

Oral Hearing

Day 3 – Thursday 23 June 2022 (Closed)

Being heard before: Ms Christine Smith QC (Chair) Dr Sonia Swart (Panel Member) Mr Damian Hanbury (Assessor)

Held at: Bradford Court, Belfast

Gwen Malone Stenography Services certify the following to be a verbatim transcript of their stenographic notes in the abovenamed action.

Gwen Malone Stenography Services

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1	THE HEARING COMMENCED ON THURSDAY,	
2	23RD DAY OF JUNE, 2022 AS FOLLOWS:	
3		
4	CHAIR: Good morning everyone. Good morning,	
5	Patient 13	10:10
6	Patient 13 : Good morning.	
7	CHAIR: Patient 13, thank you for coming today. And	
8	can I just say that we, as a panel, appreciate the fact	
9	that it can be quite nerve-racking to come to speak to	
10	a room of people and I do appreciate you coming to	10:10
11	speak to us.	
12		
13	I'm Christine Smith, I'm Chair of the Inquiry and	
14	I will do most of the talking and I will lead you	
15	through your evidence this morning, if that's of	10:11
16	assistance to you.	
17	Patient 13 : Yes.	
18	CHAIR: And at the end of us having a conversation	
19	then, Dr. Sonia Swart, who is my co-panellist may have	
20	some questions. Mr. Hanbury, who is the Urology	10:11
21	Assessor to the Inquiry may also have some questions,	
22	and then Mr. Wolfe might have some too. But if, at any	
23	stage, you feel you need a break please say so.	
24	Patient 13 : Thank you.	
25	CHAIR: Or if at any stage you don't understand what	10:11
26	I am saying or what the question is, just tell us, we	
27	can put it another way so that you do understand it and	
28	there are no right or wrong answers here. It is your	
29	opportunity to tell us about what you want us to know	

		about your treatment in the Southern Health and Social	
		Care Trust.	
		I just want to remind you that we cannot make any	
		decision about the standard of care that you received	10:11
		from any medical professional and that's really a	
		matter for other bodies and has been looked at by the	
		Trust and by the GMC. So if you're ready then if	
		I could ask you to take the oath please.	
		Patient 13 Yes.	10:12
		Patient 13 , HAVI NG BEEN SWORN, GAVE HIS	
		EVIDENCE TO THE INQUIRY, AS FOLLOWS:	
		CHAIR: Now, Patient 13 , if it makes things easier for	10:12
		you, if I can just assure you, you have a bundle of	
		papers and we have the same papers and we have all read	
		them. So if I maybe take you through what we see as	
		the history of your treatment in the Urology Department	
		and if I get anything wrong you can correct me. Would	10:12
		that work for you?	
	Α.	Yes, that's good.	
1	Q.	Well, first of all, you were a patient of Michael Watt	
		in the Neurology Department in Belfast, is that	
		correct?	10:13
	Α.	And Victor Patterson, Victor Patterson was the	
		consultant at the start and Michael was a Registrar,	
		but then during my treatment Michael was upgraded then	
		to consultant.	
	1	1 Q.	 Care Trust. I just want to remind you that we cannot make any decision about the standard of care that you received from any medical professional and that's really a matter for other bodies and has been looked at by the Trust and by the GMC. So if you're ready then if I could ask you to take the oath please. I could ask you to take the oath please. I could ask you to take the oath please. I could ask you to take the oath please. I could ask you to take the oath please. I could ask you to take the oath please. I could ask you to take the oath please. I could ask you to take the same papers. CHAIR: Now, I could the same papers and we have all read them. So if I maybe take you through what we see as the history of your treatment in the Urology Department and if I get anything wrong you can correct me. Would that work for you? A. Yes, that's good. Q. Well, first of all, you were a patient of Michael Watt in the Neurology Department in Belfast, is that correct? A. And Victor Patterson, Victor Patterson was the consultant at the start and Michael was a Registrar, but then during my treatment Michael was upgraded then

1	2	Q.	And he took over your care?	
2		Α.	Well, he signed letters anyway so.	
3	3	Q.	And you were prescribed a drug at that time, which, if	
4			I have got the pronunciation right, it's	
5			Cyclophosphamide?	0:13
6		Α.	Cyclophosphamide, that's correct, yeah.	
7	4	Q.	You know it better than I do, and that prescribed drug	
8			had an attendant risk of bladder cancer?	
9		Α.	It did, yes.	
10	5	Q.	And you had been treated back in the '90's I think for $\ \ _1$	0:13
11			some urology problem?	
12		Α.	It's another tricky one, well I had dermatomyositis, it	
13			was a wasting of the muscles diagnosed in November '95.	
14			I couldn't lift my leg out of the car. I was diagnosed	
15			and then I went to Quinn House in the Royal Victoria, ${}_{1}$	0:13
16			I think it's demolished now, and that's where the	
17			Urology team were.	
18	6	Q.	Yes, that's how you ended up on this particular drug?	
19		Α.	It was, yes. Yeah, yeah. I was in twice, maybe three	
20			times, you know, as a patient during '96. But it was $_{ m 1}$	0:14
21			actually I think the Haematology, a Mr. Jones really	
22			done the trick with the muscle disease. He weighed me,	
23			I remember I was 10 stone or 11 stone and he weighed me	
24			and then he put my blood out of this arm into like a	
25			big washing machine and then put it back into this arm. ${}_{1}$	0:14
26			I got it done three times and wherever the third time,	
27			I just felt a complete change, you know, it really	
28			helped me, but then the drugs were possibly a good help	
29			too.	

1	7	Q.	Well, in fact you did have some bladder problems in the	
2			mid-90's?	
3		Α.	Yes.	
4	8	Q.	And you were then discharged ultimately in 2001?	
5		Α.	Yes.	10:14
6	9	Q.	As a patient. But you then had a further incident	
7			where you needed to go and see your GP, isn't that	
8			correct?	
9		Α.	That's correct.	
10	10	Q.	And your GP referred you into Craigavon's Urology	10:15
11			Department?	
12		Α.	That's correct.	
13	11	Q.	Okay, and that was, I think you probably know from the	
14			papers and from what you were told, that the GP	
15			referred it as a routine referral, when in fact it	10:15
16			should have been a red flag referral?	
17		Α.	Yes. Well Mr. Haynes told me that whenever I got a	
18			meeting with him, you know, whenever I got the meeting	
19			with Mr. Haynes he talked me through the whole process.	
20			So he said my GP obviously had, it's easy done he said,	10:15
21			on the keyboard you can hit the wrong button.	
22	12	Q.	But in any event, it came into Craigavon as a routine	
23			referral and it wasn't triaged. And that would have	
24			meant that somebody would have looked at that referral	
25			from your GP and decided whether it was routine or was	10:15
26			not routine and needed to be upgraded and that wasn't	
27			done in your case and you were told that, isn't that	
28			correct?	
29		Α.	Well I know Dr. Brannigan, the GP, he mentioned it	

1			first to me the SAI, as if he had initiated it, I'm not	
2			sure who, it was the obviously was the GP that started	
3			the SAI.	
4	13	Q.	Well, it was the GP who would have referred you to the	
5			hospital?	10:16
6		Α.	Yes.	
7	14	Q.	And the Hospital cottoned-on, if I can put it in	
8			colloquial language, to the fact that you had not had	
9			your letter from your GP looked at?	
10		Α.	Yes.	10:16
11	15	Q.	That they realised that you should have been upgraded?	
12		Α.	The Hospital?	
13	16	Q.	The Hospital.	
14		Α.	Right.	
15	17	Q.	And you then formed part of a Serious Adverse Incident	10:16
16			Investigation involving not just you but some other	
17			people who were not triaged at the same time?	
18		Α.	Yes.	
19	18	Q.	So it would have been the Hospital who instigated that?	
20		Α.	Who initiated it, okay. Well, it was Dr. Brannigan who	10:16
21			told me about it first and then I started to get a few	
22			letters from the Southern Trust.	
23	19	Q.	In fact, if you don't mind, I'm just going to refer to	
24			the first letter that you would have got from the Trust	
25			which is at PAT-000431. And it basically tells you in	10:17
26			that letter that you had received a urology referral	
27			from your GP and there was a delay in the processing of	
28			that referral.	
29				

1			Now, we know from the papers that you were referred in	
2			on the 28th July of 2016 and this letter is coming to	
3			you then in February 2018?	
4		Α.	Oh, yes, with the SAI.	
5	20	Q.	Yes.	10:17
6		Α.	Yes.	
7	21	Q.	And it then goes on, I'm not going to go into the	
8			details, but it explained to you in that letter what a	
9			Serious Adverse Incident Review entailed.	
10		Α.	Yeah.	10:17
11	22	Q.	It gave you the opportunity to participate in that	
12			investigation and encouraged you to do that. And it	
13			also then said it was your preference to wait until the	
14			SAI Report was complete, and did you contact the Trust	
15			at all when you got that letter about that SAI?	10:18
16		Α.	No, I just received the letters and I think I did maybe	
17			mention to Dr. Brannigan about it, the GP. I was just	
18			more concerned about trying to get better and trying to	
19			cope with what happened to me. I was just letting this	
20			SAI, it wasn't actually in my head every day like this	10:18
21			here is, you know.	
22	23	Q.	Yes, you were just letting it take its course?	
23		Α.	Just letting it take its course. I was more concerned	
24			about Dr. Brannigan, I was seeing him regularly, even	
25			Dr. Joe Hackett before that, I had been up maybe, I	10:18
26			don't know how many times a year, just to keep an eye	
27			on my CK readings because I had told him about the	
28			muscle problem. And Dr. Brannigan was the same, I	
29			would have seen him regularly.	

1			I think even in December '16 I was up with him, he	
2			checked my prostate and all, he said everything was	
3			grand. Then I went up after Christmas, that was	
4			January '17 and I told him that I had got no word from	
5			the Urology and I don't think he really answered me at 10	0:19
6			all. And then I think that was a Tuesday and then by	
7			that Friday I got the letter to say Thorndale Unit the	
8			31st of January.	
9	24	Q.	And that was	
10		Α.	So I think only I had said it, that's how I feel, only 10	0:19
11			I mentioned it to my GP who obviously had got in touch	
12			with them again, maybe he realised about the button	
13			issue, the routine on the So I think if I hadn't	
14			have highlighted it, when was it going to be	
15			highlighted. 10	0:19
16	25	Q.	Yes.	
17		Α.	Until it was all spread through me?	
18	26	Q.	So you feel that if you hadn't gone to your GP, you	
19			feel he went back to the Trust on your behalf?	
20		Α.	Obviously. Yes, that's how I feel and I still feel to	0:19
21			this day. If I hadn't have been going to him so often	
22			and seeing my doctor, because I was worried about my	
23			health, I don't know when I would have gotten my	
24			referral, two/three years?	
25	27	Q.	Well, it is possible that the Trust were looking at 10	0:20
26			cases that hadn't been triaged, that hadn't been looked	
27			at, the referrals letters hadn't been looked at, at the	
28			same time as your doctor maybe was ringing in and the	
29			two maybe coincided, we can look at that?	

1		Α.	We can speculate about that, yes.	
2	28	Q.	In any event, there was a period really of six months	
3			before you were seen in the Urology Department after	
4			your GP wrote, isn't that correct?	
5		Α.	That's correct.	10:20
6	29	Q.	When you got the SAI report you then asked to speak to	
7			someone, is that correct, and that's when you met with	
8			Mr. Haynes?	
9		Α.	Yeah. Well, I got a few letters and then I got a few	
10			phone calls as well. I always remember one name,	10:20
11			Patricia Kingsnorth, and she gave me the telephone	
12			number Personal Information redacted by . I never actually rang them, but	
13			I got the few letters as well and the few phone calls.	
14				
15			But the one phone call was, I forget the lady's name	10:20
16			now, it wasn't Patricia, to say that everything was	
17			rosy in the garden, you're not involved in this	
18			Inquiry, whatever it was. I can't remember the exact	
19			details of it. And you know, you should be happy,	
20			you're happy the way you are. And I says, you couldn't	10:21
21			be further from the truth. I said, how could I be	
22			happy, you know, the way I have been left?	
23	30	Q.	I think that phone call was maybe to alert you that	
24		-	there was going to be some Press report?	
25		Α.	Well that's another phone call.	10:21
26	31	Q.	That was a different one?	
27		À.	Yeah, yeah. That was on a Friday afternoon and my wife	
28			was beside me and I put it on loud speaker so she could	
29			hear it. I forget the lady's name as well. She said,	

she told me she was from the Southern Trust and whatever. She possibly told me her name but I can't remember it. She says that there's going to be something in Monday's newspapers, we're trying to get it stopped at the moment because Mr. O'Brien is trying 10:21 to get it stopped, but possibly if it's going to be published don't be worrying.

9 And I said, but why are you ringing me for, because the last person told me it doesn't concern me, you know, 10 10.22 11 everything is rosy in the garden with me. I said, so 12 why are you ringing me to tell me not to buy a paper on 13 Monday, which I did buy, and there was a 50-year-old gentleman with bladder cancer which had spread into his 14 prostate to prostate cancer, and to me that was me. 15 10:22 16 But I still don't know if it was me they were referring 17 to in the paper.

18 32 Well, in any event you did get these telephone calls Q. 19 from the Trust and you then had a meeting with Mr. Haynes. You asked for that meeting, is that right? 10:22 20 Well the lady was a nice mannerly lady on the phone but 21 Α. 22 I just said to myself, look, you don't know what I am 23 going through. This is only the start. This is the 24 start of my journey here. So she says, I can see you're a wee bit upset, Patient 13, I'll get one of 25 10.23 the team that done the lookback to maybe have a word 26 27 for you. Good enough for her, she arranged a meeting with Mr. Haynes. 28

29 33 Q. And you went in and you met him?

8

1		Α.	I met Mr. Haynes.	
2	34	Q.	And he certainly was able to answer all the questions,	
3			I think that was in November 2020 you met with him?	
4		Α.	That's right, yeah.	
5	35	Q.	And he was able to answer all the questions that you	10:23
6			asked about your treatment, about your bladder cancer,	
7			about the drugs	
8		Α.	Oh yes, he was very informed so he was, and he is a	
9			very good doctor too because he saved my Personal Information redacted by USI	
10			a few years ago and Personal Information	10:23
11			. I have good regards for Aidan as	
12			well and Michael Watt, they done their best for me	
13			I thought at the time, you know. Obviously they were	
14			snowed in with work too maybe.	
15	36	Q.	But certainly in regards to the communication with	10:23
16			Mr. Haynes, you felt that he was able to answer the	
17			questions that you were asking and that you wanted	
18			answers to?	
19		Α.	Well, he answered the questions. But if they were	
20			satisfactory for me, I don't think they were, because	10:24
21			I would have looked at some of them a different way	
22			but	
23	37	Q.	I think one of the things that you were concerned about	
24			was whether or not the drug that you had been on had	
25			actually caused the cancer?	10:24
26		Α.	That's correct.	
27	38	Q.	Wasn't that the big worry?	
28		Α.	Yeah, it was Mr. John Keane actually said it to me in	
29			the City Hospital that he done the he was the	

surgeon and it was him said to me about the 1 2 Cyclophosphamide, he mentioned. Anybody that I've went to, even the glaucoma in my eyes from 2000, 3 Mr. Sharkey, the Ophthalmologist, whatever you call 4 5 them, he highlights the Cyclophosphamide. Every 10:24 doctor or anything I've went to, this Cyclophosphamide 6 7 keeps hitting me, you know, and nobody seemed to 8 follow anything up, you know, I'm on such a high dose of it. 150 milligrams-a-day, 50 in the morning, 100 9 at night or whatever it was. 10 10.2511 39 Q. Just in relation to Mr. Haynes, there was one question, according to what you told us in your guestionnaire and 12 13 that's at PAT-000479, you had asked him if you hadn't gone back to your GP in early January 2017 to find out 14 what was the delay in Urology contacting you, when did 15 10:25 16 he think you would have been called and he didn't 17 answer? 18 That's correct. Α. 19 40 But he seemed to give you reassurance that the delay Q. 20 hadn't adversely affected your bladder cancer? 10:25 That's correct. 21 Α. 22 And that your treatment path would have been the same? 41 Q. Would have been the same, yeah. But he did mention it 23 Α. 24 could be something to do about the invasive, something to do with the muscle, possibly could be one or the 25 10.25other I think in that letter too, type of a bladder 26 27 cancer. Non-invasive or invasive, I'm not sure. I don't know if it's in the thing, maybe you have it in 28 29 the letter there. But he answered the questions that

		I asked him anyway.	
		I mentioned to him about this Cyclophosphamide again	
		and he said that it was, smoking is the biggest cause	
		of bladder cancer, and he said, do you smoke? And	10:26
		I says, well I did smoke until I got my diagnosis and	
		I smoked about 10-a-day. So he seemed to be blaming	
		more on the smoking end of it than being on that drug.	
42	Q.	Well I'm not a medical expert, I wouldn't like to	
		comment at all on that. But did you ever, when you	10:26
		were told that there was this Serious Adverse Incident	
		Investigation being carried out, you were told that in	
		February 2018?	
	Α.	Mm-hmm.	
43	Q.	But you didn't get a report until two years after that,	10:26
		did you ever question the delay?	
	Α.	I was just more worried in living and trying to cope	
		with the condition I was left with. And scans, and	
		hoping scans, hoping the phone doesn't ring after you	
		get a scan and things like that.	10:27
		CHAIR: That's fine. Well Patient 13 , thank you very	
		much. I don't have any more questions that I want to	
		ask you, but I'm going to hand over to my co-panellist	
		here, Dr. Swart, and she may have something that she	
		wishes to ask.	10:27
		DR. SWART: So thank you very much for telling us how	
		it has impacted on you so far and I am sure you will	
		have more to tell us. I'm interested in what	
		information you were given at various stages about the	
		A. 43 Q.	 I mentioned to him about this Cyclophosphamide again and he said that it was, smoking is the biggest cause of bladder cancer, and he said, do you smoke? And I says, well I did smoke until I got my diagnosis and I smoked about 10-a-day. So he seemed to be blaming more on the smoking end of it than being on that drug. 42 Q. Well I'm not a medical expert, I wouldn't like to comment at all on that. But did you ever, when you were told that there was this Serious Adverse Incident Investigation being carried out, you were told that in February 2018? A. Mm-hmm. 43 Q. But you didn't get a report until two years after that, did you ever question the delay? A. I was just more worried in living and trying to cope with the condition I was left with. And scans, and hoping scans, hoping the phone doesn't ring after you get a scan and things like that. CHAIR: That's fine. Well, thank you very much. I don't have any more questions that I want to ask you, but I'm going to hand over to my co-panellist here, Dr. Swart, and she may have something that she wishes to ask. DR. SWART: So thank you very much for telling us how it has impacted on you so far and I am sure you will have more to tell us. I'm interested in what

things that you were happening to you, going back to 1 2 when you were started on Cyclophosphamide, but also 3 what did they tell you about it when you later on. started to take it and it who told you? 4 5 Well Victor Patterson, the Consultant Neurologist, told 10:27 Α. me it was a life-threatening illness. 6 7 44 Yes. Q. 8 And that the Cyclophosphamide was part of getting Α. 9 better process, you know, but never was anything mentioned about the toxicity of it, or that it was -10 10.28 11 I didn't even know it was a form of chemotherapy. 12 when did you find out that? 45 Q. 13 Just whenever everything started after the operation Α. and these phone calls and letters and I started to 14 enquire a few things about it. But I always knew that 15 10:28 16 there was something about that drug that should have been, like on my doctor's notes, Dr. Hackett always had 17 18 it on the paper notes from way back years, "allergies penicillin". Like it would have been so simple to 19 20 write down four or five years of Cyclophosphamide 150 10:28 21 milligrams below it, and just to keep a check on the red cells or whatever it is, you know. 22 Do you think your GP understood about the risks 23 46 Yes. Q. 24 of Cyclophosphamide? I don't know if he knew the 25 Oh he was very thorough. Α. 10.28 risks, he never mentioned bladder cancer to me now, 26 27 nobody ever mentioned cancer to me at all about it. Ιt was just whenever we looked up this John Hopkins and 28 29 different things and my solicitor looked up things and

1			Mr. Keane had mentioned it too, that Cyclophosphamide	
2			was a dangerous drug as well. And I think it was	
3			actually in one of the books they handed to me in the	
4			Thorndale Unit, invasive bladder cancer. I can't	
5			remember, it's like a green and white book, I think the	10:29
6			solicitor has it, and it does mention the	
7			Cyclophosphamide in it and then me and my wife, it sort	
8			of highlighted it more to us.	
9	47	Q.	And in the Thorndale Unit what information did they	
10			give you then?	10:29
11		Α.	On the 31st January?	
12	48	Q.	When you had your book about the bladder cancer?	
13		Α.	Just take it home with you and read it. I went in that	
14			day and it was my Personal Information redacted by USI	
15			and my wife was panicking to get things organised for	10:29
16			his birthday. And I says, I shouldn't be too long	
17			here, it was only about 2 o'clock and I think it was	
18			near six before I got out of it.	
19				
20			But when I was on the treatment table the two nurses,	10:29
21			they had to put a camera up in, and whatever they seen	
22			on the screen they called for Mr. Jacob and he come in	
23			and looked at it. And he went to his table and he	
24			started to write and the nurses started to hand me all	
25			these pages and sheets, and don't read too much into	10:30
26			it, that's what they told me.	
27	49	Q.	Right.	
28		Α.	So I still didn't know what was wrong with me but	
29			I knew there was something bad.	

1	50	Q.	They didn't sit down and talk to you at that time to	
2			explain	
3		Α.	Nobody said there was a possibility of cancer.	
4	51	Q.	Okay.	
5		Α.	So that was another, but I don't know when it was.	10:30
6			Good enough, it moved pretty quickly then. Every two	
7			weeks there was something, maybe 'til the end of	
8			February or March-time and then there was a long lull	
9			then to the operation in the City Hospital. But at	
10			that time, like I was really, whenever I wasn't being	10:30
11			looked at by anybody, I was too much time to think	
12			about things and worry.	
13	52	Q.	Yes.	
14		Α.	And my wife was saying we'll plant these wee flowers	
15			for summer. I says, I mightn't see summer, you know,	10:30
16			I couldn't live really.	
17	53	Q.	Mm-hmm?	
18		Α.	So then I had to go to the Tower Hill in Armagh.	
19			Dr. Damien O'Donnell sent me to it for - and I had a	
20			Personal Information redacted by USI	10:31
21				
22	54	Q.	At that time, you know, if the Trust at that time could	
23			have handled that whole information thing a bit better,	
24			what do you think they could have done? What would be	
25			your advice to them having gone through this?	10:31
26		Α.	Well, I would highlight, I don't know if they're still	
27			using that drug, but if there's anybody still using it	
28			please keep an eye on them patients because it can lead	
29			to a lot of trouble.	

1 55 And what do you think you would have liked to have Q. 2 known as a patient? Well, I would like to have even a yearly check-up. 3 Α. Like I was going to my doctor, my GP regularly, maybe 4 5 every two/three months for a long time. And then once 10:31 the glaucoma in the eyes started to set-in I was more 6 7 focussed on it. I had to get, as they call them, a 8 "trapdoor" in each eye to let the pressure out and 9 I was seeing Mr. Rankin in the Royal Hospital. I suppose really the "noughties", as they call them, 10 10.32 11 was more to do with my eyes and still would have the 12 weakness in the muscles as well. 13 14 And the bladder, the bladder was still, the bladder always played up, you know. I was up two/three times 15 10:32 16 at night. I would only go to the toilet for a small while and then it would sort of get sore and then 17 18 things would stop. So there always was a wee problem 19 in my eyes. But it wasn't the end of the world and 20 I wasn't going to torture the doctor about it. But no 10:32 21 urology was ever mentioned from 2001. Mr. Wilson in 22 the Poly Clinic in Banbridge and he just says, you're 23 okay. And by the time you were diagnosed with your bladder 24 56 Q. 25 cancer and you needed to have an operation, did you get 10:32 given appropriate information at that time? 26 27 Α. Oh Mr. Keane was excellent. He was a big loss to Belfast. 28 29 57 Q. Yes.

1		Α.	An excellent surgeon.
2	58	Q.	You felt informed then, did you, you felt you
3			understood what it was all about?
4		Α.	Yes. Well, they told me, Mr. Keane said it was life
5			changing but I think it was actually more than that, 10:33
6			you know. It's more than life changing like.
7			DR. SWART: Thank you very much.
8			CHAIR: Mr. Hanbury?
9			MR. HANBURY: Thank you very much for your very
10			enlightening evidence. I would just like to take you 10:33
11			back to the mid-90's, 1996. This is on PAT-000446. So
12			in fact you saw Mr. O'Brien around about that time when
13			you had the bladder trouble from your Cyclophosphamide
14			and had a blader examination about that time.
15		Α.	It wasn't from the Cyclophosphamide then. I think 10:33
16			that's what they are trying to say now that the bladder
17			problem has been ongoing. There's a different type of
18			a bladder problem in '96. I hadn't maybe even started
19			the Cyclophosphamide at that stage. The
20			dermatomyositis is a wasting of the muscles and I had, $10:33$
21			everything was going. They were worried about my heart
22			because that was the biggest muscle and I couldn't
23			brush my teeth, I had to hold the toothbrush like this.
24			Couldn't get dressed. Couldn't get out of bed really.
25			So the bladder, the problems that I had with my bladder $_{10:34}$
26			were different, pre-Cyclophosphamide if you can
27			understand that, then post-Cyclophosphamide I started
28			to get different symptoms and blood as well I think.
29	59	Q.	Right. Okay. But I think nonetheless Mr. O'Brien or

1			his team did the bladder examination?	
2		Α.	Yeah, yeah, yeah.	
3	60	Q.	and did some biopsies. Then at 1997, according to	
4			the paperwork, on PAT-000447 there was a recommendation	
5			that you should have another bladder examination?	0:34
6		Α.	Yes.	
7	61	Q.	At an interval. But I don't think that ever happened,	
8			is that correct?	
9		Α.	No.	
10	62	Q.	So did you chase that? What is your recollection about $_{10}$	0:34
11			that, you just felt that	
12		Α.	I never chased it now. The GP never mentioned it to	
13			me. I think Mr. Hackett was still living then. So	
14			I still would have had the symptoms for it now, but	
15			there was no follow-up appointment. As I say, 10	0:35
16			Mr. Wilson, he ended it all in 2001.	
17	63	Q.	I think there was	
18		Α.	You mean to say I should have maybe enquired?	
19	64	Q.	No, I'm not saying that, I wonder if you had	
20			communication from the Trust?	0:35
21		Α.	I don't think I had, no. No. Any appointment I would	
22			have went to it. Never cancelled any appointment and	
23			I have had quite a few.	
24	65	Q.	Absolutely yes, thank you. So then moving ahead to	
25			2017, you had had the operation at Craigavon. They had $_{10}$	0:35
26			removed the tumour, or at least some of it through the	
27			telescope, and I think you saw Mr. Glackin. And this	
28			is PAT-000481. And you make a comment that that was	
29			quite a traumatic interview and you were told the	

1			initial diagnosis?
2		Α.	Yes, it was for me and my wife.
3	66	Q.	It was a shock, a new cancer diagnosis. Did you, apart
4	00	۷.	from Mr. Glackin, were you offered any other
5			individuals to see for more support at that time?
6		Α.	I'd say I was. The nurses would have maybe mentioned
7		<i>/</i>	the Macmillan and different I went to Charis in
8			Cookstown which helped me. I went on my own steam, me
9			and Personal Information redacted by USI
10			So we went up to Charis Cancer Centre and we had, just 10:36
11			maybe once-a-week, you know, just for a bit of a
12			therapy and a bit of pipe music or whatever they call
13			it, that panpipes. It's was a great wee place for the
14			cancer.
15	67	Q.	So you had some, you felt you were supported at that 10:36
16		•	time?
17		Α.	Yes.
18	68	Q.	which is good, okay, thank you?
19		Α.	I never hear tell of Macmillan though. I think I wrote
20			to them or sent something, but I have yet to hear 10:36
21			anything from Macmillan or financial help or anything.
22	69	Q.	All right, thank you. Then things moved fairly quickly
23			and you saw Mr. Keane in Belfast after that.
24		Α.	Yeah.
25	70	Q.	Did you, I wasn't sure whether you had any chemotherapy 10:37
26			leading up to that or?
27		Α.	Mr. Keane mentioned maybe a dose of chemotherapy, but
28			then he said because of the one kidney, and he said it
29			would probably lead to kidney dialysis later, I suppose

1			if you survived really, he thought it was too big of a	
2			risk.	
3	71	Q.	So you had a conversation that was offered?	
4		Α.	Oh, yes, Mr. Keane.	
5	72	Q.	Just to recap, you felt you were well-supported then	10:37
6			with	
7		Α.	Well, Mr. Keane was fantastic. But, you know, even	
8			seeing the stoma nurse. I didn't know what a stoma was	
9			that day I went in, maybe whatever it was, a couple of	
10			weeks before the operation. And she said, this is what	10:37
11			is going to happen and it just more or less went over	
12			my head. I suppose I wasn't in the right place at the	
13			time, you know, it was a bit of a shock when I woke up	
14			again and seen it.	
15	73	Q.	Yes.	10:37
16		Α.	The nurse, now the young nurse that drew, that comes	
17			around and draws the stencil on your stomach, she took	
18			a long time at measuring and moving this about in my	
19			stomach. And then it actually was the worst place you	
20			could have put it because it was, the sides of the	10:38
21			stoma bag really goes into the indent of the belly	
22			button, and unfortunately when I was in the City	
23			Hospital I took MRSA and they had to keep the wound	
24			open.	
25				10:38
26			So I have actually two belly buttons and then the stoma	
27			bag, this is what caused the leakages a lot too. So	
28			I think the young nurse, now she had done her best, but	
29			I think if she had kept it even 2 centimetres over this	

1			way just so the bag wouldn't be like a dent in it and	
2			it seems to leak.	
3	74	Q.	So that would have been a stoma therapy nurse probably,	
4			yes.	
5		Α.	Yeah, yeah.	10:38
6	75	Q.	But I believe in some of the paperwork you maybe are	
7			being considered to have that revised.	
8		Α.	Hopefully. Now I'm seeing Mr. O'Kane, I think is my	
9			new consultant, this day next week down in the City	
10			Hospital so I have the appointment for it.	10:39
11			MR. HANBURY: Right, okay. I haven't got any other	
12			questions.	
13			CHAIR: Mr. Wolfe, have you any questions?	
14			MR. WOLFE QC: Just one question, Patient 13 . The	
15			Chairman referred you to page 431, PAT-000431, and	10:39
16			that's the letter of the 19th February 2018 where they	
17			are telling you, that's the Trust are telling you, that	
18			there was a delay in the processing of your GP	
19			referral. Now, you got your initial appointment with	
20			the Trust on 31st January, the year before.	10:39
21		Α.	Yes.	
22	76	Q.	And then you were in to see Mr. Jacob in March and no	
23			doubt lots of contact?	
24		Α.	Yes.	
25	77	Q.	With the Trust throughout 2017?	10:40
26		Α.	Yeah.	
27	78	Q.	Is this letter dated, as I say, February '18, is that	
28			the first time you were told that there had been this	
29			delay in processing your GP referral?	

Well that's the first letter I got about it, yeah. 1 Α. 2 I think the GP had mentioned it to me, I don't know the exact date, that there was a SAI ongoing. 3 I didn't know what it meant so he explained it to me that 4 5 because of the delay in maybe it being seen, you know. 10:40 But I thought the GP had initiated it but... 6 7 79 Yes, and that is what I was coming to. I said I was Q. 8 only going to ask you one question, but is it possible 9 that the GP was initiating his own SAI or similar process because, if you like, the mistake made at their 10:40 10 11 end, the failure to refer you as a red flag? Well I didn't know that until the meeting with 12 Α. 13 Mr. Haynes and he said to me the fault was at the GP That is what -- it's very easy done, that's the 14 end. words he said. He said, you can accidentally hit, you 15 10:41 16 scroll down and you could hit the wrong button. So it was a big mistake to make like in a way too. 17 18 80 And I think in fairness to Mr. Haynes he was telling Q. 19 you there was a mistake at the GP end, but when that 20 referral came in to the Trust there was a mistake at 10:41 21 their end in that the responsible consultant didn't 22 triage? Well I don't think that's in my notes now, but he 23 Α. 24 possibly did say that to me. But it was more, it was 25 more focussing on the GP's mistake. 10.41If we turn to the notes of your meeting with, 26 81 Q. Yes. 27 PAT-000434, you remember going in to see Mr. Haynes in November of 2020. What he said to you, of course 28 referring to the GP, what he says to you, if you look 29

1 at the top PAT-000435. He said: 2 "Unfortunately triage did not take place." 3 4 5 So that's a reference to the hospital process of 10:42 looking at the GP letter and checking out whether it 6 7 has been properly graded. So maybe you don't recall 8 Mr. Haynes talking in those terms? He possibly did now. The lady that was present, Carly 9 Α. Connolly, Carly was taking all the notes, so whatever 10 10.42 was said is on them notes. 11 12 **M**R. HANBURY: Okay, thank you. , thank you very much. We have no 13 CHAI R: 14 more questions for you. Thank you very much for coming along this morning. It is important that we hear 15 10:43 16 firsthand from patients about their experiences and we really do appreciate you coming along. 17 Patient 13 Thank you. Thanks everybody. 18 Is that 19 it? 20 Ladies and Gentlemen, that brings us to the end 10:43 CHAI R: of this week's hearing sessions. We will be in touch 21 22 with each of you to let you know when we're due to hear 23 some more patients. Hopefully in the autumn I'm 24 hopefully going to organise that for September, if at 25 all possible. Then when you come back at that time you 10:43 will see that the chamber will have been transformed, 26 27 we should have our audiovisual system up and running. There will be communication from the Inquiry secretary 28 shortly asking you for any feedback over this week 29

1	about various issues that we will obviously need to	
2	sort out for everyone's benefit. And if there are any	
3	questions please do direct them to Ms. Marshall and her	
4	team. I'll see you again in the autumn and have a good	
5	summer. Thank you.	10:44
6		
7	THE HEARING WAS CONCLUDED	
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