

# Patient Organisation involvement in the Management of Hepatitis C

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In Ireland, there are 145 persons with Haemophilia who have Hepatitis C. A further 108 have died of HIV or Hepatitis C of whom 71 were co-infected. An increased incidence of cirrhosis, hepatocellular carcinoma and requirement for liver transplant have now become apparent. Up to May 2012, a total of 10 Irish people with Haemophilia had undergone a total of 14 liver transplants with 4 of these transplants required in the 9 months to May 2012. Of the 10 recipients, 4 remain alive. In view of the deteriorating clinical situation of many of our members with Hepatitis C and the availability of new treatments for genotype 1 Hepatitis C, the Irish Haemophilia Society have prioritised the provision of information, education and assistance to members who require or are contemplating treatment. An individual phone survey was carried out on the Hepatitis C genotype of members. Provision of tests for the genetic markers IL28B and KIR-2DS3 were co-ordinated with the treatment centres.

## Information

Meetings were organised in two cities in December 2011 to provide information on the new treatments available for genotype 1. The first in a planned series of specific newsletters on Hepatitis C was produced in December 2011 and the second in June 2012.

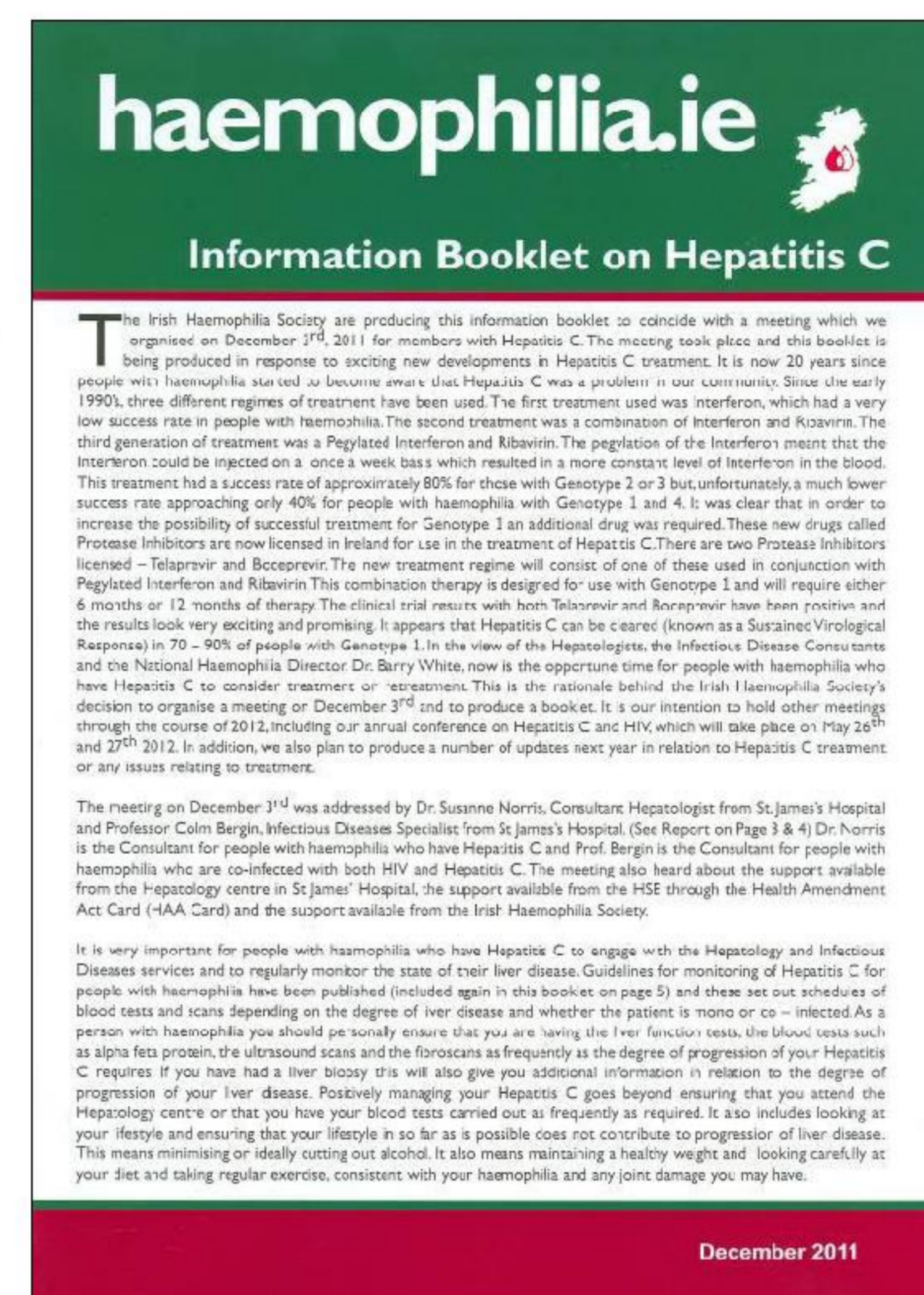
The newsletter included information on the 2 new protease inhibitors - Telaprevir (Incivo) and Boceprevir (Victrelis), information on side effects and the Guidelines for Monitoring and Managing Hepatitis C agreed with the Hepatology clinicians.

A specific Conference is organised annually for members with Hepatitis C and/ or HIV. The conference in May 2012 included sessions on the new treatments, managing side effects, psychological management of treatment and information for spouses and partners.

## Advocacy

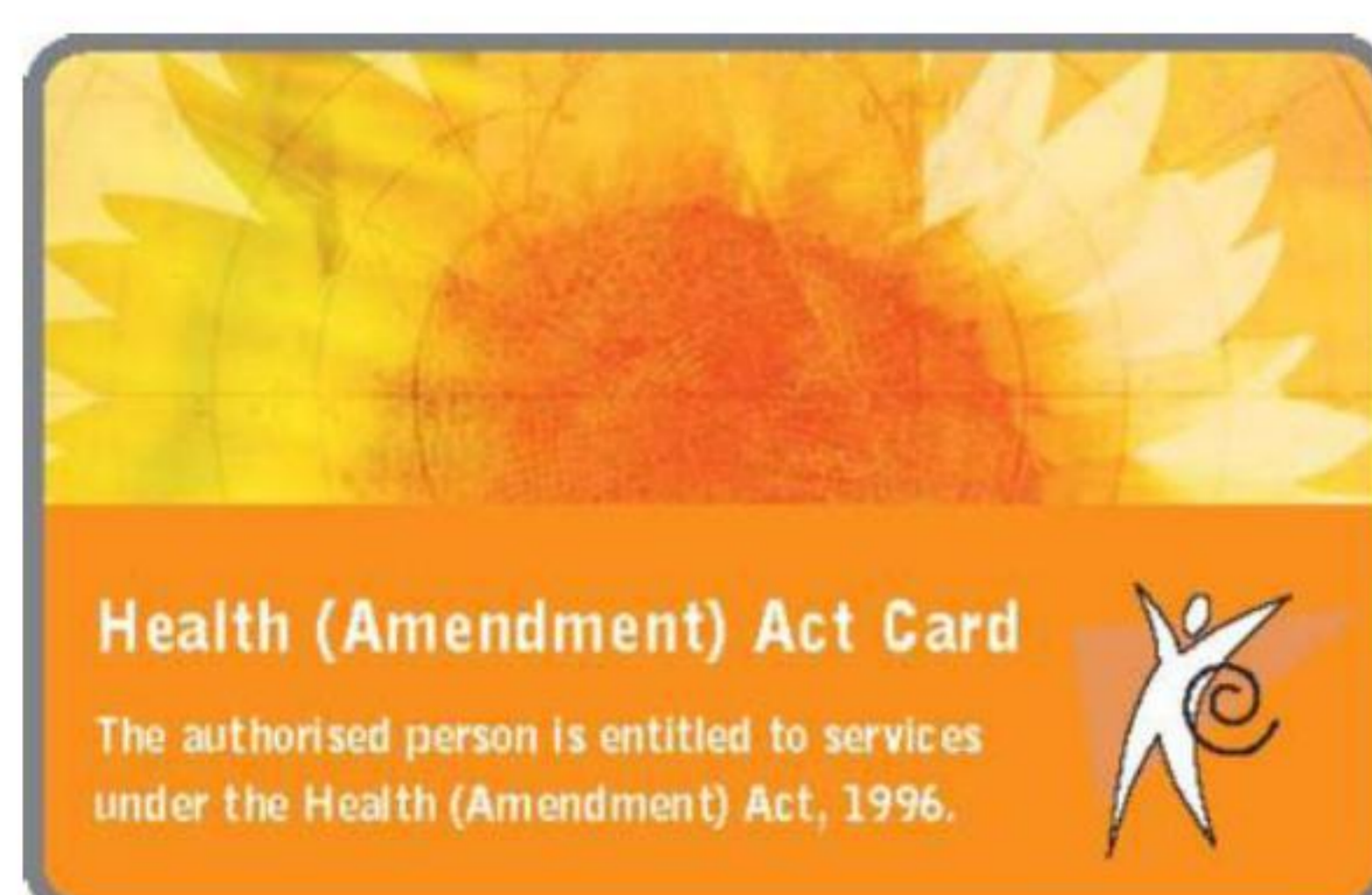
The new products were subjected to Health Technology Assessments (HTA) and the Society made a submission in relation to this assessment. Both products were found to be cost effective using the HTA process with both products demonstrating an incremental cost effectiveness ratio per QALY under €20,000.

The Society met with the Minister for Health on World Haemophilia Day and secured his agreement for the immediate approval of reimbursement for both protease inhibitors.



## Practical Assistance

The Society has worked with the health authorities to arrange for assessments of each individual's requirements and provision of assistance required during treatment including counselling, assistance with domestic work, aids and appliances and access to complementary therapies. These services are available to each person with Haemophilia who has Hepatitis C via their Health Amendment Act (HAA) card which gives them access to a range of medical and support services free of charge as a result of specific legislation - the Health (Amendment) Act 1996.



	Non-cirrhotic or Fibrosis stage unknown	Cirrhotic, Pre-Cirrhotic or Bridging Fibrosis
<b>Hepatitis C PCR Positive &amp; HIV Positive</b>	3-4 monthly review in Co-infection Clinic as directed & review in Hepatology as recommended by physician Liver ultrasound as indicated by physician Liver function tests & blood test for alpha-fetoprotein 6 monthly	3-4 monthly review in Co-infection Clinic & review in Hepatology as recommended Liver ultrasound 6 monthly Liver function tests & blood test for alpha-fetoprotein 6 monthly OGD every 2-3 years and more frequently if varices identified
<b>Hepatitis C PCR Positive &amp; HIV Negative</b>	6 monthly review in Hepatology Liver ultrasound as indicated by physician Liver function tests & blood test for alpha-fetoprotein 6 monthly	6 monthly review in Hepatology Liver ultrasound 6 monthly Liver function tests & blood test for alpha-fetoprotein 6 monthly OGD every 2-3 years and more frequently if varices identified

The Society provides financial assistance and accommodation for members with Hepatitis C or HIV with mobility difficulties or severe side effects from treatment who have to travel significant distances to the treatment centres frequently for treatment monitoring.

Our objective is to ensure that all those with Hepatitis C genotype 1 who could avail of treatment are aware of the new therapies, actively consider treatment and receive all the support necessary to enable them to comply with the treatment regime and hopefully achieve a sustained virological response.

