



Autumn 2009 Newsletter

International Developments

Scottish Hepatitis C Patients Forum

By Patricia Brown, Forum Chairperson

At the Stakeholders Conference in Perth on Oct 1st the Hepatitis C Resource Centre will be introducing the Scottish Hepatitis C Patient Forum.

The purpose of the patient forum is to give patients a platform to voice opinions, share experiences and to raise concerns to ensure patients' needs are addressed, and that the best care and support is provided to all who are affected by Hepatitis C throughout Scotland.

The patient forum will also provide information, advice and support and will be active in improving all aspects of the care system and support services concerned with Hepatitis C.

With an estimated 50,000 people living in Scotland with Hepatitis C, it is hoped that as many as possible will get involved, be better informed and feel reassured they are not alone.

More information about developments

and how to get involved will be in the next newsletter. Watch this space!

New Treatments for Hepatitis C

By Rebecca Turner, Support Worker

I've spent quite a bit of time looking into some exciting new developments in Hep C treatment which should reach our shelves within the next 2 – 5 years. In particular two drugs Telaprevir and Boceprevir have been granted fast-track status in the US and should be finished trials in 2010 / 11.

When taken along with Peg-Interferon and Ribavirin, Telaprevir clears the virus in 41 – 73% of previous non-responders or relapsers (depending on dose) and Boceprevir doubles the number of people who clear compared

with standard treatment. Also being developed is an oral combination therapy of two drugs, R7128 and R7227, which left 25% of patients with undetectable levels of the virus after only 14 days. Many similar drugs are being developed, which interfere at all stages of the virus life cycle. With a number of these drugs on the market in a few years, treatment options will be much improved and side-effects should be a lot less severe.

There are of course herbal remedies and vitamin supplements available, quite a few of which have been

considered useful in helping with Hep C associated fatigue. Vitamin B12 has been a subject of ongoing debate – as it's involved with red blood cell production, Vitamin B12 is crucial for bringing oxygen throughout the body to provide energy. For this reason, people with anaemia can feel more energised after taking a Vitamin B12 supplement. If you feel you could benefit, it's worth having a chat with your doctor or specialist.

Service Update

Welcome to our Autumn newsletter!

Since the last newsletter we have had some exciting developments, including the recruitment of two new members of staff, partnership working in West Lothian and

awareness raising workshops throughout Edinburgh and Lothian.

In addition we have are several new developments planned for C Plus over the next couple of months. We have an open day on Thursday 12th

November, which is open to everyone, to come along and find out about what we do. We will be starting a Moving On group, for people who have completed treatment and our support groups will be re-launched.

New Faces at C Plus

We would like to welcome two new members of staff. C Plus now has a new Manager and a new Support Worker to compliment the existing two Support Workers. Sharon Smillie and Rebecca Turner started in August .

Sharon comes from an advocacy, volunteering and training background and has worked in a variety of locations throughout Scotland. She started her career as Co-ordinator of the Patients Advocacy Service (PAS) based at The State Hospital,

Carstairs; where she provided advocacy to some of the most vulnerable people within the mental health system. More recently she worked as a Regional Training Officer with ASH Scotland, training healthcare professionals to support people to quit smoking. Sharon's main focus will be to increase support and assistance to service users within local communities as well as to promote joint working between C Plus and local voluntary and statutory organisations.



**Sharon Smillie
Manager**



**Rebecca Turner
Support Worker**

Rebecca has come from a background in voluntary work in youth work, adult literacy, mental health awareness raising and advocacy. In addition Rebecca has worked within biochemistry and recruitment field. Rebecca is looking forward to supporting people at C Plus and will also be working within East Lothian. She has recently moved to Edinburgh

from Lanark and is enjoying going to nice restaurants, cycling the Water of Leith and going to the cinema and libraries.

Sharon and Rebecca join Alison and Julia, who have continued to provide support and assistance to service users in the interim.

Service User Support

C plus offers a variety of services which we hope cover most the needs of the people who come to us for support and or information.

Most our interactions start with a phone call you can call us directly or other organisations can call for you or a friend can too. Please tell any of your friends who are affected (and this includes people whose friend's family or partners have Hep C). We will give you information over the phone and offer you the opportunity to come in and speak to

us a 1 to 1. If you find it difficult to get to the office we can arrange to meet you at another location.

If you decide to come and talk with us we will give you information about Hep C and try to establish what would be helpful for you. We can support you when you have hospital appointments assist you with various aspects of your life that having Hep C affect. What you can expect if you go down the treatment pathway and more!

Your visits are not limited, you can come whenever you need to but it helps if you let us know first. We can be really busy! We run various groups and therapies too.

If you think Hep C is affecting your thinking, Brain Fog is a very common symptom, we can help you with forms or if your illness is causing you other problems come and talk to us. If we don't have answers we will help you find some one who does.

Group	Times
Women's Group	Monday 11:30 – 1:00pm
Group Support	Wednesday 12noon – 2:30pm
Massages	Wednesdays 12 noon (at a special rate £5, thank you Masseurs) Reflexology on request
Walking Group	Thursday and every third Saturday (please ask to be sent the Walking Group Newsletter for full information)

West Lothian Update

C Plus hold a joint clinic with NHS Lothian at the Howden centre every Wednesday from 2:00 – 4:00pm; where people can access testing, information about Blood Borne Viruses (BBV), Immunisation for Hepatitis A & B as well as support. Information about the work carried out at the joint clinic has been included in the CHCP West Lothian website and local Council newsletter.

Further to the joint clinic we work in partnership with the local BBV Nurse to raise awareness of Hepatitis C with local voluntary and statutory agencies. Recently we have visited the following organisations:

- Bethany (West Calder)
- Penumbra
- Bethany (Broxburn)
- West Lothian Council
- Mental Health

- Advocacy Project
- Blackburn Homeless Hostel
- Quentin Homeless Hostel
- Open Door Supported Accommodation
- West Lothian Drug and Alcohol Service (WLDAS)

C Plus also provides outreach work within West Lothian; including supporting clients to hospital appointments as well as holistic support.

Mid & East Lothian Update

In Mid and East Lothian we are hoping to develop outreach working in combination with a new BBV nurse who will be based in these areas, hopefully by the end of November. We will be building up contacts with other organisations in this area and including visits to the PETE project in Musselburgh (an employability project

for those with substance misuse issues) and MyPas in Dalkeith (project for improving the health and wellbeing of young people). C Plus will also be linking in with the NEON bus during its Tuesday visits to Musselburgh and we will be linking in with the Midlothian Substance Misuse Service in Dalkeith to promote joint working.

Invitation to C Plus Open Day

17 Academy Street,
Edinburgh
Thursday 12th November
10:00am – 1:00pm

Come along and find out what we do.

Learn about:

- What C Plus does
- The support we provide
- Different groups we run
- Workshops and Awareness Raising
- Training Opportunities
- Steering Group
- Service user perspective

Everyone is invited to attend and we will supply some tasty lunch!

To book a place please contact Sharon Smillie on ssmillie@mainliners.org.uk or call (0131) 478 7929

Moving On Group

Have you recently completed or will be completing Hepatitis C treatment?

Unsure about where to go from here?

C Plus will be starting a Moving On group specifically for people

who have finished or are finishing treatment.

The group will be service user led and will focus on personal development, gaining skills and knowledge, building capacity and supporting each other to

achieve your goals.

If you would like to come along to the Moving On group or would like more information about the group, please contact Sharon Smillie on ssmillie@mainliners.org.uk or call (0131) 478 7929

Service Use Tips

"When I learnt (I was on the waiting list at the time) that I would soon be starting treatment I prepared myself. I had spoken (at Cap C and C plus) with many people who had been through treatment and I knew it could be hard.

I cleaned and organised my home, warned and organised my family and friends, you know, "I may be very irritable, I may be constantly tired but unable to sleep. I may not be able to sleep or eat but stay by me I will get there! And I did, I spent a lot of time in bed and I was irritable but I cleared!

So my tip, prepare and then chill as much as you can and be absolutely sure you have support in place!"

"Before I went on treatment (third time lucky for me) I was always very aware of my health and used massages and acupuncture and other therapies to help to help me. I am still a great believer in Milk Thistle and although I have cleared I still take it and use other alternative therapies."

"I made sure my family knew what I was heading for when I went on treatment. They helped me with shopping and my house so I wasn't too stressed and now I'm clear. Let people know what's happening and get support."

"I haven't managed to clear Hep C so I look after myself I'm careful with my diet and eat liver friendly food. No fatty foods, loads of fresh food preferably organic (no nasty chemicals!) I enjoy exercise, walking and yoga and enjoy life. I know a cure is coming because big business knows how much money there is to be made. That keeps me smiling! And smiling and laughing are good for you!"



International Hepatitis C Conference

Lowry Hotel, Manchester
16th – 18th November 2009

The 11th International Hepatitis C Conference is being organised by Mainliners, in conjunction with Manchester University the Greater Manchester Hepatitis C Strategy, to host a rich programme of presentations from some of the best

known and widely read researchers in the field, from around the world.

The Conference is a three day event which aims to provide a full programme on the most up to date tools, theories and research on how to help combat Hepatitis C in

a variety of places and walks of life.

For more information and booking forms visit the Conference website www.hepc09.org.uk or contact Mainliners on 020 7022 1890

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