Witness Name: Lynne Kelly
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**EXHIBIT WITN3988068**

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Hepatitis C Workshop 18th December 2013 : Lynne Kelly

The purpose of the meeting was to ascertain what data the Skipton Fund holds and discuss how they fit with other datasets/evidence and what impact the new therapies may have on this particular cohort of patients. In particular it focussed on the differences in outcomes between Haemophilia and non Haemophilia patients.

Attendees : Prof Howard Thomas Hepatologist, Imperial London, Skipton Fund Chair and Caxton Trustee, Nick Fish, Skipton, Prof Geoff Dusheiko UCL Institute Liver and Digestive Health, Prof Will Irving, Chair Of Advisory Group Hepatitis, Dr Helen Harris PHE, Dr Koye Balogun PHE, Dr Mike Makris UkHCDO (teleconference), Dr Magdalena Harris Hep C Trust, lecturer and researcher in HCV at LSHTM, Dr Ailsa Wight DH, Ben Cole, DH, Naomi Balabanoff, DH, Dr Andrew Parker, DH, Ginny Brunton EPPI Centre.

Mike Makris joined by Teleconference for 2 hours with fairly bad reception, Ben Cole will distribute Minutes which is why I feel we need to reinforce the key points at the end with the UKHCDO in case Mike didn't hear some of it.

**Nick Fish Skipton Fund presented Skipton data.** As far as Skipton are aware 3100 stage 1s are still alive,( given that the age range is up to 109 years this is doubtful.) 70-110 stage 1s have converted to stage 2. It was apparent that less people with IBDs progressed to stage 2 than those without, there was a good deal of discussion about this. I made the point for many with IBDs biopsies were too risky, access to Hepatology,Fibroscans and interpretation of results were patchy through out the UK, also the effect of HIV medication on scans and test results and efficacy of new HCV caused further complications. Many could not afford to start HCV treatment, they had jobs and families to support and could not forfeit loss of earnings. We need to find out how many Hepatologists and Fibroscanners are in the UK. I asked how could deaths be accurately recorded when only the fact of death was recorded and not the cause of death, the DH said that this was the responsibility of the clinician when completing the Death certificate, there were no plans to change this in the future. Re : Haemophilia community being exposed to multiple genotypes HCV and co infected with HIV and other viruses , Geoff Dusheiko UCL Institiute Liver and Digestive Health said there was no evidence to suggest that those infected at an early age would progress more quickly with HCV as in the first 15-20 years progression is slow.

Nick Fish has been given the task improving Skipton data and it was agreed that he would meet with Mike Makris to ascertain S1 figures.

There was some discussion about Caxton data but Howard Thomas said that Caxton doesn't gather data, Skipton is the data repository?

**New Therapies** : Geoff Dusheiko UCL: By 2015 Interferon Free Hep C treatment would be available in the UK. Sofosbuvir, Simeprevir, Faldaprevir and Ledipasvir have promising results. For HIV co infected Sofasbuvir +RBV 70% SVR as cleared by kidney not liver. With Sofasbuvir and RBV to prevent reinfection post transplant 95%. Sofasbuvir+ Ledispasvir+ RBV close to 100% SVR. Daclatasvir +Sofasbuvir +RBV for 12 weeks in previous treatment failures. Mike Makris confirmed there would be no difference for Haemophiliacs with Inhibitors. Geoff Dusheiko has written to Peter Moss Advisory Group on Hepatitis as Interferon free treatments are showing particularly

encouraging results for patients who have failed previous treatment, have compensated cirrhosis, HIV and who will have decompensated within a year. These patients will deteriorate within a year and will not be able to wait for NICE approval to start treatment. He has asked Peter Moss to write to the Secretary of State for Health to fund treatment of a suitable cohort and has suggested that the Haemophilia Society ask for patients who are in this category to be considered for this fast track funding. He needs to know how many Haemophiliacs with cirrhosis, high albumin and portal hypertension could be considered,. It was agreed that 700 Stage 2 Skipton could be used to identify suitable patients to be specific focus for rapid access for new treatments. Can the Society contact Mike Makris about this as some of this was discussed after he left the meeting. It was also agreed that with Interferon based treatments the risks of developing an Inhibitor to Factor and the increase in treatment costs associated with this would increase the chances of funding the Haemophilia cohort. The Society could contact Geoff Dusheiko about this.

It was agreed that AGH Report on Auto immune Disease should state that with Interferon Haemophiliacs can develop Inhibitors. Geoff Dusheiko said that the current Report has no mention of Haemophilia patients, did we have any input to the AGH previously as they will advise the Chief medical Officers of England, Scotland, Wales and N Ireland on appropriate policies for Hep C and unless Haemophiliacs are specifically mentioned it is unlikely we will get the best treatment.

A National Liver Plan needs to be developed urgently to influence Commissioners nationally this is ongoing with the AGH.

The DH has commissioned the EPI centre to review a natural history of Hep C, Ginny Brunton, a Methodologist will do a met analysis of Hep C, HRQL and 46 extra Hepatic conditions. 16,000 cases were submitted in June, they will take into account Penrose findings in March. They access unpublished literature, charities databases 'grey literature'. They are keen to hear from stakeholders to gather information.

**Key Points:**

1.Skipton data is limited and incomplete generally but particularly with regard to S1 deaths : Nick Fish will meet with Mike Makris to share UKHCDO data on deaths.

2. General consensus from Prof Howard Thomas, Prof Geoff Dusheiko, Dr Will Irving and Dr Mike Makris was that exposure to multiple HCV gentoypes and HIV even at an early age showed little difference between Haemophiliacs and non Haemophiliacs. Although it was agreed that the risk of Inhibitors in haemophilia patients could be increased with RBV and Interferon based treatments.

3. No one knows how many Fibroscans are available in the UK

4. The DH has no plans to ask for cause of death from UKHCDO for patients with Hep C?

5. Caxton doesn't gather data?

6.**We should contact Prof Geoff Dusheiko either directly or via Mike Makris to ensure that Haemophilia patients with Hep C, cirhossis and compensated liver disease are a specific focus for**

rapid access for new Interferon free treatments as they will have decompensated within a year and can't wait for NICE approval.

7. The Inhibitor risk for patients with Haemophilia must be included in the AGH Report. Geoff Dusheiko stated after the meeting when Mike Makris was no longer on teleconference that there is no mention of Haemophilia in the Report , bearing in mind this Report will advise the Chief Medical Officers of England, Scotland, Wales and N Ireland on appropriate policies for Hep C it is essential Haemophiliacs are included.

8. I raised other issues with regard to financial support and difficulties patients are encountering from all Funds, also regardless of infection all are denied access to Life Insurance and Mortgage protection.

9. A National Liver Plan needs to be developed nationally.