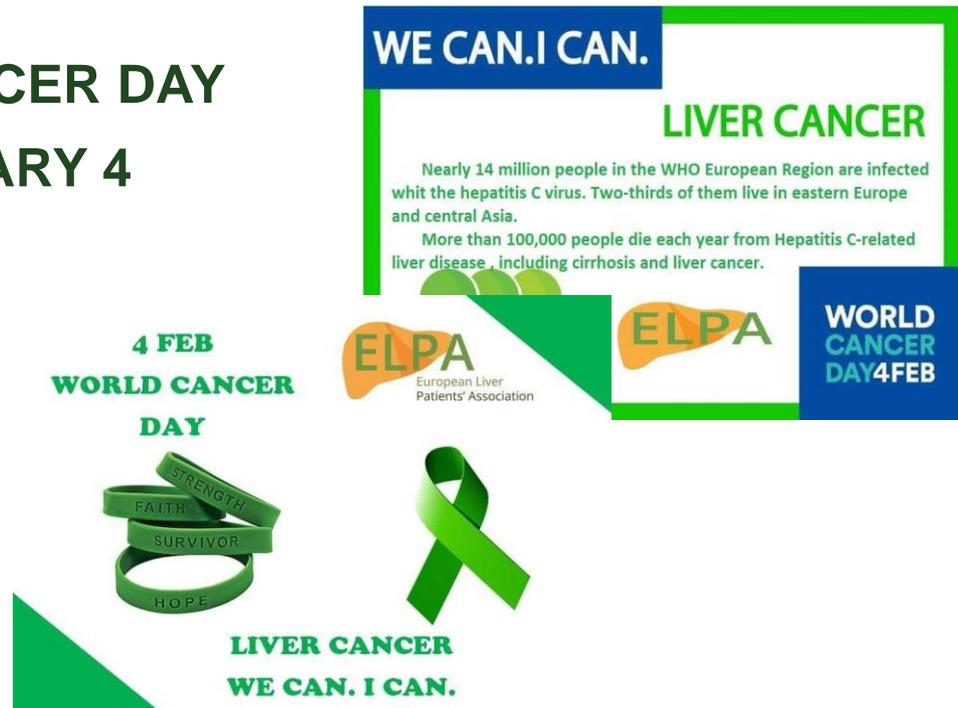


The aim of this 2 day Conference was to bring together major stakeholders in the field of HCV and combine their expertise to better understand the burden of HCV, strategies to enhance prevention, testing, linkage to care and treatment, and current progress and future directions for working towards the WHO goal of eliminating HCV by 2030. As an invited speaker in the session “How far are we from reaching the WHO targets of HCV elimination?” ELPA President **Tatjana Reic** gave a lecture entitled the Role of patients.



LIVER CANCER DAY FEBRUARY 4

In order to support and raise awareness about increasing number of deaths caused by liver cancer ELPA marked the **Liver Cancer Day** through social media campaign and by posting a video clip with message from ELPA President on February 4th 2018.

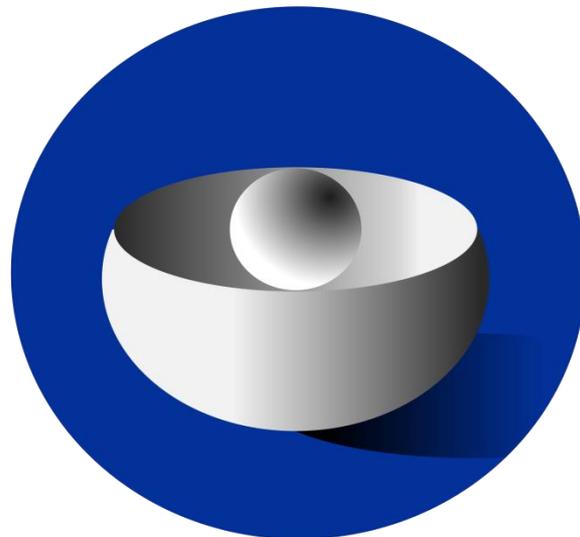


Board meeting in Berlin and changes in ELPA team

The Board meeting took place on 3 and 4 February in Berlin. During the meeting, members of the Board have heard the update on projects that are in progress, as well as overviewed plans for 2018 and discussed potential new members. As recognized a while ago, since ELPA has grown up rapidly last half a decade, the need of employing a person within headquarters in Brussels office became more and more obvious. In order to keep the established ELPA's operations running smoothly, in 2017 ELPA Board has decided to employ **Lana Crnjac** as of Feb 5 2018. She has so far been intensively included in overseeing ELPA's activities over the 2017 as well as assisted in their coordination. She was invited to take over the role of the **Interim CEO**.

ELPA remains European Medicine Agency's (EMA) eligible organization

After finalizing re-evaluation of ELPA's eligibility at the beginning of February, Head of EMA's Public Engagement Department **Mr. Juan Garcia Burgos**, kindly informed us that we continue to comply with the definition of patient's/consumers' organizations and fulfil all the necessary criteria.





ECDC expert panel meeting on HBV, HCV and HIV testing

Ad-hoc scientific panel consultation
Testing for HBV, HCV and HIV

ECDC, 5-7 February 2018

Monday, 5 February

ELPA President attended *high level expert panel meeting* organized by ECDC from 5th - 7th February in Stockholm.

The scope of this 2.5 days meeting was to review the body of evidence on **HBV, HCV and HIV testing in the EU/EEA** resulting from the systematic reviews and the complementary evidence gathering activities, as well as to formulate evidence-based options for implementation based on a consensus-building approach.



SESSION 1: INTRODUCTION
TO, LARA TAVOSCHI and for the meeting and the scope
ing guidance for HIV and hepatitis B and C (L Tavoschi)
testing (P Easterbrook)
ty to develop public health guidance (H Carvalho Gomes)
and analysis (S Croxford; L Mason)
b)
PRIMARY HEALTH CARE
e body of evidence and formulate evidence-based options for implementation
synthesis and draft advice (S Desai)
e-defined questions [REF session working document]
GENERAL POPULATION HCV TESTING AND HIV TESTING INDICATIONS
e body of evidence and formulate evidence-based options for implementation
(L Mason)
considerations from Ireland (E Robinson)
considerations from France (Y Yazanpanah)
e-defined questions [REF session working document]
ting – results from OptTEST WP6 (Y Yazanpanah)
e-defined questions [REF session working document]

ELPA@Home, Cyprus

A very successful ELPA @ home project continues this year with Cyprus where 2 days of **ELPA@home** workshop were organized due to the fact that many challenges are in front of the hepatitis elimination process. On day one **Marko Korenjak** and ELPA@Home Project Leader **Julio Burman** held a workshop with NGOs who are working on Thalassemia, liver transplantation and PWIDs. Although they are all committed to the elimination of viral hepatitis, it was first time ever they were sitting together at the same table. The second day was organized to hear about specific problems from governmental and clinicians' perspectives. The workshop was closed by **Tatjana Reić**, President of ELPA, who addressed the participants and expressed satisfaction with the successfully conducted meetings, followed by Press conference.



A year-long capacity building programme *on liver health and advocacy.*



ELPA University - Cyprus

A course, designed in 3 – 4 modules, has been developed to enable ELPA members to confidently advocate for improved liver health services and care within their countries.



In 2018 we have continued with the good practice and organized a Year 3 module 2 for patient groups' representatives in Cyprus from 11-14 February.

ELPA University Year 3 *Module 2*

The module was consisted of two and a half days of training, with nine theory sessions and two practical workshops.

The training was led by six expert speakers including **Jeffrey Lazarus**, *IS Global* and **Bridie Taylor**, *World Hepatitis Alliance*.

A total of 13 participants from nine different countries attended ELPA University Module 2.



Board meetings and changes in ELPA Board

ELPA Board met in Brussels on 22nd of February to interview the candidate for the **membership in ELPA**: Schweizerische Hepatitis C Vereinigung, represented by their President **Daniel Horowitz**. On that occasion Board members have also discussed the updates on projects and activities, as well as the co-option of the new Board member who would join others in representing ELPA and its mission. The Board has decided to offer this position in the Board first to **Teresa Casanovas** from ASSCAT, clinician and the member of ELPA Scientific Committee. After the Board meeting in Brussels, Teresa was contacted, asked whether she would be interested in this position and following her confirmation, on 28th of February, the ELPA Board co-opted her at an extraordinary session. The vote on Teresa's accession to the Board is expected at the upcoming AGM in Paris.



Liver Screen project meeting

ELPA was part of a **kick-off meeting** held on 26th of February in Barcelona, for the project **LIVERSCREEN**, supported by European Institute for Innovation and Technology - section for health (EIT Health). On that occasion **Marko Korenjak** presented the "Role of ELPA in the dissemination of Liver Screen information".

In the first phase, the project will include screening for early detection of liver diseases in general population in Spain (Barcelona) and in France (Paris).

In the next phases, it will include more centers in several countries including also the screening of 20 000 people in Europe with **FibroScan**.

This is going to be the biggest screening project for early detection of liver diseases in general public in Europe. ELPA is responsible for dissemination and communication part of the project.



ELPA Scientific Committee

Together with **Marko Korenjak**, members of our **Scientific team**, under the leadership of **Ingo van Thiel**, have been working since last summer on preparation for ELPA Symposium to be held at ILC 2018 in Paris entitled "Symptom management across liver diseases" Is there a big picture".

Hard work has recently come to its final phase and is announced at EASL's on line programme at

<https://program.m-anage.com/ilc2018/en-GB/ProgramSearch/Program/?programid=52816>

With this year's symposium, we would like to take a new approach to symptom management rather than look at one particular liver disease and its symptoms, we would like to look at frequent symptoms, and compare their causes and management options across a variety of liver diseases.

The Scientific team has been strengthened recently with a new member - **Teresa Casanovas**, ASSCAT



Announcing the Spring European Testing Week

SPRING EUROPEAN TESTING WEEK
18-25 MAY 2018

Test.Treat.Prevent.
Test for hepatitis, HIV and STIs

Spring
EUROPEAN
HEPATITIS-HIV
TESTING
WEEK
18-25
MAY
2018
TEST.TREAT.PREVENT.
www.testingweek.eu



#springtestingweek

"Nice occasion
although this

"This has proved
approach to show
possibility to org
MSM testing at
are using ETW el
advocate for sim
activities during t
year."

Announcing t

We have read your comm
therefore, we are pleased

For 2018, in collaboration
Association, the Testing W
will provide another opportunity to promote testing and
increase awareness of knowing one's hepatitis/HIV status and assess interest and feasibility of
having more than one Testing Week during the year. Additionally, this pilot will focus on integrated
testing for hepatitis and HIV and identify the barriers that ETW participants experience in
implementing integrated testing throughout Europe.

**Spring Testing Week is not replacing the annual European Testing Week that occurs
during the last week of November.**

The European Testing Week initiative will still carry out Testing Week in November (which is planned
for 23-30 November 2018).

**If you would like to participate in the Spring European Testing Week pilot, please sign-
up and register!**

Please do not hesitate to contact us if you have any questions, send all questions to
hie.rigshospitalet@regionh.dk

Stay tuned for more information soon!

We are always here for you throughout the year

We are always available to answer questions. Please email your questions
to hie.rigshospitalet@regionh.dk and follow us on **Facebook** and **Twitter** to get regular updates!

In 2018 will be piloting the first Spring European testing week. The testing week will be held on 18th – 24th of May throughout the Europe, in collaboration with [INTEGRATE Joint Action](#).

Hepatitis community has been demanding the additional testing week for a long time now and in that light ELPA has started this initiative supported also by the World Hepatitis Alliance.

As representatives from ELPA member organizations, on behalf of those affected by and at risk of hepatitis C we demand that hepatitis testing is given the importance it deserves in such that the Hepatitis testing week be a separate event from European HIV-Hepatitis Testing Week and moved to the week of May 19th (previous World Hepatitis day).

To learn more about ELPA's initiative please follow this link:

<http://www.elpa.eu/news/feb-2018/request-additional-testing-week>

EUROPEAN LIVER PATIENTS' ASSOCIATION

REQUEST FOR VIRAL HEPATITIS TESTING WEEK

Signature page:

	Organization:	Representative:
1.	RHC	Tove Frisch
2.	ALPC	Ammal Motwally Dr. Amma
3.	HAA-Hepatitis Aid Austria	Angelika Wölflinger
4.	ASSCAT	Teresa Casanova
5.	Deutsche Leberhilfe e.V.	Ingo van Thiel
6.	Soc Hepatitis	Glória Rodrigues
7.	Hepactive	Silvana Desidrenska
8.	HEPYASAM	HILAL UNALMIS DYDA Zdenka Simonovic Dmytro Koval CREPU MIHAELA SANA VISIC Rachal Haljuel
15.	LIVER PATIENT ASSOCIATION TROMOS - SERBIA	Ivana Petrovic
16.	Hepoz Centor Bioloq. Macedonia	Milica Miroslav
17.	BPAC ONCOS	Marek Bestek
	SARAJEVO HEP	Marko Komar

PBC Webinar in 2018 - next steps-

The PBC Network Group Call was held on Tuesday 13 March. ELPA President, **Tatjana Reic** and representatives of PBC network were discussing the work strategy for 2018 as well as future activities envisaged with the strategy.



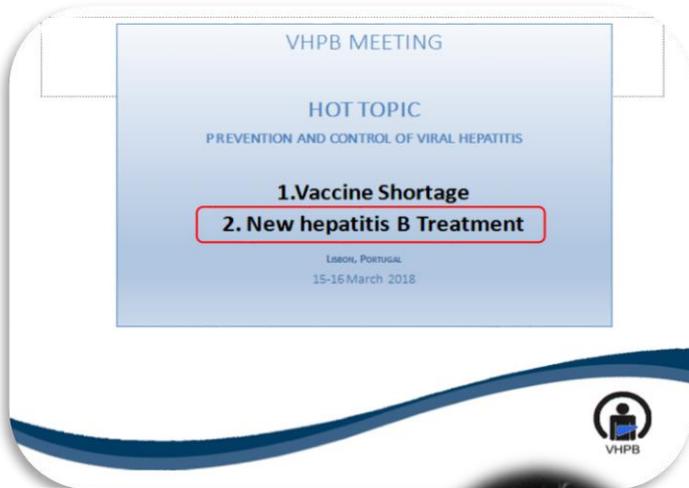
VHPB meetings

On March 14 VHPB Advisory meeting took place in Lisbon, Portugal and was followed by a Technical meeting on 15-16 March 2018 entitled **Hot Topics in prevention and control of Viral Hepatitis** divided in 2 sessions covering **Vaccine shortage** and **New hepatitis B treatmentl**.

Vaccine shortage sessions objectives were to: discuss the actions that are needed to avoid future vaccine shortages and minimize the impact of hepatitis vaccine supply constraints on public health, review the current hepatitis A and B vaccine supply constraints and the (potential) impact on public health and to investigate the role of different stakeholders. Intended Impact of this session was to have an overview of the current hepatitis vaccine shortage situation, the involved stakeholders and a proposal for the possible way forward to minimize the impact on public health and to avoid future shortages.

2. New hepatitis B treatment objectives were to present an overview of the different new treatment compounds that will be available in the (near) future and their impact on transmission, morbidity and mortality caused by hepatitis B, discuss the synergies, competition and lessons learnt between /from hepatitis C treatment, all in a public health framework. Intended Impact of this session was to inform public health policymakers on what can be expected on hepatitis B treatment in the near future and evaluate their preparedness. At the meeting were present hepatitis community representatives - stakeholders, opinion leaders, policymakers, healthcare professionals, experts from different European, international organizations, VHPB advisors and a selected number of observers.

Together with prof. dr. **Mojca Matičič** ELPA President, **Tatjana Reič** was chairing a panel discussion session Investigate the public health needs to implement hepatitis B treatment protocols in the European countries and the impact they will have on the WHO's hepatitis elimination goals.



Meeting of Minds



A number of patients' representatives associations have met in London on 15th of March for a meeting focused on people aging with HIV and possible complications that can follow. Vice President **Marko Korenjak** attended this meeting speaking about the problem of people aging with HIV as they develop liver damage because of the treatments prescribed, as well as the about the aging co-infected patients. The group containing cancer, kidney, mental health and many other disease focuses explored the possibilities of joint actions to support the activities of HIV community.

WHO and civil society meeting on HIV, TB, Hepatitis, STIs and UHC

ELPA participated at the **WHO and civil society meeting on HIV, TB, Hepatitis, STIs and UHC**, held in Geneva on 22-23 March. At this two day meeting the participants underlined that “universal health coverage and communicable diseases” is not an either or agenda or an end to vertical programming, but that universal health coverage suggests we should be collaborating closely to rethink how disease programs are designed and delivered in the future. During the meeting participants worked on the draft discussion paper, which will be finalized by the end of April and made available for sessions at key events later this year including the World Health Assembly, the AIDS 2018 Conference in Amsterdam and the United Nations High Level Meeting on Tuberculosis.



Technical Consultation on development of National Action plan for Viral Hepatitis

Upon the invitation from ELPA member patients' organization Hepar - Centar, Bitola, WHO held **Technical Consultation on the development of National Action plan for Viral Hepatitis** held in Skopje, on 23-24th March 2018.

The overall purpose of this National technical consultation was to identify national strategic directions as a basis towards a national action plan for viral hepatitis prevention, control and management in Macedonia.



Technical Consultation on development of National Action plan for Viral Hepatitis (cont.)

The meeting aimed to gather National Experts and other international Key participants in order to contribute to an overall assessment of the Hepatitis situation.

To define the problem in the country through sharing of available data and information about the magnitude, scope, characteristics and consequences of viral hepatitis.

Identify the challenges and opportunities to develop a national action plan for elimination of viral hepatitis, define strategic priorities (goals, objectives, targets, activities) for achievable interventions in the next 4 years.



Technical Consultation on development of National Action plan for Viral Hepatitis (cont.)

Agree on further steps to advocate, initiate and roll out the 4-year national Plan of action for elimination of viral Hepatitis based on the WHO regional and global action plans with goals to draft Outline of National Action plan with identified priorities for the next four years and to form a national technical working group to support MOH oversees the development of an operational plan and the roll out implementation.

During the meeting ELPA's President **Tatjana Reić** moderated Session 7: Reducing costs – access to affordable medicines and diagnostics and ELPA's member **Ivana Dragojević** from Hronos, moderated the Session 8 with Prof. dr. **Viktoria Čalovska**.



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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