



IAPO Member Case Study



Journey to the World Health Organization and a Resolution: the Experience of the World Hepatitis Alliance

Introduction

This case study describes the activities carried out by us, the [World Hepatitis Alliance](#), leading up to the Sixty-third [World Health Organization's](#) (WHO) [World Health Assembly](#) (WHA) where, as both President of the World Hepatitis Alliance and as an International Alliance of Patients' Organizations (IAPO) representative, I made an intervention. The intervention was to support the first ever resolution on viral hepatitis, which was successfully adopted. This case study describes the process leading up to this, the key outcomes of the intervention and some of the challenges we faced.

Background

As a coalition of advocacy groups, the World Hepatitis Alliance is a global voice for the 500 million people worldwide living with chronic viral hepatitis B or C. Through better

awareness, prevention, care, support and access to treatment, our ultimate goal is to work with governments to eradicate these diseases. Of the 500 million people chronically infected with viral hepatitis, one million die every year, yet it had never been acknowledged as a major global health issue. So in 2007, patients' organizations from around the world met to discuss what to do and decided to establish an unofficial World Hepatitis Day on 19 May of each year. Following the meeting, patient representatives went away to work on the World Hepatitis Day campaign, asking for their national governments to support the day. Some patient groups reported that their governments required World Hepatitis Day to be official in order for them to support it. It was realised that in order to make the day a success, and have viral hepatitis recognized as a major global health

issue, we would need to go to the WHO for official recognition of the day. We later learnt that this would require a resolution to be adopted at the WHA.

The WHO Executive Board

To achieve the resolution, we would first need to get the [WHO Executive Board](#) (EB) to put viral hepatitis on the WHA agenda and, after sustained lobbying, four countries successfully did that in January 2009. In spring 2009, a resolution was proposed for adoption at the WHA in May of that year. However, at the WHA, discussion of viral hepatitis was postponed until the following year because the H1N1 influenza virus dominated the agenda. This gave us the opportunity to develop the resolution and make it more patient-centred. Following the WHA we wrote to EB members, suggesting changes to the resolution, and I



contacted IAPO to ask to attend the EB meeting in January 2010, as a member of IAPO. Through IAPO's Official Relations status with WHO, IAPO can make interventions at the EB and WHA and we worked with IAPO to write the intervention.

At the January 2010 EB meeting, on behalf of the World Hepatitis Alliance and facilitated by IAPO, I made an intervention under the agenda item: viral hepatitis. A new resolution was then agreed and ready for consideration by the World Health Assembly in May 2010.

► **Attending and addressing the EB meeting with the advice and support of IAPO was a big step forward and helped to achieve the viral hepatitis resolution and raise the profile of the World Hepatitis Alliance with country delegations and with WHO.**

In the run-up to the Assembly we published a research report we had undertaken for WHO called *Viral Hepatitis: Global Policy*, which surveyed member states to determine the current policies in place in each country. It also asked countries what assistance they would like

from WHO. The results showed a remarkably uniform desire to tackle viral hepatitis but equally an almost universal desire for technical help in doing so. We then wrote to all 193 member states asking them to support the resolution, using the report as evidence of a clear mandate for action.

The World Health Assembly

In May 2010, I attended the sixty-third WHA and again, through IAPO's Official Relations with WHO, made an intervention to support the resolution on viral hepatitis. When the agenda item viral hepatitis came up on 20 May 2010, 17 countries spoke and amendments were proposed. After all country delegations have spoken, NGOs in Official Relations with WHO have the opportunity to make an intervention. It was at this point that I delivered our intervention, addressing the Assembly as a patient and on behalf of IAPO, the World Hepatitis Alliance and the 500 million people infected with chronic viral hepatitis B and C.

I highlighted the urgent need to address viral hepatitis and adopt the resolution to provide a robust and effective framework to prevent and control viral hepatitis, and that this would be the crucial first step in tackling viral hepatitis in a

comprehensive, global manner. We asked all member states to act in unison to address viral hepatitis and to communicate to all stakeholders that viral hepatitis is now a global health priority. Following this, to my relief, the Chairman asked WHO to add in the proposed amendments and resubmit it the following day. The next day viral hepatitis was on the agenda and, when it came up, the resolution was adopted without any comment.

Outcomes and successes

► **The resolution is a great success as it acknowledges the seriousness of viral hepatitis as a global public health issue, establishes an official World Hepatitis Day on 28 July each year and requires WHO to develop a global strategy for hepatitis prevention and control. We are in discussion with WHO to ensure that patients are fully involved in all of these initiatives.**

World Hepatitis Day provides an opportunity to promote awareness and encourages our members to work with their countries to achieve the implementation of the resolution at country level. We have been offering support to countries to organise their

World Hepatitis Day and highlighting the need to implement the resolution. Working together with our members, with IAPO, WHO, member states and other key experts has been crucial to our success. The journey has been one of learning, commitment and collaboration and now that the resolution has been adopted, we are continuing to work together to achieve an effective, patient-centred Global Strategy for viral hepatitis. The official World Hepatitis Day is 28 July and is the 6th official world day to be recognised by WHO. The first took place in 2011, with events running all over the world.

In 2012, the World Hepatitis Alliance attended the EB Meeting as part of IAPO's delegation where our Official Relations status with WHO was confirmed. This status recognises our work with WHO to implement the resolution on viral hepatitis to prevent new infections and provide support to the millions of people living with viral hepatitis worldwide.

Challenges

During this process, we met some challenges. Firstly, we were told that getting the resolution would be impossible and that no-one wanted any more 'disease days'. However, our argument, that there is no disease area where the gap between the level of awareness and the size

of the problem is so great, was finally accepted. Another challenge we faced was over the content of the resolution; Brazil put a couple of clauses in that we were told would not be accepted by some European countries. We worked very hard behind the scenes to persuade these countries that the resolution was too important to be sabotaged and that a compromise had to be found. With a few small adjustments to the wording, we were able to get the resolution passed.

Next steps

Looking forward, the World Hepatitis Alliance will be working with WHO to develop the messaging and materials for World Hepatitis Day and on the distribution of these materials. We will also be working to get as many stakeholders, including Ministries of Health, involved in supporting the Day as possible and we will continue to work with WHO to implement the resolution on viral hepatitis.

How can IAPO further support this work?

IAPO can further support this work by encouraging WHO to formally involve patients in all of its programmes and projects.

Charles Gore, Chief Executive, Hepatitis C Trust, and President, World Hepatitis Alliance



Further reading

- ▶ [World Hepatitis Alliance website](#)
- ▶ [Hepatitis C Trust website](#)
- ▶ [How to be More Engaged at the World Health Assembly: IAPO site](#)
- ▶ [World Hepatitis Alliance Push for Adoption of a Resolution on Viral Hepatitis: IAPO site](#)
- ▶ [World Health Organization \(WHO\) Executive Board 126th Session – Update from the Hepatitis C Trust: IAPO site](#)
- ▶ [World Health Organization \(WHO\) website](#)
- ▶ [Viral Hepatitis Report by the Secretariat: WHO site](#)
- ▶ [63rd WHA Viral Hepatitis Resolution 2010: WHO site](#)
- ▶ [Executive Board: WHO site](#)
- ▶ [World Health Assembly: WHO site](#)

