Dear Readers,
Welcome to the February’s issue of the ELPA newsletter!

At the end of 2012, an ELPA Advisory Board Meeting took place in Istanbul where members of the Steering Committee met representatives of the pharmaceutical industry to discuss new medical developments. A few days earlier, the European Medicines Agency gathered patients’ organizations to discuss numerous important issues, including policy on conflict of interests and funding of patients’ organizations.

At the outset of the new 2013, the vigorous members of the Steering Committee of ELPA repeatedly demonstrated their strong commitment to affirm the significance of liver disease by attending multiple conferences throughout Europe, namely, the Conference on Hepatitis B and C in Mediterranean and Balkan Countries in Cyprus, the 20th Hadziyannis HBV/HCV Meeting in Greece and the National HCV Meeting in Ukraine.

Moreover, the activities of member organizations of ELPA comprised an educational HCV programme and screening and counseling campaign in Spain organized by ASSCAT, the development of a National Hepatitis Strategy and an Action Plan in Croatia supported by HULOH Hepatos, a presentation of the results of the Euro Hepatitis Care Index in Romania (APAH-RO) and the commemoration of the World Hepatitis Day 2012 in Italy with the notable involvement of EPAC. In terms of industry news, we offer to your attention the latest social involvement initiatives of Boehringer Ingelheim and Janssen.

Enjoy your time reading!

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With the approval of the first generation of direct acting antivirals in 2011, chances of curing hepatitis C have drastically increased. However, the first generation of antiviral drugs still has to be combined in the form of the so-called triple therapy with peg-interferon and ribavirin. The current standard therapy benefits only some patients due to additional side effects, drug interactions, resistant viruses and contraindications. Therefore, the patient community eagerly awaits improved treatments with fewer side effects and even better efficacy. At the AASLD liver congress in Boston in November 2012, some of the new treatments achieved cure rates between 85 to 100% in selected patients, with and without interferon. Data for more difficult-to-treat patients is still limited, but urgently expected: many patients who cannot benefit from today’s therapies are already seriously ill and in dire need of improved treatments.

In the context of these developments, ELPA invited the companies Abbott and MSD to present data from their ongoing trials with approved and experimental hepatitis C drugs, especially their pipelines of interferon-free therapies.
The European Medicines Agency Meets Patients’ Organizations

On November 30, 2012 the Human Scientific Committees’ Working Party with Patients’ and Consumers’ organizations (PCWP) met with the entitled organizations to discuss the involvement of patients’ organizations in the activities of the European Medicines Agency (EMA). The meeting touched on numerous challenging issues such as the policy on conflict of interests, funding of patients’ organizations, training strategy and benefit/risk evaluations. Furthermore, the participants in the event discussed the not less important issues new legislation on pharmacovigilance, the Innovative Medicines Initiative and the European Patients’ Academy on Therapeutic Innovation. The European Liver Patients’ Association was represented at the event by Mr. Ivan Gardini, Vice President and Dr. Stanimir Hasardzhiev, Executive Director.

Conference on Hepatitis B and C in Mediterranean and Balkan Countries

December 2012 was marked by an extremely important event in light of the fight against hepatitis which addressed the pressing questions of prevention, diagnostics and treatment Mediterranean and Balkan countries which are rather challenging in this respect. Held on December 5-7, the Conference on Hepatitis B and C in Mediterranean and Balkan Countries laid the ground for precise discussions over existing and new data and promotion and management of new policy approaches to tackling the issue.

Organized by the Hepatitis B and C Public Policy Association and under the auspices of the Cyprus Presidency of the Council of Ministers of the European Union, the Conference was truly great in scale and commitment for it gathered key EU-level officials, health associations and medical and high-level political representatives from a number of countries in region. The Conference in Cyprus aimed to reaffirm the need for the Call-to-Action which outlines six crucial measures to improve awareness, prevention and surveillance policies, enhance access to cost-effective technologies and therapies including counseling and to further expand the research pool for the hepatitis disease. The Call-to-Action is vigorously supported and promoted by the European Association for the Study of the Liver (EASL), the European Liver Patients’ Association (ELPA) and the World Hepatitis Alliance (WHA).

The Hepatitis B and C Public Policy Association is strongly determined to facilitate the implementation of targeted policies and programmes both at the national and international levels to effectively address the problems of patients with hepatitis. Among the other valuable initiatives of the organization are the 2010 Summit Conference on Hepatitis B and C in Brussels which enjoyed an independent supplementary in the Journal of Viral Hepatitis, a quarterly newsletter, high level meeting of policy experts in London in 2011 and close collaboration with the relevant EU institutions.

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The newly founded Hellenic Liver Patient Association (HELPA) has already (prior to its foundation) been creating active contact with the scientific community and so it continues to do, participating in numerous Hepatitis congresses and meetings in Greece and abroad. The most recent meeting, the 20th “Hadziyannis” International Hepatitis B and C Meeting (named after Honorary Prof. Stefanos Hadziyannis) took place in Athens in January 26-27 2013 and was organized by Hepatitis B & C association and the Hellenic Association for the Study of Liver.

The two-day meeting offered well documented presentations and lectures as well as broad discussions. More specifically, the dialogue focused on the latest epidemiological, clinical, laboratorial, genetic and therapeutical data as well as on the parameters of Hepatitis B and C and their complications around the globe. Among granted scientists invited from abroad we had the honour to attend lectures by professors R. Esteban and M. Buti from Spain and K. Agarwal from the UK.

Additionally there were round tables and presentations upon the sociological and state issues related to the disease, its management and its impact on public health, especially those in Greece and other European countries, in times of long term financial crisis and recession. Particularly interesting facts were presented by Mr Stanimir Hasardzhiev, Executive Director of ELPA, on the Euro-Hepatitis Index and the good practice examples in Bulgaria and Croatia. On behalf of the Greek patients, Mr George Kalamitsis, president of HELPA, introduced the new patient association to the audience and stated its first official activities and immediate targets. Mrs Niki Voudouri, representative of the Greek NGO PRAKsis. displayed the exceptionally significant activity taken by the organization in the streets of Athens, on Hepatitis B and C and HIV testing of intravenous drug users and other special populations vulnerable to the above infections.

On the other hand, special data on intervention in the IVDU population of Northern Greece were presented by the Greek state organization against drugs (OKANA) and vivid discussion was initiated by Mr. P. Efstathiou, head of the Greek National Health Utilities Center, an essential health administrative organization that coordinates the administration of hospitals as well as various state interventions in the field of public health. Among other issues, Mr Efstathiou is responsible for state health provisions for migrants and citizens without insurance. In his presentation he stated that he Greek Health Department intends to take special care for the treatment of the above mentioned viral infections in these sub-populations. However, participants expressed that they were not convinced by the data he displayed.

HELPA in collaboration and with support of Professor of epidemiology Dr.Hatzakis is already planning a meeting with Mr. Efstathiou, in which we intend to state the critical issues of billing and insurance coverage of the molecular diagnostic tests for Hepatitis B and C as well as the medication coverage for all infected patients within the country, regardless their legal or insurance status. For that reason we are already in contact with experts from the University Dept. of Health Finance in order to obtain a relevant cost-effectiveness analysis.

Source: George Kalamitsis
At a roundtable discussion titled "Access to treatment of hepatitis C in Ukraine: Prospects for program management" during the National HCV Meeting (January 16-19, 2013) in Kiev, Ukraine, was affirmed that the situation around the hepatitis C epidemic in Ukraine is critical. According to WHO, 3.5 million Ukrainians are infected with viral hepatitis (B and C), which is 8% of the country's population. Ukraine has the highest viral hepatitis growth rate in Europe. At the same time, the country has no government strategy to combat the epidemic: there is no approved national program to contain the spread of viral hepatitis and no national treatment guidelines. Since Ukraine gained its independence, the Government has never funded measures to treat and prevent this dangerous disease. Because of market monopolization and lack of social responsibility on part of pharmaceutical companies, the cost of medical treatment for viral hepatitis in Ukraine stands at UAH 115,000 per year, which is several dozen times more than the minimum wage of an average Ukrainian.

Thanks to advocacy efforts made by patient and community groups, in late 2012 the President of Ukraine signed the Order “On certain matters related to preventing the spread of TB, HIV/AIDS and viral hepatitis epidemics”.

With such consideration, the patients who participated in the roundtable demanded the following:

1. The epidemic of Hepatitis C is recognized by the State and National Program and Clinical Guidelines to prevent and treat viral hepatitis should be approved in 2013;
2. The drugs to treat hepatitis C should be made available in Ukraine with the state budget funds already in 2013;
3. The Egyptian national model for overcoming hepatitis C epidemic should be implemented in Ukraine, including reduction of drug prices to UAH 16,000;
4. Promotion the inclusion drugs to treat hepatitis C in the WHO Model List of Essential Medicines by the state bodies and NGOs.

Source: UCAB
ASSCAT and gTt-VIH, with the Collaboration of FNETH, Create an Educational Health Programme for Hepatitis C Patients

Maintaining good adherence is, in all likelihood, one of the most important challenges in the therapeutic approach of any disease. The arrival of new direct-acting antiviral agents against hepatitis C virus genotype 1 has provoked a dramatically improvement of efficiency with a subsequent increase in complexity in terms of dosage schedule, the number of pills, dietary restrictions or other high-impact decisions, such as problems related to toxicity.

In this new scenario of treating hepatitis C, the use of new antivirals requires a high level of patients compliance to the given prescription regimen to avoid the development of viral mutations that confer resistance to drugs. The adhesion control depends almost exclusively on patients so good adherence is mandatory throughout treatment. To this end, it is essential to educate patients about to start treatment with a protease inhibitor against HCV in the appropriate use of these drugs. For instance, introducing key concepts such as adherence (what is it and how to maintain a good level) and drug resistance (how does it develop and how can it be avoided).

Asscat and gTt-VIH have created an educational health program for hepatitis C patients to address the matter of adherence to new antiviral treatments and facilitate empowerment to patients. In order to do that, several educational talks will take place in different cities of the Spanish territory (Zaragoza, Oviedo, Barcelona, Bilbao, Valencia and Madrid in the first phase) and there will be a publication of a guide to new treatment options for hepatitis C. This educational guide explains, in easy to understand language, the challenges of making a combination therapy for hepatitis C, and addresses, among other things, how the triple therapy for HCV works; why it is important to maintain good adherence to treatment, and what advices are useful while taking prescribed medication and keeping oneself healthy during the treatment.

The guide will be available soon in patient organizations, NGOs and the units of digestive diseases and infectious of Spanish hospitals. Furthermore, the guide will be also accessible to download as a PDF at the websites of the ASSCAT (www.asscat-hepatitis.org) and gTt-VIH (www.gtt-vih.org).

On 20th November 2012 the ASSCAT and Spanish Red Cross carried out an act of solidarity and information on Hepatitis C in Barceloneta (Barcelona). This activity is part of a public awareness plan on hepatitis C that ASSCAT conducted several times during 2011 and 2012. The main idea is to offer a rapid test to detect antibodies of HCV (swab of saliva) as well as counseling and information leaflets. This test allows rapid diagnosis in 20 minutes without involving drawing blood. The type of test is anonymous (only questions regarding age and country of origin are included). The activity was carried out thanks to the the volunteers of Red Cross and ASSCAT, with the help of a Red Cross ambulance.

Source: ASSCAT
Croatia has taken the 8th place in the European Hepatitis Index.

The 8th place among 30 European countries is a good result for a small country like Croatia, especially because they leave behind many richer countries such as Norway, Switzerland, Belgium, The Netherlands, Austria and many more.

The European Hepatitis Index shows that Croatia is successful in prevention in comparison with other countries, and the good result is largely owed to routine vaccination of newborns, which results in protection of over 90% of the Croatian children. At the same time, only some of the biggest risk groups are routinely vaccinated, among them are healthcare workers, family members of HBV patients and drug addicts.

According to the results of the Index, Croatia still has a lot to do in advancement of treatment of viral hepatitis, because the newest drugs and treatments are still not available in the country.

The Index is also highlighting the shortcomings in screening of the population, because it is still not easy to find free and anonymous testing and counseling, even though screening for hepatitis is subsidized by the healthcare system.

Routine screening is not conducted in a systematic manner, neither in the general population, nor among the members of the risk groups.

As a result, the creation of the Croatian National hepatitis strategy and Action plan began in July 2012 - a very important step that has largely contributed to Croatia’s ranking in the Index.

The expert group that is developing the National strategy, composed of leading Croatian experts and coordinated by Dr. Irena Hrstic, met on February 1st in Zagreb and agreed on further active involvement in its advancement.

The first measure from the draft strategy and action plan, that could be implemented even before the document is finished, is the circular letter that is going to be sent to all Croatian GPs aiming to improve case-finding among the risk groups.

The letter recommends the GPs to send to serological testing (viral hepatitis markers: HBsAg, antiHBs, antiHBc, antiHCV) all their patients who belong to risk groups, if that hasn’t been done already.

The initiative is supported by the Referral center for diagnostics and treatment of viral hepatitis of the Ministry of Health, Croatian Society of Gastroenterology, Croatian Society of Infectology, Croatian Institute of Public Health and the Croatian Alliance of Hepatitis Patients.

Only several countries in Europe have implemented national hepatitis strategies and action plans, namely France and Scotland, and there are several other countries that are still in the process of development of their national plans (Germany, Bulgaria, Greece and Croatia). With this initiative Croatia joined the small group of countries that have seriously committed to tackle this vicious disease.

Read more...

Source: HULOH Hepatos
On November 6, 2012 the Romanian organization of patients with hepatitis APAH-RO presented the EURO Hepatitis Care Index in Bucharest. Ranked 25th among the 30 countries included in the survey, Romania demonstrates unsatisfactory results in terms of hepatitis screening, treatment, prevention and patient involvement. According to the Euro Hepatitis Care Index, Romania achieves better patient care and treatment as compared to the Czech Republic, Hungary, Latvia, Estonia and Lithuania.

Despite the strict routine vaccination of infants, there are serious prevention weaknesses, namely, lack of systematic vaccination of risk groups and reimbursement paths and limited access to innovative therapies. Romania further experiences deficiencies in screening characterized by lack of government funding, counseling and anonymous free testing as well as absence of policies to ensure routine screening in high risk groups.

In light of the results from the survey, Marinela Debu, President of APAH-EN, outlined the need to adapt and implement good practices from other countries. She further emphasized the importance of raising public awareness about the risk of exposure to hepatitis, to ensure universal access to treatment with particular attention to those citizens who have undergone blood transfusion or surgery before 1995, relatives of patients and care-givers.

In recognition of the significance of the issue, Prof. Dr. Victoria Arama, MD (National Institute for Infectious Diseases) said: "I think this Index will be a great tool for health authorities and for the entire system to better assess what our country needs to do next, what deficiencies exist at the moment and what can be done to improve both in terms of prevention and early diagnosis of the disease to ensure access to treatment for patients."
On November 9, 2012, Boehringer Ingelheim Pharmaceuticals announced the launch of HepCRedefined.com, an online portal to help improve the lives of those living with the hepatitis C virus (HCV) through education, information and understanding. HepCRedefined.com aims to redefine the HCV journey by providing downloadable and shareable resources to healthcare providers, advocates, caregivers and patients.

In order to bring together information that is most relevant to those impacted by HCV, the portal was developed in close collaboration with HCV community advocates as well as healthcare practitioners who are currently treating HCV patients. Resources available on the portal can be shared via social media channels, embedded on other web sources and viewed on various smart devices.

HCV is an infectious disease of the liver and is a leading cause of chronic liver disease, transplant and failure that affects as many as 150 million people globally. Since 1999 there has been a significant increase in deaths due to chronic HCV, accounting for 15,000 deaths in the United Sates in 2007.

“The entire HCV community is in need of simple tools and resources to talk about the disease in an informed, supportive way. There is information about HCV across the web, but HepCRedefined.com is designed to aggregate straightforward and accurate information in a single virtual destination,” said Michael Ninburg, Executive Director, Hepatitis Education Project. “I’m proud to have contributed to the development of HepCRedefined.com and look forward to working with other advocates to reach communities nationwide.”

HepCRedefined.com offers tips and tools to facilitate discussion about HCV, including:

- A video series for healthcare providers offering tips on support sources, clinic program highlights and patient diaries
- A comprehensive and interactive checklist tool to help patients manage considerations of being in care and getting ready for treatment
- A frequently asked questions section about the spread of HCV
- A key facts page about HCV mortality
- A page featuring multiple at-a-glance information cards covering topics about patients and the disease itself designed to help debunk myths surrounding HCV
- A community “C Pledge” where healthcare providers, patients and caregivers can take an oath to redefine the patient journey and the way HCV is perceived

“Boehringer Ingelheim understands that the HCV journey can be a difficult process for patients, caregivers, healthcare providers and advocates alike,” said Steve Smith, Vice President Established Brands, Boehringer Ingelheim Pharmaceuticals, Inc. “Through our work with the HCV community to develop HepCRedefined.com, we hope to offer support to the many individuals impacted by HCV with useful information and interactive resources that are easy to find. The more we empower ourselves to learn about the challenges associated with HCV, the better we will be able to provide patient management and come closer to a cure for this disease.”

Follow Boeringer Ingelheim on Twitter at https://twitter.com/boehringerus
A new Economist Intelligence Unit (EIU) report titled “The Silent Pandemic: Tackling Hepatitis C with Policy Innovation”, supported by Janssen, was launched recently.

The report investigates the health challenge posed by the hepatitis C virus (HCV), and how systemic innovation can minimise its impact, the findings of this report are based on desk research and interviews with a range of healthcare experts.

The report, launched at a global media event (watch the recorded webcast here) in London, highlights the urgent need for countries around the world to develop strategies to tackle head-on the growing health, social and economic issues associated with HCV. Charles Gore, President of the World Hepatitis Alliance, who was interviewed for the report, represented the patient perspective at the event speaking specifically on challenging the stigma associated with hepatitis C.

While the total magnitude of HCV is unknown due to a lack of available data, the World Health Organization (WHO) estimates that approximately 150 million people globally are currently living with the blood-borne infectious disease, HCV. Of these, up to two-thirds will develop chronic liver disease and one in five will develop cirrhosis. HCV is also the leading cause of liver transplants worldwide and, in the US, the disease now accounts for more deaths than HIV.

The report also highlights that worldwide, despite the significant burden of HCV, governments have failed to ascertain the scale and impact of the disease. In both developed and developing countries, the true human, social and economic cost of HCV will continue to rise unless policy makers confront this urgent public health issue now.

Despite the devastating effects of HCV, the report states that it is now considered preventable and largely curable due to recent advances in treatment. The report notes, however, that as few as 10% of patients are currently receiving treatments and there is a large disparity in care across countries.

As a result, the report calls for countries to take a “comprehensive approach” which takes into account local needs and available resources. This includes the following:

- Effective disease surveillance to create an accurate picture of the problem and ensure effective policies can be developed. The report claims that too few countries – developed or developing – have recently conducted the epidemiological studies necessary for good policy-making at a national, let alone a local, level. In the EU alone, 16 countries have epidemiological data that is either poor or non-existent.
- Better public awareness is needed to help remove the stigma associated with the disease and create better understanding of HCV. A survey by the European Liver Patients Association found that only 20% of those diagnosed had heard of hepatitis B or C before being told they had it.
- Prevention measures to prevent high-risk behaviour and education on healthy lifestyle choices for those already infected. The report also calls for measures to prevent transmission via healthcare systems, which are the major route of transmission of HCV in developing countries.
- Innovative ways to reach out to patients to ensure those who need treatment receive it before end-stage conditions develop.

For more information and to download the report visit www.janssen-emea.com/The-silent-pandemic
On November 28, 2012 Italy commemorated the World Hepatitis Day 2012 (WHD 2012) with a press conference at the Ministry of Health with the participation of the Italian Hepatitis Alliance (ACE). The event marked the efforts to fight viral hepatitis and further encouraged discussions over concrete measures to address the disease, namely, a development of a national strategic plan and a corresponding awareness campaign over the radio. Young doctors, representatives of companies and institutions were awarded for their actions and initiatives against hepatitis and liver disease.

The Italian press-conference gathered government officials and patient representatives such as the Hepatitis Alliance (ACE), a coalition between FIRE Fund (Italian Foundation for Research in Hepatology) and EpaC (Association of Patients with Liver Disease) which aims to increase social sensitivity and the sense of urgency for the management of viral hepatitis. The discussion highlighted the need for the development of a National Health Plan to ensure early diagnosis and treatment, accelerated access to treatment and the establishment of specialized centres to conduct major research projects.

The World Hepatitis Day 2012, organized by the European Liver Patients’ Association and the World Hepatitis Alliance, is commemorated annually worldwide on July, 28. The key message of this years’ campaign emphasized the potential threat of hepatitis which is rarely manifested with symptoms yet affects one in 12 people. The ultimate goal of the campaign: get tested!
## February 2013

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Since its foundation in 2005, the European Liver Patients’ Association (ELPA) – a not-for-profit organization with 21 members across Europe – has been at the forefront of raising awareness of liver diseases, in particular hepatitis, throughout the EU. In line with the main challenge for hepatitis carriers, which is to “become a patient”, ELPA calls for targeted screening of risk groups in order to facilitate early diagnosis and, if appropriate, treatment.

To this end, ELPA and its members have embarked on a multi-level lobbying campaign, involving EU and national policymakers, liver specialist associations and public health experts. First successes include the adoption of the European Parliament’s Written Declaration on Hepatitis C and the European Centre for Disease Prevention and Control’s (ECDC) decision to include viral hepatitis in its annual work plan as of 2008, as well as a compilation of expert recommendations on screening, which were endorsed by the European Association for the Study of the Liver (EASL).

For a sustainable change in the perception of liver diseases by the public and decision-makers in public health and a subsequent improvement of the situation for patients and specialists, it will be important for both to move beyond the immediate doctor–patient relationship and address jointly a wider audience. Essential in this context is the link to cancer.

Policymakers have to know that by taking preventative measures (primary and secondary) against liver disease, they prevent liver cancer, one of the few cancers on the rise in Europe.