

ELPA



**Report on
Hepatitis Patient Self-Help in Europe
by the European Liver Patients Association
(ELPA)**

September 2010



FOREWORD

The following report showcases the work of liver patient groups in Europe, and investigates what impact, if any, they have on a country's attitude towards liver disease.

Before doing so, it is first important to reflect on a couple of questions related to the legitimization and limitations of patient groups in general, as well as the particularities of liver patient groups, more specifically.

Like other organisations in the self-help domain, patient groups are set up by people who share a common concern or problem and would like to take action. Patient groups provide fora to share experiences, exchange information and provide those affected by the disease with moral support. This "internal-facing" aspect of their work appears to be well-recognised and appreciated by non-patients, be they policymakers, healthcare professionals or the general public, who agree that patients should be best placed to provide this kind of support to fellow patients.

More problematic on the other hand seems to be the "external-facing" aspect of their work, i.e. the fact that patient groups increasingly campaign for what they call their rights, demanding access to early diagnosis, appropriate medication and generally seeking to raise awareness of the disease: "You are only representing a small fraction of patients – in our role, however, we need to consider the greater good of public health", patient groups are often told by policy-makers or public health authorities. It is certainly true that human-beings suffer from a multitude of diseases and conditions and that a specific patient group can only speak of the disease(s) its members are suffering from. It is equally true that in light of limited resources, one has to find a fair way of allocating the public health funding available according to the best possible use amongst all these different patients. Clearly, this is not an easy task.

Notwithstanding the above, one has to bear in mind that the rather abstract term "public health" means nothing else but the health of a nation. For a nation to be healthy all these different diseases need to be addressed. Out of experience, countries which do not confine themselves to spending a lot of money on treatment, fare much better in this endeavour. Instead, "good practice" countries are also sufficiently forward looking and are hence installing measures that either completely prevent certain diseases in the future, or lighten their burden. This can be done by investing in measures which lower the risk of contracting the disease, which promote early diagnosis and the development of better treatment. Naturally, from their own experience, present-day patients are in a position to give advice to decision-makers at various levels and on various issues – e.g. on how a public health campaign can be made more effective, why patients are diagnosed so late, or how adherence to treatment can be improved.

Representing 21 national patient groups who strive to be active in both the "fellow-patient/internal-facing" and "external-facing" field, the European Liver Patients Association (ELPA) does advocacy work mainly at EU level. Whilst usually covering a multitude of liver diseases, the majority of our members focus on viral hepatitis B and C. This is why ELPA, for the time being, also concentrates on viral hepatitis B and C in its policy work.

Outside the circles of public health specialists and gastroenterologists, viral hepatitis B and C are largely an unknown quantity in more than one respect – awareness, symptoms, disease classification, to name a few. A survey conducted on behalf of ELPA reveals that only 20% of patients had heard of the virus before their diagnosis and 27% knew of their risk. Furthermore, the disease is rightly described as a silent killer – it is rather asymptomatic and the disease can progress for decades with the infected person feeling unwell, but without being really sick. Then, the carrier's condition worsens rather suddenly and is frequently irreversible, because of the follow-on diseases which have developed unnoticed.

This rather unspectacular disease progression attacking an organ of which nobody quite knows what it is actually there for, might explain the rather disappointing media-uptake: there is no point denying that viral hepatitis patient groups sometimes look with jealousy at the many headlines produced by HIV/AIDS or swine flu. This is not to say that we would advocate a return to eminence-based policymaking. It is just that complete and comparable data are difficult and costly to generate and at the moment there seems to be a vicious circle: no data – no problem, no problem – no money, no money – no data and ultimately no improvement of the situation.

Despite the general lack of data (which is also related to the asymptomatic nature of the disease), there are examples of good, evidence-based action to take up the fight against viral hepatitis. In Europe, France and Scotland are examples of such good practice. More recently, and outside Europe, the U.S. have commissioned and adopted a national strategy on viral hepatitis and liver cancer.

The following survey is meant to be a tribute to all those liver patient groups in Europe which want to make a difference to current patients, but also to the great number of those who do not yet know of their infection. As such, it illustrates the patient groups' initiatives and activities, the successes they have, the problems they face, the hopes they entertain for the future. Finally, it investigates, if their work is linked to relevant policy measures.

Wishing you an interesting and insightful read.

A handwritten signature in black ink, appearing to read 'Nadine Piorkowsky'. The signature is fluid and cursive, with a long, sweeping tail on the final letter.

Nadine Piorkowsky

Table of Contents

FOREWORD	II
EXECUTIVE SUMMARY	2
INTRODUCTION.....	3
VIRAL HEPATITIS.....	4
Viral hepatitis - what it is	4
Viral hepatitis – what is its impact.....	4
Viral hepatitis - why ignorance is dangerous.....	4
Viral hepatitis – what is being done to tackle it at EU level.....	5
METHODOLOGY	6
Approach.....	6
Survey Structure	6
Patient Associations.....	6
Discussion and Dialogue	7
Viral hepatitis focus	7
Definitions	7
Limitations	7
ANALYSIS.....	8
Patient Associations.....	8
Evaluation	12
Challenges.....	14
CONCLUSIONS AND RECOMMENDATIONS.....	14
ANNEX I: COUNTRY SHEETS	16
Austria.....	16
Belgium	17
Bosnia-Herzegovina	19
Bulgaria	20
Croatia.....	21
France.....	23
Germany.....	24
Italy	26
Poland	28
Portugal.....	29
Romania	30
Slovakia	32
Spain.....	33
Sweden.....	35
The Netherlands.....	36
United Kingdom	37
ANNEX II: PATIENT SELF-HELP SURVEY	40

EXECUTIVE SUMMARY

The report aims to illustrate the important contribution patient self-help can make to a country's public health system, by supporting patients and their families, educating healthcare professionals and raising public awareness. On the basis of information received during interviews with 20 European liver patient groups concerning the viral hepatitis threat in their respective countries, good practices in viral hepatitis-related public health projects in the different Member States are analysed while identifying challenges that these groups are facing.

Patient groups vary considerable in their set-up, size and staff. They work extensively with volunteers and engage mostly in counseling and awareness raising campaigns. Although facing budget constraints on a constant basis, patient groups are the only body to provide patients with psychological support at the time of diagnosis and throughout treatment.

The awareness raising campaigns are directed at the general public as well as specific risk groups. The World Hepatitis Day plays an important milestone for their activities including free testing initiatives, distribution of information in form of flyers or brochures as well as launching advertorials in the media. A number of patient groups also directly interact with risk-groups such as drug addicts, prisoners and tattoo studios.

Patient groups engage extensively with stakeholders: in particular, the support received from specialists is well established. In addition, a number of celebrities have been cooperative and although building relationships with policy makers is not an easy task, significant progress has been made.

While access to treatment is not an issue in the majority of Member States, the greatest challenge faced by patient groups is in the area of secondary prevention, i.e. screening. Further challenges identified are the availability of sufficient scientific data on the health risk of viral hepatitis, stigmatization of the disease and insufficient cooperation on behalf of general practitioners representatives.

National strategies are therefore needed to reduce the burden of the disease by identifying and treating a greater number of viral hepatitis carriers. Furthermore, viral hepatitis does not recognise national borders. There is therefore a need for greater cross-border coordination and an EU-wide approach on how to implement screening strategies. A Council Recommendation on viral hepatitis B and C screening of risk groups would therefore be a powerful tool in this context.

INTRODUCTION

The report collates and analyses the interview responses of 20 European liver patient groups concerning the viral hepatitis threat in their respective countries; the work they do; as well as the potential success they have had in advocating for sustainable policy initiatives which seek to address and reduce this threat.

The report seeks to illustrate the important contribution patient self-help can make to a country's public health system, by supporting patients and their families, educating healthcare professionals and raising public awareness. Furthermore, the report aims to identify good practice in viral hepatitis-related public health projects which exists in some Member States at either national or regional level, and to outline the challenges that remain.

With these findings, recommendations to policymakers and relevant stakeholders will be developed on how to further improve the situation, encouraging them to engage in the fight against viral hepatitis and, together with patient groups, reduce the viral hepatitis-related burden.

The report is divided in the following sections:

- Viral hepatitis
- Methodology
- Analysis of the responses
 - Size and set-up of the patient groups
 - Sources of financing
 - Main activities
 - Targets of awareness campaigns
 - Evaluation
- Conclusion & Recommendations
- Summary of patient group responses by country

VIRAL HEPATITIS

Viral hepatitis - what it is

Hepatitis is the Latin word for liver inflammation. It is characterised by the destruction of a number of liver cells and the presence of inflammatory cells in the liver tissue. A person can develop hepatitis if they contract one of the viruses that can cause liver inflammation, or as a result of exposure to substances that can cause hepatitis such as alcohol, fungal toxins and certain medicines.

The main symptoms of viral hepatitis start with tiredness, general malaise and slight fever. It can extend to an increased need for sleep, aching muscles and joints and periodic light pressure or pain below the right ribs caused by an enlarged liver. Jaundice is a very late symptom of chronic viral hepatitis and is a sign that the disease has become serious.

However, many patients have no symptoms for a long time leading to a situation in which most infected people are unaware of their condition. The greatest challenge for patients is therefore the timely identification of their infection.

Viral hepatitis – what is its impact

In Europe, 14 million people are infected with chronic viral hepatitis B (HBV) and 9 million people with viral hepatitis C. 36.000 people in Europe die each year due to HBV-related causes, while 86.000 people succumb to HBC-related diseases. Viral hepatitis B and C are therefore listed among the most dangerous infectious diseases in terms of mortality, transmission and disease burden, comparable to communicable diseases such as influenza, MRSA and HIV/AIDS.

The majority of viral hepatitis sufferers in Europe are unaware of their condition. In the case of viral hepatitis C, estimates by the Eurasian Harm Reduction Network (EHRN - formerly the Central and Eastern European Harm Reduction Network - CEERHN) suggest that up to 90% of viral hepatitis C carriers do not know that they are infected.¹

This is confirmed by two surveys which ELPA has conducted amongst its members and fellow viral hepatitis patients. Throughout Europe, an average of only 21.5% knew of viral hepatitis at the time of their infection (23% for viral hepatitis B and 20% for viral hepatitis C) and only 27% knew that they were at risk (both for viral hepatitis B and C).

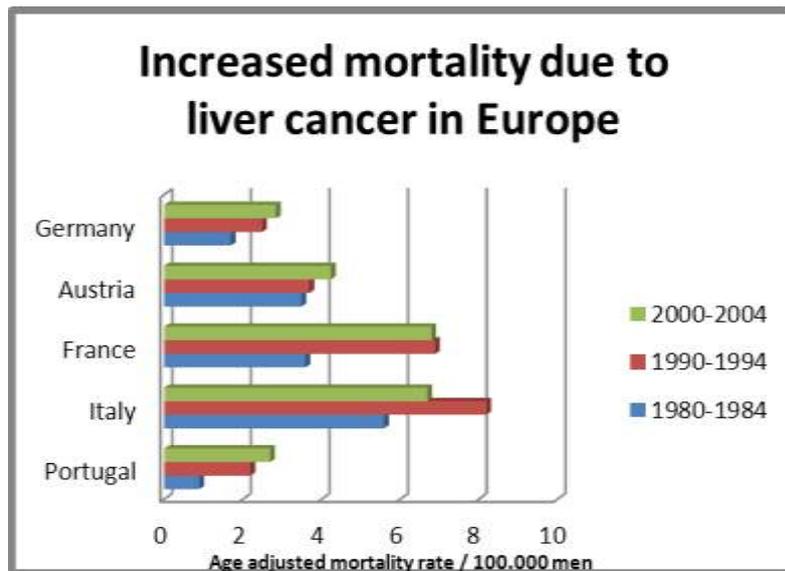
Viral hepatitis - why ignorance is dangerous

The long-term consequences of late diagnosis – liver cirrhosis and liver cancer – can be severe and potentially fatal. 75% to 85% of cases of primary liver cancer are attributable to chronic infections with viral hepatitis B or viral hepatitis C.² Liver cancer is the third highest cause of cancer deaths worldwide, and in Europe, liver cancer-related deaths have increased significantly over the past two decades (Figure 1).

¹ Eurasian Harm Reduction Network (EHRN), "HCV Infection in Europe", 1 October 2007, available at: <http://www.ihra.net/Assets/484/1/CEEHRNReportHCVInfectioninEurope2007.pdf>

² Bosch, FX, Ribes J, Diaz M, Cleries R., Primary Liver Cancer: Worldwide Incidence and Trends. Gastroenterology 2004; 127: 5–16

Figure 1: Increasing mortality due to liver cancer in Europe (1980 – 2004)³



What is more, the peak in the number of patients suffering from cirrhosis and cancer, or of patients waiting for a life-saving liver transplant, has not yet been reached, as many of the chronically infected have not yet attained the advanced stages of the disease. This is why the World Health Organisation (WHO) has compared viral hepatitis to a “viral time bomb”.⁴

However, despite the serious health risks associated with it, viral hepatitis is not on the radar screen of decision makers, and the public is generally not aware of this threat. This lack of political will to introduce strong measures to prevent the spread of viral hepatitis and further the identification of viral hepatitis patients not only ignores the human suffering caused by the disease, but also disregards the considerable socio-economic burden placed on national health systems and the economy at large.

Viral hepatitis – what is being done to tackle it at EU level

The EU is focused almost exclusively on primary prevention; the prevention of contracting the virus. The importance of primary prevention was highlighted in the 2006 European Parliament Resolution on “protecting European healthcare workers from blood-borne infections due to needle stick injuries”.⁵

Only one EU initiative has so far sought to promote case-finding, the EU Council Recommendation on drug-related harm⁶, which advises Member States on how to identify viral hepatitis infected drug users. Again, ELPA is supportive of this EU legislation. However, there are other risk groups besides drug users, which need to be specifically addressed as well with a view to identify viral hepatitis carriers before it is too late.

³ Bosetti, C. et al. Trends in mortality from hepatocellular carcinoma in Europe, 1980–2004. *Hepatology* (2008) 48: 137

⁴ World Health Organisation, Viral Cancers Fact Sheet, available at

http://www.who.int/vaccine_research/diseases/viral_cancers/en/index2.html

⁵ <http://www.europarl.europa.eu/sides/getDoc.do?objRefId=93641&language=EN>

⁶ <http://eur-lex.europa.eu/LexUriServ/LexUriServ.do?uri=OJ:L:2003:165:0031:0033:EN:PDF>

METHODOLOGY

Approach

In order to assess the activities and the contribution of self-help patient groups across Europe, first as well as second hand information has been gathered. Given that this is the first evaluation of its kind on a European scale, a survey has been drawn-up specifically for this purpose (see Annex II). Where necessary, the survey has been complemented by additional literature and desk research.

Survey Structure

The survey contains three sections. The first is designed to gather background information about the patient self-help group including their activities, main practices, liver disease focus and working methods. The second section has been designed to extract quantitative as well as qualitative information on the liver awareness raising campaign carried out e.g. outreach activities, the tools used and possible relationship building with policy makers. The last section is dedicated to the evaluation, which is mainly targeted at assessing the results of the respective efforts, as well as the standing the fight against viral hepatitis has in the country's public health programmes.

Patient Associations

In order to obtain a representative picture of the patient self-help activities as well as the context in which the associations operate, information from 20 patient associations from countries all over Europe, including accession countries has been gathered through the survey.

Country	Name of Patient Association
Austria	Hepatitis Aid Austria
Belgium	Carrefour Hépatites-Aide et Contact (CHAC)
Belgium	Vereniging voor Hepatitis C Patiënten (VHC)
Bosnia Herzegovina	The Chronic Viral Hepatitis Patients Association, "B18"
Bulgaria	Hepasist
Croatia	HULOH/CATIH "Hepatos"
France	SOS Hépatites Fédération
Germany	Deutsche Leberhilfe e.V.
Germany	Deutsches Hepatitis C Forum e.V.
Italy	Educazione, informazione e Prevenzione sull'Epatite C (EpaC)
The Netherlands	The National Hepatitis Centre
Poland	The Star of Hope
Portugal	SOS Hépatites Portugal
Romania	Sano-Hep
Slovakia	HEP HELP KLUB
Spain	Asociación Española de Enfermos de Hepatitis C (AsoEEHC)
Spain	Associació Catalana de Malalts d'Hepatitis (ASSCAT)
Sweden	Riksföreningen Hepatit C (RHC)
UK	British Liver Trust
UK	The Hepatitis C Trust

Discussion and Dialogue

To ensure the quality of the results, the survey has been carried out in the respective national languages where possible and in most cases a translated version has also been provided. The survey was the basis for an actual interview, which was carried out by face-to-face meetings where possible or by phone.

Viral hepatitis focus

Whilst “liver diseases” are mentioned in the survey and in this report, the focus of ELPA (for capacity reasons) as well as for most patient groups lies almost exclusively on viral hepatitis B and C. These are the most frequent forms of liver disease and if undiagnosed can lead to serious follow-on diseases such as liver cirrhosis and liver cancer. Whilst most patient associations interviewed provide services also for other liver diseases, such as Haemochromatosis, non-alcoholic fatty liver disease, Morbus Wilson, or autoimmune liver diseases, almost all have a strong focus on viral hepatitis. 17 out of the 20 patient associations have viral hepatitis even included in their organisation’s name. In light of this, a strong focus is placed on viral hepatitis also in this report and a majority of examples relate to viral hepatitis.

Definitions

For the purpose of this report, following definitions⁷, drawn-up by the World Health Organisation (WHO) are used for primary and secondary prevention:

- **Primary prevention:** This stage of prevention covers all activities designed to ‘reduce’ the instances of an illness in a population and thus to reduce, as far as possible, the risk of new cases appearing; in speech and language therapy this mainly covers information and health education of a population, as well as training all those who have a role to play with the population in question.
- **Secondary prevention:** This covers activities aimed at ‘reducing the prevalence of an illness in a population and thus to reduce its duration’; in speech and language therapy this mainly concerns identification and early screening.

In addition, **screening** is understood as “the examination of a group of usually asymptomatic individuals to detect those with a high probability of having or developing a given disease”.⁸

Limitations

The limitations that were encountered in this process are twofold. Firstly, not all EU Member States have liver patient self-help groups or are yet fully established. Some countries such as the Baltic States therefore remained inaccessible for the purpose of this analysis.

Secondly, the survey as well as the evaluation have been carried out by ELPA and are based on first hand information from the various patient groups. While this provides an important insight into their work and allows for key learnings to be identified, the views of other stakeholders on patient self-help such as policy makers, for instance, are not captured.

⁷ World Health Organisation definition drawn-up in 1948, retrieved from <http://www.cpolol.eu/eng/prevention.htm#defin>, August 2010

⁸ The American Heritage® Medical Dictionary Copyright © 2007, 2004 by Houghton Mifflin Company. Published by Houghton Mifflin Company. retrieved from <http://medical-dictionary.thefreedictionary.com/screening>, August 2010

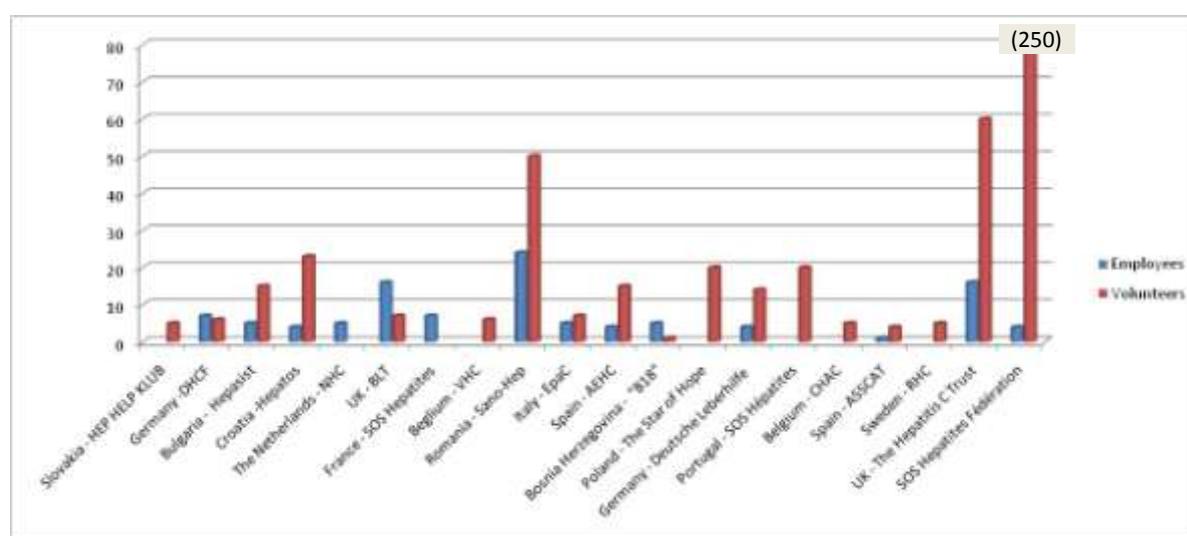
ANALYSIS

Patient Associations

SIZE AND HUMAN RESOURCES

The patient associations interviewed for the purpose of this assessment vary considerably in set-up, size and staff. The largest patient associations in terms of employees are Sano-hep in Romania (24 employees), the UK Hepatitis C Trust (16 employees) and the British Liver Trust (16 employees). Taking volunteers into account, SOS Hepatitis Fédération, Hepatos from Croatia, Bulgaria's Hepasist, the Deutsche Leberhilfe, the Star of Hope from Poland and AsoEEHC Spain can also be added to this list.

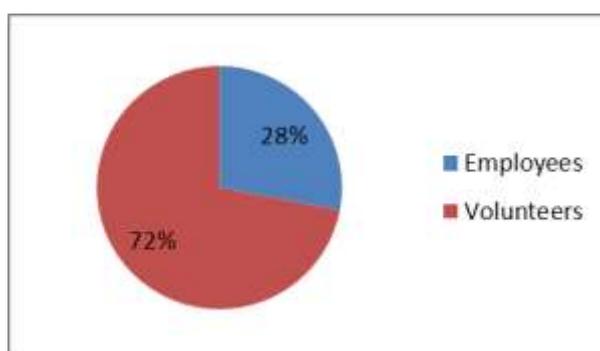
Figure 1: Number of Employees and Volunteers per patient association



The work of volunteers is fundamental to the work of all patient groups. For instance, Hep-Help from Slovakia, the Belgian organisations VHC and CHAC, as well as the Portuguese SOS Hepatitis and RHC Sweden, work exclusively with volunteers.

Figure 2 illustrates that 72% of the human resources of the patient associations interviewed are volunteers. Clearly, their status as volunteers has repercussions on the amount of work they can shoulder. While the majority of the people working for patient groups are actual patients, they are helped by a number of volunteers of different backgrounds including specialists, doctors, scientists and former patients.

Figure 2: Percentage of employees and volunteers in all patient associations interviewed



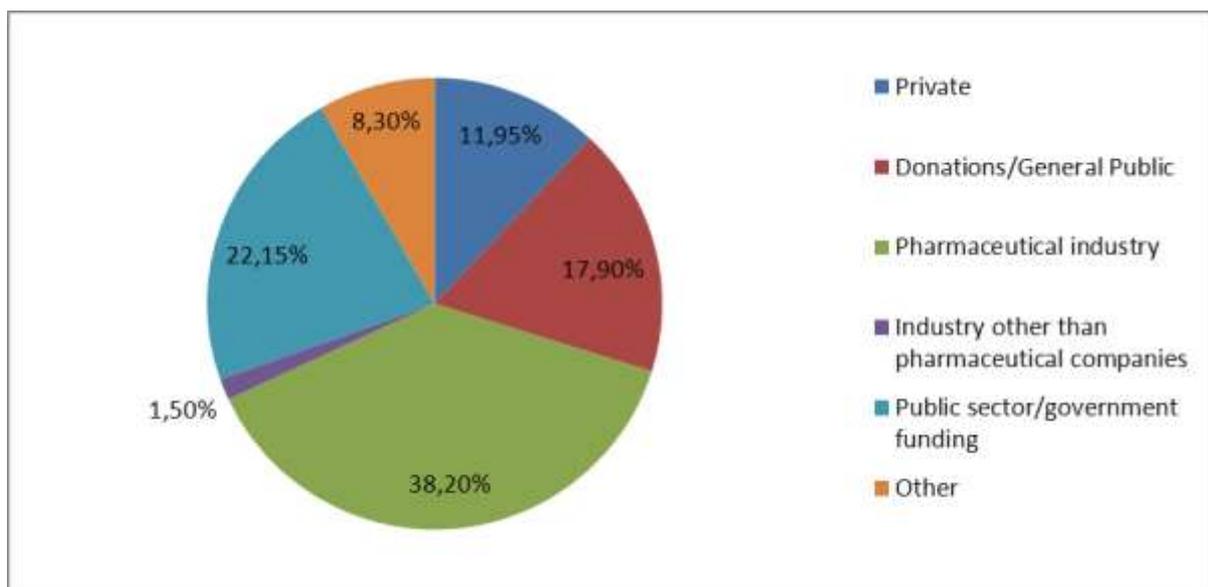
SOURCES OF FINANCING

The apparent lack of professional structures and to some extent operational practices is also the result of the lack of funding, which patient groups are facing on a constant basis. Their struggle to receive funding is reflected in the scattered nature of their sources of financing, as illustrated in figure 3.

The pharmaceutical industry is the major source of financing for the majority of patient groups. This is often complemented by public sector/government funding and donations from the general public. Some patient groups also engage in exceptional activities for fund raising such as the Chronic Viral Hepatitis Patient Association B18 from Bosnia-Herzegovina who organised a rock concert to raise funds in 2005.

Patient groups are frequently being criticised for accepting funding from the pharmaceutical industry. In light of the difficulty of finding alternative funding sources and given their financial situation, patient groups do not have enough room for manoeuvre. In addition, all patient associations have diversified their funding sources and are therefore not dominated by one single pharmaceutical company.

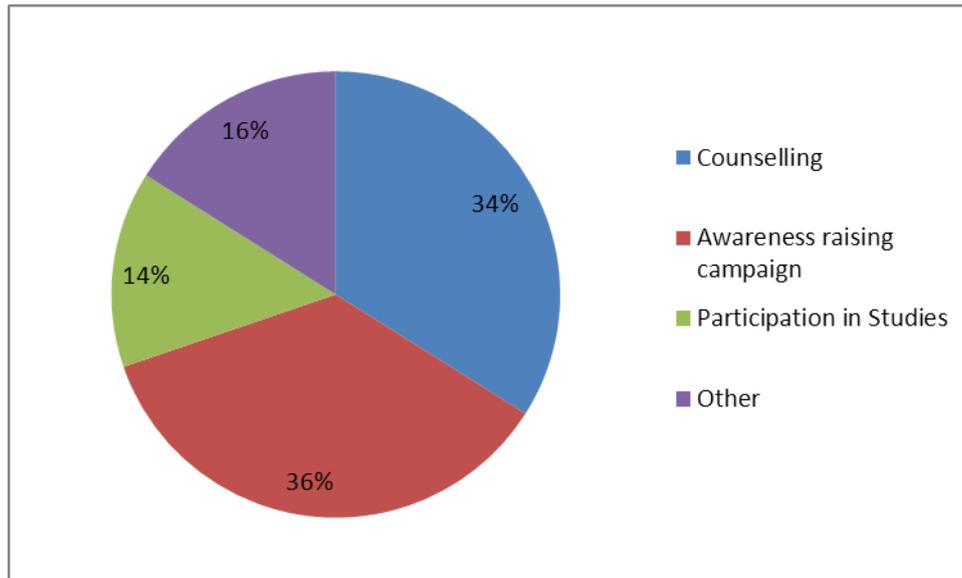
Figure 3: Sources of financing in %



MAIN ACTIVITIES

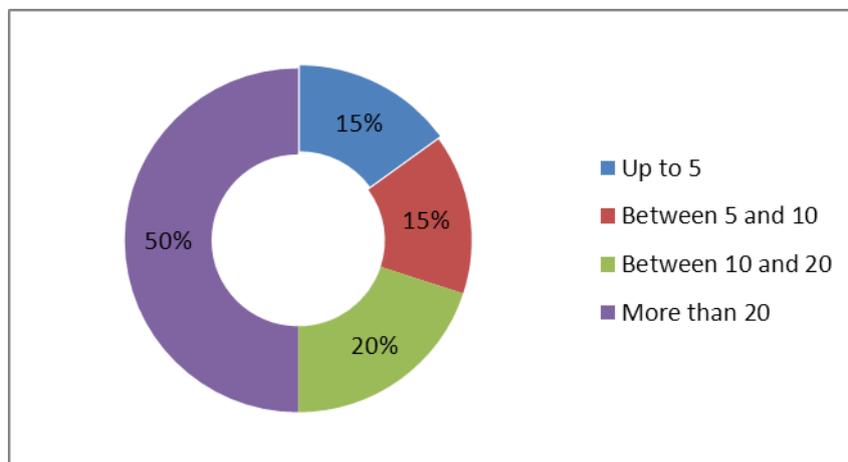
The patient groups across Europe are active in a variety of ways. They engage mostly in counselling and awareness raising campaigns (see Figure 4). In addition, participating in scientific studies also constitutes an important element in their work. Activities indicated for 'other' include public policy and free-of-charge screening tests.

Figure 4: Main Activities of Patient Associations (%)



The first core activity, counselling, is fundamental to the objectives and missions of each patient group. Their counselling activities entail direct interaction with patients to support them and their families through information on the disease, treatment options and medical institutions. As illustrated in Figure 5, half of all patient groups interviewed advice more than 20 patients a week, including up to 50 in the case of the UK Hepatitis C trust and the British Liver Trust as well as Bulgaria’s Hepasist, 30/40 in the case of the Portuguese SOS Hepatites and even up to 180 patients being advised by the Italian EPAC onlus.

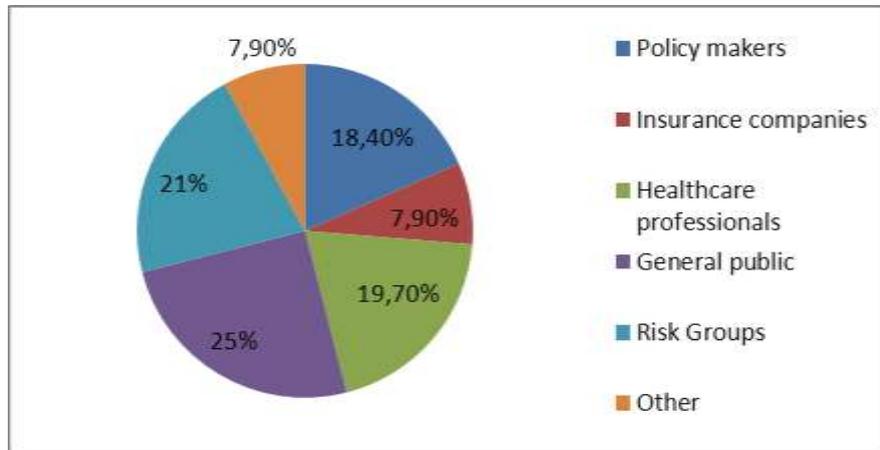
Figure 5: Number of patients advised per week (%)



In addition the psychological aspect of the counselling work is significant and often constitutes the majority of patient groups’ counselling activities. The psychological burden of the disease is a problem, which is largely neglected by medical centres and hospitals. Viral hepatitis is a disease that is highly stigmatised in the majority of countries as it is often considered as self-inflicted, through for instance drug-use or prostitution. The patient groups’ added value to the few existing contact points available to patients is clearly illustrated in this particular activity of psychological support. In some cases, assistance to receive legal support is also provided.

The second core activity, awareness-raising, aims at increasing the knowledge of liver diseases amongst various target groups. As shown in Figure 6, the general public, policy makers, healthcare professionals and risk groups are identified as the most important target groups for this purpose.

Figure 6: Target groups at which the awareness raising campaigns are directed (%)



Awareness-raising campaigns encompass a wide range of activities and can be designed relatively freely according to the specific needs and purpose. The most common forms used by the patient groups interviewed are information stands in public places, personal meetings with experts and politicians as well as seminars and roundtables. To spread information and as a means of communication, the internet, e-mails and letters, leaflets, newspapers, specialised journals, television and radio are being used extensively.

TARGETS OF AWARENESS RAISING CAMPAIGNS

Up to 90% of infected people are not aware of their condition. Out of those diagnosed, 20% had never heard of viral hepatitis at the time of their diagnoses and 27% did not know of their belonging to a risk group.

As a result, both the general public and specific risk groups are targets of disease-awareness campaigns conducted by the interviewed patient groups. The trigger for an awareness-campaign which usually lasts for two or three months is the World Hepatitis Day (WHD), currently on 19 May, which also sets the global theme of the campaign. Only in Austria is WHD not that important a date, mainly because of the saturation of the Austrian media.

Some patient groups, such as the Bulgarian Hepasist, Hepatos in Croatia, Leberhilfe in Germany or the British patient groups have a second, more home-grown campaign in the second half of the year. In addition to distributing information in form of flyers or brochures and launching advertorials in the media, free public testing is offered.

In addition to the general public, viral hepatitis risk groups, where the prevalence is higher than in the total population, are the target for campaigns and projects throughout the year:

In Germany, the Deutsche Leberhilfe initiated a project on viral hepatitis prevention in the 'Ruhrgebiet' in cooperation with doctors with a Turkish immigrant background, and with the support of the minister for integration of North-Rhine-Westphalia. The doctors visit Turkish clubs and cultural organisations, to provide information in Turkish about viral hepatitis B. This way, information about the disease is disseminated with the aim of reducing further infections in the Turkish migrant risk group. Some patient groups run projects raising awareness of viral hepatitis, its risk groups and transmission in prisons (Deutsches Hepatitis C Forum, Hepatitisshilfe Österreich) and schools (Hepatitisshilfe Österreich and Romanian SANOHEP), or preventing transmission at podologists or tattoo studios by defining hygiene standards. In the Netherlands projects are ongoing

aiming at raising awareness and free screening on viral hepatitis in several migrant populations, including Chinese and Turkish citizens.

Another important target group for awareness-raising are Healthcare professionals and in particular general practitioners. They have been described by all patient groups as being insufficiently informed about the disease, since they are in theory best placed to diagnose the virus.

In practice, however, training programmes for general practitioners which specifically include liver diseases such as viral hepatitis do not exist in any of the countries covered by the survey.

Prompted by the national patient groups, Spain, however, has been willing to offer training seminars for general practitioners. Unfortunately, these were poorly attended. The British Hepatitis C Trust also experienced the difficulty of disseminating local examples of best practice in this context. Other patient associations organise such seminars themselves led by leading hepatologists. The Belgian-Flemish patient group VHC also publishes information on viral hepatitis in the *Huisarts*, a newspaper for general practitioners and the British Hepatitis-C Trust also developed an online learning tool on viral hepatitis C for general practitioners together with the Royal College of General Practitioners.

Contact with policy makers has become a strong feature of patient group activities, bearing witness to the fact that only concerted policy measures can drive a sustainable improvement to the current situation.

The Belgian-Wallonian patient group CHAC, for instance, has gained support from four senators (Georges Dallemagne (Cdh), Alain Destexhe (MR), Phippe Mahoux (PS) and Isabelle Durant (Ecolo) of the four main democratic parties to sign a charter to support CHACs activities. The German Deutsche Leberhilfe works closely with former health minister Ulla Schmidt, who is now their patroness. The Spanish AsoEEHC is currently in contact with Rosa Ramírez Fernández from the Health and Consumer Ministry after submitting a request for viral hepatitis C screening. It has to be mentioned however, that only the organisations with sufficient resources, both human and financial, have been able to engage in this political outreach.

With the media being generally disinterested in viral hepatitis, patient groups have sought to obtain public support from either celebrities who have suffered or are suffering personally from viral hepatitis or whose family members are viral hepatitis patients. Portugal, for instance, receives support from the musicians Ze Pedro, Zutos e Pontapes, Karen Jardel and Rui Reninho. The Belgian-Flemish organisation VHC used as their 'champion' Jaap Pijpen, a well known TV personality who now publishes a magazine. The British Liver Trust is supported by Andy Fordham, a darts champion.

Despite these successes, most patient groups have encountered problems motivating celebrities to make their experience with liver diseases public, due to fears of stigmatisation or possible implications for their image and careers.

In summary, patient groups engage extensively with other stakeholders. In particular, the support received from specialists is already well established; celebrities have been willing to some extent to cooperate; and although building relationships with policy makers is not always an easy activity, significant progress has been made. The most problematic interaction has, however, turned out to be with the general practitioners, who very often are not sufficiently trained to recognise the symptoms of certain liver diseases and have been reluctant to participate in trainings or to provide support for awareness raising campaigns.

Evaluation

One can evaluate the work of the patient groups, as well as the general situation concerning viral hepatitis, using different parameters.

As far as counselling is concerned, patient groups have successfully managed to provide advice and support to those who addressed them. Clearly, this work could be expanded, if greater and more stable financial resources were available.

As far as awareness-raising is concerned, it is rather difficult to measure success: one cannot measure “increased awareness”, and it usually cannot be link it to patient groups’ activities. In order to get some kind of indication, one can usually refer to the results of free testing offers, which tend to be very popular across Europe. In terms of incidence, these testing results usually match or surpass the data, provided by official sources.

In Poland a screening campaign was carried out in the Silesia region. 5000 people were tested for viral hepatitis C, which revealed an identification level of 1.5%. The campaign was widely picked up by the media and around 50 information TV spots appeared. Similarly, in Blackpool, an area with the highest rates of mortality due to chronic liver disease in England, the British Liver Trust identified 64% of those tested as having HCV.

The availability of treatment is not an issue in the majority of Member States, according to the patient groups questioned. In particular, Eastern European countries, such as Bulgaria or Croatia have recently made tremendous progress and provided special funds for viral hepatitis treatment, owing largely to the efforts of the patient groups in question. Waiting times for treatment have also been greatly reduced in these countries. On the other hand, waiting times in Poland, can still amount to 3-5 years.

Bulgaria was also one of the first countries to introduce childhood vaccination as early as 1992. Croatia followed in 1998. While both countries state the need to further improve vaccination to also capture those groups who were born before this date, the difference is quite remarkable to Western countries, such as the UK, Sweden and the Netherlands, which have no universal vaccination for viral hepatitis B in place and reimbursement is not always guaranteed.

Screening, the targeted case finding of those at risk, is the biggest concern of patient groups: with the exception of France and Scotland, no government has made sustainable efforts to improve this. Progress has sometimes been made at a local level (e.g. England), leading frequently to delays in access to treatment. This might actually be the key reason why policymakers are so reluctant to engage in screening: they might think that one more patient identified means one more patient to treat.

The relationships with policymakers take up more and more room in patient groups’ activities, provided they have sufficient staff to manage those. However, this does not mean that they necessarily lead to outcomes. Policymakers, in particular those in public office, tend to be afraid of the stigma associated with the disease (drug-user disease) and prefer to become active in other, more tangible disease areas with a “worthier” cause. Furthermore, some countries focus on Malaria or Tuberculosis, which is also mirrored by the priorities of the WHO’s Global Fund, and are hence also “institutionalised priorities”.

Austria and Germany are both examples where the government’s interest in viral hepatitis and liver diseases is very low, despite various efforts on behalf of both patients and specialist associations, as well as individual policymakers.

On the other hand, the UK and Croatia are examples where the adoption of a liver strategy has either just been achieved or is within reach. It remains to be seen how and when this will actually be implemented.

Competition sometimes proves helpful in this context: The Scottish hepatitis C strategy, triggered by the Royal College of Physicians in 2004, served as a cutting-edge example, which paved the way for greater efforts in England and Wales.

Furthermore, the Croatian Hepatos was even made the WHO national focal point for viral hepatitis, upon recommendation of the government, receiving WHO funding for 4 years.

Challenges

The majority of the patient groups interviewed have identified the following three challenges:

- Availability of data: there is only insufficient data available. This concerns not only scientific data, but also health economic data, etc. Despite the active involvement of some patient groups (the Italian Epac was recently asked by the Ministry of Health to conduct a study on prevention), this can only be changed through more consistent efforts.
- Stigma: Viral hepatitis is the most stigmatised disease – the element of guilt plays an incredibly large part in the decisions of those who could or should otherwise make a difference to public health;
- Health professionals, in particular general practitioners, have no interest and no incentive to become more educated as far as viral hepatitis is concerned. The experience in Spain, where government sponsored seminars for general practitioners were badly attended, is a proof point for the lack of interest. The case of Bulgaria, where general practitioners are only allowed to conduct liver enzyme tests when jaundice is apparent (by which time they are actually superfluous), is a case in point for the lack of incentives.

CONCLUSIONS AND RECOMMENDATIONS

The survey conducted by ELPA has sought to highlight the work of viral hepatitis patient groups throughout Europe, with a view to assessing national public health policies related to viral hepatitis since the beginning of patient advocacy.

In a nutshell, patient groups are doing a fantastic job, considering the circumstances under which they operate: viral hepatitis patient groups are usually small scale organisations, with volunteers being essential for the work of more than 75% of the patient groups questioned. Funding is frequently a problem, which can make advanced planning difficult. Furthermore, the overall lack of interest as regards viral hepatitis on behalf of the media and in particular health professionals has proved challenging.

Nonetheless, patient groups have managed to achieve significant results in a number of areas over recent years, gradually increasing their competences and output. With health professionals under time and budget constraints, they are the only body to provide fellow patients with psychological support both at the time of diagnosis and throughout treatment, hence making a contribution to patient adherence, which must not be underestimated.

Furthermore, if it was not for the consistent efforts of patient groups, in the majority of countries investigated there would not be any viral hepatitis awareness-raising campaigns. Patient groups fill the gap, frequently with official support and approval, trying to tackle the challenge of consistently low public awareness.

The good work patient groups have been doing has proved to be an asset when they sought to make contacts with policymakers. This even led to situations where governments have recommended the patient group for certain tasks, or where governments commissioned patient groups with surveys or reports.

Clearly, good links to policymakers are not automatically leading to viral hepatitis-related improvements in the areas of prevention, diagnosis and access to treatment. However, if such

improvements did occur – expansion of childhood vaccination programmes for viral hepatitis B, the launch of a liver strategy, reduction in waiting times for treatment, extra funding for viral hepatitis drugs - these developments could be linked to the efforts of a patient group.

Generally, those countries fare best which recognise the added value patient groups can provide, and support them in their work with a sustainable policy programme which is illustrated below.

With vaccination and treatment having improved – not throughout Europe, but in quite a few countries, the biggest “health systems” challenge for patient groups is in the area of secondary prevention, screening.

Targeted screening or case-finding amongst risk groups has proven effective in substantially increasing the number of identified viral hepatitis patients and enabled them to receive treatment, where appropriate, with a view to preventing serious follow-on diseases such as liver cirrhosis and/or cancer. In reality, however, general practitioners across Europe hardly have viral hepatitis on their radar screen at all, and efforts by patient groups and specialists, even supported by government funding, have frequently been made in vain.

What is therefore needed is a proper national strategy to make a difference and reduce the burden of the disease by identifying and treating a greater number of viral hepatitis carriers. While examples of such good practice do exist, they are confined to a fairly limited territory, i.e. in regions like Scotland or EU Member States such as France.

At a time when thankfully Europe is becoming more and more borderless and people have the right to travel and settle wherever it pleases them, the inertia of national decision-makers when it comes to putting in place policy measures is even more unsettling and dangerous. As with all communicable diseases, viral hepatitis does not know any borders, and efforts in one European country can be undermined by less consistent efforts in a neighbouring state. There is therefore a clear need for greater cross-border coordination and an EU-wide approach on how to implement screening strategies and target these to risk groups across Europe.

A Council Recommendation on viral hepatitis B and C screening of risk groups would be a powerful tool in this context. Although not legally binding, such a recommendation is signed by all 27 health ministers of the European Union and hence represents an important political commitment. Furthermore, member states would receive guidance on how to improve their efforts in detecting and treating unidentified viral hepatitis patients.

If Europe is serious about tackling its viral hepatitis challenge, Member States, guided by the EU, need to agree on a concerted effort. Waiting until the viral hepatitis problem will die out is not an option.

ANNEX I: COUNTRY SHEETS

This annex contains 16 country information sheets that have been put together on the basis of the information received during the interviews with the patient groups. Each country sheet provides an overview on their assessments of the situation in the respective countries including the estimated viral hepatitis prevalence, general trends, as well as access to treatment and testing. In addition, background information on the national patient groups is provided together with an overview of their main activities and their contribution and achievements to date. Lastly, the country sheets contain a summary of the main opportunities and challenges ahead.

Austria

THE SITUATION IN AUSTRIA

Estimated prevalence

In Austria the estimated prevalence for viral hepatitis B is 0.9% and for viral hepatitis C it is 1.4%.

Trends

While the trend of viral hepatitis B infections is going down because of free childhood vaccination, the effect is not very noticeable because of migration from high-endemic countries.

Prevention & Testing

Free childhood vaccination is available until the age of 15. However no targeted efforts to identify viral hepatitis cases are being undertaken.

Treatment

All standard treatments are reimbursable in Austria.

PATIENT GROUP IN AUSTRIA

○ *Hepatitis Hilfe Österreich*

Background information

“Hepatitis Hilfe Österreich” was founded in 1995 and works with 150 volunteers across Austria. “Hepatitis Hilfe Österreich” focuses primarily on viral hepatitis B and C, but also deals with fatty liver, cirrhosis and cancer, followed by haemachromatosis.

Main activities

Apart from offering counselling, the “Hepatitis Hilfe Österreich” focuses on awareness raising activities directed at the general public and healthcare professionals as well as at risk groups and prisoners.

Partnerships with celebrities or professional associations are difficult. Nonetheless, a consensus statement with a general practitioner association could be adopted. Due to a certain oversaturation of the Austrian media, as well as fear of stigma on behalf of politicians and celebrity patients, the World Hepatitis Day is not as big an event as in Germany.

Contribution and Achievements

In cooperation with regional sick funds, so-called info-points for a healthy liver have been created, where patients and their carers can obtain free and anonymous support from teams including hepatologists/gastroenterologists and psychologists. A seal of accreditation for piercers, tattoo artists, podologists and manicurists has also been introduced.

OPPORTUNITIES AND CHALLENGES AHEAD

A major challenge faced by the “Hepatitis Hilfe Österreich” is to achieve a political statement from the government to promote risk group-specific screening and the inclusion of viral hepatitis in general check-ups.

Apart from insufficient education amongst healthcare professionals and in particular general practitioners, the biggest challenge in Austria is the stigma which a viral hepatitis infection entails. Other diseases such as cancer are far more popular with the media and politicians.

Belgium

THE SITUATION IN BELGIUM

Estimated prevalence

In Wallonia the estimated prevalence of viral hepatitis B is 0.8% and that of viral hepatitis C is 1%. While the prevalence of viral hepatitis C is more or less stable, the prevalence of viral hepatitis B is on the rise, as a consequence of increased migration. In Flanders the prevalence of viral hepatitis C is also 1%.

Trends

There is a serious ignorance of, and lack of interest in, viral hepatitis from policy makers, healthcare professionals and the general public. Despite the worrying figures, there is no or only scattered national or regional policies for primary and/or secondary prevention of viral hepatitis. Viral hepatitis is not on the radar screen of policymakers, in particular compared to other diseases such as HIV/AIDS, which receive more public attention. Concrete policies aimed at primary and secondary prevention of viral hepatitis are non-existent. Little progress has been made at the political level and there is no national awareness raising campaign in Belgium, however this is changing slightly.

Treatment

While access to treatment is satisfactory and waiting times are short, there are considerable gaps in current reimbursement policies – these policies are insufficient for viral hepatitis C, and the situation has only recently improved for viral hepatitis B.

Testing

Viral hepatitis tests are not included in general check-ups.

PATIENT GROUPS IN BELGIUM

- *Vereniging voor Hepatitis C Patienten (VHC)*

Background information

The Vereniging voor Hepatitis C Patienten (VHC) is a Flemish organisation that was founded in 1989 to advise and help patients with viral hepatitis and to raise awareness of the disease. It has around 500 members. In Flanders there is no other patient organisation that focuses specifically on viral hepatitis. Patients mainly get information from doctors, libraries or the internet. They also receive information through other organizations which are not specifically focused on viral hepatitis like *Sensoa* (STD) or drug addict groups.

Main Activities

Besides counseling, VHC focuses on raising awareness of viral hepatitis. Although it has limited resources, the organisation tries to reach as many people as possible. The campaign is targeted towards policy makers, insurance companies, healthcare professionals (especially general practitioners) and several risk groups (prisoners, drugs addicts, etc.). The organisation works together with many stakeholders like the BASL (Belgian Association for the Study of the Liver), *Sensoa*, *de Sleutel* (drug addicts), *vzw Trefpunt* (umbrella

organisation of patient organizations), and also prisons. The VHC organises many different activities like seminars, symposiums, or expert meetings. It also provides information stands and reaches out towards the media.

Contribution and Achievements

One of their latest and most successful campaigns was the organisation of an academic session in November 2009 which was attended by policy makers (including the governor of Antwerp) and healthcare specialists. This activity even led to a legislative proposal. In addition, the VHC recently published a book with medical advice and testimonials from patients. It has also sent out letters and materials to all municipalities to support awareness-raising on viral hepatitis, which has already received some positive feedback. At the moment VHC is also trying to introduce viral hepatitis into a 'soap' on TV. In the past they managed to use celebrities to promote their cause and have succeeded in the past to have a godfather (Jaak Pijpen – known from TV and publishes a magazine) and a godmother (Miss Belgian Beauty).

Despite these efforts the VHC is still experiencing a lack of support and interest from policy makers and doctors. The VHC mainly regrets that there is still no national awareness raising campaign at political level. One of the reasons for the lack of success is the complex structure of the Belgian state which makes it difficult to know who to reach out to.

○ ***Carrefour Hépatites – Aide et Contact (CHAC)***

Background information

“Carrefour Hépatites – Aide et Contact” (CHAC) was founded in 2001 with the overall goal to help those infected with all forms of viral hepatitis and their families. The association has 5 volunteers, but their engagement depends on the specific activities undertaken. CHAC provides psychosocial counseling to viral hepatitis patients, and conducts numerous activities at different political levels to improve current regional legislation related to viral hepatitis screening and access to treatment. In particular, CHAC has conducted successful awareness raising campaigns in schools and amongst healthcare professionals (doctors, nurses) and insurances.

Main activities

The organisation promotes numerous awareness raising campaigns which are directed mainly at policy-makers, healthcare professionals, risk groups, relevant third party stakeholders (AIDS groups, organ donation associations, organisations combating alcoholism etc.) and the wider public. CHAC conducts the campaigns essentially through seminars, roundtables, expert meetings or public information stands. Furthermore, CHAC organises media outreach activities in order to promote public support for tackling the disease. CHAC also regularly arranges bilateral meetings with disease experts and supports political declarations both at the regional (Wallonian) and the European level.

Contribution and Achievements

CHAC has been successful in forming alliances with general practitioners, key politicians and relevant disease associations. The association has managed to raise awareness of viral hepatitis over the past few years and has achieved considerable successes at the political level. In particular, the association has been able to secure the support of four councillors representing the four main political parties in Wallonia, who have co-signed a charter to support CHAC's activities.

OPPORTUNITIES AND CHALLENGES AHEAD

One of the main challenges to overcome in Belgium is the formal inclusion of primary and secondary prevention into the national healthcare system. In general, raising further

awareness of the disease amongst policymakers, healthcare professionals and the wider public remains a priority for both organisations. Policy makers should develop and implement a sustainable programme for viral hepatitis and a screening strategy.

Bosnia-Herzegovina

THE SITUATION IN BOSNIA - HERZEGOVINA

Estimated prevalence

In Bosnia-Herzegovina (BH) the prevalence of viral hepatitis is of 1% for the hepatitis C virus and of 2% for viral hepatitis B. Testing and treatments (primary and secondary prevention) are both included in the national healthcare system.

Trends

To date there is insufficient data to assess whether the situation is improving. However, as the health services are improving and governments make improved health initiatives more widely available it is expected that new infections will diminish in the coming years.

Treatment

Treatment is included in the national healthcare system and patients are able to access it by looking for a public health centre. However, the national healthcare system in Bosnia-Herzegovina is divided into three regions. This means that different regions get access to medication at different times. In addition, there are different waiting times and different levels for quality of treatment. Government efforts to minimize these disparities do however exist.

Testing

Testing for viral hepatitis can be carried out in public healthcare centers for free but they are not mandatory.

PATIENT GROUPS IN BOSNIA-HERZEGOVINA

- "B18" Group

Background information

The Chronic Viral Hepatitis Association "B18" was founded in Bosnia-Herzegovina in 2004 and aims at supporting viral hepatitis patients in dealing with their difficulties related to the disease. The B18 reaches out to about 20 viral hepatitis B and C patients per week and provides them with adequate and professional counselling as well as with the space and possibility to interact with each other and to exchange views.

Main activities

Awareness raising campaigns organised by "B18" are directed at both policy-makers and the general public with a relatively positive result. The "B18" group organises everything from seminars to expert meetings, to information stands in public places and free testing opportunities. The organisation focuses on informing the population on preventive behaviours and how to deal with the virus at a personal and societal level.

Contribution and Achievements

The organisation's greatest achievement was the inclusion, in 2005, of viral hepatitis treatment available into the national healthcare system after a long and successful media outreach campaign. Its national relevance as an actor in the field is marked by its positive and effective work in informing people and supporting patients at a basic primary stage. The "B18" organisation meets with policy-makers around twice per year.

OPPORTUNITIES AND CHALLENGES AHEAD

After having secured the right to treatment at a national level, the main challenge is to ensure the good functioning of the healthcare providers and the proper attention to the disease from healthcare staff.

Additionally, cooperation with policy-makers still needs to be improved at a local, regional and national level in order to secure greater influencing capacities.

Bulgaria

THE SITUATION IN BULGARIA

Estimated prevalence

Bulgaria does not have official data on the prevalence of viral hepatitis. It is however estimated that for viral hepatitis C, the prevalence ranges between 1% and 3%. These figures are confirmed by the results of patient group's "Hepasist" anonymous free testing activities. For viral hepatitis B estimates vary between 4% and 8%, which is again confirmed by "Hepasist"'s own testing initiatives.

Trends

The trend for viral hepatitis C is rising but declining for viral hepatitis B thanks to childhood vaccination.

Treatment

After the government's decision in 2009 to remove the cap on the number of people which can be treated, people receiving treatment tripled. All state of the art medicine is available now. Whilst treatment schemes still need to be optimized (e.g. currently, drug users do not receive treatment), waiting time also improved significantly since 2009 (from 2 years to 4-6 months).

Prevention & Testing

Bulgaria was one of the first countries in Europe to introduce childhood vaccination in 1992. However, there are still gaps among vulnerable groups, e.g. Sinti and Roma, and considerable efforts need to be made to capture age groups born before 1992. No special programmes for secondary prevention or testing exist. For example, medical doctors are only allowed to undertake ALT tests, when the patients already suffer from jaundice.

PATIENT GROUP IN BULGARIA

○ *Hepasist*

Background information

Hepasist is the national association for the fight against viral hepatitis in Bulgaria. It was founded in 2005 and works with 5 employees and 15 volunteers across their three offices, their main office is in Sofia and the other two are regional offices.

Their mission is to raise awareness of viral hepatitis and defending patients' rights. In Bulgaria, the general trust in the public health system is very low. Hepasist therefore recommends clinics and facilitates the contact to specialist. In addition, there is an NGO specialised in the provision of psychological support during treatment. Hepasist primarily deals with viral hepatitis B and C patients (equally important). These are followed by viral hepatitis A patients, then cirrhosis/ liver cancer patients and lastly alcohol-related hepatitis and haemachromatosis.

Main activities

Apart from counseling, the awareness-raising of viral hepatitis amongst risk groups, healthcare professionals and the general public, as well as the provision of advice to policymakers are the main activities of Hepasist. Twice a year, Hepasist runs a two-month long campaign – one on the occasion of World Hepatitis Day and the other, more domestic, campaign in September/ October, reaching out to the media and offering free testings. Hepasist is in close cooperation with a cross-party group in the Bulgarian Parliament on social diseases. Whilst the relationship with the national GP association is patchy, Hepasist has launched a joint initiative with the Bulgarian Dentist Association to promote the prevention of viral hepatitis infection at the dentist.

Contribution and Achievements

Rather spectacularly, Hepasist succeeded in making viral hepatitis a topic in the Bulgarian version of the popular TV show, “Big Brother” on the occasion of the World Hepatitis Day 2009, raising awareness of the diseases, its risk groups and the need to get tested. Furthermore, they campaigned actively and successfully for improved access to medication.

OPPORTUNITIES AND CHALLENGES AHEAD

The biggest challenges are the lack of education amongst general practitioners, the lack of good prevalence data and the general lack of funding available for the prevention of the disease. The Department of Health in Bulgaria concentrates on AIDS, malaria and tuberculosis, due among other reasons to the funding received from the Global Fund. Other diseases are also more attractive, as they are more tangible.

Furthermore, liver enzyme tests and/or viral hepatitis tests should be part of the annual check-up that all patients are entitled to once a year and free of charge. Furthermore, the Ministry of Health should adopt and implement a programme for primary (prevention of dissemination) and secondary (case-finding through testing) prevention.

Croatia

THE SITUATION IN CROATIA

Estimated prevalence

The estimated prevalence of viral hepatitis B in Croatia is 1% and 1.3% for viral hepatitis C.

Trends

Viral hepatitis is apparently on the rise. With regard to viral hepatitis B this is mainly due to the exogenous population growth, triggered by migration from Bosnia after the Bosnian War. This neutralizes the positive effects achieved through the introduction of viral hepatitis B vaccination in 1998.

Prevention & Testing

Viral hepatitis B vaccination is available for all 12 year olds since 1998; in addition newborn vaccination has been introduced in 2007 and has been occasionally complemented by ‘catch-up programmes’ in several counties to capture the remaining age groups. While progress has been made in secondary prevention, the level still has to be improved significantly.

Treatment

Gold standard treatment for viral hepatitis C patients has been achieved thanks to viral hepatitis being included in a special fund for high-quality drugs. However, only one treatment was registered for viral hepatitis B. Since July 2010 two more drugs became available in Croatia. The waiting time for treatment for viral hepatitis C has been reduced from 2 to 3 years in 2006 to an average of only 2 months to date.

PATIENT GROUP IN CROATIA

○ *Hepatos*

Background information

The “Croatian Association of treated and ill with viral hepatitis - Hepatos” was founded in 2000 and works with 4 employees and 23 volunteers. Their headquarters is situated in Split with two regional offices in two additional towns. Hepatos was primarily concerned with viral hepatitis C, but nowadays it is concerned with viral hepatitis B and viral hepatitis C and other viral hepatides. For patients with cirrhosis and/or liver cancer, Hepatos facilitates contacts with specialists. Hepatos engages mainly with patients directly given that medical staff do not have the capacity to provide the necessary information nor to offer free psychological support. Their mission is to engage in local, national and international activities aiming at the prevention of the spreading of the disease, decreasing discrimination and raising the quality of life of patients and families.

Main activities

In addition to the counselling of patients, Hepatos undertakes an annual campaign to increase awareness of viral hepatitis amongst healthcare professionals, policymakers, risk groups and the public at large. This campaign usually lasts for two months around World Hepatitis Day, including media appearances (402 hits in 2009 versus 17 in 2003) and the organisation of public events. Hepatos hosts seminars and roundtables with policymakers and public health experts, and offers free testing.

Hepatos has cooperation agreements with the respective referral centres of the national Ministry of Health and Social Welfare for chronic liver diseases and that for diagnosis and treatment of viral hepatitis. Upon recommendation by the Croatian Ministry of Health, Hepatos was made the WHO national focal point for viral hepatitis.

Hepatos also works in partnership with the national association of gastroenterologists and can rely on celebrity patients for testimonials. In addition, the WHO funding enables projects to promote general practitioner education, as well as adherence amongst drug addicts.

Contribution and Achievements

Hepatos has successfully campaigned for better access to treatment and childhood vaccination. Politically, Hepatos was the main driver behind a resolution of the Croatian Parliament on the fight against viral hepatitis in 2009. The resolution was complemented by a consensus statement from representatives from the health and NGO sector concerning a national strategy for combating viral hepatitis.

OPPORTUNITIES AND CHALLENGES AHEAD

The adoption and implementation of concrete measures, to promote risk group specific screening remains Hepatos’ main goal. Nonetheless, the lack of education on viral hepatitis amongst healthcare professionals and the lack of good data are seen as the biggest challenge by Hepatos. Furthermore, other diseases get more attention due to WHO Global Fund activities. For the future, it will be important to ensure that the national strategy will be converted into a concrete action plan which all concerned stakeholders are committed to implementing.

France

THE SITUATION IN FRANCE

Estimated prevalence

In France the prevalence of viral hepatitis is around 0,89% for viral hepatitis C and 0.68% for viral hepatitis B. France is one of the few countries in the EU which keeps track of official viral hepatitis data.

Trends

The “Institut de Veille Sanitaire” carried out a prevalence study in 2003-2004, which found that whilst the prevalence of viral hepatitis C is relatively stable, the prevalence for viral hepatitis B had been underestimated. Under the third National Plan for the fight against viral hepatitis B and C (Plan national de lutte contre les hépatites B et C 2009-2012) another prevalence survey is foreseen.

In addition, some groups, such as immigrants who come from countries where prevention is not in place, might suggest a new increase in the prevalence of viral hepatitis, which is not entirely captured in the statistics.

Vaccination against viral hepatitis B is free of charge in France; however 60 % of all teenagers are not vaccinated, which represents a serious threat for further viral hepatitis B infections in the future. The vaccination of newborns, however, is improving, from 20% being vaccinated in 1997 to 60 % receiving vaccination today.

Treatment

The French national health system includes primary and secondary prevention and recently reviewed its viral hepatitis-specific action, leading to the approval of the third National Plan for the fight against viral hepatitis B and C for the period 2009 – 2012. The plan recognises national shortcomings in prevention and screening, and establishes goal-oriented measures for the future.

Treatment is accessible in France; however patients usually need a referral to a specialist from their general practitioner. A reimbursement scheme is also available for the patients; nonetheless, early diagnosis remains a challenge.

Testing

Patients can request to be tested for viral hepatitis and can get referred to a specialist by their general practitioner. Screening initiatives are included in the viral hepatitis-prevention programme. Patient groups endorse these and emphasise that screening is most effective if carried out in a targeted way in high risk groups.

PATIENT GROUPS IN FRANCE

○ *SOS Hépatites Fédération*

Background information

The *SOS Hépatites Fédération* was founded in 1996. The organisation is actively involved in awareness raising campaigns and also participates in a number of studies, including information guides, statistics and reports on the viral hepatitis situation in France. The main aim of *SOS Hépatites* is to support and defend all those who suffer from viral hepatitis, no matter the type of virus or the way they were infected.

Awareness raising campaign

The Federation promotes and carries out varied campaigns aimed at risk groups, the general public and healthcare professionals. It resorts to using all available instruments (internet, documents, studies, face to face meetings) and their campaigns include information stands, email outreach efforts, meetings with experts and the use of media, including television. The federation is successful in attracting supporters from the general public, the media, healthcare professionals and some policy-makers. The use of scientific data as well as publications in specialised studies are important elements in their work. While interaction with policy makers is not standardised, SOS Hépatites is in touch with relevant contacts at the political level and is interacting with these on an ad-hoc basis. For 7 years, SOS Hépatites has been training general practitioners in the framework of a special programme focusing on Therapeutic Education (more than 1200 general practitioners have been trained to date).

Contribution and Achievements

Over the past years, SOS Hépatites has managed to achieve progress in a number of areas. Among others, the federation managed to be represented and make its voice heard in a number of forums including the “Conseil d’administration des hôpitaux”, the “Commission régionale de la santé”, the expert group “Haute autorité de santé”, the National Research Agency for HIV/Aids and Viral Hepatitis (Agence nationale de recherches sur le sida et les hépatites virales – ANRS), and the National Health and Medical Research Institute (Institut national de la santé et de la recherche médicale – Inserm), as well as the “Collectif Inter Associatif sur la santé”, which is a strong lobby association composed of a number of different disease groups

The Vice-President of SOS Hépatites is also the Vice-President of the national committee giving follow-up to the national plan for the fight against viral hepatitis B and C. The Federation has also asked the Minister of Health Roselyne Bachelot-Narquin to promote France’s “best practices” in the field of viral hepatitis at the European level. Another major achievement has also been the programme on therapeutic education of the patient by the HAS (Haute Autorité de Santé), which has been included in a law (loi Hôpital, Patients, Santé et Territoires - HPST) that provides a definition on therapeutic education.

OPPORTUNITIES AND CHALLENGES AHEAD

Overall, the French system is at the forefront in the field of viral hepatitis prevention in Europe. The national plan for the fight against viral hepatitis B and C includes primary as well as secondary prevention, which recognises the need for political initiatives in this disease area. Nonetheless, SOS Hépatites continues to face the challenge to fight viral hepatitis by detecting all those who are infected whilst simultaneously providing support in their daily life. Furthermore, at the political level, it needs to be ensured that the disease receives sufficient consideration and funding, given that other diseases like AIDS are considered an even greater health threat by policy makers. While the national plan is an important milestone for progress in this field, adequate follow-up to the actions outlined in the plan needs to be given in practice.

Germany

THE SITUATION IN GERMANY

Estimated prevalence

The official numbers in Germany indicate that 400.000 - 500.000 people (0.5%) are infected with viral hepatitis B. The same official numbers apply to the prevalence of viral hepatitis C. However, recent trials and screenings show that the prevalence may be higher. A study

carried out by Professor Berg (Charite 2009), estimates that 2.4% of the population is infected with the hepatitis C virus. Although the overall trend is considered to be stable the prevalence in the drug scene is on the rise.

Trends

The general public interest in viral hepatitis has been growing but there is still neither a national government-led strategy nor viral hepatitis screening. Primary and secondary prevention are still inadequate to date. Vaccination is generally reimbursed for children and teenagers up to 18 years, and risk groups. Some insurance companies also reimburse 'travel vaccinations' for adults, especially on business trips; however there is a general trend of 'vaccination tiredness' in particular by parents in Germany. The government does not participate in any viral hepatitis awareness raising activity and there is no systematic screening strategy in place. In addition, the vaccination rates for viral hepatitis B are extremely low among for instance diabetics and other liver diseases.

Treatment

Access to treatment is adequate in Germany. Once the patient has been diagnosed, the appropriate treatment is available, and waiting times are usually very short (treatment can be made available after one or two weeks). The legal insurance GKV (*Gesetzliche Krankenversicherung*) in Germany ensures that reimbursement for treatment is available for everyone.

Testing

A patient can request a liver test or an antibody test for viral hepatitis B and C to be carried out but these are not included in a normal blood test nor are they included in the post-35 check-up .

PATIENT GROUPS IN GERMANY

○ *Deutsche Leberhilfe e.V.*

Background information

The Deutsche Leberhilfe e.V. has been established in 1987 and operates all over Germany. Its mission is to help liver patients to help themselves. They encourage and support prevention as well as early diagnosis. In case of specific medical questions, the Deutsche Leberhilfe e.V. is assisted by specialised scientists and hepatologists.

Main activities

The Deutsche Leberhilfe e.V. is the central information office for liver patients in Germany and offers counseling via the phone, e-mail and letters. Extensive information is being distributed to patients and relatives. In addition, their awareness raising campaign includes extensive activities involving seminars, expert meetings, face to face meetings with politicians, media outreach and the use of studies as well as scientific data and cost effectiveness studies. In addition, the Deutsche Leberhilfe e.v. closely cooperates with the German Liver Foundation (Deutsche Leberstiftung).

Contribution and Achievements

Long-term relationships have been established over recent years not only with leading hepatologists but also with one of the former health minister (who is their patroness) and various members of the German government including the Health Ministry. The greatest achievement to date is the establishment of a National Liver Day on 20 November every year as well as successful activities (e.g. free liver testing in over 25 cities) on World Hepatitis Day. The creation of special programmes for viral hepatitis B and C has been achieved. Their main

challenge consists of a lack of funding and limited interest of the government in liver diseases and viral hepatitis in particular.

○ *Deutsches Hepatitis C Forum e.V.(DHCF)*

Background information

The DHCF was founded in 1997 and works exclusively with and for viral hepatitis C patients. Its mission is to raise awareness of the disease through public information. Advisory services are offered across Germany. The DHCF does not have a fixed office but bases its work on its online platform. Of the 13 volunteers, 7 are actively involved in providing counselling, working on the awareness raising campaign and running the information desk.

Main activities

The DHCF is collaborating closely with the Deutsche Leberhilfe and Deutsche Leberstiftung. They do not have their own sensibilisation/political campaign for viral hepatitis, however they work with the other two organisations on occasions such as the World Hepatitis Day and the German Liver Day. The DHCF works directly with patients and provides counselling services. They have a close relationship with specialised doctors.

Contribution and Achievements

The DHCF assists up to 20 patients weekly and information on viral hepatitis C is widely made available. Personal and direct interaction has turned out to be a successful practice, for instance specialised talks are given at schools with a high proportion of drug users. One of their main achievements is for instance the inclusion of a viral hepatitis C (HCV) test in a centre for young offenders in addition to the HIV testing. Their book ('Das DHC Handbuch') has also been a main contributor to their income and to the dissemination of information.

OPPORTUNITIES AND CHALLENGES AHEAD

The main challenge to overcome in the future is the adoption of a national strategy against viral hepatitis in Germany. This includes the implementation of a systematic screening programme. In addition, similar to the government's HIV commitments, the various patient organisations advocate funds being made available for awareness raising and primary as well as secondary prevention. At the European level recommendations to be followed by Member States should be drawn up for primary and secondary prevention.

Italy

THE SITUATION IN ITALY

Estimated prevalence

In Italy the prevalence of viral hepatitis is about 1% for viral hepatitis B and 2.7% for viral hepatitis C. According to the official numbers, 230 000 suffer from cirrhosis originating from viral hepatitis C and 100.000 originating from viral hepatitis B.

Trends

The government has some positive new working measures, programmes and private partnerships but still only vaccination for viral hepatitis B is mentioned in the healthcare programmes and there is no active identification process which could be acknowledged as a best practice. The prevalence trend seems to be declining but there is no data on new infections per year including on the infections brought by migration flows. Specifically for viral hepatitis C, there is general unawareness about the real scale of new infections every year, as the notification system is in place only for acute viral hepatitis.

Treatment

Treatment for both viral hepatitis B and C is widely available in Italy and waiting time is generally not an issue. However, this is partly due to the fact that proactive case finding is not a political priority in the healthcare sector.

Testing

Testing and primary prevention is generally poor, particularly for viral hepatitis C. A patient can only find if he/she has contracted viral hepatitis if he/she undergoes testing for other reasons e.g. prior to invasive surgery. Political willingness and drive to find and treat ill patients is still lacking.

PATIENT GROUPS IN ITALY

○ *EPAC onlus*

Background information

The EPAC onlus association was formed in 1999 with the aim to provide adequate counseling and information on viral hepatitis to those in need. Currently, it is located in Rome and Milan and has a counseling capacity of over 180 patients per week, either by phone, email or in person. Its work is highly recognized both in the public eye and with policy-makers and the organization identifies itself as the only trustworthy place that most patients can go to.

Main activities

EPAC's awareness raising campaigns are frequent and varied, reaching out to all members of society through numerous instruments, i.e. the internet, leaflets, newspapers and others. The association organises numerous campaigns throughout the years reaching out and mainly directed at the general public and policy-makers. Its methods are varied and numerous instruments are used in order to get the messages across in the most professional and effective manner.

Contribution and Achievements

EPAC onlus frequently meets with policy-makers to reinforce its views and request support. However, there is not enough funding available; hence, the impact is not always as required. One of its achievements is the recent agreement that was reached with the Ministry of Health to carry out a prevention study based on a survey. The study's results will be released in 2011. However, generally EPAC onlus struggles to include viral hepatitis treatment in its entirety (from primary to secondary prevention) into the national health plan and to make sure that all of the country's regions are able to provide the same and highest standard level of treatment to patients.

OPPORTUNITIES AND CHALLENGES AHEAD

The most important current challenge is to include all hepatitis treatments into the national health plan and ensure that patients infected through blood transfusions are compensated and fully reimbursed. In addition, the inclusion of viral hepatitis screening and prevention into the national healthcare system remains a key challenge. An important step and opportunity towards achieving these goals is to promote greater coordination between stakeholders in Italy including institutions, the pharmaceutical industry, patient associations and scientific associations. At EU level unified screening guidelines should be drawn-up and resources should be made available for research and trials of new drugs on high risk groups.

Poland

THE SITUATION IN POLAND

Estimated prevalence

Viral hepatitis B and C prevalence in Poland is between 1.5% and 2%. There are an estimated 700 000 people infected, of which many are unaware of their condition.

Trends

In theory, prevalence should decrease as the sanitary conditions in the hospitals and medical centres improve. Doctors expect however that in view of the lack of regular screening, prevalence will increase – patients who are already infected but who are not aware will start to have symptoms (which might occur even 25-30 years after their initial infection). The specialists claim that all people who have undergone a medical procedure before 1991 should be tested for HBV/HCV.

Treatment

Viral hepatitis B and C are not high on the political agenda, the financial resources for the screening tests but also for the therapy are therefore limited. This is coupled with the lack of awareness among general practitioners about the symptoms at the early stage of the disease. Poland does not include primary or secondary prevention in its national health plan. Some of the treatment that is provided for viral Hepatitis B is too old and not up to current standards. In addition it may take up to 3-5 years for patients to start treatment on Interferon.

Testing

Viral hepatitis tests are currently not included in the basic check-ups e.g. obligatory test for pre-employment. Although the infrastructure is broadly in place, there are not enough financial resources to finance tests or treatments. The patient needs to go to a specialist to be prescribed a free-of-charge test; otherwise the patient needs to bear the costs privately.

PATIENT GROUP IN POLAND

○ *The Star of Hope*

Background information

The Star of Hope organisation was created in 2007 in Katowice, Poland. Its main goal is to help patients with liver diseases regardless of the cause, provide them with counselling and, in a way, substituting official bodies in the task of identifying infected people. The Star of Hope cooperates with other organisations including the Hepa-Help Association, Against the Yellow River Current Foundation and the SOS-WZW Association.

Main activities

Awareness raising is one of the main activities of the Star of Hope. In addition to the 20 volunteers including doctors, which assist in the promotion of the campaigns, the association partners with other specialised organisations and individual general practitioners in order to get the message across and receive feedback.

Most of the campaigns are locally focused and consist of expert meetings, meetings with politicians, media outreach, information stands in public places and free testing initiatives. The instruments used for the messaging vary from leaflets to newspapers, specialised journals and the most important arguments are found in scientific studies.

Contribution and Achievements

The most successful campaign that was carried out consisted of a screening campaign in the Silesia region. 5000 people were tested for viral hepatitis C which revealed an identification

level of 1.5%. The campaign was widely picked up by media (national, regional including press, radio and TV programmes); in addition around 50 TV information spots appeared. Patients are still turning to the association after this campaign and the media wants to continue reporting about the viral hepatitis danger.

The Association is in contact with the decision makers at ministerial level once a year, usually in case of a concrete problem (e.g. the suspension of the financing for oncology patients due to the lack of adequate regulations). It maintains more regular contacts with the local politicians. However, there is a general feeling that viral hepatitis is not on the priority list for the decision maker and the problem is widely underestimated.

OPPORTUNITIES AND CHALLENGES AHEAD

At the strategic level the main challenge in Poland is to convince the government and healthcare professionals of the seriousness of the disease and to increase the political will. The Star of Hope believes that it would be important to reach out to more regions in the country and to try to influence policy-makers at a broader level.

Ensuring that the problem is high on the political agenda and that adequate financing is secured remains an important goal. In addition, the inclusion of primary and secondary prevention in the national health plan and the introduction of viral hepatitis tests into basic check-ups e.g. the obligatory test for pre-employment, is important. Awareness-raising campaigns targeted at society at large as well as general practitioners will need to be further conducted and promoted.

Portugal

THE SITUATION IN PORTUGAL

Estimated prevalence

In Portugal the estimated prevalence of viral hepatitis C is 1.5% while about 1% suffers from viral hepatitis B. However, given the lack of official data, numbers are believed to be slightly higher than these figures, in addition to the new cases that also go unregistered.

Trends

Given that viral hepatitis B vaccination is obligatory for all newborns, the disease is not considered a major problem by the government, although the majority of the population is not vaccinated. The main concerns in Portugal are risk-groups and immigrants who live outside of the legal system and therefore do not receive access to the national health system.

Treatment

Testing in Portugal is possible but not easily accessible. Usually, after being diagnosed, patients will need to face long queues and significant waiting time if they require any further testing while direct access to treatment is slightly quicker. Another issue faced by patients is discrimination by healthcare professionals (as they are associated with drug addicts, prostitutes, alcoholics) and, sometimes, negligent behaviour. Treatment is, nonetheless, free of charge.

Testing

A viral hepatitis check is only carried out upon request of the patient or if the patient is considered to be part of a risk group. In SOS Hepatitis view, the largest groups at risk are ex-combatants from the overseas war (Angola, Mozambique, Guinea ...), women who became mothers, women who have abortions, any person who was operated before the year 1992, or has received a blood transfusions before 1992. Today these people are 50/60 years old, many have been infected for many years and most are pre-cirrhotic without knowing it.

PATIENT GROUPS IN PORTUGAL

○ *SOS Hepatitis Support Group*

Background information

The SOS Hepatitis Support Group was founded in 2005 and is now represented in 7 different cities and is entirely run by volunteers. Its objective is to provide counseling and clarification to patients of practically all liver conditions, as well as the promotion of awareness to the general public and health professionals as well as providing input to official studies. The association suffers from a great lack of funding (mostly private/public donations) and public support justified by the low status of viral hepatitis in Portugal and its taboo-like image.

Main activities

Awareness-raising campaigns are not the main activity of SOS Hepatitis due to lack of funding and time. Essentially, the focus is on expert and face to face meetings as well as seminars. With these actions the volunteers aim to gather policy-makers and healthcare professionals support, in addition to the general public's attention. However, the best reception of the information experienced to date has actually come from school children who are far more open to the topic (children actively participate in open sessions and explain these experiences to their parents).

Contribution and Achievements

SOS Hepatitis has a considerable number of celebrity public supporters ranging from footballers to rock musicians and Members of the European Parliament (MEPs) including for instance the former MEP, Fausto Correia, S&D. Furthermore, on the World Hepatitis Day and on other significant occasions they take the opportunity to organise public actions, such as distributing condoms to help prevention. Their greatest achievement was the organisation of an awareness raising seminar at the University Hospital of Coimbra, which had the participation of over 150 healthcare professionals and students.

OPPORTUNITIES AND CHALLENGES AHEAD

The main challenge for SOS Hepatitis is to improve public opinion and demystify the taboo around viral hepatitis. In Portugal, the main obstacle to policy development is the perception of the illness and the lack of knowledge which surrounds it. A change in perception would assist both the national healthcare system to work better and the association to receive more funding.

Romania

THE SITUATION IN ROMANIA

Estimated prevalence

In Romania the prevalence of viral hepatitis B and C together is around 10% representing over 2 million people with a tendency to rise.

Trends

In spite of the increasing tendency of viral hepatitis prevalence, treatment and vaccination for viral hepatitis and even liver cirrhosis are not included in the national healthcare systems.

Treatment

Viral hepatitis is currently not included in the national health programmes nor in its vaccination or medical reimbursement system, hence the high cost especially for patients that are under interferon therapy. Viral hepatitis is considered a chronic disease but is not

part of national programmes which would provide for larger subsidies, as well as easier access to treatment. (Cirrhosis might be included in a national programme in the future.) Waiting time for treatment can amount to 1 year. In addition, treatment is often linked to age instead of to the extent to which the liver is affected.

Testing

Viral hepatitis tests are not included in general set of tests.

PATIENT GROUPS IN ROMANIA

○ *SANOHEP Romania*

Background information

SANOHEP Romania was founded in 2001 with the overall goal to educate people on viral hepatitis and promote informed behaviour. Their added value is the facilitation to patients of psychological counseling and the possibility of free testing but also their soft approach to both awareness campaigns and policy-making. Their current specific goal is to identify and screen target groups under risk and to include viral hepatitis in general check-up tests.

Main activities

The organisation promotes numerous awareness raising campaigns which are directed mainly at policy-makers and risk groups, although accessible to the whole population. SANOHEP conducts the campaigns essentially through seminars, roundtables, expert meetings or free test initiatives, depending on the specific objective. Moreover, they also organise media outreach campaigns in order to promote public support for tackling the disease.

The main means used to pass on the message are the internet, leaflets and television in what concerns general awareness campaigns. Whereas, the best mechanisms found for a more in-depth approach are face to face meetings with specialists and political declarations with some kind of effective consequence.

Contribution and Achievements

The most recent campaign targeted school children and teenagers from 9 pilot counties in Romania. It was the first such initiative targeting children. The objective was to provide them with information on viral hepatitis A (especially for primary school children, who were asked to show the leaflets we distributed to their parents), viral hepatitis B and C (for 5-8 and 9-12 of age). They were invited to informal debates conducted by the volunteers. Very good feedback was received especially from teachers and the media coverage was also very good.

SANOHEP has built a long-standing partnership with the Ministry of Health and obtained observer status in some of the local and national committees responsible for the decisions on treatment availability and policy development. They also partner with individual general practitioners and other horizontal patients associations demonstrating that there is a network in place, in Romania, to deal with the challenges of viral hepatitis and work on public awareness.

OPPORTUNITIES AND CHALLENGES AHEAD

SANOHEP's main challenge is to try and include viral hepatitis in the general set of tests provided by the Government and help identifying target groups under risk. In addition, free treatment and the inclusion of primary and secondary prevention into the national healthcare system are being pursued. Awareness raising and increasing the knowledge of prevention mechanism close to the risk groups remain top priorities for SANOHEP. Another challenge to overcome is that a patient's age should no longer be a criterion for the initiation of treatment.

Slovakia

THE SITUATION IN SLOVAKIA

Estimated prevalence

There is an estimated prevalence of viral hepatitis B as well as C is of 1% but the lack of official data makes it rather difficult to assess the real situation.

Trends

As there is no official data on viral hepatitis prevalence it is equally hard to determine whether or not the number of infected people is rising or decreasing. In any case, reports from the European Monitoring Centre for Drugs and Drug Addiction (EMCDDA) state that amongst drug users the situation is stable, although high, and government measures are relatively effective.

Treatment

Whilst primary prevention programmes are inadequate, reimbursement, waiting time, and the availability of treatment seem to be adequate both at the political and the operational levels.

Testing

Testing has been available free of charge since 2009 in most of the general practitioners practices. All patients may request it but it is not yet part of the general blood test.

PATIENT GROUPS IN SLOVAKIA

○ *HEP HELP KLUB*

Background information

HEP HELP KLUB was formed in 2006 with the objective of increasing expert knowledge in the area of medicine and public health with an emphasis on viral hepatitis C and other diseases of the liver. The association is supported by 5 volunteers who ensure partnerships with individual and collective associations of medical doctors as well as to ensure the counseling of around 5 patients per week.

Main activities

The HEP HELP KLUB frequently organises all types of awareness raising events from expert meetings to seminars and free testing initiatives. As a small organisation it does very well in terms of diversifying messaging instruments and frequently uses the internet, email, TV, newspapers and others to transmit its message.

Contribution and Achievements

HEP HELP KLUB's greatest achievement to date is the significant shift in public opinion and perception of viral hepatitis B and C. This was achieved through the numerous awareness raising campaigns that were organised and an effort to contact policy-makers by means of written communication. Through their activities more information could be disseminated to the general public, achieving greater awareness of the disease.

OPPORTUNITIES AND CHALLENGES AHEAD

Viral hepatitis is not a particularly neglected disease in Slovakia, however there is still a lack of general public awareness. Hence, the association's main opportunity is to increase knowledge of the disease in the area of public health. Furthermore, the association is aiming to include viral hepatitis in routine blood screenings and try to better educate the Slovak healthcare staff.

Spain

THE SITUATION IN SPAIN

Estimated prevalence

In Spain, 3% of the population suffers from viral hepatitis C and another 3% is believed to be infected without knowing it. Less data is available on the prevalence of viral hepatitis B infections but it is estimated that about 1.5-2% of the population suffers from viral hepatitis B.

Trends

Given that viral hepatitis B vaccination is available free of charge and is even obligatory for all newborns, the disease is not considered a major problem by the government. However, taking into account the higher prevalence among migrants, the patient groups in Spain ascertain that viral hepatitis B remains a major risk to public health. In addition, viral hepatitis is highly stigmatized in Spain and the psychological aspect is often neglected. Hepatology teams of main hospitals in collaboration with patient groups are starting to offer training and awareness activities to general practitioners and nurses so that patients can be diagnosed at an earlier stage.

Treatment

Once diagnosed, the viral hepatitis patient has access to the appropriate treatment and to hepatologists. The main problem however remains early diagnosis as no systematic public screening is carried out and there is generally a lack of knowledge of the disease. In addition, General Practitioners, who are a patient's first point of contact, are often not adequately educated in this field to diagnose the disease in a timely manner.

Testing

A viral hepatitis check is only carried out upon request of the patient, it is thus not included in a normal blood test for instance. In particular, people with tattoos or people who received blood transfusions before the 1990s as well as the immigrant population (e.g. from China, Romania and South America) are major risk groups.

PATIENT GROUPS IN SPAIN

- *AsoEEHC "Asociación Española de Enfermos de Hepatitis C"*

Background information

AsoEEHC is the Spanish patient association operating at the national level since 1998. Its mission is to lead on defending the collective and individual interests of viral hepatitis C patients. AsoEEHC works with professionals, psychologists, lawyers and social workers.

Main Activities

In the context of its awareness raising campaign, AsoEEHC is involved in a wide range of activities including seminars, roundtables, meetings with politicians, and trainings of general practitioners, media outreach and information stands. In addition, given the stigmatisation of viral hepatitis strong focus is placed on the psychological dimension of the disease.

Contribution and Achievements

Over the years AsoEEHC has established long term relationships with policy makers as well as with the media. With the Ministry for Health AsoEEHC has for instance organised 'work tables' to address the topic of viral hepatitis and to present concrete cases. Policy makers at national level have been receptive to AsoEEHC activities, and have supported the organisation in elaborating practical guides on viral hepatitis C for general practitioners, by

participating in days dedicated to patients and their families as well as speaking on co-infection in penitentiaries. AsoEEHC collaborates well with policy makers, however own-initiatives by the government are rare. In April 2010, AsoEEHC submitted a request for viral hepatitis C screening in risk groups to the health department, which is currently under review. Their main success to date is the positive impact of the World Hepatitis day, the right to a second opinion by the patient and their active participation in studies.

In November 2010, AsoEEHC will be carrying out a study on the realisation of screening among the risk group population in collaboration with the Health Department of the Region of Valencia and with the support of the counsellor for public health. The study will be presented by the regional ministry of Valencia to general practitioners as well as to patients, their families and the general public.

○ *ASSCAT “Associació Catalana de Malalts d’Hepatitis”*

Background information

ASSCAT was founded in the year 2000 and is the Association for Hepatitis Patients in the autonomous region of Catalonia. Its mission is to help the patients and their families from the moment of diagnosis by informing on all aspects of viral hepatitis. Their added value to other establishment such as the Primary Care Centres (the patient’s first point of contact) is their ‘patient to patient’ approach. Their experience as patients contributes to providing practical and emotional support.

Main activities

ASSCAT’s awareness raising campaign is mainly directed at healthcare professionals, the general public and risk groups such as drug addicts. To this end, expert meetings and information days are organised for health personnel, the general public, academics and the immigrant population.

Contribution and Achievements

The results of these efforts are however limited to some extent due to a lack of resources and a lack of support by the Catalanian government, which does not consider viral hepatitis as a priority issue. Over the years ASSCAT managed to build strong links with hepatologists who support their campaign with their professional expertise e.g. training seminars for General Practitioners. Media coverage is highly dependent on the nature of the news and whether there is a major development. Despite these constraints, ASSCAT nonetheless secured two meetings with the Health Department and ensured that they committed to distributing information leaflets on viral hepatitis to all Primary Care Centres in 2011.

OPPORTUNITIES AND CHALLENGES AHEAD

Whilst funding commitments for viral hepatitis treatment are available and adequate in Spain, no resources are devoted to the early detection of the disease, e.g. there is no screening programme in place. Viral hepatitis is not included in the government health programme nor is there a specific prevention campaign.

The challenges for these organisations include achieving greater visibility and sufficient information on viral hepatitis. This includes extensive information campaigns by the public administrations and adequate training of general practitioners. A public screening plan for viral hepatitis C risk groups represents a major challenge and is actively pursued. In support of these efforts, access and production of more data in Spain but also across Europe would significantly contribute to achieving these goals.

Sweden

THE SITUATION IN SWEDEN

Estimated prevalence

In Sweden there is an estimated prevalence of viral hepatitis C of around 0.5% and most cases (90%) are identified in drug users.

Trends

Overall, the trend is for the virus to decrease in terms of the general population but not necessarily amongst the most affected risk groups due to the lack of government support to prevention.

Treatment

Treatment is available in hospitals and follows the normal healthcare provisions of the Swedish State. This means that if the patient is identified as a risk group, treatment will be free and if this is not the case the normal health insurance schemes applies.

Testing

Vaccination of new born children is not a main priority in Sweden. It is not included in the national health system scheme and is one of the biggest issues for the patient groups. Testing is only possible on request and through the payment of a fee.

PATIENT GROUPS IN SWEDEN

- *Riksföreningen Hepatit C (RHC)*

Background information

The National Union of Hepatitis C (RHC) is a small patient association which works mainly on raising awareness, minimizing the spread of the disease and supporting a small number of patients (around 5 per week) suffering from viral hepatitis C infection. Its dependence on 5 volunteers does not allow them to organize many campaigns or public actions beyond the World Hepatitis Day.

Awareness raising campaign

As a small association the RHC does not have the ability to coordinate many awareness raising campaigns so its members prefer to put together face to face meetings between patients and specialists or engage in the dissemination of relevant studies and data through the use of the internet and email.

Contribution and Achievements

The World Hepatitis Day is the yearly campaign where the association gathers most of its funding and it is usually the biggest public activity they organise. In terms of achievement, the association is happy with the degree of information disseminated through leaflets and flyers in markets and other public locations.

Its most important contribution is the support they provide to those infected and to their families (as they are the only association) but also the dialogue it tries to establish with health care and decision-makers.

OPPORTUNITIES AND CHALLENGES AHEAD

As the organisation mainly focuses on viral hepatitis C, the work of the association concentrates on risk groups. Hence, the main challenge of RHC is to raise awareness and influence public policy to create better conditions for those within the risk groups suffering from viral hepatitis.

The main challenge is to educate healthcare professionals to ensure the necessary awareness of viral hepatitis and promote the importance of primary prevention. In fact, the support of healthcare professionals is a significant factor in their awareness raising campaign and in order to receive policy-makers attention. Dialogue with policy-makers is another challenging task for RHC as there is very little political will to support the viral hepatitis C cause in Sweden.

The Netherlands

THE SITUATION IN THE NETHERLANDS

Estimated prevalence

In the Netherlands the prevalence for both chronic viral hepatitis B and C is about 0.1% to 0.3%. The prevalence of viral hepatitis B is higher among certain risk groups including immigrants from endemic areas and (former) drug users. In the Netherlands there is less data on the prevalence of viral hepatitis C; the risk groups are among others (former) drug users and people who had a blood transfusion or received other blood products (haemophiliacs) before 1991.

Trends

Although no national screening strategy is in place, screening of targeted groups receives more attention. Since 1998 pregnant women are for instance tested for viral hepatitis B. In addition, since 2003 newborns are vaccinated if one of the parents comes from a medium or high endemic area. Prostitutes and homosexual men with multiple sexual partners can also be vaccinated for free.

Treatment

Once diagnosed, treatment is available and the costs are covered by the basic health insurance package.

Testing

Viral hepatitis tests are not included in any general check-up.

PATIENT GROUPS IN THE NETHERLANDS

- *Nationaal Hepatitis Centrum (NHC)*

Background information

The Nationaal Hepatitis Centrum (NHC) in the Netherlands was founded in 1995 to take up a central place in and to contribute to the social and societal aspects of viral hepatitis. As an independent organisation NHC works together with doctors and other patient organizations to raise awareness and to be a general helpdesk for people dealing with viral Hepatitis and other liver diseases, both from a professional or private angle. The NHC advises between 10 and 20 patients per week, but also health care workers, physicians and other professionals are advised on viral hepatitis.

Main activities

The NHC organises very broad campaigns to raise awareness on liver diseases and viral hepatitis. The campaigns are directed towards a number of target groups including policy makers, insurance companies, healthcare professionals, risk groups, and the general public. A variety of communication channels combined with a broad range of activities like seminars, media outreach, information stands and free testing is being used. This is supported by specialised studies, scientific data, cross-country comparison and meetings with specialists.

To reach as many people as possible, the NHC is working together with a variety of stakeholders such as the Associations of General Practitioners (e.g. *Nederlands Huisartsen Genootschap*), horizontal patient associations (e.g. *Nationaal Instituut voor Gezondheidsbevordering en Ziektepreventie*) and specialised organizations (e.g. *Nederlandse Leverpatienten Vereniging*).

Contribution and Achievements

Their greatest achievement of the NHC is the significant media attention they obtained on the occasion of the World Hepatitis Day. More than 150 websites published their press release and there were also interviews in the radio and television. 'Universal vaccination will be implemented in the Dutch Childrens' vaccination programme in 2011, an achievement of many professionals and organisations working in the field of viral hepatitis, including the NHC.' Generally the NHC faces the obstacle that there is a lack of interest among policy makers and healthcare professionals.

OPPORTUNITIES AND CHALLENGES AHEAD

The NHC is vigorously pursuing screening for viral hepatitis in several risk groups. In addition, the development of a hepatitis monitoring system is needed. The NHC will continue to raise awareness of the seriousness of viral hepatitis among the general public, healthcare professionals and politicians. Furthermore, increased media coverage of viral hepatitis is being further pursued.

United Kingdom

THE SITUATION IN THE UNITED KINGDOM

Estimated prevalence

The prevalence of viral hepatitis C in the United Kingdom (UK) is 0.5% to 1%. Government figures for viral hepatitis B suggest the prevalence is 0.3% (about 180 000) but independent estimates put it at twice that figure.

Trends

Prevalence is believed to be on the rise. There is still no universal vaccination for viral hepatitis B in place and there is no systematic screening strategy in the UK. Data is relatively poor as there is no prevalence study being carried out, except amongst injecting drug users. In addition, National Health Service provision varies throughout the UK which complicates the access to treatment and patients' rights in general.

Treatment

Access to treatment and reimbursement is generally not an issue. However on occasions retreatment can be problematic and in some areas specialists are not spread evenly. Hepatitis care for drug users and prisoners is also rather poor.

Waiting times have generally become much better. They are more of a problem in those areas where diagnosis through the implementation of testing programmes has improved.

Vaccination for viral hepatitis B ranks from being free for certain risk groups listed in the so called 'green book' to £200 in some places.

Testing

Primary prevention and case findings are generally poor. Especially among drug users, not even testing targets are met.

PATIENT GROUPS IN THE UNITED KINGDOM

○ *The Hepatitis C Trust*

Background information

The Hepatitis C Trust was founded in 2001 and has offices in London, Coventry and Edinburgh. They work with 16 full time employees and 60 volunteers across the country. Patients are generally informed about The Hepatitis C Trust's existence at the time of hospital referral. Their mission is to provide information and support people with viral hepatitis C, as well as raising awareness and preventing unnecessary deaths.

Main activities

Apart from counselling, The Hepatitis C Trust leads awareness campaigns directed at risk groups, healthcare professionals, policymakers and the general public. For these campaigns it makes increasingly use of new media such as facebook and twitter, but also produces patient testimonials for radio stations which are broadcasted every 3 months.

The Trust has established partnerships with both specialist (e.g. the British Association for the Study of the Liver) and general practitioner associations (e.g. Royal College of General Practitioners). With the latter, they are developing an online learning tool on viral hepatitis C for general practitioners.

Furthermore, the Trust runs the secretariat for the all-party hepatology group in Parliament and works closely, at regulatory level, with the National Institute of Clinical Excellence (NICE), whom it has recently advised on access to antivirals for drug users.

Finally, the different health systems in England, Scotland and Wales have proved to be helpful. The Scottish hepatitis C strategy, triggered by the Royal College of Physicians consensus conference in 2004, led the way for greater efforts in England and Wales.

Contribution and Achievements

At policy level, the Trust conducted an award-winning campaign for a national liver strategy which was then kicked off by the Department of Health in October 2010. Its chief executive Charles Gore is now co-chair of one of the workstreams and sits on the liver strategy's steering group.

Furthermore, thanks to the help of VIP patient Dame Anita Roddick, the Hepatitis C trust managed to raise the profile of Hepatitis C significantly in the UK media and has managed to maintain this level, despite Dame Anita's tragic death in October 2007.

○ *British Liver Trust*

Background information

The British Liver Trust was founded in 1988 and is the only liver charity for adults in the country. Their mission is to help adults with liver disease and to prevent liver disease. Its objectives include advancing education and awareness among the public, patients and health professionals, endorsing health education and promoting medical as well as scientific research relating to diseases and disorders of the liver.

Main activities

The campaigns of the British Liver Trust are far reaching and include interaction with policy-makers and healthcare professionals, the general public and risk groups. A number of seminars, expert meetings and information stands are organised regularly. In addition, media outreach is an important tool used as along with the internet, leaflets, newspapers and other sources of information such as scientific studies and cross-country comparisons. Generally there is a good reception of the campaigns concerning liver disease, but both the media and the public opinion are not too favourable to "self inflicted" case studies i.e.

former drug users. A regular relationship has been built with about 10 people from the Department of Health.

Contribution and Achievements

Amongst its main achievements is the recent pharmacy testing event in Blackpool (an area with the highest rates of mortality due to chronic liver disease in England) and identified 64% of those tested as having HCV. The British Liver Trust's greatest problem is however the considerable lack of attention from policy makers, healthcare professionals and the media. The FaCe campaign for Hepatitis C in the UK is led by the Health Department, however it is on hold since the elections in the UK.

Nonetheless, they have recently achieved a commitment from the Government for a National Liver Strategy and the Government has appointed a Liver Tsar (Dr. Martin Lombard) to formulate it. In this process statistics and scientific evidence that liver is the only disease among the 'big killers' that is on the rise have proven key. The strategy will encompass efficiency ideas and will have a clinical focus rather than on spending or promoting public awareness.

Opportunities and challenges ahead

The British Liver Trust's main goal is the implementation of the national liver strategy. The lack of education on viral hepatitis C amongst healthcare professionals is the biggest challenge in the Hepatitis C Trust's endeavour to improve case finding. While there are examples of good practice at local level, it is rather challenging to make them known more widely, so they can be emulated. The cooperation with the Royal College of General Practitioners and the special interest group of general practitioners for drug addiction are opportunities in this context.

Another challenge is the lack of both scientific and health economic data, as well as the nature of the disease itself, which people find hard to relate to.

The British Liver Trust's also aims at ensuring that the implementation of universal vaccination for viral hepatitis B, which includes the need for better prevalence figures. In the context of the National Liver Strategy, they want to ensure that the newly appointed "liver tsar" becomes an efficient post and starts to change the current situation at a national level.

The overarching challenges remain to be the identification of all those suffering from liver disease and create joined up programmes aimed at risk groups to ensure appropriate care. Better case finding initiatives with a commitment to treating people upon identification are being pursued as well as increasing the knowledge in the healthcare community of liver diseases.

ANNEX II: PATIENT SELF-HELP SURVEY

Section 1: About the organization

1. Name of the patient self-help group/organization?

2. What country are you based in?

3. When was your group/organization founded?

4. What is your mission?

5. What are your main activities?

- a. Counseling
- b. Awareness raising campaign
- c. Participation in studies
- d. Other:

6. How many patients do you advise per week?

- a. Up to 5
- b. Between 5 and 10
- c. Between 10 and 20
- d. More than 20 (please specify)

7. Why do they come to you? Do they have other places to go to?

- a. We are the only place they can go to
- b. We are complementing other places

If you answered option b) Please give details about where else patients go to and what your added value is:

8. Please rank in order of importance the liver diseases you are dealing with:

- Viral Hepatitis A
- Viral Hepatitis B
- Viral Hepatitis C
- Hepatitis due to alcohol consumption
- Non-alcoholic fatty liver disease
- Liver cirrhosis
- Liver Cancer
- Haemochromatosis
- Other

9. Do you work with volunteers and/or employees?

- a. Yes – Please indicate the number:
 - Employees:
 - Volunteers:
- b. No

10. How do you finance yourself? Please provide estimated percentages.

- a. Private %
- b. Donations/general public %
- c. Pharmaceutical industry %
- d. Industry other than pharmaceutical companies %
- e. Public sector/government funding %
- f. Other: %

Section 2: Liver awareness raising campaign

11. Do you organize campaigns to raise awareness of liver diseases and/or hepatitis?

- a. Yes
- b. No

If yes, please proceed to question 12.

If not, please explain the reasons e.g. no need, not the focus, no resources:

12. At whom is your awareness raising campaign directed?

- a. Policy makers
- b. Insurance companies
- c. Healthcare professionals
- d. General public

- e. Risk groups (e.g. drug addicts)
- f. Other:

13. Are you satisfied with the result?

- a. Yes
- b. More or less
- c. No

Please explain:

14. Do you have a long term relationship with policy makers or other stakeholders, e.g. VIP patient or supporter?

- a. Yes
- b. No

If yes, please specify. If no, what are the reasons?

15. What are the main activities you carry out to promote awareness of hepatitis?

- a. Seminars/roundtables
- b. Expert meetings
- c. Meetings with politicians
- d. Media outreach
- e. Information stands in public places
- f. Free testing
- g. Other:

16. What channels do you use to raise awareness of hepatitis?

- a. Internet
- b. E-mail/letters
- c. Leaflets
- d. Newspapers
- e. Specialised journals
- f. Life Style magazines
- g. Television
- h. Other:

17. What main tools and arguments do you use to raise awareness of hepatitis?

- a. Specialised studies
- b. Scientific data (e.g. graphs, tables)
- c. Cross-country comparisons
- d. Face to face meetings including specialists

- e. Political statements e.g. European Parliament Written declaration
- f. Other:

18. Do you partner with any other stakeholders? (please specify)

- a. Specialised organizations
- b. Individual General Practitioners
- c. Associations of General Practitioners
- d. Horizontal patient associations
- e. VIP patient or supporter?
- f. Other:

Section 3: Evaluation

19. What is the estimated hepatitis prevalence in your country; is there a general rising or declining trend?

20. Is hepatitis primary and/or secondary prevention included in the public health care programmes/policies of your country?

- a. Yes, primary and secondary prevention
- b. Only primary prevention
- c. Only secondary prevention
- d. Neither

Please specify:

21. Please specify how you would rate the attention that is given to hepatitis at political and operational level?

	Criteria	Political will/initiative/support (adequate/inadequate)	Operational set-up (adequate/inadequate)
a.	Reimbursement availability		
b.	Primary prevention		
c.	Secondary prevention		
d.	Access to treatment		
e.	Waiting time		

f.	Other:		
----	--------	--	--

22. What are your observations about how your current national health system classifies and targets hepatitis, is it a case for best practice?

23. How often do you meet with policy makers?

- a. 1 time per year
- b. 2 times per year
- c. 4 times per year
- d. 8 times per year
- e. Other:

24. Do you pursue a specific goal? e.g. political statement, refunding of hepatitis testing by insurance companies, inclusion of hepatitis in a general check-up test, risk-group specific screening etc.

- a. Yes
- b. No

If yes, please give details:

25. What is your greatest achievement in the field of hepatitis awareness rising to date?

26. What is your greatest challenge to date?

27. What are the main problems you encounter in your awareness raising campaign:

- a. Lack of interest from policy makers
- b. Lack of scientific data
- c. Lack of education of healthcare professionals
- d. Lack of media attention
- e. Other:

28. How does the World Hepatitis Day contribute to your activities?

29. How does political attention and funding commitments on hepatitis fare compare to other diseases such as HIV, tuberculosis or cancer? Do other diseases have more awareness? If so why?

30. In your view, what should sustainable policy making in your country in the field of hepatitis awareness entail? How could the situation be improved and by whom?

31. What activities/results would you like to see at the European level to support your national activities?