Viral Hepatitis

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This edition of *Viral Hepatitis* is based on material presented at the Viral Hepatitis Prevention Board meeting on **the Prevention and control of viral hepatitis: the role and impact of patient and advocacy groups in and outside Europe**, Lucca, Italy, March 12-14, 2008.

Editorial

This issue of *Viral Hepatitis* reviews topics covered at the Viral Hepatitis Prevention Board (VHPB)/European Liver Patient Association's (ELPA) spring meeting on the *Prevention and control of viral hepatitis*: *the role and impact of patient and advocacy groups in and outside Europe*, held on March 12-14, 2008 in Lucca, Italy.

The meeting brought together 12 national patient organizations from Europe and the United States, 3 umbrella organizations and one organization representing the interests of the Asian/ Pacific Islander American community, with the aim of providing an overview of the activities, role, rationale and impact of international and national patient and advocacy groups in Europe and the United States in terms of prevention and control of viral hepatitis.

The diversity of participating patient organizations to this forum favoured productive cross-fertilization, in particular in terms of objectives, functioning structure, financial resources and efficient targeted programs and actions. Hence, it created an opportunity for them to share experiences on their activities, as well as identifying their strengths and weaknesses, together with challenges and thresholds regarding their role and impact on prevention and control of viral hepatitis.

During the breakout sessions purposely devoted to the identification of strengths versus weaknesses of patient organizations, it appeared that most of them successfully fulfill a common role in disseminating reliable information to their members and the public, as well as raising awareness among healthcare workers.

Also, in addition to their active involvement in the implementation of prevention strategies, patient groups were seen as particularly successful in reaching minorities or vulnerable populations with less risk of stigmatization.

The meeting concluded with achievements and opportunities, stressing the need for improved implementation of national prevention and control plans, better access to healthcare and continuous efforts to be made to ensure equality of access to prevention and care, including hard-to-reach populations. The role and impact of various partner agencies and organizations was also assessed.

HBV is often considered as the poor cousin to HIV/AIDS in Europe and it is not until recently that it was included on the agenda of many patient organizations, mainly as a need resulting from increased immigration, associated with low socioeconomic status and inadequate healthcare provision.

Also, the growing number of younger HBV patients warrants remaining challenges of prevention strategies to be addressed, such as a more adequate provision of healthcare to vulnerable and hard-to-reach groups, ensuring the timely provision of HBV vaccine, in particular birth dose, in several countries.

More accurate data on immunization coverage and enhanced surveillance of acute and chronic HBV cases are needed for the implementation and monitoring of appropriate prevention strategies and in order to effectively counteract misleading and biased information and media stories disseminated by anti-vaccination lobbyists, with the effect of a threatened public confidence in the benefits of immunization. Surveillance data should also help correcting the misperception of HBV as a vaccine-preventable disease and therefore less of concern than HCV or HIV/AIDS for which no vaccines are available.

Hepatitis B (HBV) disease burden has significantly been reduced in the WHO European Region as a result of combined efforts towards prevention and control measures, including 16 years of VHPB activities in Europe, with the support of its members comprising the CDC, WHO, WHO/ EURO, national Ministries of Health, Universities, as well as its network of experts. HBV vaccine (including birth dose in highly endemic areas) was successfully introduced in existing routine childhood immunization programs in most countries with, as latest success, the introduction of HBV vaccine into the Irish childhood immunization schedule. However, efforts are still needed as 8 of the 53 countries in the WHO European region do not have a policy of universal vaccination. Patient groups are also well-placed to be involved in the process to persuade governments

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Prevention and control of viral hepatitis: the role and impact of patient and advocacy groups in and outside Europe

Lucca, Italy, March 12-14, 2008

Role and impact of umbrella organizations

This session was devoted to the presentations of several umbrella organizations with common aims: ELPA representing the interests of liver patients in Europe, the national roundtable working to eliminate viral hepatitis in the United States (NVHR), and an umbrella organization representing the interests of patients with rare diseases in Europe (EURORDIS). In addition, the European Federation of Pharmaceutical Industries and Associations (EFPIA) code of practice was presented within the context of relationships between industry and patient groups.

European Liver Patients Association (ELPA)

The European Liver Patients Association (ELPA, www.elpa-info.org) emerged from a desire amongst liver patient groups across Europe to share their experiences of the often different approaches adopted in different countries.

ELPA represents 20 patient groups out of 17 European countries and their aim is to promote the interests of people with liver disease, with the following mandate:

- Raise awareness and promote prevention
- Promote well-defined targeted screening of viral hepatitis across Europe
- Address the low profile of liver disease as compared to other areas of medicine such as heart disease
- Share experience of successful initiatives
- Work with professional bodies such as the European Association for the Study of the Liver (EASL) and with the EU to ensure that treatment and care are harmonised across Europe to the highest standards
- Coordinate campaigns with uniform messages across Europe

ELPA was launched in 2005 with the aims of increasing awareness and prevention among healthcare professionals, policy makers and the general public; addressing the low profile of liver disease compared to other disease areas; and share experiences of successful cases in terms of disease management through coordinated campaigns and messages across Europe.

Key priorities are part of six EU “requests” on the occasion of the 2008 World Hepatitis Day, as follows:

1. Adoption of an EU Council Recommendation on targeted screening for viral hepatitis across Europe, ensuring early diagnosis and wider access to treatment and care
2. Commitment of EU Member States to implement the future European Centre for Disease Prevention and Control (ECDC) criteria for the surveillance of viral hepatitis
3. Recognition that targeted hepatitis screening of risk groups will effectively prevent complications, such as liver scarring and liver cancer
4. Commitment to work in partnership with hepatitis patient groups to ensure a coordinated campaign to raise public awareness
5. Commitment to a European strategy to protect healthcare workers from blood-borne infections such as hepatitis due to needlestick injuries by amending Directive 2000/54/EC on risks from biological agents at work
6. Provision of EU funding for further research on treatment for viral hepatitis, especially for cases of co-infection with HIV

Key ELPA achievements in 2007 have focused on successful lobbying activities to raise the importance of viral hepatitis within the European Parliament with, as a result, the adoption of a Written Declaration, an Open Discussion Forum on HCV and a Panel Discussion for the World Hepatitis Day. ELPA also contributed to the successful inclusion of viral hepatitis in the ECDC 2008 work program.

Key ELPA objectives for 2008 aim at the generation of reliable and comparable data across the European Union, involving ECDC, and the commitment of EU Member States to implement future ECDC criteria for surveillance. Such data should, in turn, support the adoption of an EU Council Recommendation on targeted screening for viral hepatitis across Europe. These key priorities were presented at the occasion of the 2008 World Hepatitis Day (see bottom of previous page).

European patient groups for rare diseases (EURORDIS)

EURORDIS (www.eurordis.org) mission is to build a strong pan-European community of patient organizations and individuals living with rare diseases in order to be their voice at European level and, directly or indirectly, fighting against the impact of rare diseases on their lives.

EURORDIS has the following priorities:

- Empowering rare disease patient groups
- Advocating rare diseases as a public health issue
- Raising public rare disease awareness, and also that of national and international institutions
- Improving access to information, treatment, care, and support for people living with rare diseases
- Encouraging good practices in relation to these
- Promoting scientific and clinical rare disease research
- Developing rare disease treatments and orphan drugs
- Improving quality of life through patient support, social, welfare and educational services

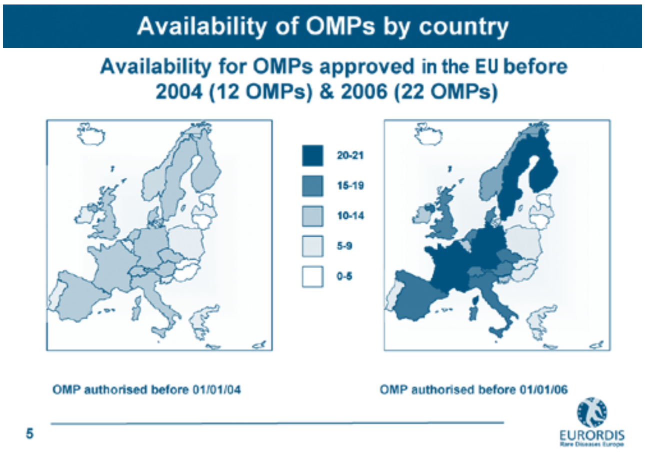
EURORDIS represents >341 member organisations in 38 different countries (24 EU members), covering more than 1000 rare diseases.

To date, 6000-8000 rare diseases have been identified, affecting a total of 30 million individuals in the EU, representing 6-8% of the population. Rare diseases are commonly defined as affecting 1-2000 citizens per country, 80 % are of genetic origin, with few and geographically spread patients. As a result, resources are limited, disease experts are few and relevant information is scarce. Research is fragmented and specialised care centres cannot be set up in every country.

Such characteristics warrant the need for an umbrella organization such as EURORDIS, aiming at **networking and information sharing** through annual membership meetings, participation at conferences, as well as website and monthly newsletter dissemination. A second priority for the organization is **advocacy and policy development** through EURORDIS presence in European institutions and platforms. **Access to information, diagnosis, treatment and care** are also key areas supported by initiatives such as the development of guidelines for the creation and management of patient groups and information services, mapping of patient group profiles and activities in Europe, scientific surveys to increase advocacy power (such as the *EURORDISCARE* program: a series of surveys to compare access to care for rare disease patients across Europe), and training sessions for patient representatives. EURORDIS is also active in promoting **therapeutic development and research** by creating programs such as *EuroBioBank*, a European network of biobanks of DNA, cells and tissue for rare disease research.

EURORDIS is also involved in the development of online patient communities via mailing lists and several solidarity initiatives at the level of individuals.

EURORDIS patient representatives also play a key role in promoting patient access to orphan drugs, mainly by contributing to policy development, in particular EU regulations; being involved in the decision-making process through active participation on the Committee on Orphan Medicinal Products (COMP) of the European Medicines Agency (EMEA), and validating information to the public. Orphan medicinal products (OMPs) were available by country in Europe, as follows:



Orphan medicinal products (OMPs)

National Viral Hepatitis Roundtable (NVHR)

NVHR (www.nvhr.org) is a coalition of more than 100 organizations working to eliminate viral hepatitis in the United States, by developing, implementing and maintaining a national strategy focusing on all aspects of viral hepatitis. Current NVHR members include professional groups, HBV and HCV advocacy groups, harm reduction organizations, AIDS/Hepatitis co-infection groups, general hepatitis organizations, general health organizations (that are concerned about viral hepatitis), federal government agencies, state and local health departments, and manufacturers.

NVHR has a 10-member board of directors, and an administrator. It had its beginning in 2002 by three founding partner organizations with financial support from industry. NVHR was officially launched in 2003 with a national meeting attended by nearly 200 individuals representing more than 100 organizations. Hepatitis A, B, and C were the focus of all discussions at the first national conference with particular attention to policy and legislation, prevention and screening, education of public and providers, care and treatment, and research. From 2004 to 2006, NVHR streamlined its work on the development and eventual publication of its action plan which was delivered to Congress in May 2006 [1].

NVHR goals to eliminate viral hepatitis:

1. Build the capacity to eliminate viral hepatitis
2. Vaccinate America
3. Counsel, test, and refer persons at risk for chronic disease
4. Care for persons with chronic hepatitis

NVHR aims to build national capacity to eliminate viral hepatitis by obtaining funding from public and private sectors for building healthcare infrastructure, disseminating information, promoting vaccination as the most humane and cost-effective intervention, accelerate the development of an HCV vaccine; expanding counselling, testing, and referral services for persons at risk for viral hepatitis; expanding healthcare services for persons with chronic hepatitis, and expanding research on viral hepatitis.

To date, NVHR main accomplishments have involved the publication of a national plan advocating for the elimination of viral hepatitis, the creation of a national coalition of organizations caring about and working together on viral hepatitis issues, dissemination of information on policy issues as needs arise, as well as an important advocacy role with CDC by bringing and enlarging community voices to policy decisions. Today, NVHR ongoing challenges are limited funding, the identification of the ideal organizational structure, continued efforts toward the implementation of its action plan by Congress.

In July 2008, NVHR, in partnership with the National Alliance of State and Territorial AIDS Directors (NASTAD), submitted a proposal to the CDC for funding under a five-year cooperative agreement for networking, partnering and information dissemination. This proposal was accepted and will commence in October 2008. The funding will enhance NVHR's capacity to link viral hepatitis coalitions and organizations in the United States; thus increasing these organizations' influence on viral hepatitis prevention and control by leveraging the resources and power of a collective voice.

European Federation of Pharmaceutical Industries and Associations (EFPIA) ethical code

EFPIA members include 32 European national industry associations and 44 pharmaceutical companies and has specialized groups, such as the European Vaccine Manufacturers (EVM, www.evm-vaccines.org).

European
Vaccine
Manufacturers

EVM has the following mission:

- Create a supportive environment for improved vaccine protection and coverage in the interest of individual and community public health
- Promote vaccine R & D to meet new challenges for innovative vaccine applications against infectious and other types of diseases
- Foster a favorable policy climate for the vaccine industry in Europe to bring new vaccines to the world

EFPIA's rationale to collaborate with patient groups is to better understand and address patient needs and concerns on research, medicines and medical interventions; support programs that improve public health and lives of individuals with medical conditions; and share priorities on access to medical interventions (prevention and treatment) that best meet patient needs.

EVM's perspective on the importance of working with patient groups focuses on specific aspects related to vaccines, such as the introduction of new products for healthy children and adults and the need to ensure adoption of vaccination programs by the general public, hence the key role played by patient groups in terms of awareness, education, information/communication and advocacy.

EFPIA has established a code of practice with patient organizations to ensure that relationships take place in an ethical and transparent manner, guaranteeing the independence of patient groups (e.g. funding from multiple sources), mutual respect, transparency, and non-promotion of prescription-only medicines.

The EFPIA code of practice was updated in 2006 in order to ensure consistent ethical industry behaviour across Europe; help meeting stakeholders' expectations of transparency and contribute to successful relationships and partnership with patient groups. Its scope is to define the relationship between EFPIA members/subsidiaries/contracted 3rd parties and patient organizations operating in Europe in the form of non-profit (and umbrella) organizations composed of patients and/or caregivers who represent and/or support the needs of their members.

The latest version of the code is effective as of 1 July 2008 and should be implemented by EFPIA member associations at national level; its provisions are listed below:

1. Non-promotion of prescription medicines: prevents advertising to general public
2. Written agreements with patient groups: ensure a clear role of industry and patient groups with the help of a document template mentioning purpose, amount of direct funding, and indirect financial/non-financial support
3. Use of logos and proprietary materials: written permission should be obtained from patient organisation to use them
4. Editorial control: no influence should be exerted on editorial content to favour commercial interest
5. Transparency: sponsorship should be clearly acknowledged and companies should make a list of sponsored patient groups (including financial/non-financial support) publicly available on a yearly basis
6. Diversified funding: prevents companies from being sole funders of patient groups or their major programs
7. Events and hospitality: must be held in appropriate venues, with reasonable level, and secondary to purpose of event; they should be limited to travel, meals, accommodation and registration fees
8. Enforcement: implementation and procedures are laid down in the appendices of the code

Reference

[1] Eliminating Hepatitis: A Call To Action. NHVR Plan to Eliminate Viral Hepatitis available at www.nvhr.org/pdf/NVHR_CalltoAction.pdf, accessed on 20 June 2008.

Based on presentations by
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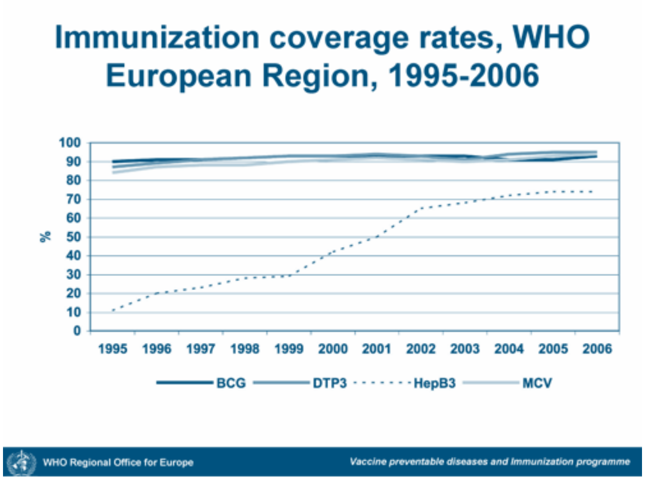
Wide-reaching initiatives to get attention and increase awareness on prevention of viral hepatitis

European Immunization Week (EIW)

The European Immunization Week (EIW) is a recent initiative of WHO's Regional Office for Europe aimed to promote immunization through advocacy and communication across the region. Despite the strong immunization programs in place in most countries of the WHO European region, member states still face challenges warranting support of initiatives such as the EIW. HBV immunization coverage rates in the WHO European Region increased from 42% in 2000 to 74% in 2006 but coverage is still lower than for traditional vaccines (see graph below).


Immunization coverage rates, WHO European Region, 1995-2006

WHO Regional Office for Europe
Vaccine preventable diseases and Immunization programme

The overall high coverage rates sometimes hide groups of high risk unvaccinated children still existing across the European Region. For instance in some Caucasian countries (Armenia, Georgia and Azerbaijan) with high national coverage, some regions do not reach 75% coverage for traditional vaccines. Also, some countries do not report to WHO and no data are available.

Based on coverage rates it is estimated that in the European region, annually, up to 600,000 infants still miss routine immunization with traditional vaccines and that 32,000 young children die every year from vaccine-preventable diseases. Outbreaks of infectious diseases continue to occur with a remaining risk of re-emergence of diseases effectively controlled to date. In addition, public confidence in vaccines became affected by groups, websites or the press questioning the necessity and safety of vaccination. Unfortunately, immunization loses political commitment in some countries due to other competing health priorities. Therefore, in 2005, the WHO Europe regional committee adopted resolution EUR/RC55/R7 urging all European region countries to support, where appropriate, the implementation of an immunization week to promote immunization within the region.

The long-term objective of the EIW is to increase the success of immunization programs by raising awareness on the need and right of every child to be protected against vaccine-preventable diseases, placing a special focus on vulnerable, high risk groups and taking into consideration the differences in health system organization across the different countries, while aiming at the same time for a common initiative.

The EIW is coordinated from an overall perspective by the WHO Regional Office for Europe by providing a common framework (e.g. planning guidelines, development and dissemination of fact sheets, websites and promotional materials [1]). These can be adapted and implemented by the different member states according to their needs and challenges at national and regional level, which is usually done through National Working groups. Furthermore, a range of important regional and national partners, including the European Centre for Disease Prevention and Control (ECDC) and UNICEF, support the planning and implementation of EIW.

European Immunization Week
Prevent Protect Immunize

The aim is to establish a common framework to:

- Raise awareness at all levels across the region through advocacy and communication
- Join forces to mobilize resources for immunization
- Establish a mechanism for inter-country exchange of knowledge and experiences
- Combine efforts and maximize synergy – through a common and coordinated approach

The first EIW took place in October 2005, engaging 9 member states (Belarus, Belgium, Hungary, Ireland, Italy (South Tyrol), Russian Federation, Tajikistan, Macedonia and Serbia). Activities during this pilot initiative included the launch of a website as well as outreach activities of mobile teams vaccinating children in remote regions or vulnerable communities.

An evaluation of this pilot EIW was overall very positive with the following recommendations:

- to continue and expand the initiative
- to make the EIW an annual initiative
- to involve more countries, making it a region-wide initiative
- to change the timing of the week

The second EIW took place in April 2007 involving 25 member states, thereby covering a substantial part of the WHO European region.

Numerous challenges were targeted at national level during this second EIW, depending on country needs. Some countries focused on vulnerable high risk children and communities (e.g. Rumania, Albania and Macedonia), other countries targeted young adults (Germany, France, Belgium) or women of childbearing age (Turkey).

Activities were related to different topics, such as polio eradication, measles and rubella vaccination, the introduction of new or underutilized vaccines, or quality and safety of immunization. Different approaches were used, including dissemination of information materials for parents and health professionals, organization of outreach activities performing actual vaccinations, emphasis on planned immunization activities, as well as organization of trainings, conferences and workshops. Most countries involved the mass media and some were able to engage decision makers.

In order to ensure a common character of this initiative with its different individual activities, a common slogan and logo was used region-wide and adapted into national contexts and languages.

Discussion of the results of this second EIW concluded that the 2007 EIW succeeded in high level political commitment, not only at regional level but also at national level. Importantly, activities were not limited to dissemination of information and many countries tried to engage target groups in a constructive dialogue, thereby making the EIW an innovative and creative initiative aiming to reach target groups through numerous channels, beyond campaign activities. In some countries (e.g. Belgium), general practitioners use the EIW as an opportunity and common moment to organize their activities around raising awareness on the importance of immunization.

All countries recommended participation in the 2008 EIW, as most considered the 2007 EIW to be a success (with positive media coverage in all but one country) and are convinced that the initiative will help increase immunization coverage, especially in remote and vulnerable groups.

Future challenges are to maintain successes and achievements, and consolidate commitment from member states. From discussions during this meeting it was felt that more proactive involvement of patient groups in this annual initiative would be of added value.

The third EIW took place 21-27 April 2008 with 33 countries participating. The fourth edition is scheduled for the week of 20-26 April 2009 [1].

World Hepatitis Day (WHD)

Back in 2002, the British Liver Trust suggested the idea of getting together European hepatitis C patient groups. In 2004, these groups chose the first of October to be Hepatitis C Awareness Day. Meanwhile, the groups created a formal organisation called the European Liver Patients Association (ELPA) in June 2004 and formally launched it at the 2005 meeting of the European Association for the Study of the Liver (EASL) in Paris. In 2006, Hepatitis C Awareness Day was broadened to World Hepatitis Awareness Day (WHAD) bringing HBV and HCV patient groups together, as it was felt that combining both diseases would increase the impact. Unfortunately, October 1 clashed with other events in some parts of the world and so several patient groups would not participate. In addition, the driving force behind WHAD was the pharmaceutical industry and many patient groups felt this was inappropriate.

In consequence, patient groups took the initiative and organised a meeting in Barcelona during EASL 2007 of patient representatives from Europe, North America, South America, Africa, China and Australasia as well as industry and WHO's Regional Office for Europe. It was agreed that a single World Hepatitis Day was essential, despite the recognition that there are already too many 'world days'. May 19th was chosen as the day and it was agreed to set up a steering committee to organize the initiative. However, the meeting failed to come to an agreement on common messages addressing both diseases, in particular due to discrepancies in terms of vaccine availability and access to treatment but also generally due to national and regional differences in terms of key issues relating to HBV and HCV.

Towards the end of 2007 the organising committee was formally established as a Geneva-based NGO called the World Hepatitis Alliance with a board of patient groups each representing one of seven world regions: Europe, Eastern Mediterranean, North Africa, North America, South America, Australasia and Western Pacific. The Alliance is responsible for the administrative and financial aspects of the WHD organization.

One of the components of the WHD initiative involves a teaser campaign Am I number 12? (see illustration next column), to be used in public places and draw media attention to the fact that, globally, 1 in 12 individuals are estimated to be chronically infected with HBV or HCV, which equates to around 500 million people [2,3]. Interest is also raised via a website (http://www.worldhepatitisday.com or www.aminumber12.org) providing information on countries involved and events organized.

The aims of the WHD:

- to provide a focus for countries to support their individual messaging
- to ensure that WHO endorses the day (19 May 2008 was the opening day of the WHO General Assembly)
- to persuade WHO to adopt viral hepatitis as one of its key disease areas, along with HIV/AIDS, malaria and tuberculosis (TB)
- to put pressure on national governments to adopt 12 key measures to tackle viral hepatitis effectively (see below)
- to improve surveillance of chronic viral hepatitis worldwide
- to build momentum

Governments and policy makers will be asked to take urgent action to address the chronic HBV and HCV epidemics. The twelve key measures represent political requests for a commitment to a sound hepatitis program to be adopted by 2012.

The following 6 requests are common across all countries:

1. Public recognition of chronic viral hepatitis as an urgent public health issue
2. Appointment of an individual to lead government strategy nationally
3. Development of a patient pathway for screening, diagnosis, referral and treatment
4. Clear, quantifiable targets for reducing incidence and prevalence
5. Clear, quantifiable targets for reducing mortality
6. Clear, quantifiable targets for screening

The 6 remaining requests depend on the circumstances in individual countries. An example would be:

1. Effective surveillance and publication of national incidence and prevalence statistics
2. Commitment to examine cases of best practice internationally
3. Commitment to work with patient groups in policy design and implementation
4. Provision of free and anonymous (or confidential) testing
5. Public awareness campaign that alerts people to the issue and is committed to reducing stigma
6. Commitment to an ongoing national vaccination program

The first global WHD was launched on 19 May 2008 in Geneva with the World Hepatitis Alliance, international health and patient groups and campaign sponsors coming together to raise awareness on the staggering global impact of viral hepatitis. Activities will not be limited to 19 May since WHD is an ongoing project with particular focus on the need for improved surveillance to address the lack or limited availability of good national prevalence and incidence data on HBV and HCV. Examples of best practice will be provided using printed and interactive web-based materials.

The WHD is an entirely patient-driven project to raise public awareness. To date, the World Hepatitis Alliance represents more than 200 HBV and HCV patient groups from around the world. However, endorsement and partnership with many partners is required to make it a successful initiative. Other important world health organizations (e.g. GAVI Alliance, Pan American Health Organisation (PAHO), Médecins sans Frontières) have endorsed the initiative, as well as professional organizations (e.g., European Association for the Study of the Liver (EASL), the Latin American Association for the Study of the Liver (ALEH)), VHPB and non-pharmaceutical industry.

Endorsement from WHO is considered of substantial importance and has been requested. To aid this, a unified, general consensus on an updated figure for the global disease burden of viral hepatitis (both HBV and HCV) is required, since this number will make the message compelling. The Global Burden of Disease Project (www.globalburden.org) is currently working with WHO on this, in collaboration with the Alliance.

Hepatitis B priority area for European policy: call for action by the European Parliament

HBV recommendations were made in a document issued by an expert group chaired by Dr T. Ulmer, Member of European Parliament (MEP), and entitled *European orientation towards the better management of Hepatitis B in Europe*. This document is the result of a collaborative effort between MEPs, EASL, VHPB and ELPA. The development of these recommendations was initiated during the Stakeholders' meeting at the European Parliament in April 2006, followed by a *call for action* in the European Parliament in the same year. A group of experts then prepared the document which was finalized during the Stakeholders' meeting at the European Parliament in 2007.

Unlike other infectious diseases such as HIV/AIDS, HBV has not received appropriate political focus in European policy, hence the following recommendations:

- To present key recommendations that may help build a cohesive European policy on the management of HBV. The recommendations form a policy document and aim to raise awareness amongst European as well as national policymakers of the critical importance of HBV in Europe and beyond and encourage all stakeholders to take ownership for the better management of HBV within their respective spheres of activity
- To this end, the recommendations propose critical areas where policies are needed and offer a practical list of actions that, if implemented, may help pave the way to improving the prevention and management of HBV across Europe and beyond

The HBV recommendations together with the *Written Declaration on Hepatitis C* (issued by ELPA) should be seen as complementary documents for a comprehensive EU policy on viral hepatitis.

A first point addressed in the HBV recommendations document is the need for Europe to take the lead in recognizing chronic HBV as one of the most important blood-borne and sexually transmitted infections and making it a priority area for public health policies and actions. The European Commission should set clear public health objectives that may be quantified at each country level for the gradual eradication of HBV. It is also recommended that HBV is a focal point of World Hepatitis Day 2008.

The recommended strategy is a holistic strategy involving all European countries, aiming to improve the prevention and management of HBV, with focus on the quality of life of those affected by HBV, and involving HBV advocacy groups as well as professional and scientific organizations. Furthermore, national policies must have as an explicit goal the social integration of HBV-infected individuals and seek to actively protect their human rights and combat stigma and discrimination against them, as has been done in the past for patients with HIV/AIDS.

Advocacy groups should work with policymakers, public health departments, health professionals and other stakeholders to ensure that, wherever they access the health system, individuals are offered clear, consistent and complete information on prevention, screening and treatment options for HBV. This should increase awareness and understanding of the disease and overturn misconceptions. A uniform and cohesive vaccination policy is needed across the EU, given the high levels of immigration. Lack of uniformity in vaccination policies threatens the potential for EU-wide strategies to contain the spread of HBV. In addition, vaccination programs for immigrants must include full follow-up for all persons vaccinated focussing on the quality of appropriate care, counselling and treatment options offered as a complete health service package.

The first report on HBV surveillance across Europe, published by the ECDC in June 2007, found significant heterogeneity in the availability and quality of data on HBV across Europe. The HBV recommendations therefore state that it is essential to develop reliable data collection systems that measure the full burden posed by HBV, in terms of acute and chronic disease, so that appropriate public health measures may be taken.

Like vaccination, screening is equally important. In particular, local communities with high proportions of immigrants from high-prevalence countries should be engaged in the prevention of HBV within their communities. Advocacy groups can play an important role in ensuring that the human rights and civic liberties implications of screening of immigrants are considered and addressed explicitly in all governing policies.
Finally, the recommendations foresee that the EU HBV strategy have to be implemented at national level across the EU and beyond (e.g. meetings in national parliaments in Germany, Italy and France).

References

[1] World Health Organization, Regional Office for Europe. European Immunization Week. www.euro.who.int/eiw. Accessed 28 May 2008.

[2] Lavanchy D. Hepatitis B virus epidemiology, disease burden, treatment, and current and emerging prevention and control measures. J Viral Hepat 2004;11:97-107.

[3] World Health Organization. Initiative for Vaccine Research, Viral Cancers, Hepatitis C. 2006. www.who.int/vaccine_research/diseases/viral_cancers/en/index2.html. Accessed 28 May 2008.

Based on presentations by
Ludmila Mosina, WHO's Regional Office for Europe;
Charles Gore, World Hepatitis Alliance/Hepatitis C Trust.

Role and impact of patient and advocacy groups: country presentations

This session was devoted to presentations of national patient organizations from different countries, focusing on each organization's history, role and objectives, structure, target audience, support and financing, and services and activities, including any specific initiatives relating to disease prevention. Strengths and challenges of each organization, with particular focus towards improved prevention, were also discussed and, wherever appropriate, country initiatives or experiences of particular interest were highlighted. When available, information was also provided on related groups active in the country.

Belgium: Carrefour Hépatites-Aide et Contact (CHAC) /Vereniging voor hepatitis C patienten (VHC)

Organizations' history, structure, funding, objectives and target audience

Belgium has 2 associations operating in their own language: French-speaking CHAC has ~1000 members and was founded in 2001 while Dutch-speaking VHC has 700 members and was founded in 1999, sharing a common aim of helping patients and lobbying for a national prevention and patient care plan.

CHAC and VHC's role and objectives can be further described as:

- Unite fellow sufferers
- Gather and distribute information
- Claim prevention and battle against hepatitis
- Draw authorities' & medical professions' attention to hepatitis
- Look after our members' interests
- Provide information to the media

CHAC and VHC members are volunteers, including a president, secretary, treasurer and a few other helping hands. All decisions are made by consensus during their team meetings. Both organisations work together with an advisory board composed of medical doctors. Financial support is obtained through membership fees, donations (with tax reduction incentive), fundraising events and through local branches of pharmaceutical industries. No structural governmental support is provided but limited support is occasionally received for specific actions.

CHAC and VHC's main target audience includes patients and their families, risk groups, government and media whom they reach via information phone line, email, viral hepatitis newsletter (paper and electronic version), website: www.hepatites.be [CHAC]/www.hepatitisc.be [VHC] and online forum. CHAC and VHC also organize fora in various cities, conferences in schools and nursing schools and take part in Parliament commissions to prepare law projects.

Activities including prevention initiatives

CHAC and VHC are mainly active in the dissemination of information, which is checked and approved by medical doctors. They also provide support services to patients. Both organizations are following up the latest national and international research in the field and conduct surveys e.g. on patient perception of their illness. All information is disseminated via different communication channels, publishing books (e.g. testimonials and specialist information) and flyers; mailing; organizing meetings and conferences, as well as question/answer sessions in several hospitals, etc. Furthermore, CHAC and VHC are taking part in public and media events and are actively lobbying at several governmental levels in Belgium.

A poster, a flyer

Book: patient testimonials

With regards to specific activities targeted at prevention, CHAC and VHC have their own information folder distributed to general practitioners, schools, drug prevention centres, etc. Conferences and symposia are organized to inform the population and guidelines for tattooing are disseminated. A national campaign for HAV and HBV vaccination (see illustration below) was organized together with partners while ongoing lobbying activities aim at obtaining reimbursement for HAV and HBV vaccination of chronic HCV patients. Finally, CHAC and VHC are also active in the development of a law project related to prevention.

Strengths and challenges

CHAC and VHC are the only two hepatitis patient associations in Belgium, providing information to media and patients, as well as committed to the organization of a national campaign on the occasion of the WHD. CHAC and VHC are two main organizations supported by all hepatologists in Belgium and the Belgian Association for the Study of the Liver (BASL). Other related groups active in the field include Belgian, Flemish and Walloon patient platforms, hospital physicians, the liver transplant association, several medical professional associations including the Flemish and Walloon associations of gastroenterology, drug prevention and HIV associations, as well as prisons.

In terms of strengths towards improved prevention, CHAC and VHC contributed to the reimbursement of medication obtained for most patients (except for children, patients with normal ALT, relapsers and acute chronic HCV patients); they are actively involved in efforts towards the setting up of a national prevention campaign and are continuously seeking to raise disease awareness among medical professions and governments.
In terms of challenges to be faced, despite intense lobbying efforts CHAC and VHC have not succeeded yet in securing a comprehensive informa-

tion and prevention plan for viral hepatitis at national level, providing, for example, a framework for actions at national level, such as the collection of incidence and prevalence data; and they are still seeking to obtain governmental support and funding, while also trying to increase the number of collaborators providing help on a daily basis.

Highlights

Both CHAC and VHC contributed to making medication reimbursable for most patients. Their activities are mainly focused on general awareness raising, helping patients, and lobbying for a national prevention and patient care plan.

Based on presentations by
Muriel Colinet and Marie-Fabienne Vanden Berghe,
CHAC/VHC, Belgium.

Bulgaria: Bulgarian National Association for fighting Hepatitis (HEPASIST)

Organization's history, structure, funding, objectives and target audience

HEPASIST was founded at the beginning of 2005 by seven people including patients and their relatives, medical doctors and media specialists. Its functional structure comprises a mixture of voluntary and paid staff members, including a voluntary honourable chairman with representative function, a voluntary general secretary with managing and representative functions, two paid coordinators with executive functions, a paid lawyer, 3 paid medical consultants who are medical students providing online consultations, working with patients and answering the toll free line, 5 voluntary medical advisors, as well as members of the organization and additional volunteers.

HEPASIST members do not pay fees and are participating to some activities on a voluntary basis. Financial support is obtained from rare private donors and fundraising events but mainly from pharmaceutical companies on a monthly basis and for each HEPASIST project. No government funding is received.

Before 2005, hepatitis was considered as the *disease of dirty hands* and there were no organized patient groups to support and stand for patient rights in Bulgaria. The civil society was in its initial stage and prevention measures were exclusively taken by health authorities, such as the implementation of a newborn vaccination program since 1992. There were few medical specialists in the country, only present in big cities, and information in Bulgarian was scarce for most hepatitis issues.

The role and objectives of HEPASIST are primarily to:

- Inform society and raise awareness through public media events, information campaigns, books, leaflets, etc.
- Promote prevention by raising vaccination awareness, actively fight against anti-vaccine lobbyists, provide vaccines to vulnerable and risk group populations and facilitate access to screening and early diagnostic of viral hepatitis
- Defend patient rights by establishing contacts with health institutions, providing legal support to patients and initiating civil society actions to ensure access to treatment

HEPASIST's target audience includes patients with viral hepatitis and their relatives, >600 HEPASIST members over the country (mainly patients/relatives), health authorities, healthcare specialists and the media.

HEPASIST is the only hepatitis patient organization in Bulgaria, working in close collaboration with other patient groups with common interests, such as kidney insufficiency, haemodialysis, HIV, drug users and transplantation associations.

Activities including prevention initiatives

HEPASIST objectives are supported by corresponding activities, including dissemination of information through a website in Bulgarian language (www.hepasist.org) with interactive options, online consultations, patient forum, news, etc; a toll free line providing patient support through medical consultations; print and online publication of information books and leaflets for prevention, treatment, etc.; awareness and advertising campaigns involving media partnership, press conferences and media events, interviews, television and radio shows.

In terms of activities focused on access to treatment, HEPASIST was the main initiator of all actions standing for patient rights in the form of protests, civil and public claims against national institutions, roundtables and wide media campaigns with international support from ELPA and its members.
Such actions were taken by HEPASIST as the treatment program for chronic viral hepatitis was stopped due to lack of financing in March 2006, and successfully resulted in the reopening of the treatment program in February 2007, with the promise from Bulgarian health authorities to collaborate with HEPASIST as representative of viral hepatitis patients in all future activities.

In terms of prevention activities, HEPASIST initiated a fundraising campaign to provide vaccines to affected poor regions of Bulgaria as a consequence of rain floods in spring 2006. Several actions were taken such as a television show in partnership with the national television, a VIP Big Brother edition in partnership with the Bulgarian "Big Brother", SMS fundraising, and vaccine donations with the help of a manufacturer.
Funds raised were used to provide vaccines to vulnerable and risk groups in flooded regions. Shortly after this campaign, HEPASIST, together with the United Nations Development Programme (UNDP) and a vaccine manufacturer, provided vaccination in mixed schools attended by Bulgarians and gypsies, in order to help control a HAV epidemic started in a gypsy area and spreading in many other regions of the country.
Other prevention activities conducted by HEPASIST with the support of vaccine manufacturers and the pharmaceutical industry have involved awareness campaigns such as *It is easy to get infected. It is also easy to be protected* with advertising in main print media, toll free vaccination line, advertisement and extended working hours of vaccination and specialized medical centres. Screening campaigns were also conducted during 2007 whereby >3000 individuals were tested for HBV and HCV in 5 major cities of Bulgaria.

Strengths and challenges

Three years after its foundation in 2005 HEPASIST has become a reference source of information and support for hepatitis patients and their relatives in Bulgaria, with wide media coverage and participation to all its activities, with the support of ELPA and important pharmaceutical companies. As part of the civil society, HEPASIST has established itself as an important partner in institutional policy related to viral hepatitis.

With regards to HEPASIST strengths in the area of prevention activities, the association had proven its ability to organize awareness and information campaigns with large public and media impact, with positive results obtained from collaboration with health authorities.

HEPASIST's main challenge in the near future is the adoption of a national hepatitis strategy by the Bulgarian Ministry of Health in 2008 and the voting of its budget by the Parliament in 2009. This strategic plan should mainly focus on improved prevention measures such as accessible information to the general population as well as vulnerable and risk groups, access to free testing and diagnostics, vaccination campaigns for risk groups and educational programs. However, limited financial resources from government for prevention activities, strong prejudices against vaccines, and difficult collaboration with health institutions in Bulgaria remain obstacles which need to be overcome. In addition, HEPASIST also considers the following challenges to be faced, such as increasing the number of treated patients, improving the level of early diagnosis, increasing funding sources in order to ensure independent functioning of the organization and better collaboration with institutions for improvement of treatment, diagnosis, awareness and prevention

Highlights

HEPASIST is actively involved in vaccination campaigns and vaccine delivery to vulnerable and risk group populations. In a country with a history of policy exclusively decided at the level of public institutions, HEPASIST is recognized as a partner representing civil society and patient rights in institutional policy.

Based on a
presentation by Stanimir Hasurdjiev,
HEPASIST, Bulgaria.

Croatia: Croatian Association of Treated and Ill with Hepatitis (HEPATOS)

Organization's history, structure, funding, objectives and target audience

HEPATOS was founded in 2000 with an organizational structure based on an assembly which is the steering body of the association comprising all active members whereas an executive board is empowered to take decisions between two assembly meetings under supervision of a supervisory board and counselled by an advisory board.

HEPATOS members are either regular, supporting or honorary and pay no membership fees. Main financial support is obtained from government grants and contracts, foreign government support, the pharmaceutical industry, as well as foundation and corporate grants.

HEPATOS is a high profile non-governmental organization (NGO) with good relationships with its members and beneficiaries (>2000), recognition and support from the community and donors, the government and the media. HEPATOS is a member of the *Croatian Alliance of Hepatitis Patient Association* founded in 2004 and it effectively collaborates with the Croatian Chron's Association and other NGOs dealing with addiction illnesses, HIV, transplantation, etc. HEPATOS is recognized as a competent and transparent organization, publicly speaking about hepatitis and conducting awareness campaigns, with clear long-term aims of hepatitis prevention, improved quality of life of hepatitis patients, and increased public awareness.

HULOH "HEPATOS" HEPATOS objectives target:

- Prevention of viral hepatitis
- Improvement of status and quality of hepatitis patients' lives
- Reorganization of healthcare
- Protection of reproductive health in children and youth
- Help to hepatitis patients
- Education of risk groups (children, youth, pregnant women, war veterans, drug addicts, prisoners, etc.)
- Raising awareness, destigmatization of viral hepatitis
- Promotion of rights and interests of hepatitis patients
- Promotion of civil society and volunteering

HEPATOS target hepatitis patients and their families, children and youth and risk groups (such as drug users, war veterans and prisoners) reached through media appearances and billboards, website (www.hepatos.hr), and distribution of information and educational materials in health and educational institutions.

Activities including prevention initiatives

HEPATOS plays a major role in informing the public through its website, with >500 appearances in the media within 6 years. It is also actively involved in specific prevention initiatives, distributing information and educational materials (e.g. >5000 6th grade elementary school pupils receiving hepatitis brochures every year), as well as conducting educational lectures at high school for 4 consecutive years.

Other activities include support the WHD (over 2004-2008), counselling patients and their families and offering them free informative, psychological and legal help and advice; toll free phone; public, school and risk group lectures and tribunes; advocacy and lobbying; promoting health by founding branches and new associations, also outside Croatia.

Strengths and challenges

HEPATOS defines its strengths as the values included in their vision: hardihood, enthusiasm, prudence and dedication, activism, team work, openness and skilfulness (competence). As main achievements, HEPATOS has contributed to amendments of law regulations in the interest of patients, such as the implementation of best care standards for all HCV infected patients regardless of their genotype and mandatory HBV vaccination of newborns; HEPATOS activities have also led to the reduction of the pool of patients infected with HBV or HCV.

In terms of prevention, HEPATOS has helped hepatitis becoming a conversation topic in public life; it has contributed to the development of a cooperation network between different sectors and made information accessible to children and youth, with the aim of improved healthcare and integration of health and sexual education at school; it has conducted continuous campaigns of public sensitization and destigmatization of hepatitis patients; it has organized free screening test activities.

HEPATOS challenges ahead include increased social services delivery and healthcare through a future INFOHEP centre; enhanced cooperation between NGOs and public institutions for risk group treatment (e.g. prisons); further development of civil society in Croatia and development of assistance in health sector of civil society in Western Balkan countries.

On the occasion of a National Roundtable which is to take place in April 2008 as part of WHD 2008 marking, HEPATOS intends to emphasize the need for a national program to be completed by the end of 2008.

Highlights

HEPATOS has contributed to democratization and civil society development in Croatia and the promotion of human rights of hepatitis patients by decreasing healthcare discrimination and ensuring provision and accessibility of new social services, and decreasing stigmatization in community. HEPATOS has also actively contributed to implementation of mandatory HBV vaccination of newborns and school students.

Based on a presentation by
Tatjana Reic, HEPATOS, Croatia.

Germany: Deutsche Leberhilfe

Organization’s history, structure, funding, objectives and target audience

LEBERHILFE is an organization for patients suffering from all kind of liver diseases, founded in 1987, and currently counting 2,000 members while maintaining contact with ~17,000 patients in the past 10 years. It is organized around a board of directors with a majority of patients maintained and including two hepatologists (Prof. Claus Niederau, Prof. Michael Manns), a central office employing a manager, counsellor/administrator, editor/counsellor and 2 voluntary workers and 13 voluntary local patient advisors. An additional scientific advisory board consists of 36 liver and viral hepatitis specialists (including Prof. Zeuzem, Prof. Blum and Prof. Jilg). LEBERHILFE is financed through membership fees, private donations, support from health insurances and pharmaceutical companies, and limited government funding for individual projects.

LEBERHILFE mainly targets liver patients, their friends and families, general practitioners and the general public through phone, fax, email, websites and patient seminars.

LEBERHILFE’s aims are:

- Helping patients
- Informing the public, and
- Cooperating with the scientific community

Activities including prevention initiatives

LEBERHILFE offers counselling; it maintains several websites (www.leberhilfe.org, www.lebertest.de, www.hep-b.info, www.lebertag.org, www.welthepatitistag.info); it makes medical information accessible to all in cooperation with specialists through information brochures in everyday language, patient quarterly magazines and medical publications, as well as organization of patient seminars; it provides contact details of medical doctors, clinics and self-help groups; and it represents patient interests in the development of German medical guidelines for HBV, HCV and gallstones.

In terms of activities specifically aiming at prevention, LEBERHILFE has organized a school vaccination championship for school classes reaching the highest rate of HBV vaccinations; it participates at the German Liver Day, informing the general public about liver diseases and how to prevent them; it offers counselling to patient friends, partners and relatives on transmission routes; and, importantly, LEBERHILFE has initiated cooperation with religious leaders from the Turkish community living in Germany in order to inform Turkish citizens about the risk, prevention and treatment of HBV. A similar approach is currently under consideration for other populations, e.g. Russian community.

LEBERHILFE works in collaboration with local patient advisors and self-help groups, as well as several partner patient organizations for liver transplant, viral hepatitis, hemochromatosis, cancer, etc. and other institutions, such as the German Liver Foundation, Robert Koch Institute, the German Network of Competence for viral hepatitis (Hep-Net research project), the German Society of Digestive and Metabolic Diseases (DGVS), the Association of German Independent Gastroenterologists (BNG), and the German Association for the Study of the Liver (GASL).

Strengths and challenges

LEBERHILFE has played a major role in the dissemination of high quality but easy-to-understand medical information. Unified and consistent messages which are checked by specialists as accurate and up-to-date, are disseminated. The organization may help as a mediator between patients and medical doctors; it is efficient and structured with influence in decision and policy making and is the official organizer of important events, such as the German Liver Day or WHD in Germany. It also has media coverage, with regular radio broadcasts and press conferences.

However, LEBERHILFE has to face the lack of financial resources and governmental support linked to the absence of governmental prevention programs. The organization also suffers from liver diseases stigma often reinforced by the press, such as dirtiness, alcohol, drugs and sex while liver patients are considered as *doomed* (no treatment for HCV) and *highly infectious*. Stigmatization contributes to misconceptions (e.g. some individuals would not shake hands with a hepatitis patient for fear of disease transmission while they are unaware of the dangers of piercing or tattoo) and low profile lobbying in comparison to other diseases, such as HIV or cancer.

Highlights

LEBERHILFE has initiated cooperation with religious leaders and cultural institutes in Germany, including translations into different languages, in order to overcome language and cultural barriers which reinforce problems with difficult to reach individuals in vulnerable migrant populations. LEBERHILFE organizes prevention activities such as HBV vaccination championships for schools reaching the highest rate of HBV vaccination.

Based on a presentation by
Achim Kautz, Leberhilfe e. V., Germany.

Italy: EpaC

Organization’s history, structure, funding, objectives and target audience

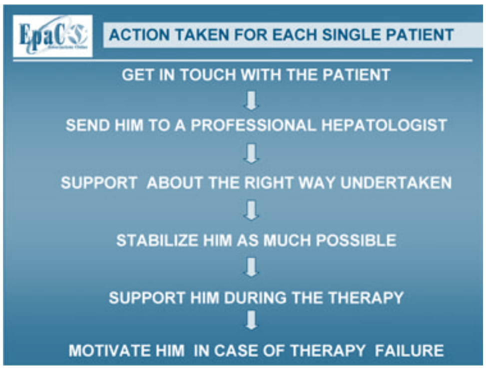
EpaC was founded by two patients in 1999 in order to provide HCV patients with free information in Italian language.

EpaC Educazione Prevenzione Ricerca sull'Epatite C Associazione Onlus

EpaC's objectives:

- Inform the general population
- Provide tailored counselling for patients and their families
- Educate family doctors
- Finance research projects

EpaC has a patient *take care policy*, involving personalized and tailored informative assistance, accompanying the patient and overall aiming at improved quality of life through a course of actions taken for each patient:



ACTION TAKEN FOR EACH SINGLE PATIENT

GET IN TOUCH WITH THE PATIENT

SEND HIM TO A PROFESSIONAL HEPATOLOGIST

SUPPORT ABOUT THE RIGHT WAY UNDERTAKEN

STABILIZE HIM AS MUCH POSSIBLE

SUPPORT HIM DURING THE THERAPY

MOTIVATE HIM IN CASE OF THERAPY FAILURE

EpaC has 2 offices, respectively in Milan and Rome, structured around a president, vice-president, fundraiser and website manager; 5 regional contact persons; 10 collaborators; 15 volunteers; a scientific committee; 2 lawyers; 1 nutritionist and other professionals. EpaC's distinctive feature is that its steering committee is exclusively composed of patients (and their relatives) while medical doctors strictly provide external support. Five steering committee members take decisions three times a year while an assembly of 21 members vote once a year via a chatline.

Funding is mainly provided by members and 7500 supporters (43%), followed by companies (37%) and other sources (20%) and is mainly spent on the organization's mission (74%) while 26% is spent on structure.

EpaC's target audience is composed of the general population (55 million, 50% reached in 10 years) reached via the mass media, newspapers, internet (www.epac.it), television spots and leaflets; patients (2 million, 40-60% reached) are reached via newsletter (30,000 subscribers), informative brochures, videos, etc; family doctors (55,000, 20% reached) are reached via the internet and professional manuals.

EpaC has recently been recognized by ELPA as premier patient organization in Europe for *Excellence in patient support*.

Activities including prevention initiatives

EpaC'services and activities are focused on information of the general population, mainly through 5 national awareness campaigns.

Awareness Poster

Education of Family doctors

In terms of information for patients and their families, EpaC refers to scientific materials and guidelines developed by the Italian Association for the Study of the Liver or to other European and international guidelines. Yearly requests for EpaC counselling by phone, email, personal contact or self-help groups have risen from 980 in 1999 to 8970 in 2007. Materials are also produced for the education of family doctors.

EpaC supports research projects and has provided donations for several initiatives including an investigation on mother to newborn transmission (Padua), a database of transplanted patients (Turin), an epidemiological database of children infected with HCV (Padua) and several publications relating to pediatric and gynaecological guidelines on HCV (Padua).

EpaC has participated to several awareness raising activities including a petition to the Italian Ministry of Health, a law proposal, a demonstration in front of the Italian Parliament and meetings with Italian politicians active at EU level.

The most important liver-related association in Italy is Liver-Pool, the Italian Federation of Liver Patient Associations counting more than 15 local associations as members and chaired by a hepatologist.

Strengths and challenges

EpaC is the largest, most respected and renowned association of liver patients in Italy, representing a uniquely large public resource for high quality epidemiological information collected on a daily basis. Also, EpaC is uniquely focused on patient quality of life because members are patients themselves and can move people to action.

In terms of prevention, EpaC has provided evidence of the importance of hepatitis as a transmitted disease, thereby trying to force the former Italian government to face the problem and the need for a governmental approach on prevention plans. To this end, EpaC intends to continue to keep members of the government sensitive to the recognition of hepatitis as a real and serious health problem.

Highlights

EpaC is a unique association which is 100% patient-led. The main focus is the patients' quality of life. With around 9000 requests for counselling annually they are the largest liver patient group in Italy.

Based on a presentation by
Ivan Gardini, EpaC, Italy.

Poland: HCV Patients Association PROMETEUSZE

Organization's history, structure, funding, objectives and target audience

The Polish HCV patients association PROMETEUSZE was founded in 2002 in Cracow by a group of HCV infected patients. Currently the head office of the organization is in Walbrzych and has 5 regional branches. PROMETEUSZE is a non-profit organization represented by its Management Board. The association functions on the basis of knowledge and experience of its members who are all unpaid volunteers advised by medical doctors and staff from epidemiological institutions. Currently the association has over 2,000 members comprising 70% HCV infected patients, 10% HBV infected patients and 20% other volunteers (such as IT specialists, medical doctors, psychologists, nutritionists, etc.).

Financial support is mainly obtained from pharmaceutical companies (90%) and rare private donations, as well as non-mandatory membership fees.

Before 2002, there was a general lack of awareness among the Polish society about viral hepatitis and up to 97% of infected individuals in Poland were unaware of their status. At that time, access to diagnosis and antiviral therapy was limited in the country.

The primary role and objectives of PROMETEUSZE are to:

- Reach the HCV/HBV infected patients unaware of their infection
- Spread information on viral hepatitis (HBV and HCV)
- Provide health education in order to restrain HBV/HCV epidemics
- Provide direct help for people infected with HBV/HCV
- Offer support during the time of infection via support groups and psychological help

The audience targeted by PROMETEUSZE includes patients affected with HCV or HBV, autoimmune hepatitis, hemochromatosis, steatorrhoeic hepatosis, etc. The organization mainly reaches out to this population through the internet, information boards in hospitals or the media.

PROMETEUSZE works in close partnership with “Life after Liver Transplantation”, a national patient organization dealing with liver transplantations. Other related groups in Poland operating at regional level include “Against the Yellow River”, “Hepa-Help”, “WZW-SOS” and a few smaller organizations active in infectious disease hospitals in different cities.

Activities including prevention initiatives

General informational activities are organized through internet sites (www.prometeusze.pl and www.wzw.pl), chat, discussion groups, meetings, informational leaflets, national and local media, and cooperation with other patient organizations.

Education is provided through national actions and educational campaigns financed by pharmaceutical companies, training for staff of medical care institutions and education of young people. In terms of educational activities, PROMETEUSZE also relies on cooperation with the Polish HCV Experts Group, a group of renowned scientists and doctors specialized in infectious diseases.

Activities with particular focus on prevention consist of developing educational and informational programs and cooperation with epidemiological institutions, such as reporting encountered irregularities or cases of breaking safety rules in medical care institutions.

Strengths and challenges

PROMETEUSZE has evolved to a liver patient association operating at national level with over 2,000 members and 20 representatives, all volunteers willing to help in different actions. The organization is largely supported and respected by society, representatives of several medical professions, members of parliament, and the mass media.

With regards to strengths towards improved prevention, PROMETEUSZE has played an important role in increasing awareness of risks for HCV transmission (80% of cases infected in medical care institutions), reporting irregularities to adequate supervising institutions, supervising the detection of new HCV infections, making attempts to implement “The National Program Against HCV”, and in popularizing HBV vaccination in Poland.

PROMETEUSZE’s challenges for the near future remain the low detection rate of HCV infections, the lack of correct HBV/HCV statistics, insufficient interest of decision-makers about viral hepatitis (HBV/HCV), and insufficient knowledge in general public. In particular, the continuing low awareness in the field of HCV among staff of medical care institutions deserves further attention and efforts from the organization. Limited financial resources for diagnosis and treatment and the lack of an anti-HCV program also remain important challenges, such as reducing the average 2-year waiting list (range 1-5 years) for access to antiviral therapy of diagnosed cases. The limited influence on how health and safety-at-work rules are respected is one of the major obstacles to be overcome in order to ensure further improvement of prevention.

Highlights

PROMETEUSZE is well-supported and respected in Poland. In collaboration with supervising institutions, the organization has had an important impact in increasing awareness of viral hepatitis and focussing on risks of HCV transmission (80% was nosocomial).

Based on a presentation by
Ilona Sikorska, Prometeusze, Poland.

The Netherlands: National Hepatitis Centre (NHC)

Organization’s history, structure, funding, objectives and target audience

The National Hepatitis Centre (NHC) was founded as a knowledge and information centre in 1997 by the Dutch liver patient association and the Haemophilia patient association, supported by liver specialists. NHC is a foundation without members and is organized around the NHC Board which consists of representatives from patient organizations, hepatologists and an independent chairman. The NHC Advisory Committee comprises scientists from different areas including medical care, occupational healthcare, public health and addiction care. The NHC Office employs 3 staff workers and 3 project leaders.

NHC’s structural activities are financially supported by the Ministry of Health (delegated to the Centre of Infectious Disease prevention since 2007), and by pharmaceutical companies. NHC’s projects receive financial support from different national funds, governmental and others (e.g. funds from insurance companies), and from pharmaceutical companies.

The foundation was initiated because it was felt that there was a lack of information for patients and a low awareness among healthcare workers.

The NHC informs the general public through brochures, a website (www.hepatitis.nl) and a helpline. Patients and patient organizations are supported via lobby and advocacy to government and policy makers, education and support for patient self-support groups, and individual support for patients receiving antiviral therapy. Professionals and healthcare workers are reached by the NHC through guidelines, education and training, and the NHC website.

NHC
NATIONAAL HEPATITIS CENTRUM
Kenniscentrum voor hepatitis

The role and objectives of the NHC are to:

- Improve the coordination and cooperation of activities on hepatitis
- Document and disseminate the knowledge, expertise and experience
- Advance education and information on (the prevention of) hepatitis
- Support patients with hepatitis
- Offer expertise to healthcare workers and others
- Offer facilities to associations, organizations and foundations with similar objectives
- Identify gaps in knowledge and expertise regarding hepatitis

Other related groups interacting with NHC in The Netherlands mainly include patient organizations (self-support groups). The NHC also collaborates with the National Institute for Disease Prevention (NIGZ), its governmental partner in HCV campaigns. Furthermore, NHC cooperates with "Mainline", an independent organization providing support for patients with drug related hepatitis, which is also NHC's partner in HCV campaign.

Activities including prevention initiatives

NHC is mainly active in disseminating information and advice (through website, brochures, helpline and electronic newsletter), and providing training and education for health professionals including GPs, nurses, public health care workers, and occupational healthcare professionals. NHC activities are always evidence-based, taking into account national and international guidelines as well as expert opinions. In addition, NHC also participates to several projects, such as providing education during the National hepatitis week, raising awareness through the National Hepatitis C campaign and lobbying through organization of symposia for policy makers. Other projects are related to providing care for chronic HBV patients (Short Chain project), blood exposure accidents, HBV and pregnancy, and safety systems to prevent needle stick accidents.

With regards to prevention activities, the NHC is lobbying for routine HBV vaccination of all newborns and free vaccination programs for groups at risk, including patients with chronic liver disease, people with a mental handicap, and occupational risk groups. In addition, NHC has taken initiatives aimed at reduction of occupational exposure by issuing needle stick accident guidelines, providing a specific educational and training program, and by studying the introduction of safety systems in healthcare.

Strengths and challenges

NHC is an independent foundation, accessible for everyone, working from a patient perspective, with evidence-based activities. The foundation creates a meeting place for medical, social, public health and political working fields on hepatitis.

In terms of challenges to be faced, despite important efforts in the last years, awareness on hepatitis still needs to be further increased in The Netherlands. The interest of the general public for hepatitis needs to be brought to the same level as it is, e.g. for HIV or avian flu. Work is still to be done in convincing the government and politicians that hepatitis is a severe health issue. Because The Netherlands is a country of low endemicity, general practitioners and other healthcare workers have less experience with hepatitis, the disease is often perceived as "a health problem from elsewhere" and there is important competition with other health care problems in terms of resource allocation. Future activities will need to take into account that the number of hepatitis patients is increasing through immigration and that many infected individuals do not speak Dutch.

Furthermore, public health officers and first line healthcare staff should be motivated to perform active detection of hepatitis, develop specific, culturally tailored, detection programs for vulnerable ethnic groups and cooperate in providing increased access to treatment. Detection and treatment of hepatitis patients should be seen as primary prevention of severe liver disease and as secondary prevention of disease spread.
Implementation of a national HBV vaccination program remains an important challenge towards improved prevention in The Netherlands.

Highlights

One unique aspect of the NHC is that it is a government supported foundation that also represents patients. Its activities are evidence-based, conform (inter)national guidelines and expert opinion.

Based on a presentation by
Paula Van Leeuwen, NHC, The Netherlands.

UK: British Liver Trust (BLT)

Organization's history, structure, funding, objectives and target audience

The British Liver Trust (BLT) was founded by Dame Sheila Sherlock in 1988 as a national UK charity for all forms of liver disease. The BLT is organized in three departments: the Information and Education department deals with public relations, publications, marketing, the helpline and website (www.britishlivertrust.org.uk); the Fundraising department is responsible for all matters related to community, trust, statuses, and corporate while the Operations division takes care of administration, human resources and finance. Currently, the BLT counts a total of 18 paid staff members and 6 volunteers, and interacts with a large team of medical advisers and trustees. A helpline was started in 2003 and the Trust website was re-launched in August 2007. Financing is obtained mainly from trusts (40%) and individual donations (21%) but also from statutory (17%), corporate (14%) and community (5%) support.

The last decade has seen a wider recognition of liver disease in UK society and alcohol, obesity and HCV have been described by the UK Chief Medical Officer as a 'potential triple hit'.

With respect to target audience, the trust established a wide reach in different sectors of society, including people who drink alcohol at hazardous and harmful levels or people who may be overweight and more susceptible to fatty liver, high risk groups for viral hepatitis, and people with hereditary or genetic conditions relating to the liver. Currently the trust is supported by nearly 20 pharmaceutical companies and interacts with 7,000 stakeholders, including healthcare professionals, healthcare workers, patients, carers, families and occupational health officers. The success of the trust is reflected in its 2007 figures: over 1 million people visited the trust's website, publication sales increased by 128% and calls to the helpline increased by 39%.

BRITISH LIVER TRUST

BLT's mission:

Reduce the incidence of liver disease and help everyone affected by liver disease, through the provision of information, support and research.

Working to:

- Support people with all kinds of liver disease
- Improve knowledge and understanding of the liver and related health issues
- Encourage and fund research into new treatment
- Lobby for better services

Other patient groups active in the UK and of interest to the BLT are the “Children's Liver Disease Foundation”, “C-Level” (a voluntary organization offering support to those affected by HCV), “Liver Transplant Support”, “Mainliners” (a charity working across blood-borne viruses, drugs and sexual health), “Obstetric Cholestasis Support”, the “Primary Biliary Cirrhosis (PBC) Foundation”, the “Primary Sclerosing Cholangitis (PSC) Trust”, the “Hepatitis C Trust” and the “'Hepatitis B Foundation”.

Activities including prevention initiatives

General services provided by the BLT include patient information (23 patient information publications) and supporting people and their families through the whole course of liver disease from prevention, diagnosis, treatment, and where necessary, coping with symptoms and managing complications of cirrhosis. Other general activities relate to research, lobbying, public relations and press coverage.

Activities with particular focus on prevention include providing advice through helpline and online support and through publications. The BLT also lobbies for better public protection through vaccination and public awareness campaigns, and initiated a project using graphic images to encourage those in custody to change their behavior for better protection against blood-borne viruses. Importantly, the trust provides advice in other languages to respond to needs of migrants at risk of viral hepatitis and its complications.

BLT has contributed to several successful prevention activities. Together with stakeholders a campaign was launched on HBV awareness and promotion of vaccination (B Aware initiative) and another campaign on HCV awareness and screening was set up (FaCe It) in collaboration with the government. The BLT supports activities of the All Party Parliamentary Hepatology Group (APPHG), is key stakeholder in the National Institute for Health and Clinical Excellence (NICE) and does other stakeholder work on HCV for World Hepatitis Day and Parliamentary Group. Furthermore, a BBC Radio 4 program on preventing liver disease was organized and work was done to raise awareness on hazards of alcohol and ease of liver damage. Finally, plans for new prevention publications are being developed for the future.

Strengths and challenges

The BLT is a national organization focusing on all forms of liver disease, with strong links to hepatologists and wide services including patient support groups, helpline, publications and a website with online patient forum. The trust is respected, well-known and regularly quoted in national press (television, print and online). The BLT feels that the high media and political interest in alcohol-related diseases could be used to broaden the approach and to raise the profile of viral hepatitis. The trust is also part of the coalition of health organizations regarding alcohol-related diseases (Alcohol Health Alliance) and submits review of liver services to the Department of Health.

Despite these successes, important challenges remain for the near future. In the UK, the impact of liver disease continues to increase, as opposed to decreasing mortality due to respiratory diseases, heart disease, stroke and cancer. There still is no government action plan to counter viral hepatitis. The high rates of inward migration to the UK from areas with high prevalence of viral hepatitis require adequate policy changes to adapt to this situation. Public awareness and education about the liver remains low in the UK and confusion exists between different types of viral hepatitis: HAV vaccination rates amongst travellers are high but often result in a false sense of protection against HBV and HCV. Also, liver disease is still perceived as stigmatizing. There appear to be important delays and barriers to availability of antiviral treatment through long NICE appraisal procedures. Furthermore, the patient group sector in the UK is crowded with numerous small, non-cohesive groups and with liver charities facing competition. In general, fundraising remains a challenge with corporates, government and individuals. Media attention can also have a negative influence, for instance linking liver disease to alcohol use to have easier access to media coverage but it can also confirm stigmatizing stereotypes.

The BLT is facing several challenges to improve prevention. Responsibilities for prevention are segmented; for example the prevention policy for injecting drug users, for viral hepatitis, and for youth is now split between three government departments and there is no joint reflection on how to improve policy. One of the major challenges remains the lack of universal HBV vaccination in the UK. Primary care physicians receive no incentive or are not covered for providing prevention services, including HBV vaccination, which is a strong disincentive for UK patients who have to pay to get immunized. The awareness of risk factors for HBV and HCV transmission remains low and the lack of approved statistics on prevalence of liver disease emphasizes the need for official prevalence studies. In the UK, HBV did not receive the same attention as HCV did during the last decade, resulting in some discrepancies between prevention policies on either disease, for example the *FaCe It* Government campaign only covered HCV.

Highlights

BLT is one of the oldest liver patient organizations in the UK, with a lot of experience in organizing successful prevention activities together with governments, media, hepatologists, as well as patients, to complete their mission. Major challenges still remain, among them the competitive environment of liver charities in the UK, due to the crowded patient group sector.

Based on a presentation by
Sarah Matthews, BLT, UK.

US: The Hepatitis Foundation International (HFI)

Organization's history, structure, funding, objectives and target audience

The Hepatitis Foundation International (HFI) was founded November 1994 in Cedar Grove, New Jersey, US. The foundation is organized around a Board of Directors with 14 members and the Medical Advisory Board with 15 members. Paid staff is composed of the Chair and Chief Executive Officer, the Chief Operations Officer, the executive director, an office manager, two administrative assistants and a part-time webmaster.

At the time of its foundation, the HFI was conceived as an organization that would serve as the leader in promoting liver wellness as the key to primary prevention of viral hepatitis.

HFI's objectives are to:

- Educate the public, patients, and professionals about prevention, diagnosis and treatment of viral hepatitis
- Prevent viral hepatitis and promote healthy lifestyles
- Serve as advocates for patients and the medical community worldwide
- Support research into prevention, treatment and cures for viral hepatitis

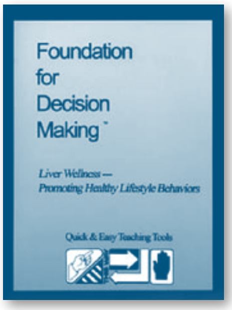
Financial support is obtained mainly from private donors and occasionally from foundations and governmental grants or other sources (sale of DVDs, curricula, and print materials). Pharmaceutical partners provide funding for educational programs.

The HFI's target audience includes pre-kindergarten staff members, teachers, college/ university faculty and students, patients, healthcare professionals, counsellors and social workers, juvenile justice workers, justice department personnel and the general public. These are approached through a free quarterly newsletter (Hepatitis Alert, readership of 10,000 individuals), the HFI website (www.hepatitisfoundation.org; www.hepfi.org) and a toll-free information and referral hotline.

There are over 400 related support groups across the US. HFI refers patients to these groups via the information hotline and provides support groups with literature, DVDs, and newsletters.

Activities including prevention initiatives

The HFI is working on prevention by providing training for educators and healthcare workers, brochures, information sheets, and posters for sale to the public and healthcare agencies. DVDs promoting liver wellness and prevention of blood-borne pathogens and substance abuse are also produced for use by schools, clinics, health departments, prisons and support groups. The foundation developed an original training approach: "Foundation for Decision Making"™ (see illustration).



Foundation for Decision Making™

Liver Wellness — Promoting Healthy Lifestyle Behaviors

Quick & Easy Teaching Tools

Is your liver giving you the silent treatment?

Strengths and challenges

With regards to HFI's strengths in the area of prevention activities, the foundation provides the missing element in primary prevention by focusing on liver wellness. The "Foundation for Decision Making"™ training approach uses humor and real-life examples so people can relate to and remember the messages. The HFI provides quick and easy tools that are easy to use for educators, healthcare professionals and community leaders.

HFI's main challenge for the future relates to the identification of new sources of funding for expanded awareness campaigns and other projects, including providing all teachers with effective skills and age-appropriate materials for promoting primary prevention and liver health education in all schools. Also, support from elected officials for new legislation needs to be gained in order to strengthen education, emphasize prevention, and further support healthy lifestyles.

Highlights

The HFI is promoting liver wellness and healthier lifestyle behavior as the key to primary prevention of viral hepatitis and avoiding liver-damaging activities whereas other patient groups focus on the disease. The foundation is mainly focusing on education and therefore creates original training materials, easy to use for educators and healthcare workers, to create awareness and promote liver wellness.

Based on a presentation by
Thelma King Thiel, HFI, USA.

Advocating for immigrant communities at risk: Asian Liver Centre (ALC)

Organization's history, structure, funding, objectives and target audience

The Asian Liver Center (ALC) was founded in 1996 as a non-profit organization established to address the disproportionately high incidence of chronic HBV infection and liver cancer in Asians and Asian Americans. The organization is funded by donations, foundations and US federal grants.

Asian Liver Center at Stanford University

ALC's primary goal: Eradicate HBV and reduce the incidence and mortality of hepatocellular carcinoma worldwide.

3-pronged approach:

- Liver cancer research (cancer genomics, biomarkers, stem cells)
- Prevention and community health research
- Outreach, education, training, and advocacy

ALC specifically targets the Asian and Pacific Islander (API) American population, the fastest growing ethnic population in the United States in terms of percentage growth, which increased from 3.7 million in 1980 to 15.2 million in 2006. For instance, one out of 8 Californians is API. About 66% of API are born outside the US. Of these, 75% are born in countries with chronic HBV prevalence rates of 8-15%. Among American API, liver disease is the second cause of cancer death, after lung and bronchus cancer. The potential pool of API having chronic HBV is estimated to be over 860,000 individuals. For example, in 2006 in San Francisco, 84.1% of persons with chronic HBV infection were API, with 74% of them born in an HBV endemic country. The most important risk factors for chronic HBV in San Francisco are being born in an endemic country (74%) and MSM, man having sex with men (12%). As many as two out of three API who tested positive for chronic HBV infection were not aware of their status [1,2]. Almost half of API with chronic HBV infection were diagnosed at the occasion of a screening test (i.e. asymptomatic) while less than 10% are diagnosed because of abnormal liver enzymes.

Activities including prevention initiatives

ALC works in partnership with CDC and the Office of Minority Health (OMH) of the US Department of Health to address gaps in current HBV immunization, screening and treatment strategies, as well as gaps in federal guidelines. For instance, two HBV measures that could become national healthcare standards were introduced and endorsed by the US National Quality Forum (NQF) in 2007-08, namely foreign born persons from endemic countries should be routinely screened for HBV and newborns to mothers with chronic HBV should receive vaccine and hepatitis B immunoglobulin (HBIG) within 12 hours. ALC also advocates for an evidence-based national report on the prevention and control of chronic viral hepatitis (HBV and HCV) by the Institute of Medicine of the National Academies.

ALC is actively involved in research to provide policy makers with evidence-based data from studies published in the scientific literature. For example, an ALC study showed that it is cost effective to screen all Asian Americans for chronic HBV infection [3]. These ALC studies lend support to the subsequent recommendations issued by the CDC to expand routine HBV screening to all foreign born persons in the US from regions with chronic HBV prevalence rate of two percent or greater and unvaccinated US born persons whose parents were born in regions with high HBV endemicity [4]. Resources to address gaps in community and physician education are offered for free, such as brochures in different languages for different countries, physician's guidelines on HBV (including one posted on the CDC's website), a website (http://liver.stanford.edu) and a toll free hotline.

ALC also collaborated with legislators in creating the first Hepatitis B Bill that was introduced in December 2005 to members of the US Congress and in June 2006 to the US Senate to establish and implement a comprehensive HBV prevention, education, research and medical treatment program to reduce liver cirrhosis and cancer incidence, and improve liver cancer survival caused by chronic HBV infection.

ALC plays a major role in increasing awareness in the public and healthcare community about the prevalence of HBV in the API community, and the relation between HBV and liver cancer. To this end, the **Jade Ribbon Campaign** was launched in May 2001 to prevent and fight HBV and liver cancer, urging people to be tested, vaccinated, treated and screened for liver cancer.

Unite against HBV and liver cancer

Another initiative is the LIVERight run/walk event organized to raise awareness about HBV and liver cancer in the API community. In 2007, ALC and its partners expanded the Jade Ribbon Campaign into the largest hepatitis B campaign in North America: the San Francisco Hep B Free Campaign. A two-year campaign that calls for all API to get tested, vaccinated or treated for hepatitis B (www.sfhepbfree.org).

Since its founding in 1996, ALC has been dedicated to serving the Asian community through a variety of outreach programs and regularly participates in community events providing free screenings and low-cost vaccinations, hosting educational booths and games, speaking to healthcare providers and developing workshops to spread awareness about HBV and liver cancer. The organization brought the largest free HBV catch-up vaccination and education program to China.

ALC closely works together with the media to increase HBV and liver cancer awareness, through international news, national newspapers and magazines, radio and television interviews, as well as documentaries and the organization has a long list of actively participating partners.

Challenges

ALC's continuing challenge for the future is to increase awareness among providers, the community, and legislators about HBV prevalence, benefits of screening. The poor knowledge level regarding HBV prevention, transmission, symptoms and risk of liver cancer also needs to be addressed.

Highlights

Similarly to the HIV Red Ribbon, ALC launched the Jade Ribbon campaign to raise awareness in the public and healthcare community about the prevalence of HBV in the API community, and the relation between HBV and liver cancer. ALC's activities have international outreach, e.g. several initiatives organized in China.

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Based on a presentation by
Samuel So, ALC, CA, USA.

Breakout sessions: strengths and opportunities versus weaknesses and obstacles

During the breakout sessions, participating patient organizations were given the opportunity to identify their strengths and weaknesses, together with challenges and thresholds regarding their role and impact on prevention and control of viral hepatitis.

Weaknesses and obstacles

Limited or lacking funding and governmental support is an important weakness faced by many patient organizations that have to rely on voluntary workers, leading to understaffed teams competing for scarce resources.

As a result, there is a lack of clearinghouse function, preventing patient organizations to benefit from increased awareness and mutual recognition which would foster communication between them and improve interaction with stakeholders, e.g. health insurance bodies and governments. Instead, overlapping interests tend to be of a competitive nature.

Patient groups sometimes perceive themselves as “amateur” and could benefit from training, particularly in the field of communication, public relations and fundraising, however they are often not aware of training opportunities and how to access them. Also, self-evaluation of their activities would help improve their performance. Vagueness about the role of pharmaceutical industry can cause doubt and suspicion on the role and activities of some groups.

As a correlated issue, patient groups are not represented in technical agencies and are not involved in technical activities although they would have a lot of experience to offer. In that respect, the possibility of inviting an ELPA member to participate in future VHPB activities was raised.

Stigmatization of hepatitis patients also remains an obstacle, with prejudices such as *dirty diseases, incurable* and *HCV-positive people need to be isolated*, impeding the work of patient representatives. Together with the need to counter stigmatization, there is also a lack of high profile lobby that could bring attention to viral hepatitis to the same level as it is for HIV/AIDS or cancer.

Language and cultural differences were also identified as potential barriers, for instance when information is available in a single language. Various patient organizations have a segmented work portfolio. While targeting small, well-defined populations is limiting their global impact, there is a clear need to reach out to these specific, vulnerable populations.

There is a need for stronger and more vocal positive messages to counter negative propaganda communicated by anti-vaccination lobbyists, responsible for mis- or dis-information, sometimes reinforced by negative media coverage.

At national level, some patient organizations reported the lack of a comprehensive prevention program or the lack of implementation of governmental plans. Some countries also reported the absence of an HBV vaccination program. Such deficits are generally coupled with a lack of solid epidemiological data on HBV and HCV infection and disease. Misconceptions about routes of transmission of HBV are still prevailing and a high proportion of HCV-positive individuals are unaware of their status due to limited funding available for diagnosis and treatment.

There is an overall lack of awareness about viral hepatitis among the general population. Particularly, the insufficient knowledge about HBV and HCV among health workers leads to breaches of infection control. There is also little evidence of the cost-effectiveness of screening and treatments and the need for screening and practice guidelines was identified.

The interest level for viral hepatitis among decision makers is low, which calls for further advocacy. Collaboration with official health institutions is sometimes difficult, especially in countries where public institutions have only recently opened the dialogue with entities representing civil society, such as patient groups. Cases were mentioned of resistance on the part of governmental institutions, resenting successes and popularity of small patient groups. Politics can negatively influence their work, for instance in the case of changes in government, or with respect to collaborative efforts among patient organizations.

Strengths and Opportunities

Patient organizations are perceived as influential by numerous stakeholders and are supported, more trusted, and more respected by the media than other organizations. They have a proven ability to get their messages across, which they disseminate through various means, mainly websites (including online discussion fora and chatlines), newsletters and brochures. Patient organizations are well-used public resources of information, providing materials which are considered as easy to understand, accurate, credible and unified, while messages and language are adapted depending on the target patient groups. Their multilingualism is seen as an advantage and is particularly beneficial for some hard to reach groups, such as immigrants and vulnerable populations. As an example of added value with respect to cultural sensitivity, they can reach out to certain religious or cultural organizations with less risk of stigmatization than in the case of specialists approaching vulnerable populations.

Patient organizations have the ability to network more easily than other groups because they face fewer bureaucratic barriers. They represent a free or relatively inexpensive resource, which is important to persuade governments: they are able “to do the governments’ job cheaper” and they can fill gaps in governments’ health programs, as well as auditing and monitoring various activities related to policy, guidelines, treatment protocols, etc.

Qualities of patient groups include uniqueness, legitimacy, trust, dedication, energy and passion, with a common purpose of improving services and care for the individual, as well as for the population at large.

Patient organizations are able to operate at national and international level; some are umbrella organizations, covering several groups with common aims. They form partnerships and many have professional teams and strong links with professionals, providing them with easy access to specialists. The work of patient organizations is broadly supported by professional bodies and associations, as well as members of parliament allowing them to provide input into policy and decision-making processes while offering a neutral status. They contribute to the development of civil society and have the ability to report breaches of good practice, in particular those increasing HCV transmission.

Patient organizations can also favour relationships between doctor and patient since they have the unique ability to provide social care for individuals diagnosed with viral hepatitis, while physicians can often offer no or limited support due to lack of time.

There is an opportunity for patient groups to use their influence and experience to persuade governments that there are good economic reasons to introduce interventions like screening or reinforce existing measures like implementing universal HBV vaccination.

There is a considerable potential for greater involvement of patient groups in primary prevention of viral hepatitis, data collection and a more consistent approach to the development of guidelines and synergistic collaboration with specialists.

Patient organizations are also seen as an opportunity to improve the quality of life through quality of care, with equity of access to care, primary prevention and treatment.

There is an opportunity to raise the profile of viral hepatitis, for instance by broadening the approach, linking hepatitis to cancer campaigns or hooking to alcohol-related diseases. The need was also expressed for a global viral hepatitis initiative, ensuring sustainability, consistency and coordinated action.

Based on feedback from breakout sessions and
D. FitzSimons’ presentation, WHO.

Conclusions

Patient organizations' structure, objectives, target audience and activities

The structure and organization of patient organizations range from small groups of volunteers with none or a few paid professionals to full membership organizations with assemblies, boards, directors, advisors and trustees. Some charge their members with fees whereas others are traditional associations. Some organizations have formal, traditional decision-making processes, others make use of innovative e-governance such as electronic fora organized to reach consensuses. They are funded via a variety of sources, with largely varying proportions: fees, fund-raising activities, private donations, grants, government support or pharmaceutical industry sponsoring. In order to maintain their independence, some patient organizations limit pharmaceutical support.

Patient organizations' objectives vary from focus on patient welfare and support, sometimes for one condition only, to broad activities covering all forms of liver disease, including non-viral conditions and immunization in general. Some organizations centre their activities on prevention initiatives while others play a major role in counselling. Most of them are involved in information dissemination, including educational materials and all aim at increasing public awareness. Many are involved in advocacy and lobbying activities, others are coordinating other groups and some are actively involved in research.

Patient organizations target a broad audience ranging from patients and individuals at risk to the general population, and national and professional bodies. Medical and professional information is spread and awareness is raised, often through conferences, among general practitioners and healthcare workers including prevention of occupational exposure to blood-borne viruses. Some organizations are active in issuing guidelines for the medical profession and public, others organize campaigns focusing on the need for screening.

Patient organizations provide a range of services and activities, including networking, online and chat fora; informational and educational materials (through printed or electronic media); toll-free telephone help lines; campaigns and talks in schools. Some organize conferences and counselling centres or conduct surveys on perception of illness. Many of them are active in public relations campaigns and participate in World Hepatitis Day or national liver days. Advocacy and lobbying are key activities to influence policy through decision makers in order to ensure implementation of legislative proposals and to advocate for accurate prevention strategies, vaccine development, vaccination programs and their funding. Some patient organizations are also actively involved in vaccine delivery campaigns.

Strengths and opportunities versus weaknesses and challenges

Successes achieved by patient organizations to date are mainly attributable to their strengths as influential and reliable resources to communicate and interact with a broad range of stakeholders; their key role as representatives of civil society and their direct contribution to improved quality of life of infected individuals. Such strengths create opportunities for these organizations to be more involved in primary prevention, data collection, development of guidelines (e.g. screening programs) and synergistic collaboration with government and specialists in order to raise the profile of viral hepatitis, counter anti-vaccination propaganda and promote initiatives at global level.

However, limited or lack of funding and governmental support and related competing interests, sometimes coupled with limited involvement in specialist activities and low profile advocacy, were identified as remaining challenges to be faced by many patient groups.

Achievements and challenges for the future

Many objectives have been achieved to date: awareness about liver disease has been raised through the use of media or high-profile innovative campaigns; patient organizations' support has facilitated changes in laws and legislation and they have also helped in setting the gold standard as well as increasing access for HCV treatment. Furthermore, they have contributed to the introduction of routine newborn HBV vaccination, decreased HBV and HCV disease burden and prevalence, and destigmatization as well as increased recognition of patients' human rights. Patient organizations have also managed to organize free testing and screening of patients and to promote HBV vaccination in HCV-positive patients. Patient organizations' cultural and immigrant outreach has been particularly beneficial for vulnerable, hard to reach groups.

Despite an impressive list of achievements made during the last years, important challenges remain to be faced for the near future.

Some proposed legislations and programs still need to be implemented and advocacy for implementation of national plans has to continue. In some regions, e.g. the West Balkans, further development of assistance in the health sector is needed. In addition, outreach to hard to reach populations such as injecting drug users and immigrants, remains important, using an appropriate approach and language.

Awareness should be increased at global level and reinforced support of the World Hepatitis Day is needed while cooperation and partnership to build on successes during European Immunization Week should be ensured. Other, more specific challenges include increased awareness and knowledge among healthcare workers and improved quality of epidemiological data.

Patient organizations' activities should be expanded across borders, between countries, as was shown by the example of Germany and Turkey successfully collaborating in prevention programs.

Patient organizations also felt that the impact of their activities needs to be evaluated, taking into account what has been achieved and how cost-effective the activities were.

Finally, opportunities for the future were also considered such as VHPB endorsement of the World Hepatitis Day and ELPA representation on VHPB board.

Based on a presentation by D. FitzSimons, WHO.

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