

## **President of the Executive Board**



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### **Experience and suitability for the role, including viral hepatitis status**

Charles Gore was diagnosed with hepatitis C in 1995 and cirrhosis in 1998. Troubled by his own inability to find clear, accurate and unbiased information and by the lack of any organisation providing support in the UK, in 2000 he set up The Hepatitis C Trust together with 3 friends who also had hepatitis C. Despite no previous experience of working in the voluntary sector he agreed to take on the role of running the charity. Within the first year he started a year's course of pegylated interferon and ribavirin treatment, which was cut short when the interferon precipitated pancreatitis and the onset of type 1 diabetes. Happily by then the interferon had eradicated the hepatitis C.

Right from the beginning Charles has been committed to the principle of patient-centred medicine and believed that, as a patient organisation, the Trust should be led and run by patients and the great majority of its trustees, staff and volunteers have or have had hepatitis C.

As part of this remit he has worked with a wide variety of stakeholders to champion the patient perspective. This has included the devolved Governments in the UK, the NHS, NICE and the NTA.

In Scotland he wrote the key parts of the conclusion to the Edinburgh Hepatitis C Consensus Conference that was so influential in the development of the Scottish Hepatitis C Action Plan. Charles then actively participated in the development of the Action Plan and sat on the oversight board. In order to support the Action Plan he decided to establish a Trust office in Edinburgh.

In Wales he worked over 3 years to help the National Public Health Service to develop a comprehensive blood-borne virus strategy and then lobbied relentlessly to have it published and actioned when this process stalled, convinced that the delays were costing lives.

In England the Trust began operating just too late to be involved in the development of the Hepatitis C Strategy for England. He came to believe that the Strategy and the ensuing Action Plan were deeply flawed. In particular, he disliked the awareness campaign that formed a central part of it, convinced that it served only to increase the stigmatisation of people with hepatitis C and in fact prevented people coming forward for testing. Therefore, he instigated a series of audits of hepatitis C services in both PCTs and hospital trusts. These showed conclusively that the Action Plan was failing. So, in 2007, the Trust began calling loudly and publicly for a comprehensive liver strategy to address the spiralling death toll from liver disease to which hepatitis C is an important contributor. In 2009 the Government agreed to establish a liver strategy and asked Charles to sit on the panel to choose a National Clinical Director for Liver Disease. Charles is now working with the Department of Health to develop the strategy and ensure it is indeed patient-centred.

Understanding the importance of sharing best practice across borders, he became closely involved in the creation of the European Liver Patients Association and was

elected its first President in 2004, promoting the cause of hepatitis C, and also hepatitis B, at European level.

He became increasingly frustrated at the lack of profile and priority of viral hepatitis at an international level: even though globally 500 million people have chronic hepatitis B or C and between them these two diseases kill one million people every year, there was almost no awareness and no sign of any political will to change this. So in 2007 he organised a meeting of hepatitis patient organisations from around the world to agree on co-ordinated global action. From this emerged the decision to hold an annual World Hepatitis Day and to create a new NGO, the World Hepatitis Alliance. The Alliance now has member organisations from more than 60 countries and Charles is the President. As such he has been responsible for organising World Hepatitis Day and for lobbying world governments for action.

As a result of these efforts viral hepatitis was put on the agenda of the World Health Organization and in 2010, just 3 years after the creation of the Alliance, Charles addressed the WHO at both the Executive Board meeting and the World Health Assembly. He asked, on behalf of the 500 million people living with hepatitis B or C, for a global strategy to control and prevent viral hepatitis and the WHO duly passed the first ever resolution on viral hepatitis, which mandates just such a strategy and also establishes an official World Hepatitis Day, only the 7<sup>th</sup> official WHO world day. He is now working with the WHO to develop the global strategy and to organise World Hepatitis Day 2011.