1 GRO-A RULING 12 9 14.DOCX

10 GRO-A CHRONOLOGY FINAL.PDF

28 GRO-A - REPORT FROM DR COLVIN.PD

41 GRO-A - ROI.PDF

42 GRO-A - NARRATIVE CONCLUSION 1.PDF

BEFORE H.M. SENIOR CORONER FOR MILTON KEYNES

INQUEST INTO THE DEATH OF GRO-A

PIR

Overview of relevant law

1. Article 2 contains two different duties relating to an investigation:

   1.1. There is a "duty of enhanced investigation" by which the state must proactively bring about an effective and independent investigation. This was the duty considered in *Middleton.*

   1.2. The state must set up a judicial system which, as a whole, enables any citizen to access an independent, practical and effective investigation of the facts of any death.

(i) The duty of enhanced investigation

2. This duty is triggered, inter alia, if it is arguable that there was a failure by healthcare authorities to put in place appropriate systems of operation: *R (Humberstone) v Legal Services Commission* [2011] 1 WLR 1460 §§58, 69–70.

3. It is necessary to show that there was a real risk *to life* (not just of bodily harm) before article 2 can impose an obligation to put in place suitable systems for the protection of life. In *G.N. & Others v. Italy* application no.43134/05, judgment of 1 December 2009, the ECtHR decided that there was no substantive breach of article 2 when a number of people in Italy were infected by HIV and hepatitis C in the 1980s following blood transfusions. The main reason was that it had not been established at the material time that the authorities knew or should have known about the risk to life due to transmission of these diseases.

4. So if the risk to life only came about after the death was caused, or after any failure took place, then there will be no violation of the systemic duty.

5. There is little guidance in the caselaw as to what "appropriate systems" means, and how onerous the obligation is (at best, see *Savage v South Essex Partnership NHS Foundation Trust* [2009] 1 AC 681 at §44-45). However, it is likely to depend on factors such as whether there were good reasons not to adopt a particular system and the extent of the risk to life. The authorities must be given a discretionary area of judgment to decide which particular practical measure are appropriate. That is so in the context of the provision of healthcare to those operating the state's dangerous activities (see *Brincat v. Malta* 60908/11 & ors, 24 July 2014, §101) and must apply more forcefully in the field of healthcare to ordinary outpatients for whom the state has assumed no responsibility.

6. It is arguable that article 2 requires investigation of systemic failures even if they did not cause death, in order to assuage the anxieties of the public or to learn lessons to protect others in future. There is considerable public anxiety about the matters raised in this case. However, it is unlikely that the need to assuage that concern could require the investigation of an issue if the Coroner decides there was not even arguably a failure, or the issue could not have caused death. Similarly, the importance of learning lessons is diminished because the systems have changed so much since the problems that caused GRO-A's death occurred. But to help with this consideration, I will be asking for further evidence on the systems that are in place now, as compared to those in the 1980s.

7. The extent of the investigation required where the enhanced duty is triggered by an arguable systemic failure is not entirely clear. In *R (on the application of Amin) v. Secretary of State for the Home Department* [2004] 1 AC 653 it was said that there are minimum standards which must be met. Those standards are outlined in paragraph 41 of the family's submissions. *Humberstone* decided that the family must be able to effectively participate.

8. Several recent authorities have suggested that the procedural duty is flexible, and what is required depends on factors which include the age of the breach and the nature of the substantive obligation of which there is an arguable breach (such as *R (JL) v Secretary of State for the Home Department* [2009] 1 AC 588 at §31 and 77; *R (Ali Zaki Mousa) v Secretary of State for Defence (No 2)* [2013] HRLR 32 §170-211; *R (Long) v. Secretary of State for Defence* [2014] EWHC 2391 (Admin) at §93; and *Brecknell v. United Kingdom* [2008] 46 EHRR 42, at §71). However, it appears that even if the investigative duty is flexible, the investigation must still effectively investigate arguable systemic failures, and oral evidence must be called if it is available and if in the Coroner's view that is necessary to effectively resolve the matters at issue.

9. Those factors are important when it comes to considering whether previous investigations have satisfied any enhanced duty to investigate. If there are issues which require investigation, it is unlikely that the Archer inquiry was effective. That is because it had no power to compel anyone to attend or produce documents. A number of DoH witnesses did not give full oral evidence, and some documents were not disclosed.

10. It is not clear whether the Penrose Inquiry will effectively investigate all of the arguable systemic failures, because it is focused on Scotland. The relevant systems appear to be different to some extent.

11. But even if the pre-existing reports do not entirely discharge the article 2 enhanced duty to investigate, the Coroner may still rely on them as evidence (for example, see *R (Long) v. Secretary of State for Defence* [2014] EWHC 2391 (Admin) at §91). It may be that those reports demonstrate that there was no systemic failure which potentially caused GRO-A's death. If so, and if there is no oral evidence which the Coroner thinks may alter that conclusion, then there would be no need to continue to investigate the alleged systemic failures. The cases in paragraph 8 above indicate that the investigation does not need to be as thorough as at a death in custody inquest, if systems have been corrected, if there is a long time since the alleged failures, and where the breach involves healthcare rather than say prison suicide or police shooting. They suggest that the Coroner has some latitude in deciding whether further

evidence, including oral evidence, is necessary.

(ii) Access to a judicial system for the investigation of any death

12. Article 2 also requires there to be a judicial system which the citizen can access to bring about the practical and effective investigation of those deaths for which the enhanced duty to investigate is not triggered.

13. This duty was described in *Takoushis* at §105 as follows:

> "the state must have a system which provides for the practical and effective investigation of the facts and for the determination of civil liability".

14. And at §106:

> "in the context of the other procedures available, an inquest of the traditional kind, without any reading down of the 1988 Act by giving a wider meaning to "how" as envisaged in the *Middleton case [2004] 2 AC 182* , and provided that it carries out the kind of full and fair investigation which is discussed earlier in this judgment and which (we hope) will now take place, in our opinion satisfies the requirement that there will be a public investigation of the facts which will be both practical and effective. Moreover, the family will be able to take a full part."

15. The "full and fair investigation which is discussed earlier" refers to the requirement that, even at a traditional inquest, certain systemic failures should be investigated: §43-54.

16. Some ECtHR cases have suggested that the availability of prompt civil proceedings will be sufficient to discharge this duty.

17. However, in my view it is likely in this case that whether or not the enhanced duty to investigate was triggered, that will make no significant difference to the scope of the investigation.

18. Firstly, several cases have observed that the scope of a traditional inquest, following *Takoushis,* should be equivalent to that of a *Middleton* inquest, for example: *R (Sreedharan) v HM Coroner for Manchester* [2013] EWCA Civ 181, §18(vii); *R (Smith) v HM Oxfordshire Coroner* [2011] 1 AC 1, §§73–78, 152–154 and 208; *R (Lin) v Secretary of State for Transport* [2006] EWHC

2575 (Admin), §32.

19. It follows from those cases that the considerations set out in the previous section should apply equally to a traditional inquest. Thus, if the three conditions in paragraphs 4-6 above are met, and there are arguably systemic failures which were potentially causative and which have not been effectively investigated already, then a traditional inquest should investigate those matters.

20. That analysis is supported by *Kennedy and Black v. Lord Advocate* [2008] CSOH 21 is relevant. That case is not binding, but it is helpful because it considered what duty there was in Scotland to investigate the same matters that are raised by GRO-A's death.

21. It decided that the article 2 duty was engaged in the sense of requiring there to be a judicial system which a citizen can access, rather than in the sense of there being an enhanced duty to investigate. That is clear from the fact that the Court of Session explicitly applied the approach in paragraph 105 of *Takoushis:* §90, 92 and 128.

22. *Kennedy* decided that article 2 required an investigation because there were reasonable grounds for believing that the deaths may have resulted from "wrongful actings" on the part of those responsible for providing supplied of blood products: §75. Although *Kennedy* noted that the Archer report was pending, and that civil proceedings were available, it decided that a Fatal Accidents Inquiry or a public inquiry were the only means of offering a realistic prospect of a practical and effective investigation: §128.

Further directions

1. The family submit that the article 2 enhanced duty is triggered because GRO-A's death was, or might have been, the result of systemic failures. The family specify a number of unanswered questions, in paragraph 20, which are in summary:
   1.1. When should the Government have become aware of the dangers of importing blood, and should they have ceased to import such products at an earlier date?
   1.2. Should haemophiliacs and their families have been warned earlier about the risk of contamination of Factor VIII concentrate?
   1.3. Should the UK have moved earlier to self-sufficiency in the supply of blood products?
   1.4. Was there delay in putting in place testing for hepatitis C and HIV?
   1.5. Was there delay in putting in place heat treatment?

2. The Treasury Solicitor, on behalf of the Department of Health, accepts that if there are systemic issues relating to the provisions of contaminated blood products of potentially causative relevance to the death, and if those systemic issues have not been adequately addressed by other independent investigations into the provision of contaminated blood products, then it would be necessary to include such issues in the scope of the inquest. However, the Treasury Solicitor submits that this question cannot be properly addressed until the report of the Penrose Inquiry has been published.

3. I have decided to seek further information, namely:

   3.1. The final report of the Penrose Inquiry. This is due to be produced shortly, in autumn 2014.

   3.2. Any evidence from medical professionals involved in GRO-A's care, or other sources, regarding (i) when or within what period he received the contaminated blood products which caused his HIV and also his hepatitis C;(ii) the nature and severity of GRO-A's haemophilia, and whether it was type A or B.

3.3. A statement from the Department of Health containing a brief overview of which body was responsible for the key decisions relating to the four matters set out in paragraph 1 above during the period 1975 to 1991 (i) in England and Wales and (ii) in Scotland. The purpose of this statement is to help understand the extent to which the Penrose Inquiry's conclusions are relevant to GRO-A's case.

3.4. A statement from the Department of health giving a brief overview of what system, policy or training for the type of medical professionals who were involved in GRO-A's case about informing patients of the risks of treatment of this type and asking whether they consent to it (i) was in place between 1975 to 1991 and (ii) is in place now. Please describe whether there was any difference between the systems in England and Wales as compared to Scotland.

4. Once this information has been received, I will circulate it to interested persons, unless there is an application under r.15 of the Coroners Rules 2013. I will then determine what issues ought to be investigated by this inquest. If the interested persons wish to produce further submissions in light of the new information I will consider them, and they may wish to address the following matters:

4.1. Did the Penrose Inquiry effectively investigate any arguable systemic failures which were potentially causative of GRO-A's death?

4.2. So far as relevant, what does the article 2 enhanced procedural duty require of an investigation into systemic failures in physical healthcare for outpatients? To what extent is it necessary for relevant oral evidence to be taken? Is the duty a flexible one, and if so, are factors such as the length of time since the alleged failures relevant (see *R (Ali Zaki Mousa) v Secretary of State for Defence (No 2)* [2013] HRLR 32, §170-211)?

4.3. When did the authorities in England and Wales know, or when ought they to have known, that there was a real risk to life (not merely of bodily

harm) due to contamination of Factor VIII with hepatitis C?

4.4. When or within what period did GRO-A receive the contaminated blood products which caused (i) his HIV and (ii) his hepatitis C?

4.5. When should testing or heat treatment have been introduced?

4.6. What standards are expected by article 2 of systems relating to physical healthcare for outpatients? Is there any more specific guidance about whether the issues in paragraph 1 above could breach article 2, than that contained in *Savage v South Essex Partnership NHS Foundation Trust* [2009] 1 AC 681 at §44-45?

4.7. Are there any systemic failures relevant to GRO-A's death which remain today?

5. I regret that there has been substantial delay in this matter, GRO-A having died on 24 May 2012. I am anxious to ensure there is no further unwarranted delay.

6. However, the further information sought is liable to be of considerable importance to my decision. It may be determinative. The Penrose Inquiry is focused on Scotland but its terms of reference are broad. It is likely to produce a range of significant evidence, such as: (1) when the authorities in England and Wales knew or ought to have known that there was a risk to life due to the contamination of blood products, and what the extent of that risk was, (2) when tests for HIV and hepatitis C became available, (3) when heat treating was developed.

7. It may show whether there was a viable alternative blood product which GRO-A could have used, and whether the risks of that product were lower than the risks of Factor VIII. It may show whether the Department of Health was right to conclude that:

> "Self-sufficiency in blood products would not have prevented haemophiliacs from being infected with hepatitis C. Even if the UK had been self-sufficient, the prevalence of hepatitis C in the donor

population would have been enough to spread the virus throughout the pool".

8. I have not yet received information to show the extent to which the relevant systems apply equally to Scotland, as to England and Wales. However, it appears that there was at least some overlap, and therefore that at least some of the conclusions in the Penrose report about what went right or wrong in Scotland would apply equally to England and Wales. If so, that is likely to be an important consideration in my determination of what issues must be investigated.

9. It appears that the information set out above can be obtained fairly quickly. There is no precise date for publication of the Penrose Report, but I understand that it remains expected in autumn of this year. I would like to receive the information specified in paragraphs 3.2-3.4 above by Friday 14th November. I will then circulate relevant information, and as long as the Penrose Report is available, will at that stage set a date for further submissions and a pre-inquest review if necessary.

Thomas R. Osborne
HM Senior Coroner Milton Keynes. 12th September 2014

Silva
Legal Services

Updated (May 2016)
Chronology

Mr GRO-A

GRO-A

Northamptonshire GRO-A

DOB: GRO-A 69
DOD: GRO-A 12

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Updated (May 2016)

Chronology

GRO-A

DOB GRO-A 69
DOB GRO-A 12

Date:	Page:	Comment:
GRO-C 69	**24**	**G. P. records** Letter from Paediatric Registrar, St Bart's Hospital, London to G. P. re possible haemophilia (x2 maternal bothers affected).
18.10.69	**26**	**G. P. records** Seen by G. P. Large haematoma right groin. Sent to Queen Elizabeth Hospital. Referred to The London Hospital, Whitechapel. Plan: For follow up at Haemophilia Clinic. Family History: Maternal grandmother is haemophilia carrier. Uncle is haemophiliac.
18.10.69	**25**	**G. P. records** Letter from The London Hospital, Whitechapel confirming severe haemophilia.
1970-1976	**28-53**	**G. P. records** Letters from GRO-A District Hospital regarding admissions for bleeding issues.
20.03.75	**47**	**G. P. records** Letter from Mr K Beere, Divisional Education Officer, GRO-A, Kent. *'...No reason why GRO-A shouldn't attend normal school full-time from next term....'*
28.06.76	**58**	**G. P. records** Letter from Mr GRO-A, Principal Medical Officer, GRO-A Hospital, GRO-A to G. P. *'....Recommended that GRO-A needs the protective environment of a school for physically handicapped children....Have informed the County Education Officer...'*
1977	**68**	**G. P. records** Attended GRO-A.
1978	**69-78**	**G. P. records** Discharge letters from St Mary's Hospital, Portsmouth re admissions re bleeds.
11.05.79	**80**	**G. P. records** Letter from St Mary's Hospital, Portsmouth to G. P, GRO-A re initiation of prophylaxis. Dr O'Brien, St Mary's Hospital happy to provide

		Factor VIII.
30.06.80	**1212**	**The Royal London Hospital records** Letter from North Hampshire Health District to Dr Colvin. Patient will be boarding at the Lord Mayor Treloar College from September 1980. Request from Dr Aronstam for medial details.
19.12.80	**1215-1221**	**The Royal London Hospital records** Letter from Dr Wassef to Dr Colvin enclosing term's results. Patient on alternate day prophylaxis aiming at breaking the cycle of frequent bleeds into his right knee and elbow.
02.09.81	**92 1714**	**G. P. records/ The Royal London Hospital records** Seen on Haematology OPD clinic at The Royal London Hospital. Letter to G. P. Reply to letter from Lord Mayor Treloar Centre. GRO-A now at school. Main problem is GRO-A s failure to comply with medical advice and mother's inability to bring him for out-patient consultations and support at home. Discharged on 13.08.81 with instructions to take 500 units of FVIII daily and attend OPD 17.08.81. Failed to do this.
15.12.81	**1242**	**The Royal London Hospital records** Letter from Dr Aronstam to Dr Colvin enclosing term's results.... ....His parents attended a house conference in October and his mother came out firmly against prophylaxis. She thought the material might be affecting his brain!
02.07.82	**1248-52**	**The Royal London Hospital records** Letter from Dr Wassef to Dr Colvin enclosing term's results.
01.09.82	**98 1718**	**G. P. records/ The Royal London Hospital records** Seen by Dr Colvin, Senior Lecturer on Haematology OPD clinic at The Royal London Hospital. Letter to Treloar Haemophilia Centre dated 08.09.82 Review. Admitted over the summer due to flare up of knee. Received intensive physiotherapy under FVIII cover. Needs continuation of prophylaxis and physiotherapy.
14.12.82	**1259-64**	**The Royal London Hospital records** Letter from Dr Wassef to Dr Colvin enclosing term's results.
31.03.83	**1722**	**The Royal London Hospital records** Seen by Dr Colvin, Senior Lecturer on Haematology OPD clinic at The Royal London Hospital. Home for x3 days. Says he is all right – Doesn't seem to care....x2 right knee bleeds only during last term. Not allowed to play football. Not doing physio. Doesn't like it. Blood tests ok. x2 days ago. Bleed into right knee which has now resolved. Injections into left elbow given by mother. Happy to spend Easter playing with computer. On exam: Well, no lymphadenopathy. Liver and spleen not palpable. All joints normal except right knee. Opinion: Recent right knee bleed. Give 500 tomorrow. Then decide depending on condition.
31.03.83	**2645**	**The Royal London Hospital records** Virology results: Anti HBs Positive. HB_sAg Negative.

02.06.83	**1273** **1723**	**The Royal London Hospital records** Seen by Dr Colvin, Senior Lecturer on Haematology OPD clinic at The Royal London Hospital. Letter to Dr Aronstam dated 09.06.83. Has been on alternate day prophylaxis....physio on and off. Knee was ok until last week of term, when it bled. Mrs GRO-A doesn't like prophylaxis, GRO-A doesn't mind. Mrs GRO-A worried about AIDS, pigs blood etc. On exam: In a wheel chair. Policy: AODS explained to Mrs GRO-A- don't think knee is that much worse than usual save perhaps for increasing FFD (Fixed flexion deformity)– will write to Dr Wassef explaining Mrs GRO-A's distaste for prophylaxis. Also mention possibility of more physio and splinting +/- wearing at night.
28.06.83	**1274-5**	**The Royal London Hospital records** Letter from Dr Wassef to Dr Colvin. ...Transfusing with Armour Factorate as reacted to the Lister Concentrate.... AIDS related investigations: Clinically he exhibits none of the stigmata of AIDS. Examination of his superficial lymph nodes on 11.03.83 revealed palpable bilateral tonsillar, left axillary and bilateral shotty inguinal lymph nodes. For your information we have undertaken the enclosed AIDS related tests. We are repeating these tests before the end of term and will let you have a copy of the results when they are available.
19.03.84	**1285**	**The Royal London Hospital records** Letter from Dr Wassef to Dr Colvin. **..He was tested for Anti HTLV 3 for the first time on 12.01.84 and was found to be positive...**
29.08.84	**2647**	**The Royal London Hospital records** Virology results: Anti HBs Positive. HB_sAg Negative
06.09.84	**105** **1301**	**G. P. records/ The Royal London Hospital records** Seen by Dr Colvin, Senior Lecturer on Haematology OPD clinic at The Royal London Hospital. Letter to G. P. Review. Medication: FVIII prophylaxis 750 units every other day. Not wearing calliper regularly, but knee cool with no effusion. (May need arthrodesis in long run).
17.10.84	**103**	**G. P. records** Educational Psychologist's report: Lord Mayors Treloar College. Full IQ 116. Recommendations & Conclusions: Aim to continue with education beyond 16 in a Sixth Form College. Advantages to him doing this locally, rather than here.
12.12.84	**1302**	**The Royal London Hospital records** Letter from Dr Wassef to Dr Colvin. P.S. Lately we have changed to Heat Treated Factor VIII (Marked H in the computer sheet) for patients who were taking commercial Factor VIII. Those who were on the Lister remain unchanged.
13.06.85	**107**	**G. P. records** Genetic Counselling: No risk to sons of disease or of being carriers. All

		daughters will be carriers.
25.07.85	**108** **1307**	**G. P. records/ The Royal London Hospital records** Seen by Dr Colvin, Senior Lecturer on Haematology OPD clinic at The Royal London Hospital. Letter to G. P. dated 08.08.85. Review. Now left Lord Mayor Treloar College at Alton. Will follow up here and to continue with home treatment. Only problem is his severely damaged right knee, into which he bleeds from time to time. Referred to Mr B A Roper, Consultant Orthopaedic Surgeon, explained very young for knee replacement and a number of revisions might be necessary as he gets older, perhaps culminating in an arthrodesis at a later time. ..GRO-A not worried about AIDS but parents naturally concerned...
25.07.85	**2648**	**The Royal London Hospital records** Virology results: Anti HTLVIII positive. HB_sAg Negative
01.10.85	**2140**	**The Royal London Hospital records** Emergency admission to Royal London Hospital via A & E with bleed into knee. Anti HTLV III +ve.
01.09.86	**1323** **1740**	**The Royal London Hospital records** Seen by Dr Colvin, Senior Lecturer on Haematology OPD clinic at The Royal London Hospital. Repeated failure to attend for follow up. No more home treatment to be issued until have seen him.
01.12.86	**1742**	**The Royal London Hospital records** Seen by Dr Colvin, Senior Lecturer on Haematology OPD clinic at The Royal London Hospital. Very well. Bleed into right knee last night-woke up with bleed. Needs appointment to see local dentist. GRO-A will tell dentist blood result only if he asks. Reapplying for mobility allowance. Work- computer programmer in GRO-A for x1 year so far-another year to go. Has missed about x2 months. Hopes for work in due course. Booked to go on a boating holiday in August. Numbers of aches and pains, but no bleeds. Cancelled holiday. They need a letter confirming not well. Has not had any home treatment since October because he failed to keep appointments ... Policy: 1. Write letter re holiday 2. Send back to Mr Roper for opinion re knee surgery 3. Give home treatment supplies 4. Send appointment for CGB in x6 months. Blood tests done by Alton
04.12.86	**113** **1330**	**G. P. records/ The Royal London Hospital records** Letter from Dr Colvin, Senior Lecturer on Haematology OPD clinic at The Royal London Hospital to G. P. Review. Still having trouble with right knee. Irregular attender but well in himself, continues on home treatment and is in regular employment in a youth training scheme.
10.08.87	**1747**	**The Royal London Hospital records** Seen by Dr Colvin, Senior Lecturer on Haematology OPD clinic at The Royal London Hospital. Very well in himself. R knee is only troublesome joint. Had a bleed into knee last week – and only bleed for a long time-x1 per fortnight. Wants

		to see a dentist at home – will let him know about HIV antibodies. Has a car and has mobility allowance. Working in GRO-A. On exam: Minimum lymphadenopathy. Mouth clear, spleen not enlarged. Opinion: Unchanged. Full discussion on home treatment, Factor VIII supply, filling in returns, disposal of waste, AIDS, precautions etc. GRO-A promises to try again. Policy: Reissue home treatment. TCA Dec to arrange. Reassured that condition is clinically stable.
18.08.87	**114** **1341**	**G. P. records/The Royal London Hospital records** Seen by Dr Colvin, Senior Lecturer on Haematology OPD clinic at The Royal London Hospital. Letter to G. P. Review. Not a good attender and not complied with the rules for home treatment. Long interview. Decided to re-establish home treatment, but have some doubts as to whether will comply.
08.04.88	**1752**	**The Royal London Hospital records** Consultation between Dr Colvin and Mr GRO-A (GRO-A's uncle). Believes that his nephew has been told he cannot have come to the hospital for treatment. 'This has never been the case and indeed I have repeatedly tried to get Mr GRO-A to come for treatment. I have phoned Mrs GRO-A this evening to explain that I am willing to treat her son at any time of the day or night but cannot give him home treatment if he will not keep records or come to outpatients.
11.04.88	**1753-5**	**The Royal London Hospital records** Seen by Dr Colvin, Senior Lecturer on Haematology OPD clinic at The Royal London Hospital. ...Policy Discussion on: 1. AIDS-probably wait and see re possible treatment before illness develops. 2. x3 monthly consultations 3. Issue home treatment material 4. For further material via Brentwood if possible 5. Reissue only after receipt of forms of last set of treatment.
19.04.88	**115** **1349**	**G. P. records/ The Royal London Hospital records** Seen by Dr Colvin, Senior Lecturer on Haematology OPD clinic at The Royal London Hospital. Letter to G. P. Review. Continues to be a problem as fails to keep appointments or fill in home treatment record sheets. Remarkably well in himself and is employed by an GRO-A where very happy. Hb concentration low and evidence of iron deficiency, request for G. P. to prescribe Ferrous Sulphate.
13.06.88	**1755**	**The Royal London Hospital records** Seen by Dr Colvin, Senior Lecturer on Haematology OPD clinic at The Royal London Hospital. Further discussion on HIV. Has a girlfriend and wants to start a family. Explained that he should use a sheath and am willing to meet his girlfriend who is 16 to discuss the matter. I have said that having a child is not advisable but that if he does decide, against advice, to start a family then really the sooner the better, if his girlfriend is also HIV neg. He does not think a discussion at present would be appropriate.

18.07.88	**1353**	**The Royal London Hospital records** Referral letter from Dr Colvin, Senior Lecturer on Haematology OPD clinic at The Royal London Hospital to Mr Richards, Dept of Conservative Dentistry. Anti HBs positive, HBsAg negative and anti NIV positive.
13.10.88.	**117** **2173-** **2183**	**G. P. records/ The Royal London Hospital records** Emergency admission via A & E. Struck his head on a car bonnet whilst working on a car. No neurological deficit. Treated with 1800 units FVIII & admitted for observation.
14.12.88	**2651**	**The Royal London Hospital records** Virology results: HIV anti-core Positive HIV antigen Negative.
09.03.89	**118** **1360**	**G. P. records/ The Royal London Hospital records** Seen by Dr Colvin, Senior Lecturer on Haematology OPD clinic at The Royal London Hospital. Letter to G. P. Review. Still iron deficient. Now tried to insist he takes Ferrous Sulphate.
05.05.89	**119** **1362**	**G. P. records/ The Royal London Hospital records** Seen by Dr Colvin, Senior Lecturer on Haematology OPD clinic at The Royal London Hospital. Letter to G. P. Review. Remains very well. Has responded to Ferrous Sulphate.
26.07.89	**121** **2184-** **2189** **1763**	**G. P. records/ The Royal London Hospital records** Emergency admission with painful neck. Involved in RTC. Car rolled x2, pulled from car by girlfriend. Unable to move neck. Cervical x-ray showed fractured odontoid peg. Treated with FVIII 3,000units and reviewed by neurosurgery – fracture immobilised by a halo brace.
21.11.89	**122** **1367**	**G. P. records/ The Royal London Hospital records** Seen by Dr Colvin, Senior Lecturer on Haematology OPD clinic at The Royal London Hospital. Letter to G. P. Review. Now doing well since fractured odontoid peg and halo brace removed.
06.02.90	**123** **1369**	**G. P. records/ The Royal London Hospital records** Seen by Dr Colvin, Senior Lecturer on Haematology OPD clinic at The Royal London Hospital. Letter to G. P. Review. Recent sore throat which recovered immediately with erythromycin. No new physical signs. Blood tests normal.
22.08.90	**124** **1377**	**G. P. records/ The Royal London Hospital records** Seen by Dr Colvin, Senior Lecturer on Haematology OPD clinic at The Royal London Hospital. Letter to G. P. Review. Married GRO-A Taking no drugs and no abnormal signs save for fixed flexion deformity in his right elbow and chronic damage to right knee. Plan: Referred to Dental Dept and arranging for inhaled Pentamidine prophylaxis. Declined offer of regular Zidovudine prophylaxis and refused to have a Hep C test. Offered sexual counselling. Wife will think about Hep B and a HIV test, but refused Hep C test.

31.07.91	**129** **1384**	**G. P. records/ The Royal London Hospital records** Seen by Dr Colvin, Senior Lecturer on Haematology OPD clinic at The Royal London Hospital. Letter to G. P. dated 07.08.91. Review. Well but difficulty complying with medication. Doubt whether ever will. Explained better to take nothing than medication from time to time.
02.06.93	**133** **1399** **1786**	**G. P. records/ The Royal London Hospital records** Seen by Dr Colvin, Senior Lecturer on Haematology OPD clinic at The Royal London Hospital. Letter to G. P. dated 08.06.93. Review. Wife recently left him. Impossible to arrange satisfactory supervision of home treatment. Not compliant with HIV prophylaxis. Plan: Gone away to think about what wants to do and when decided to contact. Review Sept 93.
13.10.93	**136** **1402** **1797**	**G. P. records/ The Royal London Hospital records** Seen by Dr Colvin, Senior Lecturer on Haematology OPD clinic at The Royal London Hospital. Letter to G. P. dated 15.10.93. Review. Struggling with divorce and death of one of his friends with haemophilia.
14.12.94	**2663**	**The Royal London Hospital records** Virology results: Hep C virus detected.
16.08.95	**150** **1831**	**G. P. records** Seen by Dr Colvin, Senior Lecturer on Haematology OPD clinic at The Royal London Hospital. Letter to G. P. dated 17.08.95. Review. No factor VIII recently, feels sick after meals, no loss of appetite. x20 pints beer a week. Not filling in home treatment sheets. Symptoms are emotional. Offered counselling in Graham Hayton Unit with Dr J Sweeney for psychiatric opinion. Plan: Stopped home treatment programme.
08.10.96	**157** **1450**	**G. P. records/ The Royal London Hospital records** Seen by Dr Colvin, Senior Lecturer on Haematology OPD clinic at The Royal London Hospital. Letter to G. P. Review and consideration of restarting home treatment.
05.03.97	**160** **1455** **1872**	**G. P. records/ The Royal London Hospital records** Seen by Dr Colvin, Senior Lecturer on Haematology OPD clinic at The Royal London Hospital. Letter to G. P. dated 12.03.97 Review with Dr Sweeney, HIV Specialist. Lacks motivation, wants stronger pain killers. Tearful, when unable to suggest analgesia. Reviewed by Dr Chikanza, Consultant Rheumatologist in March 1997, who thought he was depressed and prescribed Amitriptyline.
21.05.97	**162** **1457** **1873**	**G. P. records/ The Royal London Hospital records** Seen by Dr Colvin, Senior Lecturer on Haematology OPD clinic at The Royal London Hospital. Letter to G. P. dated 03.06.97. Review. Pain better since taking Amitriptyline. Now stopped all medication save, on demand Factor VIII.
26.11.97	**165** **1461** **1878**	**G. P. records/ The Royal London Hospital records** Seen by Dr Colvin, Senior Lecturer on Haematology OPD clinic at The Royal London Hospital. Letter to G. P. dated 10.12.97. Review. Still not taking any treatment or prophylaxis for his HIV infection.

02.06.99	**168** **1476** **1888**	**G. P. records/ The Royal London Hospital records** Seen by SpR on Haematology OPD clinic at The Royal London Hospital. Letter to G. P. dated 28.06.99. Review. Still not taking any medication.
05.01.00	**169** **1891**	**G. P. records** Seen by SpR on Haematology OPD clinic at The Royal London Hospital. Letter to G. P. dated 10.01.00. Review in joint immunology/haematology clinic. Dry cough for last week. On exam: Febrile 38°. No lymphadenopathy, anaemia. Creps at left base. Clinical picture: Suggestive of pneumonia. Plan: Erythromycin, changed to Clarithromycin and review x1 week.
12.04.00	**170** **1477** **1893**	**G. P. records/ The Royal London Hospital records** Seen by Dr Colvin, Senior Lecturer in Haematology OPD clinic at The Royal London Hospital. Letter to G. P. dated 25.04.00. Review. Much better now winter over. Chest clear. Recommended to continue with inhaled Pentamidine for PCP, but not compliant. Has agreed to start specific antiviral therapy for HIV infection and agreed to accept residential supervision of his medication. Proposed regime Zidovudine and Nevirapine.
09.08.00	**171** **1482** **1895**	**G. P. records/ The Royal London Hospital records** Seen by SpR on Haematology OPD clinic at The Royal London Hospital. Letter to G. P. dated 16.08.00. Review. Took antivirals for x3 weeks, felt too tired. Opinion main cause is AZT. Plan: To try different combination of anti-HIV including Stavudine, 3TC, Nevirapine.
22.08.00	**124**	**G. P. records** Seen by Dr Colvin, Senior Lecturer on Haematology OPD clinic at The Royal London Hospital. Letter to G. P. Review. Married GRO-A, recovered from broken neck. Taking no drugs, no abnormal signs apart from chronic right knee. Plan: PCP prophylaxis, as CD4 count low. Declined regular Zidovudine prophylaxis and Hep C test. Discussed with wife re Hep B vaccination & HIV test, declined Hep C test.
08.11.00	**173** **1486** **1896**	**G. P. records/ The Royal London Hospital records** Seen by Dr Colvin, Senior Lecturer in Haematology OPD clinic at The Royal London Hospital. Letter to G. P. dated 14.11.00. Review. Great difficulty complying with medical advice. Not taken Pentamidine or antivirals.
05.09.01	**177** **1494**	**G. P. records/ The Royal London Hospital records** Seen by Registrar on Haematology OPD clinic at The Royal London Hospital. Letter to G. P. dated 19.09.01. Review. Managing antiviral medication, but not Pentamidine nebulisers. Medication: D4T & Lamivudine. US scan shows enlarged spleen. Plan: Changed to Septrin syrup for PCP prophylaxis. Have mentioned possibility of Hep C therapy, but not possible to start until HIV treatment is fully established.
24.06.02- 17.07.02	**2253-** **2371**	**G. P. records/The London Hospital records** Elective admission to The Royal London Hospital under Mr Scott, Consultant Orthopaedic Surgeon for Right TKR (Total Knee

		Replacement).
28.08.02	**180** **1507** **1911**	**G. P. records/ The Royal London Hospital records** Seen by Dr Colvin, Senior Lecturer on Haematology OPD clinic at The Royal London Hospital. Letter to G. P. Review. Unable to take retrovirals whilst in patient, now restarted 3TC, DDI and Tenofovir 1, reluctant to resume Pneumocystis prophylaxis.
17.03.04	**184** **1520**	**G. P. records/ The Royal London Hospital records** Seen by Dr Colvin, Senior Lecturer on Haematology OPD clinic at The Royal London Hospital. Letter to G. P. dated 22.03.04. Review. New regime of retro-virals: Zidovudine, 3TC, DDI Atazanavir & Fluconazole. Not using PCP prophylaxis and takes FVIII on demand.
18.03.04	**1519**	**The Royal London Hospital records** Letter from Dr Colvin to Mr GRO-A re complaint regarding TKR in 2002.
25.03.04	**1521**	**The Royal London Hospital records** Letter from Dr Skinner, Consultant in GU Medicine to Dr Colvin and G. P. confirming patient starting new anti-retroviral medication. HIV +ve since early 1980s, when he became infected through receiving blood products.
16.06.04	**186** **1524**	**G. P. records/ The Royal London Hospital records** Seen on Joint HIV/Haemophilia OPD Clinic by Heather Oakervee, SpR in Haematology at The Royal London Hospital. Letter to G. P. dated 22.06.04 Review. Problems much improved and since recent admission, compliance adherence at Sussex Beacon, has achieved nearly 100% with Atazanavir, Combivir and DDI. Remains on on-demand Factor VIII therapy rather than prophylaxis. Would be ideal to teat Hep C, but not been possible to discuss due to poor compliance with HIV medication. Ankle remains a problem, pain recurring. Plan: Review x3 months.
2005	**486**	**Oxford University Hospitals NHS Trust records** Developed a sinus. (By 2008 had x3 sinuses)
14.02.05- 19.02.05	**1780-** **1825**	**The Royal London Hospital records** Elective admission to The London Hospital under ENT for Septoplasty.
14.02.05	**1541**	**The Royal London Hospital records** Application to Skipton Fund for Additional Payment of £25,000.00 completed by Dr Colvin.
20.05.05- 27.05.05	**2425-** **2450**	**The Royal London Hospital records** Emergency admission under Haematology Team re swollen right knee.
19.10.05	**187** **1579** **1950**	**G. P. records/ The Royal London Hospital records** Seen on Joint HIV/Haemophilia OPD Clinic by J Pandya, SpR in Haematology at The Royal London Hospital. Letter to G. P. dated 26.10.05. Review.60% compliance with retroviral treatment. On Rifadin for possible mycobacter species infection of right knee joint. Continues on Factor VIII prophylaxis until 10.11.05, when will be reviewed. Has developed mutations in HIV genome, so medication choice been difficult.

		Plan: Stop retroviral treatment and review with Dr Colvin & Dr Skinner on 16.11.05.
30.11.05	**1587**	**The Royal London Hospital records** Letter from Dr Skinner to Dr F Connell, Consultant Psychiatrist. Request for Outpatient appointment.
27.09.06	**1611**	**The Royal London Hospital records** Seen at Ambrose King Centre. Letter from Dr F Connell, Consultant Psychiatrist to Dr Skinner & Dr Colvin dated 09.10.06. Patient seen at Depart Adult Mental Health. Patient bought a house near to parents in GRO-A. Keen to try increased dose of Mirtazapine and review.
02.02.07	**1649**	**The Royal London Hospital records** DNA appointment with Dr F Connell, Consultant Psychiatrist.
03.04.07-13.08.08	**2451-2644**	**Oxford University Hospitals NHS Trust records/G. P. records/ The Royal London Hospital records** Gastroscopy & banding of varices x6 sessions at The Royal London Hospital. GI bleed post-banding.
12.04.07	**1657**	**The Royal London Hospital records** Letter from Dr Skinner to Dr F Connell, Consultant Psychiatrist. Request for Outpatient appointment.
2007		**Patient moved to GRO-A.** **Still attending Barts and the London Hospital for treatment for HIV Haemophilia, Hepatitis C, B and knee surgery**
12.07.07	**1681**	**The Royal London Hospital records** Application to Skipton Fund for Additional Payment of £25,000.00 completed by Prof Pasi.
24.06.08	**199**	**G. P. records** Referral letter from Prof Pasi, Consultant Haematologist, The Royal London Hospital to Mr G Scott, Consultant Orthopaedic Surgeon re infected Right TKR.
03.07.08	**202**	**G. P. records** Letter from Mr G Scott, Consultant Orthopaedic Surgeon re infected Right TKR to Prof Pasi, Consultant Haematologist, The Royal London Hospital. Discussed surgical options with Mr GRO-A, advocated excision arthroscopy, but at present declined by Mr GRO-A
13.08.08	**204 2614-2643**	**G. P. records/ The Royal London Hospital records** Elective admission to The Royal London Hospital, Whitechapel for Gastroscopy. Findings: Small Grade 1 gastric varices.
17.09.08	**469**	**Oxford University Hospitals NHS Trust records** Transfer of care to Churchill Hospital Haemophilia Centre. (Letter dated 05.11.06). Was at Royal London. To discuss with John Pain on 22.09.08.
31.10.08	**?**	**Oxford University Hospitals NHS Trust records** Admission to Milton Keynes with septic Right TKR.
03.11.08	**207 217**	**G. P. records/ Oxford University Hospitals NHS Trust records** Referral letter from Dr L Bowles, Consultant Haematologist, The Royal

		London Hospital to Dr P Giangrande, Haemophilia Centre, John Radcliffe Hospital, Oxford. Transfer of care as now living in GRO-A. Past problem of compliance with retrovirals. Has infected right TKR, discharging with swabs that have persistently grown Staph aureus. Hep C-has had gastric varices banded and recommended endoscopy every x6 months.
06.11.08	**218**	**Oxford University Hospitals NHS Trust records** Letter from Dr Colvin to Dr P Giangrande. Referral. *'…as you will appreciate many or perhaps most of his friends at Lord Mayor Treloar have died and his uncle recently died of a Hepatoma…'*
12.11.08	**469**	**Oxford University Hospitals NHS Trust records** Seen by Prof Giangrande (Spoken to Dr Miller at Milton Keynes.
20.11.08	**473**	**Oxford University Hospitals NHS Trust records** Seen in Oxford for 1st time. Treatment: Kogenate on demand 2000-3000 units. FVIII,1%, but no bleeds-prob due to inactivity. Last joint bleed > x1 year ago. Trustee of GRO-A, trained as expert patient. No current treatment regime. Stopped on advice of BIU on 10.11.08. Anti-retrovirals: Kaletra 5mg od , Zoplione, DF1118 prn.
21.11.08	**470**	**Oxford University Hospitals NHS Trust records** Blood show anaemia-patient aware, but 'never got to bottom of it'. Hb 6.7 Plan: Admit for blood transfusion x2 units.
10.12.08	**478** **1389**	**Oxford University Hospitals NHS Trust records/ The Royal London Hospital records** Seen on joint clinic. Known oesophageal varices. Banded. Frequent blood transfusion. Poor compliance with retrovirals in past. Currently on Kaletra elixir. Right knee prosthesis-infected for last 2-3 years. Recent bout of sepsis in Milton Keynes. On exam: Thin & pale, No LN, mouth clear. Large spleen, no liver, no ascites/oedema. Plan: Needs liver US scan, capsular endoscopy and Ortho opinion re knee. Start Co-trimoxazole and review x2 months.
01.01.09	**470**	**Oxford University Hospitals NHS Trust records** Hb 7.3 Plan: Capsule camera & US scan 13.01.09. x3 units blood 02.01.09.
12.02.09	**485-89**	**Oxford University Hospitals NHS Trust records** Seen by Orthopaedics. Admitted 31.10.08 to Milton Keynes with septic Right TKR (Total Knee replacement). Knee generally sore day to day. Discharges more if moving around. On exam: x3 sinuses. Discussed with Ivor Bryon. Plan was for David Stubbs to do excision and for Adrian Taylor to reconstruct. Call to BIU was explained. Plan: Admit to BIU (Bone Infection Unit). Asap
24.02.09	**630**	**Oxford University Hospitals NHS Trust records** Seen on ward- admitted. Right TKR London 2004 due to recurrent haemoarthrosis target joint from age 9 yrs.

		On exam: Malar flush/bilateral ptosis. Notably cachetic. Issues: HIV and under treated. Hep C and varices, Haemophiliac A, infected prosthetic knee and previous episodes of sepsis. Reviewed by Plastics 25.02.09. Further review by Orthopaedics. Suggested need for x2 stage procedure.
26.02.09	**633**	**Oxford University Hospitals NHS Trust records** **Discharged** from clinic.
03.03.09	**492**	**Oxford University Hospitals NHS Trust records** Admitted to Milton Keynes for x2 units blood transfusion.
17.03.09	**822**	**Oxford University Hospitals NHS Trust records** Elective admission to Nuffield Orthopaedic Centre NHS Trust for surgery.
18.03.09	**789**	**Oxford University Hospitals NHS Trust records** **Operation Note:** 1st Stage Revision Right Total Knee Replacement Nuffield Orthopaedic Centre NHS Trust. (NOC).
18.03.09	**860**	**Oxford University Hospitals NHS Trust records** Seen by Occupational Therapy. Mobility: v limited due to pain/muscle strength/no walking aids. Sometimes hires scooter, if in town. Uses bottom to go upstairs. Care assists with all PADL's when required
21.03.09	**831**	**Oxford University Hospitals NHS Trust records** Transfer to Bone Infection Unit. Abdomen distension. Diagnosis: Ascites 2° cirrhosis. Likely decompensation of chronic liver disease 2° surgery/iv fluids/chronic infection.
25.03.09	**844**	**Oxford University Hospitals NHS Trust records** **Procedure: PICC Line insertion.**
01.04.09	**859**	**Oxford University Hospitals NHS Trust records** **Discharged** from hospital.
01.04.09	**1087**	**Oxford University Hospitals NHS Trust records** **Histopathology report: Capsule from septic right TKR.** Scattered focally heavy mixed acute and chronic inflammatory cell infiltrate. Features suspicious of active infection.
20.04.09	**501**	**Oxford University Hospitals NHS Trust records** MDT review of anaemia. Plan: Baseline bloods.
02.06.09	**974**	**Oxford University Hospitals NHS Trust records** Elective admission to Nuffield Orthopaedic Centre NHS Trust for surgery.
03.06.09	**951**	**Oxford University Hospitals NHS Trust records** **Operation Note:** 2nd Stage Revision Right Total Knee Replacement and Bone Marrow Biopsy. Nuffield Orthopaedic Centre NHS Trust.

11.06.09	**992**	**Oxford University Hospitals NHS Trust records** **Discharged** from hospital.
17.06.09	**1088**	**Oxford University Hospitals NHS Trust records** **Histopathology report: Bone marrow biopsy.** No evidence of lymphoma or a leukaemic process, no granulomas can be seen.
03.07.09- 31.09.09	**1047**	**Oxford University Hospitals NHS Trust records** Seen by Physiotherapy. Aim: To be walking with knee flex/extension x2 months. Plateaued by 31.09.09. Plan: To complete hydrotherapy, then discharge.
23.07.09	**1076**	**Oxford University Hospitals NHS Trust records** **CT Liver Triple Phase.** **Impression:** Evidence of liver cirrhosis with marked portal hypertension and spleenomegaly. Peri-oesophageal varices present. Small focus of increased vascularity in periphery of segment V-no definite liver mass identified. Appearances may represent a regenerative or dysplasic nodule. No significant intra-abdominal free fluid. Bibasal varicose bronchiectasis. TIPPS procedure feasible. Right hepatic vein poorly visualised.
June 2009	**211**	**G. P. records** Letter from Prof K J Pasi, Consultant Haematologist , Haemophilia Centre, The Royal London Hospital, Whitechapel to Mr GRO-A, copy to G. P. Letter to all patients known to be treated with UK plasma products between 1980-2001. Evidence of abnormal protein associated with variant Creutzfeldt-Jakob Disease (vCJD) found in spleen at post mortem. Patient, in his 70s and did not die or have any symptoms of the disease during life. Patient was treated in 1990s with UK plasma-sourced clotting factor (FVIII) and also transfusions of red cell and surgery. Investigations now concluded that most likely source od the VCJD infection was UK plasma-sourced clotting factors. ...At increased risk of vCJD for public health purposes and should not donate blood, not donate organs, tissues (including bone marrow, sperm, eggs or breast milk). Should tell anyone who is to perform any medical/surgical procedure about your risk of CJD. Should tell your family about increased risk in case may need surgical/medical treatment in future and unable to tell them yourself.
09.06.10	**532** **1080**	**Oxford University Hospitals NHS Trust records** **US Liver.** Comparison made to US study dated 09.12.09 & MRI study dated 14.01.10. Liver enlarged and diffusely abnormal parenchymal echogenicity. Hepatoma cannot be ruled out.
08.09.10	**533**	**Oxford University Hospitals NHS Trust records** Seen at Joint clinic. Mr GRO-A is considering transferring to another Hepatologist. Plan: For liver scan and endoscopy next month. Right ankle bleed – previous Kogenate x2 days ago. Pre FVIII 68%, post FVIII 168%.

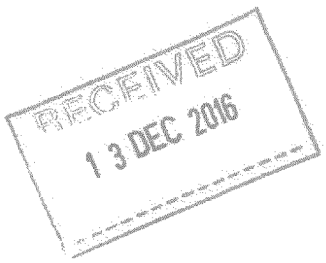
11.10.10	**610**	**Oxford University Hospitals NHS Trust records** Elective admission to John Radcliffe Hospital. Gastroscopy: Indication: Chronic liver disease. Oesophageal varices. Varices successfully eradicated in distal oesophagus, no strictures. Plan: Repeat OGD in x1 year. Ideally should be on Propanolol.
15.09.11	**556**	**Oxford University Hospitals NHS Trust records** Steroid injection into left shoulder at NOTC (Nuffield Orthopaedic Treatment Centre). (3rd injection – x2 previous injections-successful).
26.09.11	**555**	**Oxford University Hospitals NHS Trust records** Phone call from Mr GRO-A. Has had a severe bleed in shoulder and arm following steroid injection I x4 days ago. Used 30,0000 units last week!. Will attend Centre today.
03.10.11	**558**	**Oxford University Hospitals NHS Trust records** Bone Infection Unit. 2nd day post op
07.12.11	**563**	**Oxford University Hospitals NHS Trust records** Seen on combined HIV/HCV clinic. Has stopped taking Kaletra, agreed to re-start today). On exam: Small amount of ascites. Spironolactone started
28.12.11	**565**	**Oxford University Hospitals NHS Trust records** Phone call from Northampton. Mr GRO-A admitted with serious GI bleed, attributed to varices. Blood and platelet transfusion. Needs urgent endoscopy and injection of varices. Cannot delay until planned endoscopy here on 09.01.12.
29.12.11	**565**	**Oxford University Hospitals NHS Trust records** **Procedure: Emergency banding of oesophageal varices.** (Northampton General Hospital)
09.01.12	**620** **567**	**Oxford University Hospitals NHS Trust records** Elective admission to John Radcliffe Hospital. (Dr Collier) Gastroscopy: Indication: Previous examination for oesophageal varices. Recent banding at Northampton General Hospital. On exam: Quick look. No varices. Banding ulcers seen. No further banding indicated. Varices seen high up at 25cm but well covered and above perforators. Plan: repeat in x2 weeks.
14.01.12	**662**	**Oxford University Hospitals NHS Trust records** Emergency admission to Northampton General Hospital with GI bleed. Intubated prior to OGD. Senstaken Blakemore tube placed. (Size 8 COETT). Grade 2 view.
17.01.12	**662**	**Oxford University Hospitals NHS Trust records** Transferred from Northampton to Royal Free Hospital for TIPPS procedure.
18.01.12	**662**	**Oxford University Hospitals NHS Trust records** **Procedure: TIPPS.**
21.01.12	**662**	**Oxford University Hospitals NHS Trust records** Admitted to AICU (Transferred from Royal Free Hospital –intubated and ventilated due to encephalopathy following TIPPS procedure). PMH:

		Severe Haemophilia A-on Kogenate 2000 units alternate days HIV, not on retrovirals just prior to current presentation (Stopped Sept 2011)-but was on Kaletra mono-therapy prior to this. Hep C- Chronic liver disease & oesophageal varices.
24.01.12	**734**	**Oxford University Hospitals NHS Trust records** Daily assessment by Physiotherapy. Intubated 2° to TIPPS acquired encephalopathy GCS 9/15
25.01.12	**686-89**	**Oxford University Hospitals NHS Trust records** Daily review. Infection.?Organism-probable bacterial ?CMV ?PCP (not typical on Chest x-ray). Decompensating LFTs 2° to sepsis. Plan: EDTA sample. US scan abdo & sample if ascites. No growth so far. **US liver & ascitic tap.** Seen by Consultant review. Outlook pretty poor. In addition to liver disease, he now has a ventilation pneumonia-it does not look like PCP on CMV. Plan: Stop the Fluconazole and have a low threshold for withholding the retroviral drugs if the liver worsens.
26.01.12	**734**	**Oxford University Hospitals NHS Trust records** Extubated.
27.01.12	**736**	**Oxford University Hospitals NHS Trust records** Daily assessment by Physiotherapy. Patient compliant, managing well on Optiflow.
28.01.12-29.01.12	**737-740**	**Oxford University Hospitals NHS Trust records** Daily assessment by Physiotherapy. Some support required on stepping but otherwise managed well. To go out in wheelchair with family.
29.01.12 17:45hrs	**719-721**	**Oxford University Hospitals NHS Trust records** AICU daily review. Resolving . Background haematoma-F8/TXA/Vit K Arterial line out yesterday. Resolving ALT, good renal function . Plan: Discharge ward. Discuss with gastro. Aware patient leaving AICU. Discuss with Haematology- ?stop Vit K, ?F level, ?PICC line for bloods whilst in-patient. Continue antibiotics for x7 days and review. Monitor Flexiseal output. Transferred to ward from AICU.
31.01.12	**733**	**Oxford University Hospitals NHS Trust records** Patient left ward with NG tube and cannula on way to Northampton General now. Called sister-will try to bring patient back. Will let Northampton General Hospital know of patient.
01.02.12	**576**	**Oxford University Hospitals NHS Trust records** Self-**discharged**
03.02.12	**576**	**Oxford University Hospitals NHS Trust records** Seen by Haem Registrar. Review. Chance addition of Spironolactone – feels better than did, but still SOB (short of breath) at rest – obvious ascites. Decided for x1 week of alternate days Kogenate (2000 units). Venflon removed. Bloods done at Dr Collier's request. Plan: To review in x2 weeks. Discussion re prophylaxis. Mr GRO-A not

		inclined to go this way at present, rather for targeted prophylaxis. If for full, will need part r other more permanent access.
21.05.12	**578**	**Oxford University Hospitals NHS Trust records** Telephone call from Northampton A & E Dept to Prof Giogrande. Admission with suspected sepsis, site and source not clear. Provided clinical synopsis and emphasised need for full cover for any invasive procedure. Suggested A & E speak to local Haematologists to get him reviewed and contact me. Dr Collier informed.
22.05.12	**579**	**Oxford University Hospitals NHS Trust records** Dr Conlon informed of Mr GRO-A's admission to Northampton General Hospital by ANP (Advanced nurse Practitioner).
GRO-A 12	**579**	**Oxford University Hospitals NHS Trust records** **Mr GRO-A died at Northampton General Hospital.**
GRO-A 12	**579**	**Oxford University Hospitals NHS Trust records** Tel message left at Oxford to inform them of Mr GRO-A's death.
15.02.13	**215**	**G. P. records** Letter from Mrs A Pember, HM Coroner, Northampton to Consultant Haematologist, The Haemophilia Centre, The Royal London Hospital, Whitechapel.
30.08.13	**216**	**G. P. records** Letter from Dr D Hart, Senior Lecturer in Haematology, The Haemophilia Centre, The Royal London Hospital, Whitechapel to Mrs Pember, HM Coroner for County of Northampton. *'....He unfortunately contracted both HIV and Hepatitis C from infected blood products through a period of multiple transfusion transferred viral infection in the haemophilia community....'*

Report on Mr GRO-A (deceased)

GRO-A 1969 - GRO-A 2012



Requested by HM Senior Coroner Milton Keynes

Mr Tom Osborne LL.B
Civic Offices
1 Saxon Gate East
Milton Keynes
MK9 3EJ

Report prepared by:

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Director Haemophilia Centre The Royal London Hospital 1977-2007

My letter of instruction includes the statement "I shall be grateful if you will prepare a report for me setting out the details of your own involvement and treatment of GRO-A and it would also benefit my inquiry if you were able to indicate when you think it is likely on the present evidence available as to when he was infected with both HIV and hepatitis C. It would appear likely that it was at the time he was treated with blood products that were imported from the United States".

I was responsible for Mr GRO-A's care, (when he was in London), from my appointment as an Honorary Consultant at The Royal London Hospital in 1977, but my first consultation with him was in 1979 when he was a pupil at Lord Mayor Treloar College, Alton Hampshire. My responsibility ended when I retired from my post at The London in April 2007.

1. Introduction

1.1 Background to Haemophilia A

Haemophilia A is an inherited deficiency of blood clotting factor VIII, the gene for which is carried on the X chromosome. This means that, with rare exceptions, only male members of the family are severely affected but female carriers sometimes have a mild bleeding tendency. People with haemophilia (PWH), when severely affected, suffer from apparently spontaneous bleeding, mainly into the joints and muscles, bleeding after injury and surgery and sometimes intracranial bleeding.
Until treatment became available in the mid-1960s life expectancy was very poor and PWH who survived into late childhood, adolescence and adult life were often afflicted by acute and chronic joint and muscle damage which caused very marked pain and suffering. Physical and emotional disabilities were common, due to the locomotor damage suffered, a lack of secure educational opportunities and subsequent difficulty in obtaining employment.

1.2 Cryoprecipitate

In the mid-1960s it became possible to concentrate the factor VIII present in individual donor plasma units by a simple process known as "cryoprecipitation" and the era of treatment began. PWH were given cryoprecipitate by intravenous injection as soon as a bleeding episode occurred or if there was a need for surgery. Each bag of cryoprecipitate was derived from a single donor, was stored at -18° C in a freezer and a few bags were sufficient to treat a simple bleed. For more serious problems, or for surgery, 8-12 hourly injections of larger doses were required, which were continued until the risk of bleeding was over and healing had begun.

1.3 Education

Children with haemophilia were often educated at schools for the disabled, the principal school for this purpose being the Lord Mayor Treloar College in Alton Hampshire where there was a Haemophilia Centre (HC). The Director of the HC was Dr Tony Aronstam, who had an active interest in the care of the children with haemophilia and who published extensively until his retirement. Three of the children from The London Hospital HC were educated there but the improved opportunities for education at home which evolved in the 1970s eventually made referrals to Alton unnecessary.

1.4 Inhibitor development

As soon as replacement therapy began, about a quarter of treated, severely affected PWH developed antibodies to factor VIII (often known as inhibitors) and the presence of inhibitory activity made replacement therapy partly or wholly ineffective.

1.5 Large pool concentrates

By 1970, when my career in haematology began, freeze dried factor concentrates were being introduced and these were derived from many thousands of pooled donations. Concentrates could be stored at room temperature and were easy to make up by adding diluent, so that it became possible to undertake major surgery with relative ease and the introduction of home therapy (HT) was facilitated. It was quickly appreciated that these concentrates had an increased risk of transmitting hepatitis B and also an unidentified virus, which was called Non A-Non B (NANB). Hepatitis B infection was soon largely eliminated by donor selection but there was no test for NANB, which sometimes caused jaundice but often produced no symptoms, even when there was chemical evidence of inflammation on performing liver function tests (LFTs).

1.6 Non A non B Hepatitis

By the early 1980s attention turned to efforts to inactivate the NANB virus. Initial attempts were not successful but by the mid-1980s it had become clear that all PWH treated with large pool concentrates, whatever the plasma country of origin, had been exposed to NANB and that heat treatment (and later solvent/detergent treatment) of concentrates was capable of eliminating the risk of NANB transmission by viral inactivation.

1.7 HIV infection

In the late 1970s the condition known as Acquired Immune Deficiency Syndrome (AIDS) was described in the USA and by the early 1980s it was clear that PWH could be affected as a result of concentrate transfusion. By 1984 the Human Immunodeficiency Virus (HIV) had been described and identified as the cause of AIDS and a screening test for those infected was developed. Approximately 1,200 PWH were infected in the UK, particularly from concentrates derived from the USA, but also from UK sourced plasma. It became apparent in 1984/5 that the viral inactivation process which had eventually been found to be effective in eliminating the risk of NANB infection could also be used to inactivate HIV and from about 1986 onwards no further viral infection with NANB or HIV occurred.

1.8 Advances in virology

In 1989 Hepatitis C Virus (HCV) was found to be the cause of NANB and virtually all those treated with large pool concentrates before 1985 were confirmed as having been infected. Screening tests to eliminate contamination of plasma pools with HCV were then developed. It was not possible entirely to eliminate the risk of infection with non-lipid enveloped viruses such as hepatitis A (HAV) and human parvovirus. In the late 1980s and 1990s and up until the present day, there have been major advances in antiviral therapy for both HIV and HCV infection, which are both now treatable.

1.9 Consequences of infection

Sadly, many PWH fell ill and died as a consequence of HIV infection, especially in the late 1980s and 1990s but some PWH are still alive with chronic HIV infection up to the present day.
In more recent years, the long term consequences of HCV infection have become apparent, so that many PWH have experienced the very serious effects of fibrosis of the liver (cirrhosis), portal hypertension and liver cancer (hepatocellular carcinoma) and many have died.
PWH co-infected with HIV and HCV do not always die of a single specific complication of infection but rather of the debilitating illness caused by a combination of all the problems that they have suffered.

1.10 Recombinant Factor VIII

In the mid-1990s synthetic (recombinant) factor VIII became available, initially containing some human protein but more recently devoid of human or animal products.

1.11 New Variant Creutzfeldt-Jakob Disease (nvCJD)

By the beginning of the millennium a further threat to the safety of clotting factor concentrates had emerged in the UK in the form of a prion transmitted disease of the nervous system, entitled nvCJD, which was initially recognised in cattle. Human cases arose as a result of consumption of beef and it then became clear that prions were transmissible in blood products. It is likely that at least one PWH has been infected with prions which were found at autopsy in a patient who died from other causes. No case of symptomatic nvCJD has been described in the haemophilia community in the UK or elsewhere but a decision has been made to use only recombinant factors in the UK and this policy has been fully established since 2004.

1.12 Modern Therapy

The result of the modern availability of safe factor concentrates, HT, prophylaxis, recombinant factor VIII and improved strategies and treatment of those who develop inhibitors has had a dramatic effect on the life expectancy and quality of life for PWH. New long-acting concentrates may further improve quality of life and the advent of effective gene therapy now gives the prospect of cure in the coming decades.

2. Mr GRO-A's case

The account of Mr GRO-A's case is based on a review of the medical records provided to me by the Coroner and also from my personal recollection.

2.1 The Early Years (1969-1985)

2.1.1 GRO-A was born on GRO-A 1969 into a family with a history of severe haemophilia A (factor VIIIC level <0.01 i.u. /ml = <1%). The gene mutation has been confirmed as Intron 1 inversion so that his blood was effectively entirely lacking in this essential blood clotting factor and the potential consequences have been reviewed above. He did not develop an inhibitor to factor VIII at any time in his life.

2.1.2 The record shows that when a haematoma was noted in the right loin on 16th October 1969 at the age of GRO-A months, haemophilia was immediately suspected and confirmed on 18th October at The London Hospital, where he was under the care of Dr RH Dobbs, consultant paediatrician and Dr GC Jenkins, consultant haematologist. By June1970 treatment with cryoprecipitate was well established.

2.1.3 In 1971 he was under the care of Dr GRO-A at GRO-A District Hospital and frequent bleeding episodes were treated with cryoprecipitate. The record (page 43) shows that he was treated with 2 units of AHF (human) on 16th November 1973. This was an NHS UK plasma derived factor VIII concentrate and it can be assumed that infection with HCV took place on or before this date, (depending on when he was first exposed to a large pool concentrate). Treatment with cryoprecipitate and factor VIII concentrate then continued into the late 1970s, including treatment at GRO-A.

2.1.4 There is mention of a recommendation to send GRO-A to the protective environment of a school for the physically handicapped in June 1976 and knee damage is recorded as early as February 1977.

2.1.5 By 1977 he was at GRO-A and his haemophilia care was organised from St Mary's Hospital Portsmouth. Treatment was usually with a large pool concentrate which was sometimes recorded as an NHS UK plasma derived product but the record is not complete.

2.1.6 A letter from Dr Jeanne Herzog, child psychiatrist (page 84), dated 20th November 1979 gives an early indication of emotional and behavioural difficulties but by 1980 he had begun to make good progress, although the right knee had, by then, entered the phase of chronic arthropathy.

2.1.7 I saw GRO-A for the first time in 1979, when he was due to start his education at The Lord Mayor Treloar College. In a typed note of our consultation, dated 10th September 1979, we issued a new special medical card, organised a trip for him and his mother to go to Alton, discussed the advantages of home treatment, introduced the family to The Haemophilia Society and recommended Dr Peter Jones' book for patients entitled "Living with Haemophilia" (pages 1203 and 1712).

2.1.8 There is a record dated 27.12.79 noting his allergy to cryoprecipitate (page1210) and another dated 27th October 1980 stating that GRO-A was "allergic to cryoprecipitate". (page 2021). Alton decided to offer him prophylaxis because of repeated knee bleeds but I wrote a letter to Dr Wassef, dated 2nd September 1981, noting that "GRO-A has been very difficult to manage during the summer holidays" and recording his "refusal to comply with medical advice" (page 92). I also noted that the condition of his knee was beginning to deteriorate. The nursing record shows that we were issuing NHS factor VIII concentrate at the time but commercial factor VIII was also given to GRO-A at The London (for instance there is a record of this in January 1981at page 2042). I believe that Alton would also have been using imported concentrates at the time, as they were trying to offer GRO-A prophylaxis in the enclosed environment of the College, supplies of NHS concentrate were very limited and, as noted in **2.2.9**, other pupils at Alton died as a result of HCV and HIV infection.

2.1.9 GRO-A's behaviour led to a case conference at Lord Mayor Treloar in October 1981 in which he was described as having a "severe emotional disturbance" (pages 1235 -1240) and the summer holidays of 1982 were very challenging for him and for the staff at The London. On 12th July 1982 I wrote "GRO-A does not want to have haemophilia and will fight against anyone who tries to help him. There is no future at present in offering him prophylaxis, physiotherapy or any form of rehabilitation treatment." (page 2100). I suggested that I should discuss his case with Dr Tony Jackson, our consultant paediatrician, and I considered the value of referral to a child psychiatrist.

2.1.10 There is a record that we tested GRO-A's blood for hepatitis B in March 1983, a positive antibody result indicating that he had been previously infected, was immune and did not therefore require vaccination. At a consultation on 2nd June 1983 I wrote "Mrs GRO-A worried about AIDS, pigs' blood etc" and I then wrote "AIDS explained to Mrs GRO-A". I also noted Mrs GRO-A's reluctance to consider prophylaxis. GRO-A's knee was giving cause for concern and he was barely able to walk, so an orthopaedic referral was made with a view to considering performing a synovectomy. He did not always attend for his surgical appointments. In 1984 he was wearing a caliper and attempting every other day prophylaxis but compliance continued to be a problem. We began to use heat treated factor VIII during half term from Lord Mayor Treloar on 29th May 1985 and by August GRO-A had left the College and was on home treatment at The London, where we tried to provide him with appropriate care, despite his reluctance to attend.

2.2 Adult Life (1985/6 – 2007) Dr Brian Colvin The Royal London Hospital

2.2.1 On 25th July 1985 GRO-A was working locally and his knee was much better although he was unable to walk far. I wrote "GRO-A not worried about AIDS but parents naturally concerned". I then wrote "I have explained AIDS precautions and have told him and his mother the result of the anti HTLVIII test." (HTLV III is an early name for HIV). It is interesting to note that I did not actually write down the result and I think that this was probably related to my reluctance to write information about HIV in the notes at this time, for reasons of confidentiality and possible stigma. The fact that I discussed the precautions that we were taking to avoid the transmission of HIV to others confirms that I would have explained that the result was positive, indicating infection with HIV. The sample taken on 25th July was reported as positive for anti HTLVIII antibodies on 13th August. (page 2648).

2.2.2 Dr Tony Aronstam, Director of Treloar Haemophilia Centre wrote in a letter to me, dated 21st May 1986: "We have been looking back and testing laid-down samples… to check on dates of seroconversion for HTLVIII. We find that…GRO-A …seroconverted between June 1981 and April 1982" (page 1320).

2.2.3 In September 1986 I recorded "repeated failure to attend follow up and I decided that home treatment would not be possible until I had seen him again" but contact was re-established in December and home treatment recommenced. It was noted that he was anaemic and pancytopenic (low red cell, white cell and platelet counts) but there was no obvious cause for this save for iron deficiency, which was treated.

2.2.4 Mr GRO-A came under my continuing care and was seen regularly in the haemophilia, HIV and rheumatological joint care follow up clinics at The London Hospital. It cannot be said that he was a regular attender or that it was possible to achieve optimal care for him but we had a close relationship and I believe that I did my best to accommodate his wishes, needs and reluctance always to accept my advice and that of my colleagues. The exchange of letters from 3rd February1987 to 1987 (pages 1335 to 1344) illustrates this point. GRO-A generally preferred on demand to prophylactic factor VIII replacement therapy.

2.2.5 I also looked after one of GRO-A's relatives, who came to the hospital on 8th April 1988 to say "that he believes that GRO-A has been told that he cannot come to the hospital for treatment." I wrote "This has never been the case and indeed I have repeatedly tried to get Mr GRO-A to come for treatment". "I have phoned Mrs GRO-A this evening to explain that I am willing to treat her son at any time of the day or night but cannot give him home treatment if he will not keep records or come to outpatients." (page 1752)

2.2.6 In 1988 I offered some sexual counselling and we began to discuss the advantages and disadvantages of treatment with zidovudine (AZT) but we agreed together that he was unlikely to be able to comply with the strict regimen of a clinical trial. Our social worker also offered support in the fields of accommodation, employment and contact with the recently formed Macfarlane Trust. He was also offered dental care.

2.2.7 In July 1989 GRO-A was involved in a serious road traffic accident and suffered a fracture of the odontoid peg in the high cervical region (broken neck). His injury was treated conservatively, and he remained in hospital for two weeks. He was then discharged home in a brace for a further 6 weeks.

2.2.8 In August 1990 we learned that GRO-A had married and we offered sexual counselling. We also arranged for him to have inhaled pentamidine prophylaxis against pneumocystis pneumonia, as his CD4 count was consistently around 0.2/nl. He failed to attend for this on a regular basis, declined antiviral medication with zidovudine and refused a test for HCV (page 1767). In 1992 further attempts were made to provide zidovudine medication without consistent success and cotrimoxazole (Septrin) was substituted as prophylaxis against pneumocystis pneumonia. Hepatitis A vaccination was given in 1993.

2.2.9 By June 1993 GRO-A's marriage had broken down and satisfactory supervision of home treatment and HIV prophylaxis had proved impossible. As was often the case agreements to accept medical advice were not fulfilled. There is a note written by Mr Nigel Harvey on 2nd June 1993 in which he states "Mr GRO-A spoke of learning that 8 of his contemporaries from Lord Mayor Treloar had died from HIV related illness and of his feeling that he perhaps only has two or three years left of life". (page 1790). GRO-A also discussed his distress, depression and poor sleep with Mrs Sheila Hayden, Haemophilia Nurse Specialist, and a short course of sleeping tablets was prescribed. A psychiatric referral was declined. (page 1798). Inhaled pentamidine and factor VIII prophylaxis were reintroduced but could not be sustained.

2.2.10 In May 1994 a partner requested sexual counselling and an HIV test, which was negative. Further counselling was provided by Mrs Hayden.

2.2.11 On 14th December 1994 an HCV RNA test was performed and was positive (page 2663).

2.2.12 Serious emotional issues arose in 1995, and support and counselling were offered and provided by the nursing staff at the Haemophilia Centre. I had detailed discussions with GRO-A about his knee pain, offered him further advice and arranged an orthopaedic consultation. In addition, we talked about his feeling of malaise and some alcohol abuse. We considered the value of specialist counselling and even a psychiatric opinion and decided to withdraw home treatment temporarily. This was later reinstated as his condition improved.

2.2.13 In 1996 he developed molluscum contagiousum, seborrheic dermatitis and angular cheilitis of the mouth, all probably HIV related, and specialist care in the Graham Hayton Unit for HIV care continued. Further discussions on analgesia and the best orthopaedic approach also continued, all made more complex by my reluctance to prescribe long-term opiates and a desire to avoid major joint surgery in a young and immunosuppressed man.

2.2.14 In November 1996 we discussed "the potential for new drugs to treat his HIV infection" and he said that "he will think about this before we see him in the New Year." (page 158). By 3rd June 1997 he had "now stopped all his medication, save for on demand factor VIII and simple analgesia". I wrote further to his general practitioner "When we see him again in three months' time we can decide whether or not to recommend specific anti-HIV therapy, although as you know he is not a very good tablet taker". In February 1997 GRO-A was in tears in my clinic, because we were unable to control his pain and "perhaps because there is some other problem in his life that he is not sharing with us." I was reluctant to prescribe opiates and sought further help from our rheumatologists. In October 1997 it was noted that the HIV viral load was high but GRO-A wanted "to hold off treatment until he gets ill". By November 1998 he was "very reluctant to take anti-HIV therapy but will try inhaled pentamidine again, although I fear that he may not be compliant".

2.2.15 I wrote to GRO-A on 2nd December 1997, informing him of the potential risk of nvCJD from the transfusion of plasma derived factor concentrates and offering him a consultation to discuss the matter. (page 1460).

2.2.16 On 9th June 1998 I received a letter from the Macfarlane Trust which was set up to by the government to provide financial support to affected PWH in the UK. The Trust requested information (with consent) and I responded on 16th June. (pages 1464-1467)

2.2.17 In April 2000 GRO-A was "willing to consider treatment ". "He tried taking his anti-retroviral medication for about 3 weeks and then he stopped the medication as he was feeling tired." (page 1895). A different combination of drugs was suggested and started but without full success in compliance.

2.2.18 On 30th March 2001 Mr Gareth Scott, consultant orthopaedic surgeon placed Mr GRO-A on the waiting list for total knee replacement, which was performed in July 2002. There was a post-operative haematoma but the initial result was regarded as excellent.

2.2.19 At this time, he also restarted antiretroviral therapy with some partial success and felt better for it. There was some improvement in his CD4 count and it was noted that the spleen was enlarged on ultrasound. (page 2867). It was decided to review potential treatment for HCV infection.

2.2.20 In 2003 on demand factor VIII treatment continued together with effective antiretroviral therapy but he declined any anti pneumocystis pneumonia medication or treatment against HCV. It was thought that he might have some drug resistance to HIV and compliance continued to be an issue.

2.2.21 On 21st January 2004 recombinant clotting factor concentrates replaced plasma derived concentrates for all patients with haemophilia at The Haemophilia Centre at the Royal London Hospital, following a government decision. (page 1517). Further information was provided on the potential risk of nvCJD infection from plasma products. (pages 1560-1568.)

2.2.22 In 2004 I wrote a note about a complaint from GRO-A that a dose or doses of factor VIII had been omitted during his total knee replacement (page 1921). The issue seems to have troubled him greatly at the time and it was addressed in my letter to him, dated 18th March 2004. (page 1519). There also seems to have been anxiety about the amount of social support he was receiving, which was shared with Ms Deborah Jones, Haemophilia Nurse Specialist, (page 1928) and was resolved when GRO-A apologised (page 1933).

2.2.23 An application to the Skipton Fund for additional payment relating to HCV infection in PWH was completed on 14th February 2005. (pages 1541-1547).

2.2.24 By 2005 the replaced knee joint had become painful and infected but was responding to antibiotics, while GRO-A had also developed ankle problems, which had been treated with shoe inserts (orthotics) with some success. A nasal septoplasty was performed to treat nasal obstruction. An attempt was made to reintroduce factor VIII prophylaxis and manage his résistance to anti-HIV drugs.

2.2.25 In the summer of 2006 GRO-A was admitted to the Sussex Beacon for a period of two weeks for respite and for nutritional support. (pages 1601-1602.)

2.2.26 GRO-A decided to move to GRO-A to be nearer his family and he also received some support from Dr Frankie Connell, consultant psychiatrist, at this time.
During the latter part of 2006 extensive notes were written by our nursing staff about the relationship between GRO-A, our own nurse specialists and Healthcare at Home, who were providing local support. All this was very regrettable and, despite the painful content of my note, quoted below, I believe that it is appropriate to record my final summary of 1st November 2006.

"Policy
Discuss with

1. Nursing staff
2. Social services in East End and Northampton
3. Haemophilia and HIV services in Northampton
4. Oxford Haemophilia Centre

Try to arrange the best care we can.
Sister has Enduring Power of Attorney.
GRO-A understands that he may die. He chooses not to make a Living Will.

We have discussed the consequences of

1. Pneumonia or other acute illness
2. Increasing cachexia
3. Knee deterioration

GRO-A remains dissatisfied with the service the nursing staff and Healthcare at Home have provided. It is my experience that he can be difficult to please and I am afraid that the reality is that he will get even sicker with only one final result.
I will do my best to help us all to get through a very difficult time but, as ever, GRO-A's needs are paramount." (pages 1970 - 1971).

2.2.27 When he finally moved to GRO-A I wrote a letter of referral to Dr Paul Giangrande, the Director of the Oxford Comprehensive Care Centre (CCC) on 6th November, explaining the circumstances and GRO-A's poor condition. (page 1619-1620).

2.2.28 By 2007 hepatic cirrhosis had been diagnosed and GRO-A was admitted to The Royal London Hospital. Professor Pasi completed a further questionnaire for the Skipton Fund on 12th July (pages 1681-1688.) Oesophageal varices were banded by Professor Graham Foster's gastroenterology team on more than one occasion. I saw GRO-A on 3rd April, when he had had an episode of gastrointestinal bleeding, and I raised the issue of DNAR (Do Not Attempt Resuscitation) with him. We agreed together that he should be resuscitated in the event of circulatory failure. In my note I added that "I would not advise excessive resuscitation attempts, ventilation or ITU admission if this becomes an issue." (page 2507).

2.3 The Final Years (2007 -2012) Professor John Pasi The Royal London Hospital and Dr Paul Giangrande Oxford Haemophilia Centre

2.3.1 Professor John Pasi took over GRO-A's care on my retirement from the NHS and noted that the CD4 count remained very low with a detectable viral load. Banding of oesophageal varices continued and further discussions took place on the future of the infected total knee replacement. Care was complicated by the relocation to GRO-A, his haemophilia care having being transferred to Oxford Haemophilia Centre, where all his care was then coordinated.

2.3.2 In October 2008 GRO-A was admitted to Milton Keynes Hospital under the care of Dr Elizabeth Miller. He was suffering from septicaemia, secondary to knee infection, but made a fair recovery with antibiotic therapy. He became anaemic and was transfused.

2.3.3 In February and June 2009 formal letters were written regarding possible exposure to nvCJD for all PWH treated with UK sourced plasma products between 1980 and 2001. (See also **2.2.15**). The message reflected the information given above at **1.11** and was not specifically directed at GRO-A, although he was clearly a person at risk, as was anyone else of his generation.

2.3.4 There were further discussions in Oxford concerning the best management for his knee infection in all the circumstances and in March 2009 he was admitted to the Nuffield Orthopaedic Centre for removal of metalwork, the insertion of a cement spacer with a muscle flap and skin grafting.

2.3.5 In April 2009 Dr Miller reviewed GRO-A's continuing anaemia and falling white cell and platelet counts (pancytopenia). He was treated by blood transfusion and oral iron, later followed by iron infusion. Capsular endoscopy revealed possible jejunal varices, bleeding from which was thought to be a potential cause for the iron deficiency. The spleen was palpably enlarged but there was no clear evidence of hepatic dysfunction, apart from a mild increase in plasma bilirubin. Abdominal ultrasound showed no focal liver lesions, there was no evidence of hepatocellular carcinoma and the alpha fetoprotein test was normal. A bone marrow sample was taken and it was agreed that the pancytopenia was due to his liver disease.

2.3.6 On 3rd June 2009 the second stage of revision of the total knee replacement was performed successfully in Oxford, although he was left with a reduced range of movement. In addition, GRO-A developed left shoulder rotator cuff impingement which was treated by injection in November. Haemophilia prophylaxis using recombinant factor VIII on alternate days was established.

2.3.7 As a result of antiretroviral therapy for his HIV infection the viral load was fully suppressed although the CD4 count remained very low. A further attempt was made to offer anti pneumocystis prophylaxis by using a dispersible form of cotrimoxazole (Septrin). "His aversion to taking pills" was again noted. The possibility of liver transplantation was discussed and his depression was reviewed at a psychiatric consultation by Dr Brian Timins in Towcester.

2.3.8 In 2010 GRO-A's condition remained stable although he continued to express anxiety, especially concerning the state of his liver and his fear of developing hepatocellular carcinoma. Pain control was also difficult. Further endoscopy showed some oesophageal varices, which were treated. He developed an infection in his shoulder following a steroid injection, which was treated with antibiotics and resolved.

2.3.9 On 14th January 2012 GRO-A vomited blood and was taken to Northampton Hospital where oesophageal varices were banded. During this period antiretroviral therapy was not possible and his HIV viral load increased.

2.3.10 It was decided to offer a TIPSS (Transjugular Intrahepatic Porto Systemic Shunt) procedure to relieve portal hypertension and this was performed at The Royal Free Hospital in London on 18th January 2012, followed by transfer to the Intensive Therapy Unit in Oxford. He made a satisfactory recovery but he developed pneumonia and was admitted to Northampton Hospital on 21st May with suspected bronchopneumonia and drowsiness. He was treated with antibiotics and was transferred to the High Dependency Unit.
A bronchoscopy was performed on 22nd May but his condition worsened, he developed multi-organ failure and died on GRO-A 2012 at GRO-A

2.3.11 On 15th February 2013 Ms Anne Pember HM Coroner for the County of Northampton notified the Haemophilia Centre at The Royal London Hospital of Mr GRO-A's death which had taken place on GRO-A 2012. The cause of death was given as;

1a Multiorgan failure
1b Pneumocystis jiroveci (PCP) pneumonia
1c HIV & VE. Hepatitis C, Haemophilia

3. Commentary

3.1 Dates of infection

3.1.1 GRO-A had severe haemophilia A and, like the majority of people with haemophilia of his generation treated in the UK, he suffered the full effect of the tragedy of the viral contamination of large pool blood products which occurred between 1970 and 1986.

3.1.2 Cryoprecipitate, which became available in the mid-1960s, was less likely to transmit NANB hepatitis, because it was provided in single donor units, but it was certainly capable of carrying transmissible viruses and the more cryoprecipitate administered, the greater the risk. It was a relatively impure product and was often allergenic. GRO-A became allergic, as did many patients, and when large pool concentrates were introduced GRO-A was treated with them.

3.1.3 These large pool concentrates were derived from thousands of donors and it soon became apparent that they were capable of transmitting hepatitis B and NANB hepatitis. Patients relatively rarely suffered a severe acute illness and the subsequent "transaminitis" that was often seen in routine LFTs was not initially thought to be a serious problem.

3.1.4 I It began to be appreciated in the mid-1980s that over a number of decades HCV infection could cause serious and often fatal liver disease. At the same time it became apparent that any patient treated with a large pool concentrate, whether of UK or American origin, would inevitably contract the NANB hepatitis which was later confirmed to be HCV, once that virus was discovered in 1989.

3.1.5 GRO-A's HCV infection therefore took place by the end of 1973, on his first exposure to a large pool concentrate.

3.1.6 The UK was never self-sufficient in UK derived plasma for the production of factor VIII concentrate and GRO-A was certainly receiving commercial factor VIII, sourced from American plasma, by January 1981. It is not possible to determine whether he was infected with HIV from treatment prescribed at Lord Mayor Treloar College or at The London Hospital but frozen stored samples were later analysed at Lord Mayor Treloar.

3.1.7 GRO-A seroconverted to being anti HIV positive between June 1981 and April 1982 and he therefore became infected with HIV between these dates.

3.1.8 It is important to note that HIV was not identified until 1984 and that viral inactivation was not widely introduced in the UK before 1985. Between 1984 and 1986 some PWH in the UK were infected with HIV from unheated NHS concentrates because, by that time there was some HIV infection in the British donor pool. It was also the case that some early commercial heat-treated concentrates, derived from American plasma caused HIV infection in British patients, probably because of the high viral load in the concentrates and/or because of inadequate heating.

3.1.9 Nevertheless it is clear, because of the early date of infection in 1981/82, that GRO-A was infected with HIV by commercial, American sourced, plasma.

3.2 GRO-A's management

3.2.1 It was always difficult to manage GRO-A's case because of his reluctance to accept advice, to take his medication and to provide the information that was needed for proper home treatment and prophylaxis. GRO-A's difficulties and his psychological and emotional disturbance and distress were closely related to the pain and suffering of the haemophilia itself and to the absence of a conventional upbringing. His attendance at special schools for the physically disabled no doubt carried many benefits, but there were also disadvantages that affected his emotional life adversely.

3.2.2 All PWH of GRO-A's generation suffered acute and chronic joint damage but his rheumatological condition was probably exacerbated by his reluctance to accept factor VIII injections.

3.2.3 Many attempts were made to provide GRO-A with prophylaxis against HIV related pneumocystis pneumonia and to offer treatment with specific antiretroviral therapy as it became available, but he plainly stated that he wanted "to hold off treatment until he gets ill".

3.2.4 It was never possible to offer GRO-A antiviral therapy for HCV infection because:

1) courses of HCV treatment were generally ineffective in the 1990s
2) regimens available had serious side effects and were very challenging for patients
3) medication was not suitable for people with emotional difficulties, particularly as treatment could cause severe depression
4) treatment for HIV infection was correctly regarded as having a higher priority
5) experience showed that GRO-A could not have accepted a strict and unpleasant regimen lasting for a year or more.

3.2.5 Many efforts were made to accommodate GRO-A's wishes but it is acknowledged that he was sometimes unhappy with the care he was offered. There is written evidence that attempts were made to respond to and resolve his dissatisfaction.

3.3 The final years in Northampton and Oxford

3.3.1 GRO-A made the transition from London to Northampton and Oxford successfully and was well cared for during the last few years of his life.

3.3.2 Sadly he died at the age of 42 years of pneumonia and multiorgan failure, after nearly 40 years of HCV infection and approximately 30 years of HIV infection.

GRO-C

BT Colvin FRCP FRCPath
Formerly honorary consultant haematologist The Royal London Hospital

5th December 2016

Record of Inquest

Following an investigation commenced on the 31 **day of** May 2012

At an inquest hearing at Milton Keynes Coroners Court on the 23rd day of February 2017 heard before Thomas Ralph Osborne Senior Coroner in the coroner's area for Milton Keynes, the following findings and determinations were made:

1. Name of Deceased (if known)

GRO-A

2. Medical cause of death

1a **Multi Organ Failure**

b **Pneumocystis jiroveci(PCP) pneumonia**

c **HIV positive**

II **Haemophilia**
Hepatitis C

3. How, when and where, and for investigations where section 5(2) of the Coroners and Justice Act 2009 applies, in what circumstances the deceased came by his or her death

See Narrative Conclusion

4. Conclusion of the Coroner as to the death

Narrative Conclusion

5. Further particulars required by the Births and Death Registration Act 1953 to be registered concerning the death

(a) Date and place of birth
GRO-A 1969 GRO-A, London

(b) Name and Surname of deceased
GRO-A

(c) Sex
Male

(d) Maiden surname of woman who has married

(e) Date and place of death
GRO-A 2012
General Hospital, Northampton, Northamptonshire

(f) Occupation and usual address
GRO-A
GRO-A Northamptonshire

Signature of Senior Coroner GRO-C Thomas Ralph Osborne

110 Whitworth Road, Northampton NN1 4HJ
Tel: 01604 624732 Fax: 01604 623681 DX 18509 Northampton 2
Anne Pember HM Coroner for the County of Northampton

Narrative Verdict

GRO-A (deceased)

The deceased died GRO-A 2012 at Northampton General Hospital.
He was diagnosed with haemophilia as a child that contributed to his death.
He also died as a result of HIV and hepatitis C infection that he contracted after receiving contaminated blood products given for the treatment of his haemophilia. In particular the HIV infection resulted from the administration of imported blood products from the United States of America administered between June 1981 and April 1982. At the time that the blood products were given to him the risks of infection were not known and the benefit of such products far outweighed the risks of infection. The circumstances of the use and contamination of the blood products were dealt with fully in the Penrose Report following a public inquiry under the Inquiries Act 2005 published in March 2015.

GRO-C

Tom Osborne
H. M Assistant Coroner for Northamptonshire

CORONER COUNTY OF NORTHAMPTON