

**Penrose Inquiry Statement
June Ward
Haemophilia Nurse Specialist
Ninewells Hospital
Dundee
DD1 9SY**

Questions requested by Penrose Inquiry

"We would be grateful if you could ask June Ward for a brief statement setting out what the practice was in relation to:

1. providing information on HCV testing to patients; and
2. providing results of HCV tests to patients

when she started as the Haemophilia Nurse Specialist in 1995"

Background Information

- a) This is a true and as accurate description of routine practice within the haemophilia service as I can recall in 1995. When I commenced as haemophilia nurse in 1995 not all patients who were known to the department had been identified or tested for Hepatitis C (HCV). However, some had been tested prior to my employment and I cannot comment on their experience prior to my involvement.
- b) One of my roles at the outset of this new post was to assist in the identification of patients who had been exposed to pooled plasma products who may be at risk of HCV but had not yet been tested. At that time there was no designated Haemophilia nurse prior to my employment and no regular review clinics for the patients with bleeding disorders established. There was no local database of patients available, however there was a list of patients who had been identified as having a bleeding disorder and who were HCV antibody positive. One of my main goals at the outset of this new post was to identify all patients with bleeding disorders and arrange appointments for these patients to be reviewed with the consultant haematologist and Haemophilia Director at the time, Dr Philip Cachia.
- c) Clinics were arranged at the haematology day area, ward 16, Ninewells Hospital. Those patients who had been identified previously as HCV antibody positive were prioritised and invited to attend these clinics. These clinics were to offer regular review of their bleeding disorder, further confirmatory testing for HCV, investigation, monitoring and treatment for HCV. All consultations / review clinics were documented in the patients medical and nursing notes and a summary letter completed and sent to the patient's GP. At first there was some initial reluctance on the part of some patients to attend as they had managed their bleeding disorder for many years with limited routine contact with the Department. Many patients had not attended any formal review for many years nor saw the need to do so. However during 1995, most patients were contacted, offered an appointment and attended for review. At the review consultation I was usually present not only to offer practical nursing assistance when required but to begin to meet the patients, start to build a rapport with them, and develop my own knowledge and expertise in haemophilia and its complications, including HCV. However the consultation was usually led by Dr Cachia.
- d) There were no local HCV guidelines or protocols at that time - these were developed later, however the unit followed and were striving to practice in accordance with guidance provided by the *NHS Scotland Management Executive, Provision of haemophilia treatment and care, MEL (1994) 29, 23 December 1994*. The

Haemophilia Service had also been audited in 1994 by Professor Ludlam from the Comprehensive Care centre in Edinburgh prior to me taking up my post. The audit outlined that although Dundee was providing a reasonable service there were improvements that could be made. The audit proposed that in particular the service was under resourced and deficient in relation to a number of care aspects these being: prophylaxis provision, regular review of adult patients, genetic testing provision, home treatment supervision. Within this report it is documented that there were 22 patients who were HCV antibody positive. To my knowledge these key documents were presented to the Haematology Department and funding for a part-time haemophilia specialist nurse was sought to assist to address these deficiencies.

- e) Over the next few years from 1995 the service developed specific HCV protocols and both Dr Cachia and myself were involved in assisting to compose local NHS Tayside HCV protocols these are still in existence today but have been reviewed and edited to bring them up to date with current HCV knowledge and treatment. Testing and treatment programmes for HCV continue to be offered within the service. Most patients have opted for treatment and the uptake for treatment was most common in 1998/99 when combination treatment with Ribavirin and Interferon was made available. However some patients have chosen not to take treatment at all for HCV. All HCV treatment programmes are provided in close liaison with the hepatology team.

1. Providing information to Patients

- 1.1 Patients were invited to attend for review in relation to their bleeding disorder and as part of this review their HCV status was routinely reviewed and discussed. The consultation took place at the haematology day area. Dr Cachia primarily took the lead at the consultation, however in his absence and where appropriate, I would also offer the same information particularly in providing information and support to this patient group. If the patient had not been previously tested for HCV we discussed with the patient the need and value of being tested, gave information to them so they could make an informed choice whether they wished to be tested or not. Most patients had been identified as HCV antibody positive but most had not been tested for HCV PCR. This was routinely offered around this time. After discussion, all patients to my knowledge consented and took up the offer of testing. If they were previously known to be HCV positive, they were fully informed of their HCV status and given both verbal and written information.
- 1.2 At this time we used a combination of patient information booklets to assist with information provision, these were designed and produced by the Liver Trust and the Haemophilia Society. Our normal practice in the consultation was to offer information on HCV, route of transmission, how it may affect the individual in the future, discuss tests, investigations and treatment options available. In relation to treatment, in 1995 Interferon only was available and none of our patients chose to be treated with this.
- 1.3 We informed and routinely took blood from all of the patients for liver function, coagulation screen and full blood count. Often wives, partners or family members attended these routine clinics with the patients and where appropriate. testing for sexual partners was offered and the same information and practice was adopted for these individuals. Liver biopsy, when required for patients was arranged with liaison with the hepatology team, and the risks around this procedure was fully explained to the patient and consent obtained.

2. Providing results of HCV tests to patients

- 2.1 Results were provided to the patient at an organised clinic within the haematology day area. Dr Cachia took the lead in the consultation, however I was present at most appointments to allow me to understand what the patient had been told so I could

offer further information and support as required, take blood, assist to organise any other tests required and ensure ongoing follow up appointments.

- 2.2 The patient was provided with results of their HCV status. Dr Cachia discussed fully the implications of these results and offered information both verbally and in written format. Each consultation was tailored to fit the patient's needs as each patient often had many questions in relation to HCV. However normal practice was to offer information in relation to ongoing monitoring and future investigations required. Treatment options (Interferon only at that time) were fully discussed giving the patient the information regarding success rates, known side effects and how this was administered. Health promotion particularly in relation to reduction to alcohol consumption and transmission of HCV to others (e.g. barrier contraception) was discussed. Patients were given adequate time for questions to be answered and further information sourced for them if required. Ongoing appointments were arranged for review dependent on the patients needs. Some patients wished to have further information sessions and bring their wives, partners or family with them and these were arranged as required.

This above is a true testament of my recollection of practice, for patients who required HCV testing, during the period of 1995 within the haemophilia service. Of course if further information is required I am very happy to provide further assistance to the inquiry.

Signed-----

Date-----5/1/12