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

Lucca, Italy

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Objectives

- Review activities, role, rationale and impact of patient and advocacy groups in Europe and the USA on prevention and control of viral hepatitis
- Share experience of international and national groups
- Identify limitations on the role and impact of such groups and define their strengths
- Examine role and impact of partners
- Identify lessons learnt and opportunities available

Background

- Hepatitis B poor cousin to hepatitis C and HIV/AIDS in Europe; poor (acute) or non-existent (chronic) data; hepatitis B only recently included in agenda of patient organizations (immigration, low socioeconomic status, inadequate provision of health care)
- Different diseases, different approaches to hepatitis B and hepatitis C; existence of hepatitis B vaccine (plus anti-vaccine lobby activities) complicates political case; no vaccine against hepatitis C
- Legislative moves and a "viral hepatitis" approach: EU, USA
- WHO Regional Strategic Plan 2008-2013
- Hot political themes: public-private partnerships and role of pharmaceutical industry; health of migrants; regional and global initiatives: immunization weeks, hepatitis days
- Many younger hepatitis B patients represent the failure of prevention
- Numerous patient organizations working in a competitive environment
- Broadening funding base - non-traditional donors

European policy recommendations

- Recommendations for better management of hepatitis B
- Partnership and consultative process
- Holistic strategy
- Social integration
- Clear and consistent message
- Reliable data through surveillance
- Screening, migrants, and human rights
- Cohesive vaccination policy
- European leadership, nations follow (and role of pharmaceutical industry)

European Immunization Week

- Remaining risk and need to counter influence of anti-vaccine groups
- Advocacy and communication (including now nongovernmental organizations)
- Sharing experiences
- Opportunity for synergies
- High-level involvement and engagement of main target groups
- Good media response
- Potential hook for hepatitis activities at national level (opportunity for amplification of message, e.g. Belgium)

Umbrella patient organizations in Europe

- **European Liver Patients Association**
- 20 member patient groups in 17 countries
- Achievements include: inclusion of hepatitis in the work programme of the European Centre for Disease Prevention and Control; written Declaration from European parliament
- Focus on promotion of screening (EU council recommendation for screening)
- Coordination of campaigns and message
- Generate reliable and comparable surveillance data at EU level using ECDC criteria
- **European Patient Group for Rare Diseases**
- Patient-driven, nongovernmental, non-profit organization including >310 member organizations in 34 countries
- Pan-European voice, able to speak for millions of patients; multilingual
- Activities include networking, advocacy, policy development, access to care, treatment R&D
- **European Federation of Pharmaceutical Industries and Associations**
- Collaborates (e.g. through European Vaccine Manufacturers group) with patient groups to support public health programmes and access to care.
- Elaborated Code of Practice to collaborate with patient organizations, to ensure ethical conduct and transparency

National Viral Hepatitis Roundtable (USA)

- Aim: to develop, implement and maintain a national strategy to eliminate viral hepatitis in the USA
- Broad membership (>100 member organizations at national level)
- Formulated plan: “Eliminating Hepatitis: A Call To Action” (at high cost); delivered to Congress
- Acts as national coalition of organizations
- Disseminates information on policy issues
- Collaborates among others with Centers for Disease Control and Prevention in work on priority setting

Questions of terminology

- Europe (EU, EC, WHO European Region; ECDC, "Europe must lead …"
- Patient-centred
- Patient-driven
- Patient organization
- Patient (including relatives)
- Prevention (primary, secondary)
- Challenge

Patient organizations - objectives

- Range from narrow focus on patients' welfare and support, and on one condition, to broad activities covering all liver diseases (including non-viral conditions) and immunization generally
- Prevention
- Counselling
- Information dissemination (including educating general practitioners)
- Increasing public awareness
- Lobbying
- Coordination of other groups
- Research (identification of needs, support and funding)

Patient organizations - structure

- Range from small groups of volunteers and a few paid professionals to full membership organizations with assemblies, boards, directors, advisors, trustees
- Membership with fees to traditional association
- Formal traditional decision-making processes to innovative e-governance to small independent bodies
- Funding: fees, fund-raising activities, donors, pharmaceutical industry, government support; grants: EURORDIS limits funding from pharmaceutical industry to 20%

Patient organizations - services and activities

- Target audiences: similar range, from individuals (including people at risk, prisoners and war veterans) to national and professional bodies
- Networking, online forums, chat forums
- Informational ("inform, inform and inform") and educational (multimedia: print, electronic)
- Toll-free telephones
- Surveys of perception
- Campaigns, talks in schools
- Conferences
- Counselling centres

Patient organizations - services and activities (continued)

- Media work
  - Including PR campaigns (including restoration of funding for treatment)
  - World Hepatitis Day, national liver days
- Lobbying
  - Policy and parliamentarians
  - Legislative proposals
  - For vaccines, vaccination programmes, and their funding (free, reimbursement, …)
- Medical and professional information and awareness
  - General practitioners
  - Health-care workers (prevention of occupational exposure)
  - Conferences
- Guidelines (for medical profession and public, e.g. on tattoos)
- Screening campaigns

Patient organizations - weaknesses/obstacles

- Lack of/limited funds or governmental support; competition for scarce resources
- Lack of staff; reliance on volunteers
- Performance: perception as "amateur"; need for training and evaluation
- Lack of clearinghouse function to raise awareness of existence of other groups, foster communication between them and stakeholders (e.g. health insurance bodies)
- Prejudice and stigmatization remain ("dirty diseases", "incurable"; "isolate people infected with hepatitis C")
- Lack of high profile lobby (as for HIV/AIDS, breast cancer), and need to counter stigmatization
- No presence or representation in technical agencies
- Information available in only one language; language and cultural barriers
- Segmented work portfolio of some organizations, but need to reach out to vulnerable populations
- Perceptions/misperceptions about the role of pharmaceutical industry
- Some media not supportive and reinforce negative messages
- Anti-vaccination lobby/mis- or dis-information

Patient organizations - weaknesses/obstacles (continued)

- No comprehensive, national prevention programme, or lack of implementation of plans; no hepatitis B vaccination programme
- Lack of good epidemiological data on hepatitis B and hepatitis C virus infections/disease
- Misconceptions about routes of transmission
- Unawareness of most people infected with hepatitis C virus of fact that they are infected; limited funds for diagnosis and treatment
- Insufficient knowledge about hepatitis B and hepatitis C, including that of health-care workers (leading to breaches of infection control)
- Little evidence of cost-effectiveness of screening/treatments; need to produce screening and practice guidelines
- Low interest levels among decision-makers
- Collaboration with official health institutions difficult; resistance (jealousy of patient organizations) in governmental institutions
- Politics, changes in government, collaboration between patient organizations
- Role of civil society

Patient organizations – strengths

- Ability to get message across: information dissemination in various means (web sites, newsletters, …); information seen as easy to understand, accurate, unified; public resources of information; online forums for discussion, chat
- Ability to network more easily than bureaucracies and other groups
- Message and language can be adapted to target patient groups
- Multilingualism – working in many languages, especially those of some hard-to-reach groups (immigrants)
- Cultural sensitivity
- Broad support from: professional bodies/associations; parliamentarians
- Media support, trust and respect – part of a broader set of ***qualities:***
  - uniqueness, legitimacy, trust, dedication and energy, positive image, common purpose, access to specialists
- Free or relatively inexpensive resource: doing governments' job cheaper, and filling gaps in governments' health programmes
- Ability to audit and monitor various activities (policy, guidelines, treatment protocols, etc)
- Social support in preventing serious disease

Patient organizations – strengths (continued)

- Ability to operate at national level
- Partnerships/umbrella organizations
- Professional teams/strong links with professionals
- Input into policy-making and decision-taking processes
- Neutral status (including between doctor and patient)
- Capitalizing on/contributing to civil society
- Ability to report breaches of good practice that encourage transmission of hepatitis C virus
- In countries where alcohol-related problems are a high priority, focus on alcohol might offer a springboard for advocacy of viral liver disease

Patient organizations - achievements

- Successfully gained reimbursement of costs
- Increased awareness (incl. through use of media, high-profile innovative campaigns (Asian Liver Center's Jade Ribbon Campaign) etc)
- Paved way to changes in laws/legislation
- Setting gold standard for treatment of hepatitis C virus infection
- Contribution to introduction of vaccination of newborns against hepatitis B
- Contribution to a decreased disease burden/prevalence of hepatitis B and hepatitis C
- Contribution to destigmatization/increase in human rights of patients
- Organization of free testing, screening
- Promoting vaccination against hepatitis B in people infected with hepatitis C virus
- Cultural and immigrant outreach

Challenges for the future

- Introduction of legislation, implementation of programmes (funding sources - government, pharmaceutical industry); advocacy for implementation of national plans
- Information: clear and consistent message essential
- Outreach: hard to reach populations (injecting drug users, immigrants, especially in appropriate languages): hepatitis B patients harder to reach than hepatitis C patients
- Development assistance in health sector (west Balkans)
- Need to promote and awareness generally at all levels and World Hepatitis Day
- Cooperation and partnership during European Immunization Week
- How to increase awareness/knowledge of health-care workers
- How to improve quality of epidemiological data
- Continued expansion of activities across borders, between countries (e.g. Germany and Turkey)
- Evaluation of impact
- VHPB to consider endorsement of World Hepatitis Day
- VHPB seriously considering offering a seat on its Board to an ELPA member

Opportunities

- Time to "finish the job" of hepatitis B vaccination
- Using influence to persuade governments that there are good ***economic*** reasons to introduce interventions (screening, …)
- Potential for greater involvement in primary prevention, data collection, consistent approach to development of guidelines, synergistic work with specialists
- Patient organizations are well placed to reach vulnerable populations
- Opportunity to improve quality of life through quality of care
- Ensure equality of access to prevention and care
- Raise profile of the need for a healthy liver and hepatitis; place for a global viral hepatitis initiative