Positive News

Information Magazine for people with Hepatitis C and/or HIV

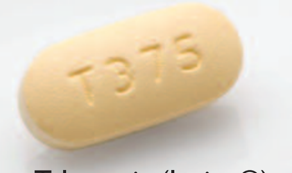
The Irish Haemophilia Society

Representing people in Ireland with
Haemophilia and related bleeding disorders.

Hepatitis C / HIV Conference 2012

A conference for people with HIV and/or Hepatitis C was held in May. The conference, which is held every year, was another success with very informative sessions and workshops. This year the conference discussed the update on treatments for Hepatitis C, mono and co-infection, and a brief overview of a small trial group of patients currently on treatment in Ireland. There were also two workshops over the weekend. The first was a discussion group for those thinking of going on treatment and how to prepare for the treatment and a second workshop for partners of people with Hepatitis C and/or HIV. There was also an update on the services and support available on the HAA card and the conference finished with an open forum where members could bring up issues that had not been discussed over the weekend.

The first session of the conference was on Practical Management of your Treatments presented by Barbara Hynes and Helena Irish, Clinical Nurse Specialists in the Hepatology unit, St. James's in Dublin. Barbara and Helena explained that between 2002 and 2010, the Hepatology unit in St. James's achieved an SVR (sustained virological response - no detectable virus up to six months after treatment) of 46% in patients with Genotype 1. This is in line with international standards for Genotype 1, however significantly less than what would be expected for Genotype 2 or 3 (80% - 90%). This has led to the development of Triple Therapy for the treatment of Genotype 1. This combines the previous therapy of Ribavirin and Peg-Interferon with a protease inhibitor, Telaprevir or Boceprevir. Barbara said that there will be exciting and challenging times for patients and for the Hepatology Centre in relation to management of this new treatment. She explained that the new protease inhibitors were different as they directly acted on the virus's ability to replicate which has not been available previously. This has lead to an SVR of 70% - 80%. In some cases a shorter duration of treatment can also be sufficient, reducing from 48 weeks to 24 weeks. These protease inhibitors are called Telaprevir (commercially known as *Incivo*) and Boceprevir (commercially known as *Victrelis*). There are 26 patients currently on a pilot study at St. James's with both Boceprevir and Telaprevir.



Telaprevir (Incivo®)

The regimen for Boceprevir in the pilot study was:

For the first 4 Weeks

* Peg interferon injected subcutaneously (under the skin) once a week
* Ribavirin tablets taken twice a day

And for the remainder of treatment

* Peg interferon injected subcutaneously (under the skin) once a week
* Ribavirin tablets taken twice a day
* Boceprevir (Victrelis) tablets taken 3 times a day with food

Boceprevir
(Victrelis®)

Edition: June 2012

The regimen for Telaprevir in the pilot study was:

For the first 12 Weeks

- * Peg interferon injected subcutaneously (under the skin) once a week
- * Ribavirin tablets taken twice a day
- * Telaprevir (Incivo) tablets taken 3 times a day with a high fat content food

And for the remainder of treatment

- * Peg interferon injected subcutaneously (under the skin) once a week
- * Ribavirin tablets taken twice a day

From the information given at the presentation, the outlook from the pilot study is very promising. There is a combination of mono-infected patients who have never tried treatment (known as 'treatment naive'), who have relapsed after treatment, who have not responded or who have cirrhosis on the study. All of the patients completed the full course of treatment and in those who are 6 months post treatment, on either drug, all have achieved an SVR (no detectable virus at 6 months). Interestingly the drugs have worked without a preference for any of the normal predictor's for response to treatment such as IL28b, BMI, Age Gender, Fibrosis staging or previous treatment experiences. In relation to side effects, the nurses said there has been an increased reporting of side effects when compared to the past dual treatment of Peg-interferon and Ribavirin. These include anal itch, depression/irritability, rash, nausea, anaemia and other haematological changes. As a result, the number of attendances at Hepatology has increased significantly with some individuals needing to attend the clinic once a week for blood tests and other monitoring. Ms. Hynes said that although the side effects have intensified with the triple therapy, management of the side effects has also increased with close monitoring and systems put in place to manage these effects, particularly with the dermatology and psychology departments within the hospital. For the treatment of anaemia, it can be managed by either dose reduction of the Peg-Interferon or additional injections of erythropoietin (EPO) she said. During the session it became clear how important it was to ensure that you take the right steps in managing your lifestyle before and during treatment. The overall recommendation was "listen to your body and don't push it to do something it is unable to do while you're on treatment".

Dr. Eoin Feeny, from the GUIDE clinic in St. James's, presented on HIV and HCV co-infection. He pointed out that there is currently limited information on co-infection as Boceprevir and Telaprevir are not yet specifically licensed for treatment of HIV and Hepatitis C co-infection. There are some studies that have been carried out showing an SVR rate of 69% - 80% for Telaprevir and 60% - 70% in Boceprevir. These were very small studies but show a trend close to that expected in mono-infection. He said generally the side effects reported were the same as those in mono-infected patients but the biggest concern from a co-infection point of view is the de-stabilisation of suppressed HIV. Boceprevir and Telaprevir can have interactions with other drugs that may be used for treatment of HIV and as a result, dose regimens may need to be adapted and close monitoring is absolutely essential for anyone that will be on treatment. The GUIDE clinic currently have no patients on the new triple treatment, however he did point out that access to treatment may be available in the near future. He discussed the need for a greater number of trials and results from drug interactions in patients with co-infection. He also discussed newer treatments that are coming but said at this point, the exact role of these drugs in HIV co-infection remains unclear.

Dr. Liz Kenny spoke about the use of the triple therapy treatment in Cork University Hospital where they had 4 patients on an early access programme for Boceprevir. Her findings were similar to those experienced in St. James's in relation to treatment and side effects. All 4 patients are on treatment currently. The virus load in the 4 patients is undetectable at this stage with only a few months to go before the end of treatment. They are happy with the progress so far and looking forward to rolling out treatment when full access is available.

On Saturday afternoon, there were two workshops. One for people infected with Hepatitis C and the other workshop was for partners. The workshop for those infected with Hepatitis C heard from an individual currently on treatment and someone who is preparing to go on treatment. They discussed the reality of side effects and the day to day impact of living with the treatment. In relation to starting the treatment they discussed the importance of reducing work, arranging help and a number of other aspects while on treatment. As one individual said, *"for the year that you are on treatment you need to put yourself first so that you have a long life to put whoever you want first"*. The partner's session, facilitated by Patricia Byrne, Psychologist, St. James's Hospital, discussed the sense of anticipatory anxiety before starting treatment and ways to manage it while waiting. They also discussed the need for support systems to be in place and the different ways people can use their own resources when dealing with a partner who is on treatment. There was also a session on the psychological management of the new treatments. The overriding theme from this session was not the side effects of the treatment but the anxiety from both people infected with Hepatitis C and their partners of the waiting to go on treatment and not knowing when it would start. The majority of people at the weekend were ready and eager to start, but waiting for the treatment to be rolled out was extremely frustrating.

On Sunday, Michele Tait gave an update on the services and supports available to those with a HAA card. There was an emphasis that the services and supports should be used particularly when someone is on treatment and unable to do their day to day activities. As always, even for those who have used the support and services there was new information.

The Irish Haemophilia Society would like to thank all the speakers for their time and informative discussions over the course of the conference. Overall the weekend was extremely successful with most of that success due to the individuals who attended the conference and the frankness of the discussions on the new treatments and the future.

The sessions at the weekend were very interactive.

New Hepatitis C Treatment – Making them available

The new treatments for Hepatitis C Genotype 1 – Telaprevir and Boceprevir - have been licenced for use since late last year. These treatments taken with Pegylated Interferon and Ribavirin offer a probable cure rate of close to 80% compared to 40% for the previous combination treatment of Pegylated Interferon and Ribavirin alone. The course of treatment will be very difficult for members with significant side effects but the results look very promising and the Society have been taking every measure to ensure that our members with Genotype 1 Hepatitis C are aware of these treatments and can avail of them. The process of getting access to the treatments has been slow and frustrating. The therapies underwent Health Technology Assessments which demonstrated that both were cost effective This was completed in January and our expectation was that treatment would commence in February.

This did not occur and the therapies were not approved for reimbursement. Consequently, we sought an urgent meeting with the Minister for Health in April and met Minister Reilly on World Haemophilia Day - April 17th. I made a strong case to him for immediate approval for these therapies and explained their vital importance for our members. The Minister approved the therapies during our meeting. Despite this, at the time of writing in early June treatment has not yet commenced. Delays within the system including staffing issues and which budget the drugs will be reimbursed from, have been delaying factors. We continue to work constantly with the Hepatologists, St. James's Hospital and the HSE via Dr. Barry White to resolve these issues without further delay. We have now received a categorical assurance from the CEO of St. James's Hospital that treatment will commence in June. If this does not occur, we will once again be contacting the Minister for Health on an urgent basis. It is not appropriate that a decision, once made at the highest level, should take so long to translate into action on the ground.

Brian O'Mahony

Brian O'Mahony, IHS, CEO with Minister Dr. James Reilly, TD

My Personal Experience with the new treatments for Hepatitis C - A Member's Story

I have been asked by the Society to pen a few lines on my personal experience of the treatment of Hepatitis C with the triple therapy treatment of Peg-Interferon, Ribavirin and Boceprevir. I am very mindful of the fact that each person's situation is different – age, duration of infection, B.M.I (Body Mass Index), lifestyle, work, home, etc.

The following is just a general overview of how I tried to cope with the treatment and may not be the same for everyone. It should be seen as some tips I learnt during the weeks and should in no way be looked upon as medical advice. This should and will come from Hepatology staff as you go through your own treatment regimen.

Background

I have mild haemophilia. I have had Hepatitis C infection since 1979 or 1982. I am Genotype 1B and prior to my current treatment I have tried the first treatment of Interferon and then the dual treatment of Peg-Interferon and Ribavirin and both times I was a null responder (no response throughout the duration of treatment). I decided to try the triple therapy of Peg-Interferon, Ribavirin and the product that was available at the time, Boceprevir.

Fears Prior to Starting

- Length of time (48 weeks)
- Change of Lifestyle
- Insomnia (I had this with previous treatment)
- Mental well being and mood and the effect that would have on family members and friends

Medication Routine

For the first 4 Weeks

- Peg interferon injected subcutaneously (under the skin) once a week
- Ribavirin tablets taken twice a day

And for the remainder of treatment

- Peg interferon injected subcutaneously (under the skin) once a week
- Ribavirin tablets taken twice a day
- Boceprevir (Victrelis) tablets taken 3 times a day (with food)

My Results so far

Week	Number of Weeks on Triple Therapy	Virus Load	Weight (kg)	Haemoglobin (Hb)
1	0	Detectable	99	15
6	1	Detectable	97	11.4 (Started Epo)
8	4	Non - Detectable	95	11.5
24	20	Non - Detectable	90	10.5 (Increased Epo)
38	34	Non - Detectable	86	12.4

Side Effects

Drop in Haemoglobin: I had a significant drop in my Haemoglobin and as a result I felt fatigued, dizzy and had some shortness of breath and headaches. I was given EPO (Erythropoietin) and I also had my Ribavirin reduced after about 20 weeks on the treatment.

Flu-like symptoms: I found I used to get flu like symptoms such as pains and feeling cold, particularly after the injection of interferon. I found that taking a paracetemol before and a couple of hours after the injection helped me.

Taste in the mouth: I got a taste in my mouth when I ate certain foods or used certain cutlery. I found mints or acid drops useful. Also I found that cold drinks with the tablets helped as well.

Stomach: I found that I would get bloating or my stomach would feel upset. I discussed it with my doctor and I was prescribed something to help with this and I took it in the morning and it worked well.

Haemorrhoids / Constipation: I had some problems with this but I talked to the doctor. There were over the counter and/or prescribed remedies which I tried and which worked.

Anal Itch: I had no problems with this, but someone I talked to, who was also on treatment, did and the doctors prescribed something to help. This is a legitimate side effect and don't be embarrassed to say it to your doctors.

Bladder: I found I needed to drink plenty of fluids, but I recommend getting as much of your fluids into your body before 6pm as I found after that I had to get up at times during the night to use the bathroom.

White blood cells: I had a reduction in White blood cells. Not much I could do, but I highly recommend good oral hygiene.

Irritable / Lose temper easily: I found it helpful to speak with the doctor when I went in for the appointments. Little things can frustrate you and normally it wouldn't bother you. When you lose your temper don't be slow to apologise (not like me).

Food with tablets: It can be difficult to know what to eat with the tablets. Snacks I found easy were fruit, rice, trifle, ice cream, yoghurt, custard, cornflakes and apple tart. This may be different for you of for another treatment.

Negatives vs. Positives

I am currently 40 weeks into treatment and my thoughts and recommendations on the positives and negatives are:

Positives	Negatives
I have a much better chance of success with this treatment. *(Almost double)*	48 weeks is a long time *Remember treatment will be stopped if not working after 12 weeks so aim for that initially.*
At the very least my body will get a break from the virus for probably the first time in years.	Restrictions of my lifestyle *Plan for each occasion and LISTEN TO YOUR BODY.*
	Side Effects *Speak to your doctor at the appointments. There is something to counteract these.*

Summary

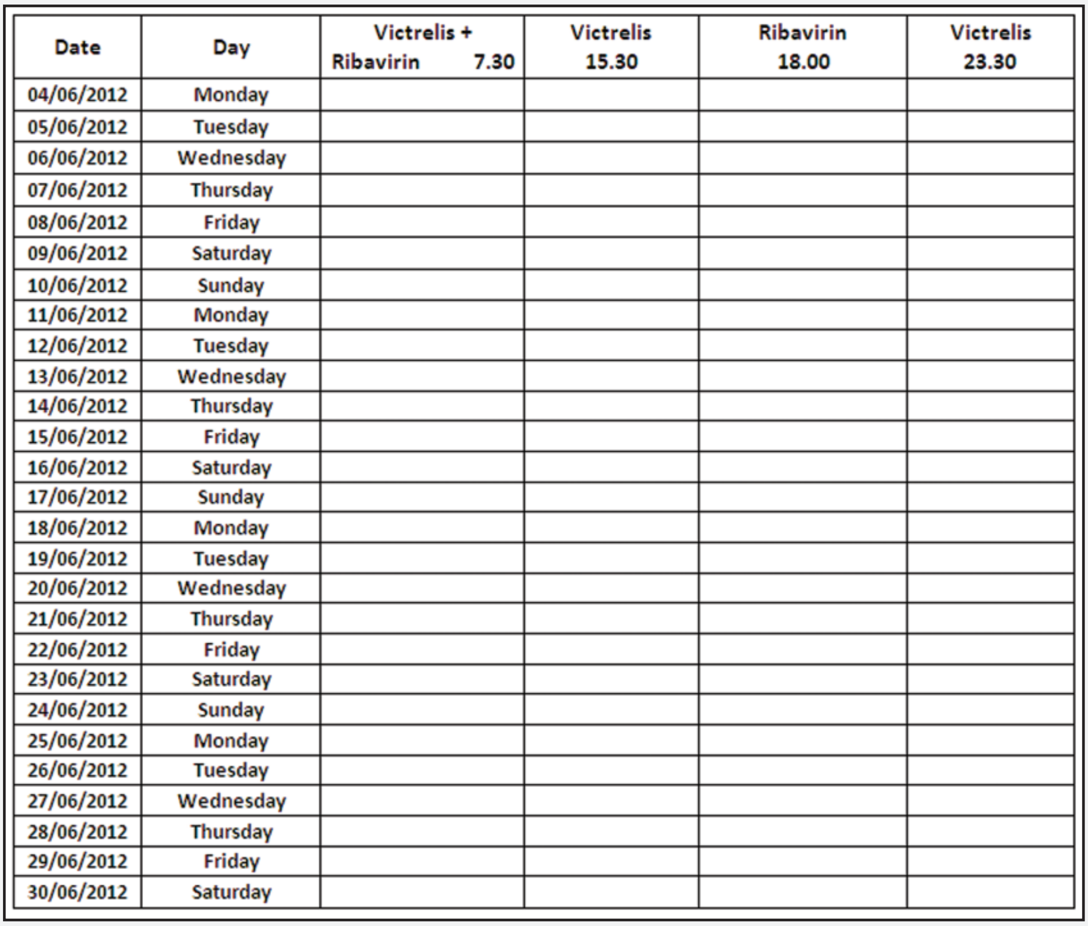
This course is doable.

Not everyone will have the same reactions or side effects. Speak to your hepatologist regarding any problems and chat with other people on treatment to compare how it is going. As I am writing this I have 40 of the 48 weeks completed and I feel it has got easier in the last 4-6 weeks. I think a person's body and mind becomes accustomed to it.

I found the mental side of it not as problematic as I feared it might be (my wife may disagree). I hoped at the start it would have as little effect on my loved ones as possible and I think we achieved this. I feel that for me, keeping my haemoglobin levels up was the key to making it easier. It is also very important to stick strictly to the times you are supposed to take the tablets as possible and sometimes you forget if you have taken them. It really helped for me to have a monthly wall chart and mark it off each time I took the tablets just to be sure (These will be available from the drug companies or from the IHS).

I am confident , even if I do not achieve a sustained virological response, I have given it my best shot. If you are considering or being offered the course of treatment, I hope this short note will be of some little help and I wish you every success.

Remember – Be advised by your Hepatology Staff



Date	Day	Victrelis + Ribavirin 7.30	Victrelis 15.30	Ribavirin 18.00	Victrelis 23.30
04/06/2012	Monday				
05/06/2012	Tuesday				
06/06/2012	Wednesday				
07/06/2012	Thursday				
08/06/2012	Friday				
09/06/2012	Saturday				
10/06/2012	Sunday				
11/06/2012	Monday				
12/06/2012	Tuesday				
13/06/2012	Wednesday				
14/06/2012	Thursday				
15/06/2012	Friday				
16/06/2012	Saturday				
17/06/2012	Sunday				
18/06/2012	Monday				
19/06/2012	Tuesday				
20/06/2012	Wednesday				
21/06/2012	Thursday				
22/06/2012	Friday				
23/06/2012	Saturday				
24/06/2012	Sunday				
25/06/2012	Monday				
26/06/2012	Tuesday				
27/06/2012	Wednesday				
28/06/2012	Thursday				
29/06/2012	Friday				
30/06/2012	Saturday				

Having a monthly wall chart, like the one pictured above, makes it easier to remember when to take your tablets.

Preparing For Hepatitis C Treatments

Preparing yourself for a lengthy course of any medical treatment demands thought, preparation and commitment. For those about to embark on the new Hepatitis C triple therapy, good preparation can make the journey a less arduous one.

Each individual is different, with different needs and circumstances. As a result, there is no one roadmap to suit us all. There are, however, some ideas that might benefit a majority of those about to undergo treatment. I would suggest breaking the preparation into two separate categories, personal and medical.

The first relates to domestic matters. Some of us are single, some married, some share accommodation, others live alone – either way, you will need support for the period of treatment. It can be from family or friends but do not think you can do this by yourself. Company, cooking, the occasional errand, cleaning, a lift somewhere, whatever it is, you will need to rely on others at some point. On the good days, you will be able to manage by yourself, but there will be difficult periods and you will then need to manage your health accordingly. This will apply to some more than others but err on the side of caution and ensure you aren't overloaded. This is one of the few times in your life when it is okay to be a little selfish. You might have to make up for it later but it will be worth it!

Those taking on the course of treatment should have a Health Amendment Act card (if you don't, contact the IHS office immediately), this card entitles you to certain support. A full list of your entitlements is on the HSE website under 'Benefits and Schemes'. Take the time to read it and don't be afraid to request these services. They will make your life much easier.

Don't overdo it; you will need your rest. But, like everything in life, it's about balance, because doing nothing isn't healthy either, for mind or body. So a routine of some sorts might be a good idea, whether it's a daily walk, time with friends or family or sitting in the garden. Even if you don't feel like it, it might be wise to get out of the house on occasion. There will be difficult moments and sometimes, it helps to share. Talk to someone, family or friend but if confidentiality is an issue, the HAA card entitles you to counselling services (also, you can always call Anne in the office).

Work is another personal matter. Some people have to take a short period of time off, at least at the beginning, but try to schedule the treatment for a time when you might not be too busy. Plan ahead and delegate, get work done in advance or put a large project off for a while. The treatment will involve trips to the hospital and you could miss days at work.

Medically, there are certain and sometimes severe side effects with these drugs and it's very important to talk to your doctor and nurse about them. Ask questions, however silly they may sound. Make a list of queries that pop into your head, as you may forget them at the clinic. Inform your GP about what you're about to do. Perhaps they could call your consultant and find out what they should be vigilant for. There are some things you can do in advance . Start applying emollients ahead of commencement – your nurse will be able to suggest the best ones – and maybe make plans for your drug intake increasing. Any creams or painkillers are available to you on the HAA card – ask your GP to add them to a prescription. A chart has been successful for others in order to record their regimen and remain compliant.

The final thing to mention is attitude – a positive approach to this will undoubtedly help you. If you think and expect that you're going to feel lousy, then you probably will but being optimistic and as upbeat as you can will go some way towards getting you to the end of your journey. This drug breakthrough is good news for people infected with Hepatitis C, Genotype 1. You have a wonderful opportunity to get rid of the virus. But the therapy can be difficult for some and it's a good idea to put things in place, personally and medically, to make this time as comfortable as possible. Good luck to all.

COPING STRATEGIES

Serious Health Issues

The following are suggestions gathered from health care professionals and members.

MIND

Do’s	Dont’s
Inform yourself * Keep up to date about treatment. * Become familiar with medical terms, names of tests and what they show. * Don’t be afraid to ask questions.	**Avoid** * It is healthier to engage with your doctors, keep appointments.
Accept Support * Use your HAA card supports. * Accept help with household duties. * Don’t be afraid to ask for help.	**Worry Excessively** * Limit the time you allow yourself worry. Don’t allow worry take over your life.
Maintain a Positive Outlook * Focus on your strengths. * Change how you think. * Change how you feel. * Show yourself compassion. * Use mindfulness technique.	**Think Negatively** * Dwelling on negative thoughts can be self-destructive.

BODY

Do’s	Dont’s
.Healthy Nutrition * Eat small meals frequently. * Eat a well balanced diet. * Check your weight regularly.	**Eat Unhealthily** * Avoid big meals * Avoid foods high in sugar & salt.
Relaxation * Listen to your body. * When tired don’t push yourself. * Practice relaxation. * Chill out before bedtime.	**Consume Alcohol** * Avoid alcohol, it will damage your liver
Exercise Appropriately * Develop a gentle exercise routine. * Ask your physiotherapist. * Don’t push yourself beyond your energy limits.	**Under or Over Work** * Doing too much can backfire. * Prolonged rest can result in weakness, reduced stamina & immobility.

FAMILY

Do’s	Dont’s
Maintain a Social Life * Make arrangements to socialise. * Keep or take up hobbies and activities.	**Withdraw from Activities** * Don’t stop doing things you enjoy. * Don’t give up hobbies. * Don’t wait for the right mood.
Maintain Relationships * Talk with your partner, children and friends. * Share how you feel.	**Withdraw from Relationships** * Don’t avoid family and friends until you feel in better form.

Starting Hepatitis C Treatment? - Practical Support from the Society

The Irish Haemophilia Society are committed to providing practical support and assistance to members who will be availing of treatment for Hepatitis C. This assistance will be available in the following specific areas:

Contact and Communication

The Society and specifically our Nurse/Counsellor Anne Duffy are available to assist you with any queries or give advice or assistance on practical issues including any difficulties or queries you may have in accessing services with your Health Amendment Act (HAA) card, HAA card assessment process, practical difficulties in attending clinics and discussing side effects of therapy. You may find it useful and beneficial to discuss how your treatment is progressing for you and the Society are there to listen and to help. Anne can be contacted on 01 657 9927 or 087 232 0255.

Accomodation

Many members whose treatment will be supervised by the Hepatology team or Infectious diseases team at St. James's Hospital may have to attend the centre very frequently during treatment. We are aware that this may be tiring for members especially given that fatigue and anaemia are recognised side effects of therapy. For members who have to travel significant distances to get to St. James's from outside Dublin, this will be a particular burden.

The Society have purchased an apartment which is 3-5 minutes walk from the Hepatology centre. This accommodation - comprising of a 2 bedroom apartment and a separate 1 bedroom studio apartment will be available to members from July 1st. A car parking space is also available for 1 car.

The accommodation is available to members from outside Dublin who are attending at St. James's Hospital for clinics. Or to their immediate family member (spouse / children) if they are admitted. A very nominal charge of €10 per person or per family per night will be levied to partially cover cleaning costs. Preference will be given to members who are undergoing treatment and to those who face a very significant journey to get to St. James's.

Bookings for the apartment can be made by contacting Anne Duffy at 01-6579900. A separate letter giving more details is enclosed.

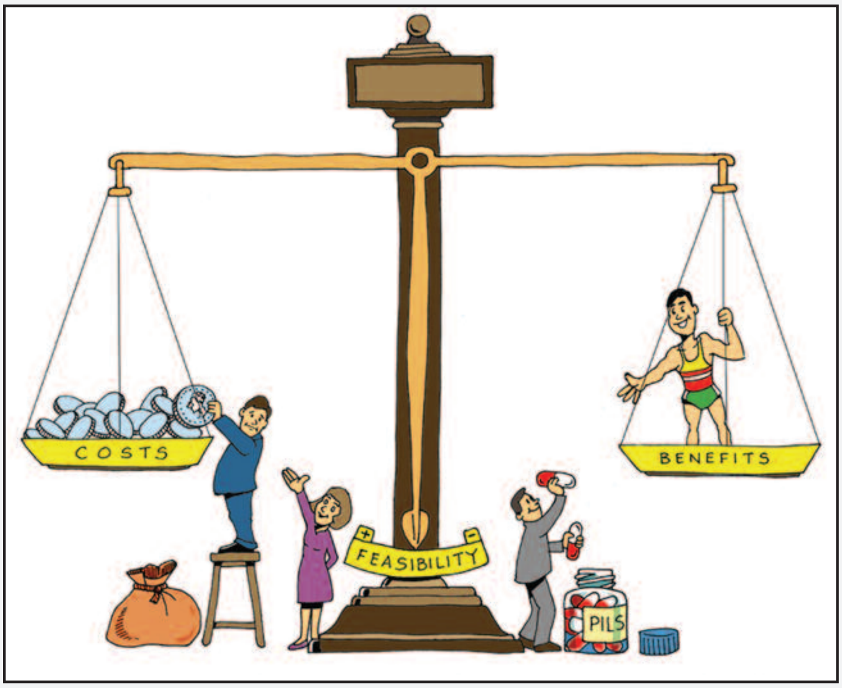
Financial Assistance

We recognise that some members will face significant transport costs during the course of their therapy. The Society will provide financial assistance of € 30 for each visit to the Hepatology or Infectious disease clinics required for your treatment management to members who require this assistance. Financial assistance will be available to members who live more than 90 minutes driving distance from St. James's Hospital.

Further details are provided in the attached letter.

The IHS apartment is located near St. James's Hospital which is practical for members attending the hospital for treatment.

Cost effectiveness of New Treatments for Hepatitis C in Ireland



As part of every new drug being reimbursed in the Irish health system, it needs to go through a cost effectiveness assessment. So, why as patients do we need to be aware of this? There are two main reasons we should pay attention to these assessments, firstly in the process of analysing the information for the assessment, the reports produce an excellent summary of clinical trials and secondly we need to be aware of the results and what they mean.

The assessment on Boceprevir was based on results from the SPRINT-2 and RESPOND clinical trials. In the SPRINT-2, an SVR (sustained virologic response, no detectable virus 6 months after the end of treatment) of 40% was achieved in a control group with Peg-Interferon and Ribavirin. This was compared to 67-68% in patients receiving the triple therapy Boceprevir, Peg-Interferon and Ribavirin. In the RESPOND study the SVR rate was significantly higher in the boceprevir triple therapy groups 59-66% compared with the control group of Peg-interferon and Ribavirin at 21%. In patients with undetectable virus load at week 8, the SVR rate was 86% after 32 weeks of triple therapy and 88% after 44 weeks of triple therapy.

The assessment on Telaprevir was based on results from the ADVANCE and REALISE clinical trials. In the ADVANCE study significantly more patient's on the Triple Therapy Telaprevir groups had an SVR of 69% - 75% compared with 44% in the control group taking Peg-Interferon and Ribavirin. A total of 58% of patients treated with Telaprevir triple therapy were eligible to receive 24 weeks of total treatment. The overall rate of discontinuation of treatment in the Telaprevir groups was 10% as compared with 7% in the Peg Interferon and Ribavirin group. In the REALISE trial the SVR were significantly higher in the Telaprevir groups at 83% - 88% compared to 24% in the Peg-Interferon and Ribavirin group. The corresponding rates for patients with a previous partial response were 54-59% with triple therapy compared to 15% with Peg-interferon and Ribavirin. In patients with no response to previous therapy the SVR rates were 29% - 33% with triple therapy and 5% in Peg-interferon and Ribavirin group.

The assessment then tries to estimate the cost of reimbursing these drugs, not solely based on monetary terms but also on how they will affect the quality of life of the individual. The way this is done is by comparing a number of different health states related to the progression of the disease (Hepatitis C, in this case) to each other such as mild chronic Hepatitis C, moderate chronic Hepatitis C and compensated cirrhosis. It also examines patients who do not achieve a SVR and progress to decompensated cirrhosis, liver transplantation, post-liver transplant or death. They then compare the costs and quality of life of each state and come up with what is known as a *Cost (€) / QALY (quality adjusted life year)* value. This represents the cost for a drug to give one patient, one year with a perfect quality of life. This is an abstract concept but applying the same process to all drugs, in theory it allows the people choosing the drug re-imbursements to compare a drug for Cancer against a drug for Epilepsy against a drug for Hepatitis C based on how effective it is.

In Ireland, when these assessments were carried out, the general threshold for new drugs was €45,000/QALY and drugs with Cost/QALY more than this were considered as not cost-effective and would generally not be reimbursed. Basically, the lower the *Cost/QALY* the more cost effective a drug is.

In relation to Boceprevir, the Cost/QALY ranged from €2,756/QALY to €16,763/QALY depending on treatment history and duration of treatment. The Cost/QALY value for Telaprevir ranged from €4,358/QALY to €14,186/QALY depending on treatment history and duration of treatment. As a result, both Boceprevir and Telaprevir were considered as extremely cost effective. Recently, the Cost/QALY threshold was reduced from €45,000/QALY to €20,000/QALY. This is the lowest in Europe and will make it difficult for many drugs to be reimbursed, presumably in an effort to reduce the cost the State's pharmaceutical expenditure. However, even with the new significantly reduced threshold, Boceprevir and Telaprevir are still cost effective.

Overall, the results from the cost effectiveness assessment clearly shows that the clinical trials for Boceprevir and Telaprevir are very positive and when assessing whether these should be reimbursed it is clear that they are extremely cost effective and will greatly improve the quality of life or individuals with Hepatitis C Genotype 1, if the treatment is successful and an SVR is achieved.

In May 2012, the Minister for Health announced in the Dail, that these drugs would be available for use in Ireland under the Hi-Tech Drugs scheme as soon as possible.

Useful Contact Details

The Irish Haemophilia Society

Anne Duffy
Phone: 01 657 9927
Mobile: 087 232 0255
Email: anne@haemophilia.ie

Brian O'Mahony
Phone: 01 657 9900
Email: brian@haemophilia.ie

Declan Noone
Phone: 01 657 9900
Email: declan@haemophilia.ie

St. James's Hospital

General Hepatology
01-4103417

Nurse Liaisons – Hepatology
01-4284506

GUIDE Clinic -
General (01) 416 2315,
Nurse Manager (01) 410 3769

NCHCD – 01- 4162141

Cork University Hospital

Hepatology
021 492 2274 / 021 454 6400

Comprehensive Coagulation Centre
021 492 2545 / 021 492 0459

Hepatitis C Liaison Officers:

Dublin North West / Dublin North / Dublin North Central and Dublin North East (Cavan, Louth, Meath & Monaghan)
Mr Larry Bathe
Tel: 046 907 6451 **Email:** larry.bathe@hse.ie

DublinSouth West / Dublin West
Michele Tait, National Coordinator
Tel: 016201712 / 016201750 **Email:** michele.tait@hse.ie

Dublin East /Dun Laoghaire / Bray / Wicklow and Dublin South / Kildare & West Wicklow
Ms Michelle Hayes,
Tel: 01 620 1840 **Email:** Michelle.hayes2@hse.ie

Laois, Longford, Offaly / Westmeath
Ms Elaine Barry
Tel: 044 938 4429 **Email:** ElaineM.Barry@hse.ie

Clare / Limerick / Tipperary North / Clare / Limerick
Ms Ellen Rush
Tel: 067 46 449 **Email:** ellen.rush@hse.ie

Leitrim / Sligo / Donegal
Mr Colin McCann,
Tel: 0749104698 / 0749109119 **Email:** colin.mccann@hse.ie

Galway / Mayo / Roscommon
Mr. Richard Broderick
Tel: 091 775416 **Email:** richard.broderick@hse.ie

Carlow / Kilkenny / Tipperary South / Waterford / Wexford
Ms Valerie McGrath,
Tel: 056 778 4101 **Email:** Valerie.mcgrath@hse.ie

Cork / Kerry
Mr Donal Murphy,
Tel: 021 492 1872 **Email:** Donal.Murphy2@hse.ie

IRISH HAEMOPHILIA SOCIETY
First Floor
Cathedral Court
New Street
Dublin 8
Tel: 01 6579900
Fax: 01 6579901
Email: info@haemophilia.ie
Website: www.haemophilia.ie