

World Hepatitis Day 2010

“Hepatitis – three years after the EP Written Declaration”

European Parliament Lunch Debate

19 May Strasbourg

Introduction

With the generous support of MEPs Alojz Peterle and Thomas Ulmer, the European Parliament kindly gave permission for the European Liver Patients Association (ELPA) and the European Association for the Study of the Liver (EASL) to jointly host an event on the occasion of World Hepatitis Day on 19 May 2010.

Besides a policy discussion on the day with high-level speakers from WHO Europe and the US Institute of Medicine (IOM), this year ELPA and EASL offered free liver testing, which over 200 people took part in, including the President of the European Parliament, Prof. Jerzy Buzek (please see info box for further information).



On the left: Mr. Alojz Peterle MEP; on the right: Prof. Mark Thursz, EASL Vice-Secretary

Background

The European Parliament voiced its concern about Europe's viral Hepatitis problem as early as 2007, when it adopted a Written Declaration on Hepatitis C. In particular, the European Parliament called upon the Council and the Commission to adopt a Council Recommendation for risk-group specific screening, in order to

promote early diagnosis amongst those at risk of being infected with the virus. In its response, the European Commission pointed to the lack of comparable data in the EU, which prevented the adoption of evidence-based policies. Whilst the European Centre for Disease Prevention and Control (ECDC) has made viral Hepatitis a priority in its work programmes over the past three years (2008-2010), it has so far not yet published a report due to its heavy workload on other communicable diseases. A survey on existing surveillance systems in the EU is envisaged for the second half of 2010, based on which the agency plans to establish a surveillance network at European level to obtain reliable and comparable data.

Discussion

With the EU still trying to generate reliable and comparable data, the discussion in Strasbourg focused on another “world region”, namely the US, to identify key learnings:

Brian McMahon, one of the authors of the recent report of the US Institute of Medicine (IOM) on Hepatitis B and C and liver cancer, illustrated its key recommendations.

The situation in the US...

The IOM was commissioned by the US government with a report in light of three worrying trends:

- Liver cancer is one of few tumour types with both rising incidence and mortality in the US. The incidence rate of primary liver cancer in the US has tripled in the last 15 years.
- Annual deaths attributable to Hepatitis B and C exceed those due to HIV/Aids. In contrast to HIV/Aids, however, most Hepatitis carriers (65% for Hepatitis B and 76% for Hepatitis C) are unaware of their infection.

- Current data underestimate the true prevalence and impact of Hepatitis B and C infections.

The current lack of awareness with regard to Hepatitis B and C is mirrored by a lack of public resource allocation: only 2% of the funding reserved for the prevention of communicable diseases is allocated to Hepatitis versus 69% for HIV.

In view of this situation, the IOM recommends the following:

- A comprehensive evaluation of the national Hepatitis B and C public health surveillance system;
- Improved healthcare provider and community education;
- Integration and enhancement of viral Hepatitis services;

In detail, the recommendations entail:

- Primary prevention: vaccination for Hepatitis B of newborns and at risk persons, including immigrants; community education to improve disease awareness and transmission risks;
- Secondary prevention: Hepatitis B and C screening amongst specific risk groups during primary care; specialist referral for treatment as appropriate;
- Screening persons with Hepatitis B or C for liver cancer.

The situation in Europe...

Is similar to the US, as Mark Thursz, Vice-Secretary of EASL explained: Like in the US, liver cancer is on the rise in Europe. Contrary to public perception, the majority of the cases are linked to a prior infection with Hepatitis B or C. For him as a clinician it is frustrating to see that liver specialists mostly get to see patients only at an advanced stage of their disease due to its asymptomatic nature. This is all the more deplorable since Hepatitis is controllable (in the case of Hepatitis B) and curable (in the case of Hepatitis C) in the vast majority of cases, if treated early. Hepatitis screening amongst those at risk is a simple and inexpensive way of promoting early diagnosis and care, hence avoiding an expensive and difficult treatment of follow-on complica-

tions of the infection such as cirrhosis or cancer. Nadine Piorkowsky, ELPA President, provided complementary information from a patient perspective: A liver transplantation is frequently the last resort for ELPA's members who often have gone undiagnosed for decades. Sadly, it is by no means a guarantee for subsequent cure. Like in the US, most people in the EU are unaware of their infection: A survey, conducted by ELPA amongst 2000 patients across Europe illustrates that almost 80% did not know of Hepatitis before being diagnosed. For Mrs. Piorkowsky, the liver



On the left: Dr. Brian McMahon, US Institute of Medicine (IOM); on the right: Dr. David Mercer, WHO Europe

as a whole is an organ totally neglected by policymakers, simple liver enzyme tests being excluded from free preventive medical check-ups in most EU countries.

David Mercer, Acting Head of Communicable Diseases at WHO-Europe, pointed to the difficulties in surveillance because of the non-existent differentiation between acute and chronic cases. For him, viral Hepatitis B and C were hidden epidemics, which are poorly addressed from a public health perspective. Whilst progress has been made with regard to Hepatitis B vaccination (immunization policies of newborns or infants in place in 22 EU Member States), governments need to firmly install the prevention and control of both Hepatitis B and C on their national health agendas, promoting risk-group specific prevention programmes and equal access to evidence-based treatment. However, whereas WHO-Europe is seeking to develop a coherent regional

strategy for viral Hepatitis, the necessary funding is often lacking.

Prompted by a question from MEP Frieda Brepoels, all speakers agreed that rather than the provision of increased public funding into Hepatitis research, it was necessary to finally put in place policy measures which lead to improved health outcomes amongst those infected and decreased transmission.



EU policy options

Whilst the generation of comprehensive and comparable data is important, current deficiencies in this regard should not be used as an excuse to delay the discussion and adoption of necessary policy measures.

Pointing to ELPA's liver testing initiative in the European Parliament, which took place in the run-up to the policy lunch debate, several members of the audience highlighted that testing for viral Hepatitis could be done very cheaply and efficiently, if only it were coordinated politically.

The provision of healthcare is solely the competence of EU Member States. Nonetheless, the European Commission has a mandate, as far as health promotion and disease prevention are concerned, and can facilitate the exchange of best practice. The EU strategy on HIV/Aids is a good example in this context.

MEPs Alojz Peterle and Thomas Ulmer pointed out two EU policy initiatives which could be of particular importance when fighting the Hepatitis challenge:

- The European Partnership on Action against Cancer, which brings together representatives from both civil society and national health authorities with a strong focus on cancer prevention. It will be important that besides colorectal, breast and cervical cancer, the Partnership will equally address the prevention of liver cancer, as one of few tumour types with rising incidence.
- A Council Recommendation on Hepatitis screening, which would provide Member States with guidance on how to promote early diagnosis whilst leaving enough flexibility to determine its implementation according to their respective national situation.

ELPA's liver testing initiative in the European Parliament

With the aim to raise awareness among policy makers and other parties of the need of targeted screening of viral Hepatitis among risk groups, ELPA offered free liver tests in the European Parliament in Strasbourg on 18 and 19 May 2010.

By means of a finger prick, 200 volunteers had their ALT liver enzymes measured during these two days. The testing was carried out by qualified medical staff, using a medical device which provided test results within 2-3 minutes. This method allowed the doctor and the test person to discuss results and any potential questions and recommendations immediately, illustrating the cost and time effectiveness of such screening and testing activities.

Elevated liver enzymes are an indication for inflammation or damage to cells in the liver, which can be the origin of chronic liver diseases. Commonly known is the damage to the liver caused by excessive consumption of alcohol, however, in most cases, chronic liver diseases are in fact due to an infection with viral Hepatitis B or C. Among the 200 test persons 8% had elevated liver enzymes and were advised to undergo further testing. This result is roughly in line with the overall prevalence of liver diseases in the general population.

The President of the European Parliament, Prof. Jerzy Buzek, supported this initiative by undergoing a liver test himself.

Speaking to the press after the testing, Prof. Buzek MEP pointed out that "Hepatitis C and Hepatitis B are very dangerous diseases. Nine out of ten carriers of Hepatitis B and C don't even know that they are ill. A simple blood test can provide clarity."



Prof. Jerzy Buzek, President of the European Parliament, MEP, participated in the WHD 2010 liver testing initiative.



Prof. Buzek and Dr. Thomas Ulmer (MEP's) with ELPA President, Mrs. Nadine Piorkowsky.



About ELPA

ELPA emerged from a desire amongst European liver patient groups to share their experiences of the often very different approaches adopted in different countries. ELPA was formally launched in Paris on April 14th 2005 during the annual conference of the European Association for the Study of the Liver (EASL) and now has 20 members from 17 countries. ELPA's aim is to promote the interests of people with liver disease by furthering awareness and prevention among health-care professionals, policymakers and the public at large; by addressing the low profile of liver disease compared to other disease areas; by sharing experience of successful case examples as regards the management of the disease; by working with professional bodies such as EASL to ensure that treatment and care are aligned across Europe to the highest standards.

Find out more about ELPA at:

www.elpa-info.org

For further information please contact:

Mrs. Nadine Piorkowsky, ELPA President
European Liver Patients Association
F. De Renesselaan, 57 B - 3800 Sint-Truiden
Email: elpa-president@t-online.de

About EASL

EASL is the leading pan-European association of medical professionals dedicated to promoting liver research and care. Through its work, EASL aims to promote research in the field of liver diseases and the education of physicians and scientists as well as to improve public awareness of liver diseases and their management.

For more information on EASL, please consult our website:

www.easl.ch

or contact:

Prof. Heiner Wedemeyer
Secretary-General EASL
EASL office
7 rue des Battoirs
CH 1205 Geneva - Switzerland
Ph. +41 22 807 03 60
Fax. + 41 22 328 07 24
Email: easloffice@easloffice.eu