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Credibility of Penrose Inquiry and cross border gross double standards affecting haemophiliacs

To whom it may concern who receive this letter.

I am writing to you in dismay and anger as the widow of an HIV/HCV infected haemophiliac and an award winning researcher on contaminated blood based in England. I have been involved in campaigning for many years with Colette Wintle and have followed Archer and Penrose Inquiry and development of new financial proposals. Concerns have arisen over underhand behaviour, inaccurate reporting and gross double standards which if not tackled now could result in very different financial schemes across borders, discrimination and pitting one haemophiliac against another. This is both sad and unethical. The question is whether I am dealing with malicious intent from government departments or simply ignorance?

So I propose to take England and Scotland as an example and show how key evidence from England has strongly contributed to assisting haemophiliacs in Scotland and vice versa which makes a nonsense of having different financial schemes!

Let me start by stating that when I heard that the Penrose inquiry was to be set up in Scotland, I immediately contacted the Inquiry team and offered to cross the border from Newcastle, submit paperwork and give evidence which I believed would inform and help Scotland as I had done to assist Lord Archer with key documentation. (You will see his acknowledgement to me within the Archer report.)

I soon learnt that the Penrose Inquiry as with Archer **"would have no power to show liability"** Penrose also had other restrictions as documented by the *BBC*, (25th March 2015).

Quote

"However, Lord Penrose did not have the power to summon witnesses from outside Scotland. This is a major limitation, since health policy before 1999 was controlled by Westminster and many crucial decisions were made by England-based politicians and civil servants."

<http://www.bbc.co.uk/news/uk-scotland-32033246>

It was made clear speaking to the Penrose Inquiry team that I would not be allowed to appear in person or submit my documents from England even though I had volunteered to do so. In utter

frustration I wrote about this in an article published in *London Progressive Journal* which I will refer to later.

So it is with shock that it has come to my attention that documents from my late husband's litigation files (Newcastle) have been used extensively through-out the Penrose Report which goes against the fact that the person who discovered these documents utilized for her research was denied the right to present her findings in person and give evidence in Scotland. Also there is a complete failure to provide an true account of how these documents came to be made available in England and later appeared in Scotland and reference their source!

Destroyed Files

To remind all concerned that in hundreds of letters sent to haemophiliacs and MPs over the years, the Westminster government maintained that "a junior civil servant had inadvertently destroyed thousands of documents" pertaining to blood policy, safety and the infection of haemophiliacs with deadly viruses. I have such letters within my dozens of crates of evidence and there is reference to this in the media,

Quote from *Herald Scotland* (2006) re destroyed/missing documents... and the files from my husband's legal case

"Last week, campaigners in Scotland also met with health minister Andy Kerr to urge him to reconsider his decision to rule out a public inquiry. While in other countries so-called "tainted blood" scandals have led to inquests and criminal convictions, in the UK requests for an investigation have been repeatedly rejected.

Margaret Unwin, chief executive of the Haemophilia Society, said she was told about the documents existence in a meeting with Department of Health officials earlier this month.

"We are eagerly awaiting information from the Department of Health about what is in the boxes," she said. "It is just very mysterious that 45 boxes could suddenly have been found, it sounds like a lot of boxes to have been mislaid, so we would be very interested to know what is in them." Unwin said she had been told it could take six months for officials to go through the papers. She added that there was speculation they could be the supposedly destroyed files which detail meetings between the blood transfusion service, health boards and consultants.

Some copies of these documents have already been located following the government's announcement in January that they had been accidentally destroyed. It emerged some files were still held by solicitors, who subsequently returned them to government officials."

<http://www.heraldsotland.com/news/12520471...> apos Destroyed apos files on blood scandal may have survived HEALTH HAEMOPHILIA Department of Health finds 45 boxes of documents/

Now let me enlighten you further as to the truth regarding these files....

The 45 boxes referred to in the article are the same boxes I had returned to the Department of Health with the assistance of Paul Saxon solicitors Blackett, Pratt and Hart (formerly offices of Deas, Mallen, Souter solicitors for infected haemophiliacs) and which have somehow been shared with the now devolved department in Scotland. There are distinguishing features on some of the documents which make them easily identifiable. During legal challenges and research for my dissertation on contaminated blood, I applied for and received permission to view the files of evidence, (though not files of individual clients naturally due to confidentiality) other than those of my late husband. In

total with individual files, the boxes numbered 69. Personal files were not included in the batch sent to the DOH.

Saxon notified the DOH of these boxes of evidence and DOH requested that they be returned. Several letters passed between myself, Saxon and the DOH. Saxon and I tried to ensure they went to an independent body but DOH (**that had so carelessly "inadvertantly destroyed" their own records**) suddenly wanted them back. Saxon agreed on condition they were released (DOH agreed to do so in batches) that they be properly referenced as coming from my husband Peter Longstaff and myself from Deas, Mallen, Souter litigation files and that I be informed of each release date.

The DOH have gone back on their word and I was certainly not informed they were being used in Scotland and that this would contribute to different schemes across borders which amounts to discrimination.

The Newcastle documents formed a major part of the Archer Inquiry as I was able to send Lord Archer copies of key evidence. He did however inform me he had to leave out those documents that showed liability (as liability was not within the Inquiry remit) such as those pertaining to Sir Joseph Smith. Smith contacted me at the time of the Inquiry to **admit his own "negligence"** (as he described it) as a key advisor on blood safety as AIDs was emerging and inform me of the **"unethical experimentation"** carried out on haemophiliacs! You will note Sir Joseph Smith's key documents are also missing from the *DOH Self-Sufficiency in Blood Products in England and Wales: A Chronology 1973 to 1991* and Penrose for the same reason.

DOH report can be read here...

http://webarchive.nationalarchives.gov.uk/20070402085944/dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_4130917

I discussed the history behind the discovery of these documents at a meeting Colette and I attended with Anne Milton, Parliamentary Under Secretary of State for Health and it is contained within my 78 page written submission I made to her, *"Haemophilia/Contaminated Blood: The Case for Partners/Carers/Widows/Widowers and Proposals for Resolution"*. Did Jeremy Hunt even bother to read this or the extensive questionnaire to infected and affected within my research dissertation before embarking on a new financial scheme?

The discovery of the Newcastle files were also documented in my 2nd submission to the Archer Inquiry where I appeared twice as a witness, once as a widow in a personal capacity and the second as a researcher.

NOTE... Strangely the Archer Inquiry website has now disappeared offline along with the Archer report and all the witness testimonies which highlighted these documents

Colette Wintle and I have spent the past year writing to solicitors to find out what happened to the many documents and evidence we submitted to solicitor Vijay Mehan secretary to the Inquiry. These documents containing often personal and highly sensitive information relating to infection as well as the general evidence must surely be protected under data protection law, yet no one can tell us where they are located. This is bizarre and again deeply disturbing that an entire Inquiry has disappeared! Was the Archer Inquiry hardcopy evidence sent to Scotland for use regarding the Penrose Inquiry? We need answers to this...

Please read the following quote, which is taken directly from the evidence I gave as a witness to Archer, (fortunately I kept a copy as did Colette with her evidence and that of her husband also.)

Second statement to Archer Inquiry (Carol Grayson)

"My dissertation highlighted many of the issues brought into this Inquiry. It was actually written in 2006 and submitted in January 2007 three months before the Inquiry began. As stated I used documents and supporting evidence that weren't at that time in the public domain. While I was writing the dissertation I was also fighting to get many documents released under Freedom Of Information with the help of solicitor Paul Saxon of Blackett, Pratt and Hart. The Government recalled all these documents and given the Governments appalling record for "inadvertently" destroying evidence I cannot be entirely sure that all the documents are or will be released into the public domain but I believe there is enough now to put the Government to shame. The Government Self-Sufficiency Report 2006 is a fairly worthless document in that it excludes most of the important evidence regarding what happened to our community. This also needs to be formally challenged as this was supposed to appease us and be accepted as an accurate picture of the contamination tragedy. The reason always given in letters for refusing haemophiliacs a public inquiry was that quote "all the information is already in the public domain". We now know this oft repeated statement was untrue. The Government can go some way now to addressing this situation by considering the future report/recommendations of the Archer Inquiry and offering an apology that is long overdue."

NOTE my dissertation (ESRC, Michael Young award) critiqued the same 2006 DOH "Self-sufficiency" report (The title itself was a joke as the UK NEVER achieved self-sufficiency) and showed that many key documents in the DOH report were EXCLUDED so how can this possible be the so called "definitive report"? Impossible...

The DOH report does not include many of the key government and other documents which I discovered in Newcastle and doesn't even have an author. Someone ought to explain this to the ignorant Nicola Blackwood MP regarding her recent comments in the Westminster Commons debate.

See following link for more information regarding my research dissertation.

<http://www.sunderland.ac.uk/newsevents/news/news/index.php?nid=628>

NOTE Labour have now changed their stance on contaminated blood, changing the language documented in Hansard from “inadvertent infection” to “negligence of public bodies” which is correct as admitted by Sir Joseph Smith. So why aren’t more people asking why and investigating?

Andy Burnham former Sec State for Health, wrote to me saying,

“I arrived in the Department of Health as Secretary of State in June 2009, shortly after the previous ministerial team had formally responded to the Archer Report. In the eyes of the Department, the matter was ‘closed’.”

The matter wasn’t closed at all, haemophiliacs made it clear by ongoing legal challenges it was very much open to them at least.

Burnham said it was only later he realized the true extent of the disaster when he spoke to Paul Goggins MP whose constituent Peter Mossman (and solicitors) I had supported for years with evidence. Burnham then said,

“I have to be honest and say that, until then, I did not have a full understanding of the full extent of suffering and injustice. But that meeting changed my perspective on the issue and, as a result, I went back to the Department of Health and asked them to reopen the issue. At my instruction, the then Public Health Minister, Gillian Merron MP was asked to initiate a review of what more could be done to help. That review eventually reported after the General Election and, as a result, there were some improvements made to the various funds.”

“However, I would be the first to accept that these changes were modest and did not go anywhere near providing a full answer. That is why, ever since, I have given my support to those campaigning for a full, fair and final settlement. Shortly before he died, Paul Goggins called a debate in Westminster Hall and you will see from the record of that debate that I attended and lent my support from the Frontbench. I have since spoken a number of times in the House on this issue.”

The Penrose Report fails to properly document evidence which highlights inaccuracy and gross double standards

The Penrose Inquiry has FAILED to document and reference key evidence pertaining to what Lord Owen rightly describes as a “cover-up” which is not in the past tense but continuing and growing!

Ironically evidence was used selectively from the files of a Newcastle solicitor yet the researcher who discovered them and used them in her critique of the Self-Sufficiency report is neither able to give evidence nor is referenced in Scotland!!!

How dare Penrose used the documents I unearthed FROM ENGLAND for my research and in support of Archer to cherry pick the evidence yet block my being a witness in person IN SCOTLAND and showing liability? GROSS DOUBLE STANDARDS! Who set the Inquiry remit?

To reiterate, fellow campaigner Colette Wintle and I have spent years assisting Scotland with evidence and in practical terms.

For example, my husband and I challenged the hepatitis waiver in the 1991 HIV litigation. It was only when we sought a QC legal opinion that my then MP Jim Cousins wrote to me thanking us. He confirmed the decision from government that once they read the legal opinion (sent to them, that the waiver would not hold up legally and could be overturned) they decided to set up Skipton to avoid further litigation. The opinion also identified how much key evidence was withheld from haemophiliacs at the time of signing the hepatitis waiver. Without this challenge and submission of what evidence was found, no financial scheme would have ever been forthcoming

Haemophiliacs in Scotland and the rest of the UK were then able to apply to Skipton and years later use it as a baseline for fighting for more financial help from government (current financial proposals).

Furthermore Dan Farthing-Sykes thanked and informed me that following Penrose, an argument I had put together from England and sent to Jeremy Hunt comparing haemophilia widows (special cases as documented in Hansard) to army widows (special cases) has been used in Scotland to argue for a “pension for life”. (This letter can be supplied and my MP will verify as he received it). Yet Jeremy Hunt turned down my argument in England! Gross double standards.

This gets most confusing... How can this argument be used if Scotland is “devolved” and not using evidence from England and why was there no reference to my work yet again which would have helped show the cross border efforts for justice?

This is particularly concerning given that my husband whose treatment came from the Haemophilia Centre in Newcastle, England also received treatment from over the border in Scotland during treatment shortages in the 1970s/80s. Newcastle in turn returned the favour if there were issues with supply in Scotland as all came under a Westminster government at that time.

Yet I am not able to apply under the Scottish scheme for widows???

How can that be when I know of a **precedent set** where haemophiliacs/families in England were able to claim for treatment received in Ireland when on holiday **so claimed money under both schemes** which was accepted. I assisted these claimants in doing so after Rosemary Daly (Irish Haemophilia Society, Malcolmson Law solicitors, Ireland) asked me to help in making sure no one that had had treatment in Eire missed out on payment. One beneficiary came from Wales, one from England, there may have been others in Scotland, in fact if there are, they could still probably register a claim if no one in Scotland alerted them to this scheme.

I point the reader to my article in *London Progressive Journal* which INCLUDES reference to a refusal letter from the Sec State for Health (which I have) to my MP to introduce a "pension for life" like that of army widows.

LETTER RECEIVED FROM NICK BROWN MP,

Dear Carol,

I have now received a reply from the Secretary of State for Health to my letter regarding contaminated blood and recent associated developments. In the reply, the Secretary of State acknowledges that many remain unhappy with the current system of financial support and has stated that the Government is awaiting the publication of the report of the Penrose Inquiry. The reply also notes the work of the All Party Parliamentary Group and recent Backbench debate in informing its eventual response.

Unfortunately, in relation to the matter of bereavement payments, the reply states that the changes made to armed forces widows/widowers benefits were for 'distinct and separate' reasons and that the Government is not considering extending this to other cases.

Please find a copy of this reply attached. I hope you find it informative in clarifying the Government's current position.

With best wishes,

Nick

Read full article here,

"Penrose Inquiry: 'Bad Blood', biological terrorism and cover-up under a failed western democracy."

<http://londonprogressivejournal.com/article/view/2158/penrose-inquiry-bad-blood-biological-terrorism-and-coverup-under-a-failed-western-democracy>

As stated, I have campaigned for years jointly with Colette who was born in Scotland and had her first treatment there, yet she is not eligible to claim under the Scottish scheme because Colette had to register under an English Trust when there was no alternative scheme in Scotland. How can that be fair anyway when all were infected under a Westminster government?

Key evidence pertaining to Scotland was also excluded from Penrose including the Reddie case where US plasma companies paid directly out to a York Hill patient for infection but it was kept quiet from other haemophiliacs who would have very likely received plasma from the same batch numbers of treatment.

I remind everyone that haemophiliacs in Scotland were also able to benefit from the US litigation initiated by my husband Pete and myself. I travelled to Edinburgh to meet our US lawyers and ensure Scottish haemophiliacs could participate IF their records had not been destroyed.

To highlight also. Those that had cases in the US do not need another full Inquiry to prove negligence as lawyers were able to make full use of the evidence from US pharmas regarding UK authorities showing they knew the risks, high-risk donors, where treatment was sourced at key time but ignored warnings from the US preferring to put profit before safety. This is why America was seen as "forum non conveniens".

The pharmas had provided enough evidence against UK authorities to show negligence in the UK, hence UK must pay out the main amount.

See following taken from a recent email which I sent out...

TO HELP EDUCATE ALL...

SPECIAL US cases

"These were always deemed the strongest legally on the grounds of negligence.

Over a period of time the US lawyers checked out our batch numbers and established a core group whose batch numbers were traced directly back to prisons and to infected donors. One of those was my husband whose treatment was traced back to HIV positive infected donors at Arkansas State

Penitentiary. Some long term prisoners became ill, even died and test results were in their prison records so some though not all could be traced for HIV and HCV. Records disappeared in prisons too.

After several years of wrangling with the pharmaceutical companies, Baxter, Bayer, Armour and Alpha agreed to pay an amount to those UK haemophiliacs WITH PROOF however it was stressed this was a TOKEN amount and under the rate of money a person could keep on benefits. Why was this accepted? The judge accepted the infections but ruled forum non conveniens. Reason... the pharmas were able to convince the judge that although they had supplied infected US treatment to the UK authorities for haemophiliacs in conditions that broke virtually every safety rule in the book, the British authorities KNEW the dangers and WENT ALONG with it. So it was deemed UK should pay the full amount. As Lord Owen clearly states, it was a "cover-up" to hide government negligence.

Example... my husband had treatment PROVEN to be from an HIV infected donor AFTER Arkansas prison plasma centre was closed down for "gross safety violations". DESPITE warnings UK authorities FAILED to withdraw the high-risk US plasma.

The pharmas successfully argued that the authorities in the UK knew where the treatment was sourced from the 1960s onwards, the high-risk donors, prison plasma made into concentrates AND the safety violations BUT began importation in 1973 (dangers referenced in Dr J Garrot Allen letter to Brit govt) as well as medical journals. UK authorities went along with it for YEARS putting profit before safety all through the most dangerous times and FAILED to withdraw the treatment DESPITE warning letters from the US which were debated as my documents show.

Some key advisors like Dr Spence Galbraith (PHLS) even did his own research, realized the terrible implications of AIDS and sent his famous 1983 warning letter to government which I unearthed and gave to BBC Newsnight. Galbraith supported me all the way. This warning was IGNORED by Sir Joseph Smith who ACTUALLY confessed HIS negligence DIRECTLY to me many years later at the time of the Archer Inquiry. Why is government not addressing this?

Labour is indeed correct calling this "negligence of public bodies".

You have to remember at that time UK haematologists (often on the payroll of US pharmas) met regularly with the pharmas, gave long paid lecture tours across the world, met up several times a year at conferences. All this and their discussions on the dangers of imported factor concentrates was documented in UKHCDO and Society minutes. I have crates of evidence filling my home. All of the above is what was conveniently excluded from the Brit govts self-sufficiency in blood products "definitive" report which I critiqued for my dissertation. This is what govt refer to and use to guide their thinking yet ALL THE KEY DOCUMENTS ARE EXCLUDED from the govt report. Why did people not listen and support me on my evidence, it was even awarded in the name of Sir Michael Young, politician and social scientist.

This is what people are not getting, WE HAVE THE EVIDENCE. Archer SAW the evidence AGREED with me but could not include certain documents himself as there was no remit for liability in the Archer Inquiry and WE SHOWED NEGLIGENCE.

Anyway the US judge accepted the token payment offered to us from the pharma ruling "forum non conveniens" and that BECAUSE UK authorities KNEW AND ACCEPTED the dangers they must pay up to those that had PROVEN their treatment in the US. We are still waiting for all our so called advocates to facilitate a meeting with government so we can find out when they will be paying out for THEIR NEGLIGENCE as ADMITTED by Smith. The same with Penrose, I was NOT ALLOWED to submit documents showing negligence. So what is the point of an inquiry when our best evidence can't be submitted?"

I remind everyone that Colette Wintle and I travelled again at our own expense to Scotland to assist the office of Malcolm Chisholm in support of Scottish haemophiliacs years before that. At one time his office contacted asking for any information I could share. Both Colette and I have old copies of letters to Chisholm and Margaret Graeme and I wrote to Chisholm to correct him regarding misinformation on the Eire settlement) which ignorant Jeremy Hunt now repeats MISINFORMING MPs along with Jane Ellison. The correspondence quotes letters I had acquired in 2004 with Colette which formed the key evidence for a Judicial Review **WON in 2010 (Andrew March/Mitchelmores) whom I assisted for months.**

Media.... I would remind everyone that Scottish journalists used to rerun information from the award winning Newcastle Journal, "Bad Blood" media campaign as we had information/evidence not available anywhere else so this also helped the campaign in Scotland.

So governments needn't play the "devolved game" with me now (when it suits) when people have been able to benefit from whatever came along by using key evidence from **BOTH sides of the border.**

This is why it is ESSENTIAL that the same scheme is introduced through-out the UK and perhaps now England, Wales and Northern Ireland can benefit from the extension of the Scottish scheme

under the different governments as Scotland has benefitted so much from work done over the border.

Colette and I call for a meeting cross border with government representatives and campaigners from through-out the UK to discuss this as a matter of urgency. Different schemes are designed to be divisive and split families and campaigners. This is immoral where you can have one family member under one scheme and another over the border on significantly less money despite both having had treatment when under a Westminster government. The reality is evidence and financial schemes have been used cross border for decades and we now need consistency and the same across the UK to avoid any further distress whichever government is administering the scheme.

I have letters showing the longstanding involvement of Colette and I with Scotland should anyone require evidence of this... I also remind everyone of Anne Milton's commitment to Colette and I in writing regarding continuous involvement in meetings with government, yet it appears we have been **DELIBERATELY EXCLUDED**. We were not invited to a pre Westminster Consultation meeting of campaigners last year with a government mediator. This goes against the government claim to have consulted all groups. **THIS IS NOT TRUE.**

We were also **EXCLUDED** from a meeting with Lord Prior, yet Colette and I have campaigned for years to have haemophiliacs, partners and bereaved partners, infected and affected pass ported out of the benefits system of reassessment.

Bizarre that I am excluded as both widow and researcher. So many have clearly benefitted from my research and documents across borders over the years and given that as far as I am aware, I am the only ESRC awarded research on contaminated blood in the UK and in addition have an award for HIV/HCV campaigning for "upholding truth and justice" I ask WHY?

Regarding the trials of the haemophilia community receiving welfare benefits please read the next edition of *Private Eye* to see what a farce this is and how unethical DWP Maximus assessors are

that lie about claimants, official complaint submitted. Companies such as Maximus, ATOS, Concentrix must not be allowed anywhere near haemophiliacs or allowed to tender to run financial trusts.

I must also ask how Scotland intends to pay what is described as “pensions” to the haemophilia community in Scotland when pensions are NOT devolved? Surely these payments must come from Westminster or the Scottish WASPI women will be up in arms.

I look forward to a response from those who receive this letter and the setting up of a cross border meeting to discuss these ongoing issues.

Yours sincerely

Carol Anne Grayson

Carol Anne Grayson is an independent writer/researcher on global health/human rights/WOT and is Executive Producer of the Oscar nominated, Incident in New Baghdad . She is a Registered Mental Nurse with a Masters in Gender Culture and Development. Carol was awarded the ESRC, Michael Young Prize for Research 2009, and the COTT ‘Action = Life’ Human Rights Award’ for “upholding truth and justice”. She is also a survivor of US “collateral damage”.