

BACKGROUND

Hepatitis B : a lack of resources for patients

Hepatitis B is one of the most common infectious diseases in the world with 350 – 400 million people being chronically infected worldwide and 10-30 million new infections every year.^{1,2} This compares with 33 million people living with HIV infection worldwide³ - yet there remains a lack of reliable resources for patients and caregivers. Recent surveys and research have found that, for many patients, a lack of knowledge and complete understanding of hepatitis B is a major issue.⁴ This can adversely affect patient-physician communication, delay testing and diagnosis, as well as patients' subsequent adherence to treatment. To help avoid these issues patients need to be more empowered with knowledge about their disease once they are diagnosed and about to start treatment. They should also be better equipped to discuss their condition with their physicians during their treatment journey.

The PATH B Programme

What is The PATH B Programme?

The **PATH B (Patients and Professionals Acting Together for Hepatitis B) Programme** has been developed as a joint initiative between patient groups and leading hepatologists all across Europe, to provide comprehensive information and support for patients to help them address the challenges of managing their long-term condition.

The PATH B Programme offers a complete resource that empowers patients through knowledge and understanding, encouraging them to talk with their physicians about disease management in an engaging way. It also aims to help patients understand the importance of long-term treatment to improve their quality of life. To help patients achieve these aims, an interactive diary is included that allows them to record their thoughts, questions and treatment details, as well as an interactive plot-able graph to help visualise the progress of blood test results and ongoing treatment.

This resource is provided as an educational service by



World Hepatitis
Alliance

Developed in partnership with

The PATH B resource is provided as an educational service by the World Hepatitis Alliance (WHA) and The European Liver Patients Association (ELPA). The European Association for the Study of The Liver (EASL) also “welcomes the scope of information the PATH B education toolkit provides to patients with chronic hepatitis B and commends ELPA and WHA for this initiative”.

The core component of the PATH B programme is a patient-centric resource, *PATH B – My journey with chronic hepatitis B*. This extensive interactive educational resource is designed to improve the lives of people living with chronic hepatitis B by providing information and tools to guide them through the different stages of chronic hepatitis B from diagnosis to long-term disease management.

Although this resource was developed primarily for patients, it can also be used by physicians to enhance dialogue with patients on disease progression, treatment and the importance of adherence and persistency.

The *PATH B* Resource : *My journey with chronic hepatitis B*

PATH B – My journey with chronic hepatitis B is an interactive PDF that offers the full benefits of a website allowing patients access without the need for internet connection. It has been designed to be consulted at length or for reference to extract information quickly and with ease. The resource operates within the framework of a roadmap to complement the stages of the patient’s journey with hepatitis B. The stages are:

- Could I have hepatitis B?
- Understanding my tests
- Being diagnosed with hepatitis B
- After my diagnosis
- Starting my treatment
- My long term management

PATH B – My journey with chronic hepatitis B will be translated into nine languages (English, Chinese, Turkish, Russian, French, German, Spanish, Italian, and Portuguese) and available through various patient groups’ websites and an online PATH B portal, from which the resource can be downloaded.

To view and download the English version of the PATH B education resource please visit www.pathb.com.

The English language version of the resource was launched at an annual Patient Advisory Group conference organised by Bristol-Myers Squibb in Hong Kong, October 21-22, 2011. The Traditional Chinese language version of the toolkit will be launched at the Asian Pacific Association for the Study of the Liver (APASL) conference, Taipei, Taiwan, February 16-19, 2012. Additional languages will be launched at the European Association for the Study of the Liver annual meeting (EASL), Barcelona, Spain, April 18-22, 2012.

The PATH B Programme Advisory Board

The PATH B Programme is steered by a distinguished advisory board of ten members who have significant experience within patient advocacy support and clinical treatment of hepatitis B. Chaired by Dr. Mark Wilkinson of Guys & St Thomas' NHS Foundation Trust Hospital, London and University College London, and Nadine Piorkowsky, former President of the European Liver Patients Association (ELPA). The advisory board delivers the programme, with funding support from Bristol-Myers Squibb.

The advisory board members included representatives from the following:

- European Liver Patients Association (ELPA) - www.elpa-info.org
- World Hepatitis Alliance (Alliance) - www.worldhepatitisalliance.org
- British Liver Trust - www.britishlivertrust.org.uk
- Associació Catalana de Malalts d'Hepatitis (ASSCAT) - www.asscat.org
- Chinese Healthy Living Centre- www.cnhlc.org.uk
- Associazione EpaC onlus - www.epac.it
- SOS Hépatites - www.soshepatites.org
- Deutsche Leberhilfe e.V - <http://www.leberhilfe.org>
- Guys & St Thomas' NHS Foundation, London, UK
- General University Hospital, 'Ippokratio', Athens, Greece

More information on these organizations is available in appendix one.

Appendix 1

European Liver Patients Association (ELPA)

The association was launched in Paris in 2005 and it now has 22 members from 14 countries.

World Hepatitis Alliance (WHA)

The World Hepatitis Alliance is a not-for-profit international umbrella Non-Governmental Organisation (NGO) whose membership is composed of organisations working in the field of viral hepatitis.

British Liver Trust

The British Liver Trust is a national registered charity based in the UK that offers dedicated resources to people with liver disease.

Associació Catalana de Malalts d'Hepatitis (ASSCAT)

The Catalan Association of Hepatitis Patients was founded in Barcelona in 2000 and aims to provide support in all aspects of the disease.

Chinese Healthy Living Centre

The Chinese National Healthy Living Centre was founded in London in 1987 to promote healthy living and access to health services for the Chinese community in the UK.

Associazione EpaC onlus

EpaC Association was founded in 1999 to give support to people living with hepatitis.

SOS Hépatites

The SOS hepatitis federation was founded in November 1996 to bring together groups of associations to work in the defence against hepatitis.

Deutsche Leberhilfe e.V.

Deutsche Leberhilfe was founded over 20 years ago and is a national non-profit organisation that aims to help patients help themselves through advice and information.



PATH B

Patients and Professionals
Acting Together on Hepatitis B
PROVIDED AS A SERVICE TO MEDICINE
BY BRISTOL-MYERS SQUIBB

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3. Global Report. Chapter introduction. Available at http://www.unaids.org/globalreport/Global_report.htm Accessed on 11 October 2011
4. Biomed Central. Abstract. Managing chronic hepatitis B. Available at <http://www.biomedcentral.com/1756-0500/4/45>. Accessed on 11 October 2011