



# Positive News

Information Magazine for people with Hepatitis C and HIV

## The Irish Haemophilia Society

*Representing people in Ireland with haemophilia and related bleeding disorders.*

It is now nine months since the first person with haemophilia received treatment with the new triple combination therapy, following their authorisation by the Minister for Health. Prior to that, one individual had been treated using combination therapy with one of the new drugs (Victrelis) in combination with Pegylated Interferon and Ribavirin on an early access programme. We are happy to report that that this individual has successfully completed his treatment and has cleared the hepatitis C virus.

Since July a further ten people with haemophilia have commenced treatment. Of those ten, two have completed 24 weeks of treatment, and are awaiting the long term outcome of their treatment. A further five are currently undergoing a 48 week course of

treatment, and three individuals stopped treatment. Of those who stopped, two individuals stopped treatment because their viral load for hepatitis C was not hitting the targets set, and unfortunately one individual died while on treatment, although his death may well have been due to an unrelated cause.

The number of people with haemophilia who have been treated to date is relatively small, and it is difficult and indeed would be unhelpful to draw too many conclusions from the results to date. Results will vary depending on the individual's previous treatment history, state of their liver, and also their genetic composition for IL28B which can help as one of the predictors of treatment outcome.

### Treatment Outcome

The Society has been working closely with many of the individuals on treatment and giving them as much help and support as we can. What has become clear to us from speaking to individuals on treatment, are the importance of a number of points as follows:

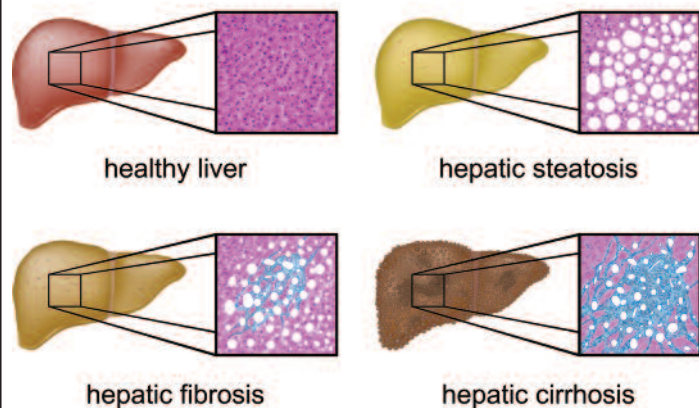
- Preparation for treatment is vital

Before starting treatment, each individual should be aware of the potential side effects and have information on the dietary requirements, if they are being treated with Incivo.

- Timing

Preparation also includes thinking carefully about when you will start treatment in relation to your family commitments, work commitments, college commitments and all other aspects of your life. Depending on your clinical picture, progression of your liver disease, and your previous treatment history, your Hepatologist and the

### Liver Disease



the Clinical Nurse Specialist in Hepatology will be able to advise you in relation to the possible duration of treatment you will require. In some cases, (for example where there is cirrhosis or previously failed treatment) then clearly 48 weeks treatment will be required. In other cases, the decision as to whether an individual will require 24 weeks or 48 weeks of treatment will not become apparent until at least four weeks of treatment has been completed. Therefore, in these situations it is better for individuals to prepare for a course of 48 weeks treatment. If the treatment includes Incivo then each dose of treatment for the first twelve weeks has to be taken with food which contains at least 20g of fat. Feedback from our members who are on treatment and also from the team in Hepatology, stress the importance of taking at least this 20g of fat with the Incivo three times per day. This ensures that the medication is properly absorbed and may prevent some unhelpful side effects. Further detailed information on dietary options to help you comply with this requirement are on pages 3, 4, 5 & 6 of this supplement.

• Work /College

In terms of work or college our advice would be to lighten your schedule as much as possible, certainly for the first 12 weeks of treatment, and arrange to take time off if possible.



It is probably easier to cope if you arrange to lighten your schedule, and then add more work/study in, if you are not suffering from side effects, than to assume that you will not suffer from side effects and then be unable to cope with your normal schedule.

• Family

It is vitally important to involve your spouse/partner or family member in relation to discussions on treatment, so that they will be fully involved and aware of the potential side effects. Peer support is very important. If you are starting treatment please do contact the Irish Haemophilia Society and we will give you as much help and support as possible. We are in contact on a personal basis with the majority of members on treatment and it has certainly been the experience of

our members to date, that talking to each other or talking to the Society has been very beneficial and helpful.

• Support from the I.H.S.

Please remember that there is also financial and logistical support available from the Society. For any member who is on treatment and who resides at least one and a half hours outside Dublin, who has to travel regularly to Dublin for treatment, the Society make financial help available towards the travel costs.



In addition, if you are on treatment and you require accommodation near St. James's Hospital, when you are visiting the centre, or if you are being kept overnight, then the Society has an apartment available adjacent to St. James's Hospital, which you can use.

In March, the first people with haemophilia who are co-infected with hepatitis C and HIV have begun treatment, and of course the requirements to deal with HIV medications in addition to hepatitis C medications will add an extra layer of complexity to their treatment.

In May, the Society will organise our annual conference for members with hepatitis C and/or HIV and their partners. If you are on treatment or contemplating treatment I would strongly urge you to attend this year to get up to date information on the current treatments and future treatments in the pipeline.

**Brian O'Mahony**



# Dietary Options While on Treatment

## **BREAKFAST IDEAS**

- 2 Scrambled eggs (15g fat) and 2 slices of wholemeal toast & butter spread (5.8g fat) = **Total = 20.8g fat**
- 1 Scrambled egg/Omelette with onion, peppers, tomatoes and mushroom (13.25g fat) and slice of wholemeal bread & butter spread (2.9g fat) plus cup of tea with two tablespoons of milk (1.15g fat) = **Total = 17.3g fat**
- 1 cup of unsweetened muesli (4.42g fat) with 125ml whole milk (4.88g fat) and an all bran muffin (8g fat) = **Total = 17.3g fat**
- 2 scrambled eggs (15g fat) and 1 grilled rasher (4.73g fat) = **Total = 19.72g fat**

## **LUNCH IDEAS**

- Salmon and green bean salad {green beans, onion, garlic, Italian dressing, lettuce & tomatoes (16.4g fat)}, one wholemeal crusty roll (1.4g fat) and a glass of whole milk (2.3g fat) = **Total = 20.1g fat**
- 2 slices of wholegrain bread and mayonnaise spread (6.89g fat) with 1 medium slice of grilled chicken (3.82g fat) with 20g piece of cheddar cheese (6.89g fat) and a grilled tomato (0.59g fat). A strawberry, banana and yoghurt smoothie (1.2g fat) = total fat content = **Total = 19.39g fat**
- Stuffed grilled chicken {peppers, feta cheese and olives (5.9g fat)} with small portion of savoury rice (9.71g fat) with glass of whole milk (2.3g fat) = **Total = 17.91g fat**

## **DINNER IDEAS**

- Shepherds pie (with ground beef, cream potatoes, cheddar cheese, peas, carrots) = **Total = 17.6g fat**
- 1 serving of homemade beef lasagne = **Total = 17g fat**
- Stir fried chicken with broccoli, peanuts and rice = **Total = 20g fat**
- Beef stew (with carrots, potatoes, peas, beef stock) = **Total = 20g fat**
- Spaghetti Carbonara = **Total = 21g fat**

## **SNACK IDEAS**

- 1 whole avocado and French dressing = **Total = 19g fat**
- 6 – 8 brazil nuts = **Total 19g fat**
- 14 halves walnuts = **Total = 18g fat**
- 24 almonds (14g fat) and a Danone natural yoghurt (3.8g fat) = **Total = 17.8g fat**
- 5 crackers and 1oz of cheese (13.5g fat) and a Danone natural yoghurt (3.8g fat) = **Total = 17.3g fat**

*(All snacks/meals taken with a glass of whole milk (2.3g fat) or tea/coffee with whole milk (1.15g fat) add up to 20g fat.)*

## **NOTES ON DIET FOR TRIPLE THERAPY REQUIRING 20G OF FAT**

### **20g of Fat**

170g Salmon Fillet  
2 Slices of full fat cheese  
1 Avocado (21g fat)  
4 Tbsps of Oil  
3 Tbsps of peanut butter  
2 Tbsps of Butter  
10g – 19g Fat  
2 Scrambled eggs (14g fat)  
10 Hazelnuts (18g fat)

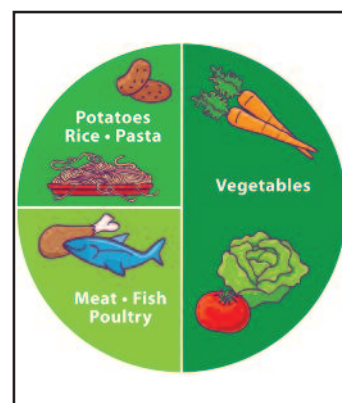
### **5g – 9g Fat**

1 Egg (7g fat)  
3 Slices of bacon (9g fat)

### **1g – 4g Fat**

2 slices of bread (2g fat)

[www.caloriecount.com](http://www.caloriecount.com) – website can be used to quantify any foods fat content. There is also an app available for download.

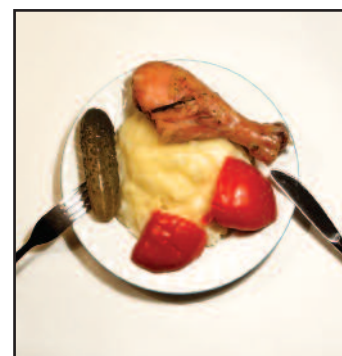


<b>BREAKFAST IDEAS</b>		
<b>Food</b>	<b>Estimated Fat Content per portion (g)</b>	<b>Fat content (per 100g)</b>
250 ml Full milk	10	
Bowl of cornflakes (dry)	0	
Porridge made with milk	4	
All bran/Shredded Wheat (dry)	1	
Weetabix (2 Biscuits) (dry)	1	
Crunchy Nut Cornflakes (dry)	1.5	
Fruit & Fibre (dry)	2	
Muesli (dry)	3	
Tesco Finest Butter Croissant	20	
Regular Croissant	12	
Bagel with 40g cream Cheese	10	
2 slices toast with butter & peanut butter	22	
Denny's Sausages (x2)	13.1	23
Clonakilty sausages		30
Mallow Sausages		28.4
Tesco Finest Toulouse Sausages (x2)	31	24
TF Garlic & Basil Sausages (x2)	28	21
2 Scrambled eggs	15	
Denny Hickory Rasher (x2)	12.8	14.9
Galtee Rasher (x2)	8	
Rudd rashers		24
	<b>Estimated Fat Content per portion (g)</b>	<b>Fat content (per 100g)</b>
<b>4pm &amp; 11pm ideas</b>		
<b>Chocolate</b>		
Snickers Bar	17.5	
Moro	16.2	
Cadbury's Fruit & Nut	12.1	
Picnic	12	
Yorkie Nut & Raisin	13	
Terry Chocolate Orange	12	
Toffee Crisp	12	
Mars bar	12	
Fun size Mars Bar	3	
<b>Ice-Cream</b>		
Ben & Jerry's Choc Fudge Brownie		13
B & J Dough Double Whammy		15
B & J Caramel Chew		16
Haagen Das Chocolate & Praline		15
HD Vanilla		15.2
Nestle Lion Bar Ice Cream bar	10	
Magnum Classic bar	15	
Magnum Almond bar	17	
<b>Cake</b>		
Glenilen Lemon Posset	28	
Glenilen Irish Cream Liqueur C'cake	25	
Tesco S'berry Jam Slice	16.8	
Tesco Iced Custard Slice	13.1	
Tesco S'berry Jam Scone	14.9	
Tesco S'berry Jam Doughnut	13	
Tesco Éclairs	10.5	
Tesco Belgian Choc Choux Bun	25.8	





	<b>Estimated Fat Content per portion (g)</b>	<b>Fat content (per 100g)</b>
Cadbury Hot Choc Pudding	16.1	
TF Butterscotch Mousse	16.4	
Mr Kipling Golden Syrup pudding	12.2	
Mr Kipling Lemon pudding	13.3	
Tesco Bramley Apple cake	13.7	
TF Toffee Pecan Roulade		22.4
Almondy Tart		27
Kelkin Butter Popcorn		27
<b>Pies etc.</b>		
Bird's Eye Chicken Pie	27	
Galway Chicken, Mushroom, Bacon pie	27	
Denny Chicken & Mushroom slice	25.7	
Denny Cornish Pasties	31.8	
Denny Jumbo Sausage Roll	18.3	
Tesco Pizza Slice	20	
Tesco Southern Fried Chicken fillet (3)	17.5	
Domino Pizza (1 slice)	7	
McDonald's Big Mac	23	
McD's Hamburger	8	
McD's Cheeseburger	12	
McD's Quarter Pounder	20	
McD's Quarter Pounder with cheese	27	
6 Chicken Nuggets	15	
Fillet o Fish	18	
McChicken Sandwich	17	
Regular French Fries	9	
Burger King Whopper	38	
Burger King Hamburger	11	
Burger King Cheeseburger	14	
King Fries	16	
Bag of crisps	between 11 and 16	
Bag of Hula Hoops	10	
Pot Noodle	9.5	
Bombay Mix 50g	13	
Roasted peanuts 30g	13	
Brazil nuts		68.3
Pecan nuts		72
Cashew nuts		48.9
Almonds		51
Walnuts		68.5



**If your treatment includes Incivo, then each dose of treatment for the first twelve weeks has to be taken with food which contains at least 20g of fat.**

**Feedback from members who are currently on treatment, and also from the team at Hepatology, stress the importance of taking this. This ensures that the medication is properly absorbed and may prevent some unhelpful side effects.**



	<b>Estimated Fat Content per portion (g)</b>	<b>Fat content (per 100g)</b>
<b>CHEESE</b>		
Mascarpone		44
Boursin		41
Stilton, blue		35
Gruyère		34
White cheddar		32
Roquefort		32
Gouda		31
Parmesan		30
Cashel/Danish Blue		29
Brie		29
Emmental		28
Gorgonzola		26
Philadelphia		23
Camembert		23
Feta		20
Mozzarella		20
<b>OTHER</b>		
100g black olives	10	
Chicken Liver Pate (average)		12
Houmous (average)		26.7
TF Coleslaw		20
Avocado	29	
<b>CREAM ETC</b>		
Clotted cream		64
Double cream		54
Whipping cream		40
Single cream		19
Crème fraîche		30
Greek yoghurt		10
Kerrygold		81
Dairygold		73
Flora		59
LowLow		53



### **DINNER OPTIONS**

**Shepard's pie** (not with lean mince – added butter to the mash topping)

**Spaghetti Carbonara** (generous parmesan)

**Spaghetti Bolognese** (as above)

**Chicken Kiev** and chips/wedges

**Lasagne**

**Bacon & Cabbage** (using full fat milk and butter to make the parsley sauce)

**Pan fried salmon and mash** (with a side salad and olive oil)

**Fried or grilled hamburger, topped with cheese or bacon**

**Quiche lorraine with coleslaw and brown bread**

**Pizza and garlic bread**

**Good size pork chop** (including rind) and mash with butter with 200ml of full fat milk

**Goat's cheese, onion tart**

**Curries** (mild) – home made with coconut milk or from a jar with Naan bread

**Fish fingers or Donegal Catch** with chips or wedges

**Stir fry with cashew or peanuts** – generous on the oil

**Beef stew** (using stewing steak, not lean beef) slow cooked and served with buttery mash

**Fish pie with salmon and mussels** – served with mash and white sauce

**Any variation on a cheese omelette** – even better with added bacon

**Roasted goat's cheese stuffed chicken breast** (If goat's cheese is too strong for some tastes, try Boursin garlic cheese)

*Add a splash of full fat milk, a chunk of butter and even cheese to all mashed potato as this would add 4-6 g of fat to an individual portion.*

# Supports available from the Society

If there is anything that the Society can help you with, please do not hesitate to contact the office on 01 6579900. We are committed to offering practical support and assistance to members on hepatitis C treatment. We are here to help and to listen. Some of the supports available are in the following areas:

## **Accommodation Facility**

The Society has purchased an apartment consisting of a two bedroom apartment and a separate one bedroom apartment. These apartments are located in Hyde Square some 200 metres from St. James's Hospital or less than 5 minutes walk from Hepatology or the National Centre for Hereditary Coagulation Disorders. The apartments are available to persons with haemophilia when they are attending at St. James's Hospital for treatment or for a review appointment, when the member is travelling from outside of Dublin. The facility should be particularly useful in circumstances such as:



- Travelling up from the country to make an early appointment.
- Attending appointments on consecutive days.

Accommodation can be availed of by the person with haemophilia along with their spouse/partner/accompanying person or family members. A nominal fee of €10.00 per booking per night will be levied to offset the cost of cleaning and routine maintenance.

If you would like to book the apartment please contact Anne Duffy on 01 6579900 / 087 232 0255. If Anne is not available please speak to Debbie Greene or if Debbie is not available any member of staff will be able to deal with your query / booking. When you make a booking to stay in the apartment we will arrange to meet with you to handover keys and to show you around if it is your first time to stay there. There is one car parking space available so on any given night there will be a space available on a first come first serve basis.

## **Financial Assistance**

We are aware that during the course of treatment some members will suffer a financial burden due to the additional cost of having to travel long distances to Dublin on a regular basis to have their treatment monitored and reviewed. The Society will provide a payment of €30.00 per visit to each person with haemophilia who is attending the Hepatology centre in St. James's or Cork University Hospital for treatment when that person lives more than 1.5 hours drive from the treatment centre they attend.

We would ask that if you attend the Hepatology centre in St. James's or at Cork University Hospital, that you ask them for a standard letter stating that you attended on that day. If you then send this into the Society on a monthly basis we will then refund you €30.00 per visit.

## **Personal Support**

Please contact Anne Duffy on 087 232 0255 or any of the Society staff with any concerns or queries you have in relation to treatment. We are there to give you as much support as possible during your course of treatment.



# IRISH HAEMOPHILIA SOCIETY



Conference for members living with  
Hepatitis C and/or HIV

**Dates: Friday 10th to Sunday 12th May, 2013**

**Venue: Pembroke Hotel, Kilkenny**

We are pleased to announce details of a weekend conference for members living with Hepatitis C and / or HIV. The conference will take place over the weekend of 10th to 12th May in the Pembroke Hotel in Kilkenny. The cost for the weekend will be subsidised by the Society at €50 per person. This will include attendance at the conference, two nights accommodation with breakfast and lunch on Saturday and on Sunday, a buffet dinner on Friday evening and dinner on Saturday evening. If you and your partner/spouse would like to attend, please return the attached booking form by Friday 19th April 2013.

## PRELIMINARY PROGRAMME

### **Friday 10th May**

18.00 – 19.00

Registration

19.00 – 20.00

Preliminary results of survey: A discussion over a buffet dinner

### **Saturday 11th May**

10.00 – 11.30

Hepatitis C – Current treatments and future prospects

Professor Suzanne Norris, St James's Hospital

11.30 – 12.00

Tea / Coffee Break

12.00 – 13.00

A review of Hepatitis C treatment - Results to date

Hepatology Nurses, St James's Hospital

13.00 – 14.00

Lunch

14.00 – 15.00

An update on treatment for Hepatitis C for co-infected persons

Professor Colm Bergin, St James's Hospital

15.00 – 15.30

Tea / Coffee Break

15.30 – 17.30

Treatment Experiences – A facilitated discussion where you will hear from the experiences of people with haemophilia on treatment

Nurse Counsellor Anne Duffy and Psychologist Sarah Jamieson

19.30

Dinner

### **Sunday 12th May**

10.00 – 12.00

For people with haemophilia: A discussion on 4 topics

1. Making treatment decisions
2. Preparing for treatment
3. Coping with treatment
4. The treatment did not work, what next?

Nurse Counsellor Anne Duffy or Psychologist Sarah Jamieson

**OR**

10.00 – 12.00

A discussion for spouses / partners

Nurse Counsellor Anne Duffy or Psychologist Sarah Jamieson

12.00 – 13.00

A full group discussion

Nurse Counsellor Anne Duffy and Psychologist Sarah Jamieson

13.00 – 14.00

Lunch & depart

**If you would like to attend this conference, please contact the office on 01 6579900.**