WITN0404 0004

UNREDACTED ORIGINAL
EXHIBIT OF W0404
DENISIA GRAY

14/01/2019

Dear Mr. Judge,

Sincere apologies for not replying sooner.
I do find it hard to relive the diagnosis and the mayhem that followed .
I will do my best to answer your questions , but if you need more or a meeting please let me know .
1. Denisia Gray

GRO-C

d.o.b GRO- 1943
I live with my husband who is now retired .( He was Consultant Radiologist at Essex County Hospital and later at Colchester University Hospital until his retirement.)
Our two adopted daughters have left home .
My health has continued to deteriorate and I need help with most household chores , but try to keep as active as possible.
Loosing my career on diagnosis of the Hep C. Was a tremendous blow as I loved my job , but was so unwell and on constant treatment, apart from the fact that nobody was going to employ me , as I was considered an infection risk !
I felt very alone and to some extent I still do.
There are aspects of my illness I wouldn't disclose to my family as I think they would be devastated at what I kept to myself , purely to protect them !

2 a as a child it was accepted that I bruised easily and had bad nose bleeds , but as my Father was in the RAF and we moved a lot , it was never investigated until I started nursing.
After investigation I was told I had Factor V , VII , and X deficiencies which I was later told it was mainly Factor X .

b I had an anaphylactic reaction to cryoprecipitate given when I had a retro peritoneal bleed , so didn't have it again.
Later I had Factor VIII concentrate prior to any surgery or procedure with transexamic acid .

c was treated at Churchill Hospital under Prof. Ritza
Royal Free Hospital , Lawn Road , under Dr Dormandy
Hackney Hospital under Dr Cardno
finally Colchester Hospital , Dr Boots followed by Dr Woods

d the time that I became more unwell than usual , and developed jaundice , was following a dental clearance by Mr Clark , anaesthetist Dr Griffin who actually gave me the Factor VIII concentrate , in 1986 .
I had numerous tooth abscesses which needed Factor cover every time one was drained , which is why the decision was made to do a clearance .

3 No

4 Never given any information personally , but kept up to date by the Haemophilia Society and general press releases .

5. I was infected with Hepatitis C .

6 I suspected something was wrong , but didn't know what , after my dental extraction as I was increasingly unwell after that.

a the infection was discovered by liver biopsy , after the intervention of Dr Woods , 6years later. I was told by the Consultant surgeon , Mr Roger Motson . He apologised but said it was fatal and I may only have 6 months to live .
The Gastroenterologist who accused me for 6 years of faking it . I have never seen him since !!!
Dr Woods gave brief information and suggested I see Prof. Dusheiko at the Royal Free Hospital , Hampstead.

b I was sent to Hampstead and offered Interferon and as I was a non responder , then the combination therapy of Interferon and Ribavyrin . This was also discontinued due to non response and severe side effects.

c. Information was given directly after diagnosis . Couldn't have been given sooner.

d. I was upset that a doctor who put me through hell telling me there was nothing the matter with me and sending me to see a psychiatrist, and telling my husband I was mentally ill , didn't have the courtesy to face me himself .

e. Just giving routine information about blood and sexual contact .

7. No

8. a no
   b no
   c. no
   d. No

9. a. My physical are my pancreas no longer works so I am on creon to digest my food.
I have biliary dyskinesia and had hepatic septicaemia.
My thyroid no longer works so am on permanent thyroxine.
I had to be fed by nasojejenal tube with peptisorb over 10 hrs daily.
I am on 30 mags morphine twice a day for pain.
I am prone to Hep C crisis where I am in bed for 3 days until it passes.
But I have to work with what I have , not what I would like to have and can never know how I will be the following day.

Mentally I was destroyed . I'd lost the job I loved .
I'd been accused of being mentally ill and didn't even receive an apology from the doctor concerned.
My parents disowned me and at my Mothers funeral , my Father declared to everyone that I had Hep C because I was a drug addict and a prostitute .
When my father died he left everything to my sister , who chose not to share it , so my children have nothingthat belonged to either my mother or father .
The sexual side of my marriage stopped and the reactions of the general public and some of my friends , was that it was a dirty disease !

Nobody knew or wanted to know how the contamination was caused .

Rumours were spread round the hospital that my husband was a homosexual and that was how I was infected .

I wasn't brave enough to take an overdose or end my life , so I've had to deal with it as best I can , but it's still hard even after all these years to go back to the days immediately after my diagnosis without feeling desperate and so alone.

b. Medical complications are chronic pancreatitis , thyroid and liver problems .

c. I had Interferon which was stopped after 6 months as a non responder .

I then had the combination therapy of Interferon and Ribavyrin which was also stopped due to non responder and very severe side effects .

Had a Hickman line for blood access.

Had a nasojejenal tube for parental feeding.

d. No

e. No

f already stated in previous paragraph .

g any surgery I have had ( cataracts and shoulder surgery ) I have to go on the end of the list and any instruments used have to be destroyed due to the possibility of Variant CJD .( although when my daughters were told I was at risk from variant CJD , they just laughed and said they always knew I was a mad cow )

10 people find it awkward to invite you to social gatherings as you have to be careful what you eat and avoid alcohol . Every gathering seems to involve alcohol .

My family know what I've been through and that I can't make plans more than 24 hrs ahead , but I'm sure my daughters feel sad that I won't interact 100% with my 7 grandchildren in order to keep them safe.

Nobody has the absolute right to know your HCV status , but if you don't tell them and they find out , they think you're keeping this big secret from everybody .

I did nothing wrong but even now it is assumed it's your lifestyle that has infected you

Family life , we cope as best we can , but the future will always be uncertain .

11 a I was immediately rendered unemployable !

b I immediately lost my job but while I was on the Interferon and combination therapy I wasn't well enough to work as I spent most of the time in bed .

c. Initially it was very hard , but eventually I was awarded disability benefits.

Receiving money from the Skipton foundation and the EIBSS has made a vast difference to my life . I can now visit friends via taxi without having to worry about the cost. My younger daughter lives in France and when I'm feeling a bit better , maybe in the summer , I can go to see her and get a taxi from the airport to her home without her having to pick me up.

12 It has destroyed my relationship with my husband and we are now two people who live in the same house rather than a husband and wife relationship.

In the beginning nobody knew what to say or do , so of course nothing was done .

I think they are protecting themselves . A classic case of burying your head in the sand and hopefully it will go away . But of course it doesn't .

I don't want to upset them so I say nothing . Fortunately I have two very good friends who are good listeners.
I long to say to my family that they can talk about it , but I don't , so we continue to plod on surviving as best we can , but that's exactly what it is , surviving not living.
I resent the fact that through no fault of my own , I'm condemned to living like this , and those responsible can't tell the truth and say sorry .
The money is great but that one little word would make such a difference to a lot of us.
It won't make us feel better but it might make us think somebody does care .
Even after all the information in the press there are still some people who think they will become infected if they drink from your cups or use your toilet.

13. I was initially refused treatment with Interferon , but persuaded Prof. Desheiko to let me have it , but after 6 months of non responding it was discontinued.
At the time the combination therapy was on a trial basis , being prescribed on a named basis.
Once again it was discontinued due to my non response and severe side effects , but at least I felt I had tried .
I did feel the senior staff ( not the Professor) were very judgemental and were only interested in those people ( mainly drug users and alcoholics) and we were a long way down their list .
I asked , and was transferred to Mr. Alexander at Addenbrookes, and my goodness what a difference .
Strangely enough my notes were never found at the Royal Free ! They had mysteriously disappeared.
Mr. Alexander if he needed to refer to the Royal Free , always called it St. Elsewhere .
I was an inpatient for 4 months but they did manage to stabilise me , giving me a feeding tube for a year.
I can never thank him enough as he actually treated me like a human being and not a diagnosis.

14. The family were never offered counselling, but I was offered counselling from the hospice. I did attend some sessions but felt I didn't want to relive everything and risk the stability I'd worked so hard to achieve. I felt if I opened the door I wouldn't be able to shut it again , and that is a risk I can't take.

15 All my information came from the Haemophilia Society.
b about 5 yrs ago I started getting help from the Skipton Fund.
Now £1000 quarterly.
Last year I applied for and was lucky to be given assistance by the EIBSS and SCM .
I received a lump sum of £9 , 560 and get £4,500 quarterly.
My main obstacle has always been the inability to gain any information from the Royal Free . To them I don't exist.

d only obstacle was being unable to give them any details of treatment at the Royal Free .

e. No

f. I feel the trusts have been fair if a little slow , but I'm grateful to anything that will improve my daily living.
Because of information required , I didn't think there was much point in persuing a claim , but fortunately Mr. James Byers persuaded me to put the claim in anyway .

Thank you for that Mr Byers ,

No amount of money can ever give you your health and life back , but that amount makes a vast difference to me , and I'm sure a lot of others .

16 & 17. have not been involved in any other litigation. It was far too expensive to go ahead with such uncertainty about the outcome , and I'm sure The Newcastle inquiry required proof I did not have .

I'm hoping the above is okay , but is you need a different format or some one to visit , please let me know.
Again apologies for the lateness of this reply .
Yours faithfully
Denisia Gray .