Obituaries

Doctor whose discoveries led to haemophilia treatment drugs

Ilsley Ingram

Guardian 28/5/04

In 1949, a young doctor, Ilsley Ingram, who has died aged 84, applied to work with Sir James Learmonth, the regius professor of surgery at Edinburgh University. Not keen on Ilsley's proferred research topic, Sir James suggested the study of thrombosis. Intent on finding a job, the newly married Ilsley agreed. Within a few years, he had made the seminal discovery that adrenalin makes the blood clot more readily, a finding that ultimately helped lead to the development of haemophilia treatment drugs.

In a subsequent career that spanned both sides of the Atlantic, Ilsley pioneered techniques for patients to treat themselves intravenously with the blood-clotting agent Factor VIII. It was during a 1960 Wellcome fellowship at the University of North Carolina that he helped to overturn a standard theory concerning blood coagulation.

Ilsley's decision to train as a doctor was governed by a sense of almost religious calling. He was born to missionary parents in Naini Tal, in the Indian state of Uttar Pradesh but, as an infant, was sent back to England for the sake of his health, after the death of his only sibling. Aged five, he developed a form of tuberculosis, and went to Switzerland with his mother, though the ailment was to recur throughout his life.

He was educated in Limpsfield, Surrey, and at Monkton Combe school, near Bath. In 1938, he began reading medicine at Trinity College, Cambridge, joined the university's Inter-Collegiate Christian Union and published his study, Village India, on how Anglican missions should work in rural parts of the subcontinent.

Ilsley then studied clinical medicine at St Thomas's hospital, London, qualifying in 1944, and, by 1945, had passed the Royal College of Physicians membership examination. His special area of interest at that time was the newly developed penicillin. He then studied medical statistics at the London School of Tropical Medicine but, while there, succumbed to another bout of tuberculosis.

Once recovered, in 1948 he worked as a locum at what was the only British TB sanatorium in Switzerland. There he met Patricia Forbes Irving, a vivacious Nightingale ward sister, and the love of his life. The couple were married, in Montana, within six weeks of meeting. Back in Britain, Ilsley had his fateful encounter with Learmonth, and, as a consequence, took up an Oxford University fellowship, researching on haematology.

In 1956, he joined the Jenner laboratory at St Thomas's hospital, combining a busy clinical workload with extensive research, publishing more than 100 papers and several books. He received the Macfarlane award of the Haemophilia Society, and was a founder member, and then fellow, of the Royal College of Pathologists. In 1972, he became a fellow of the Royal College of Physicians and was made professor of experimental haematology by London University.

Ilsley retired in 1979 and gave rein to his lifelong interest in botany — he loved wild orchids. His studies led to his election to the Linnean Society, a rare honour for an amateur botanist. He also learned to recognise no less than 27 different species of ground beetle, an interest spawned by the fact, he said, that "there were a lot of them".

Ilsley's retirement was marred by the discovery that many haemophiliacs had contracted Aids and hepatitis after unknowingly injecting themselves with contaminated blood from the United States. He worked tirelessly to ensure they received some government financial help.

A kind, generous and loving family man, Ilsley was a polymath, who published Four Score, a volume of poetry, in 2002. He had a vast reservoir of patience, combined with a sense of humour. He subscribed to the view of himself as a "family encyclopedia until superseded by the worldwide web". His wife and three children survive him.

Jane Martinson

George Ilsley Charlton Ingram, doctor, researcher and clinician, born August 11 1919; died April 12 2004

Ingram . . . polymath

BTG's dough is after a share of the slimmer's wallet

Scotsman 22/5/04

Heather Stewart

Dough seems an unlikely slimming aid but a range of new soya-based bread-products could help us battle the bulge, according to technology licensing firm BTG.

The company owns the patent for a new method of creating a soya-rich dough, and is poised to exploit concerns over obesity. "Normally, dough is five or six parts carbohydrate, one part protein — this is six parts protein one part carbohydrate," said chief executive Ian Harvey.

"It can be made into pretzels, pizzas, snacks — and it tastes great," he said. "It's being looked at by several major food manufacturers."

BTG hopes a licensing deal with a food group to sell the dough could help give its balance sheet a lift while it waits for the go-ahead to restart trials of its varicose vein treatment, Varisolve. It saw two-thirds of its market value wiped out at a stroke late last year when US regulators questioned Varisolve's safety.

Analysts hoped Varisolve could be a British biotech blockbuster. BTG was so confident of success that it set up a subsidiary company, Provensis, to develop the product. Earlier this year, BTG was forced into a £27m rights issue to fund Varisolve research until March 2005, by which time it hopes to have struck a marketing deal with a bigger firm.

Mr Harvey reaffirmed his confidence in Varisolve yesterday. He said BTG would submit a new dossier to the US regulators in November, and is now aiming at a launch in 2009, or 2007 in Europe, where phase three trials have already been completed.

"In 20 years I have never seen a technology like Varisolve in terms of risk-return profile," Mr Harvey said. The company estimates that six years after launch, Varisolve will be used in 1m cases a year in the US.

Meeting the costs of the Varisolve project accounted for more than two-thirds of the £22m pre-tax loss BTG made last year, down from £36m, its preliminary results showed yesterday. Turnover was up 55%, at £49m.

With the soya dough deal, and several other products due to generate royalties, including a cancer drug and a treatment for haemophilia B, BTG is aiming at profitability by 2005-2006, excluding Provensis.

Originally an arm of government, BTG buys technology from universities and other businesses, strikes licensing deals to commercialise them and takes royalties when they reach the market. "We're getting the pick of new technologies," Mr Harvey said.

MEDICAL A TO Z

HAEMOPHILIA

An inherited deficiency of blood clotting which can lead to spontaneous bleeding, sometimes for hours or even days. It happens as a result of a genetic deficiency of the protein Factor VIII.

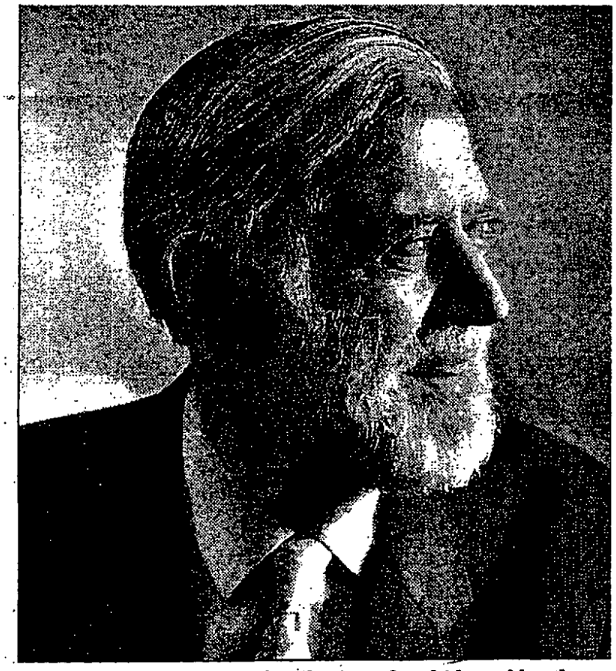
A child of someone with the gene has a 1 in 2 chance of contracting a similarly damaged gene. However, in 1 in 3 cases, a spontaneous gene abnormality is to blame and there is no family history.

Symptoms usually develop from birth and include easy bruising, sudden, painful swelling of muscles due to internal bleeding, prolonged bleeding after injury or blood in the urine.

Factor VIII can be added to the bloodstream by regular intravenous injections. In mild cases, injections may only be necessary after injury.

+ The Haemophilia Society (Scotland): 0141 332 8123

D. Telegraph 3/5/04



Ingram: also studied the distribution of orchids and beetles

Ilsley Ingram

Scientist and clinician who helped to develop new techniques for the care and treatment of haemophiliacs

Obituaries

ILSLEY INGRAM, who has died aged 84, played a prominent role in developing standards for the care and treatment of haemophiliacs.

As a leading clinician in his field, he pioneered techniques for patients to treat themselves intravenously with the blood clotting agent Factor VIII. As a scientist of international repute, he published several books and more than 100 research papers.

Born to missionary parents on August 11 1919 at Naini Tal, Uttar Pradesh, India, Ilsley Ingram returned to England as an infant to avoid an early death, the fate of many young children in India, including his only sibling.

At the age of five he developed tuberculous pleurisy and went to Switzerland with his mother, where he learned to speak French. Following schooling at Limpsfield in Surrey, and then at Monkton Combe, Somerset, he went up to Trinity College, Cambridge, in 1938 to read Medicine with a view to becoming a missionary doctor.

At Cambridge, Ingram became a keen member of the Cambridge Inter-Collegiate Christian Union; he formed a study group focusing on the activities of the Anglican Church in India. During this time he wrote *Study Village India*, a 200-page book describing how the Church's activities in rural India should best be conducted.

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As a house physician at St Thomas's, Ingram developed an interest in the newly-arrived penicillin, which led to the drug being the subject of his subsequent MD at Cambridge. He went on to study medical statistics at the London School of Tropical Medicine, and then took up an appointment at the Hospital for Nervous Diseases in London. Whilst there, he had what was to be the worst recurrence of his pulmonary tuberculosis.

Following lengthy treatment, in May 1948 he became acting medical superintendent at a sanatorium in Switzerland for British patients with tuberculosis. There he met Patricia Forbes Irving, a Nightingale ward sister recently arrived from England, and they married in Montana in September that year. On his return to Britain in 1949, Ingram was awarded a Wilkie Research Fellowship to work for six months in Oxford under Professor McFarlane and Dr Rosemary Biggs.

There he studied haematological techniques before going on to work under Sir James Learmonth, Regius Professor of Surgery at Edinburgh University. With Learmonth, he developed his particular interest in abnormal bleeding syndromes, of which haemophilia is the classic example. His research led to important papers on the underlying mechanisms of bleeding disorders. In 1956 he was appointed to the Jenner Laboratory at St Thomas's Hospital, London. He was based there until he retired in September 1979.

In 1960 Ingram was awarded a Wellcome Research Travelling Fellowship which enabled him to spend a year in the University of North Carolina with Dr John Graham, studying canine haemophilia. Studies with Graham and others led to the overturning of a leading theory concerning blood coagulation. Ingram also contributed significantly to the understanding of the effects of exercise and adrenergic drugs on blood coagulation.

Ingram's time at St Thomas's was notable for the substantial advances he made in the clinical care of haemophiliacs and in developing programmes of self-treatment. He became Director of the Supra-regional Haemophilia Reference Centre and the Supra-Regional Centre for the Diagnosis of Bleeding Disorders based at the hospital. He was also a member of the external staff of the Medical Research Council and a founder member of the Royal College of Pathologists in 1963, becoming a Fellow in 1969. In 1972 he became a Fellow of the Royal College of Physicians. In 1979 he received the McFarlane Award of the Haemophilia Society (of which he was to become a vice-president). Much later London University conferred on him the title of Professor of Experimental Haematology.

Shortly after his retirement, Ingram was confronted by the appalling news that many of his patients had been treated with Aids-contaminated blood products. He did what he could to help, and was effective in persuading John Major's government to pay some compensation to patients and their relatives.

Ingram had a life-long passion for natural history and, on retirement, became warden of Yockletts Bank Nature Reserve in Kent, famous for a number of wild orchid species. He published several papers on the distribution of orchids and surveys of ground beetles. In 1989 he was elected a Fellow of the Linnaean Society of London.

Ingram was also a keen poet, publishing a collection of his work in 2002.

Ilsley Ingram died on April 12; he is survived by his wife, Patricia, and by their son and two daughters.

No inquiry into hepatitis infection via NHS blood, minister says

The Scotsman 5/5/04

TARA WOMERSLEY
HEALTH CORRESPONDENT

MALCOLM Chisholm, the health minister, said yesterday that there would be no inquiry into how hundreds of patients contracted hepatitis C through NHS blood products unless new evidence came to light.

Mr Chisholm told the Scottish Parliament's health committee that there would be no point setting up an inquiry in the absence of any new evidence.

His words came after repeated calls from patients, mostly haemophiliacs, who became infected with hepatitis C while being treated with blood products on the NHS.

Referring to a judicial inquiry carried out in Ireland, Mr Chisholm said that the situation and circumstances relating to Scotland were different.

He added that a report carried out by officials from the health department showed that there appeared to be no blame attached to the Scottish National Blood Transfusion Service.

He said: "We need to have some new evidence. I have always said that I would keep an open mind if presented with new evidence but there is no point in setting up an inquiry if it does not have new evidence to look at."

Earlier this year haemophiliacs condemned a decision by the Crown Office and Procurator Fiscal Service to rule out a criminal investigation into how patients became infected with HIV and hepatitis C through blood products.

The announcement of the decision not to lay charges was made after consideration of a police report.

It followed on from a decision by police in England and Wales not to mount a criminal investigation, on the basis that there was no likelihood of a viable criminal prosecution.

Last year it was announced that people in Scotland suffering from hepatitis C would receive payments if they had been infected as a result of NHS treatment.

John Reid, the Health Secretary, also said that financial assistance would be provided to patients south of the Border.

Politicians yesterday raised the issue of whether patients were experiencing unnecessary delay in receiving the payments. However, Mr Chisholm, said that he would like to see the issue finalised as soon as possible.

The Skipton Fund, a joint initiative involving the UK's devolved administrations, is dealing with the issue of payments and how such a scheme should operate.

Times 4/5/04

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Professor Ilsley Ingram, researcher and clinician, was born on August 11, 1919. He died on April 12, 2004, aged 84.

Ilsley Ingram combined a distinguished medical career with a fervent interest in botany and a considerable poetic talent. He undertook important research in the treatment and management of haemophilia, and in his retirement was elected to the Linnean Society for his contributions to botanical study.

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His medical career began with the study of penicillin (the subject of his MD thesis) but by 1948 he was back in Switzerland, working at a hospital for British tuberculosis patients. There he met and married Patricia Forbes Irving. When the couple returned to England, Ingram began his interest in the problems of bleeding and clotting of blood, initially in Oxford with McFarlane and Biggs but from 1949 as a Wilkie Research Fellow in Edinburgh under Sir James Learmonth.

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Ingram left St Thomas' in 1979, just before his work for haemophiliacs was threatened by the unwitting use of HIV-contaminated blood products imported from America. He worked hard to persuade the Government to compensate those affected. Then he retired to Kent, where the Wye Downs provided a favourable setting for his botanical pursuits.

His work on wild orchids led to a Linnean Society fellowship. His collection of poems, *Four Score* (2002), included previously unpublished work from earlier years. Many of his poems had a religious theme and for much of his life he was a very religious man. He combined an innocent self-respect with a genuine concern for the welfare of others, particularly the young.

Headlines

Scotland

The Media Monitoring Agency

gill.millington@ GRO-C Tel/ Fax 01968 670599

Bereaved Families Take Health Minister to Court

Bill Whiteford, Presenter
The Health Minister's being taken to court by the bereaved families of Hepatitis C victims. They want judges to rule that Malcolm Chisholm is breaking Human Rights law. He's refused to have a full inquiry into how hundreds of NHS patients were infected by the deadly virus. Victims' lawyers say bereaved families are legally entitled to the truth. Isobel Fraser has this special report.

Isobel Fraser, Reporter
The safety of blood products is a top priority in modern medicine. Supplies are now screened and treated for deadly viruses. That wasn't the case in the seventies and eighties when the lethal Hepatitis C virus was injected and transfused into the veins of at least five hundred and fifty Scottish patients. Philip Dolan is a haemophiliac who was infected in the seventies. He, like the other victims, has a mountain of unanswered questions: how did this happen? Why was Scotland treating blood differently to England? What did doctors do when they knew there was a problem? Why, typically, were people not told they'd been infected, in his case, until twenty years later?

Philip Dolan, Haemophiliac Victim
The Government needs to come clean about this in order if you're going to believe. This Government went in on a brief of transparency and I cannot see any transparency and I think the biggest problem must be whether the Minister is an honourable person or not, is one question, but the fact is that he's advised and someone needs to question what reasons has he been given poor advice?

Isobel Fraser
The Health Minister Malcolm Chisholm has refused to have a full independent inquiry, pointing out to the Health Committee this week that there has been an internal investigation.

Health Minister Malcolm Chisholm
There is no point in setting up some kind of inquiry unless it appears that there is new evidence to be looked at so, you know, that's my general approach to this. I'm quite open-minded to looking at new evidence but I don't...I'm not persuaded that that exists at the moment.

Isobel Fraser
But today Malcolm Chisholm has been told legally he doesn't have a choice. The lawyer for the bereaved families, Frank Maguire, says people were infected while in the care of the State and Human Rights Law says the State had to investigate this fully. He argues the unanswered questions are an ongoing concern for everybody.

Frank Maguire, Lawyer
Does it have systemic faults, does it have institutional problems and how does it deal...how does it communicate with each branch of its service and has there something gone wrong there which may occur in the future? And with HIV, CJD, all these kind of things, we don't know but if there is systemic failure or institutional failure and a lack of communication and a lack of action by these authorities then that, of course, is of public interest.

Isobel Fraser
Bereaved families have also written to the Lord Advocate today asking for a fatal accident inquiry, but they say because of the large numbers of people who will be killed by this virus a judicial inquiry looking at a wide range of issues would be the best answer. In a statement this evening the Health Minister said that as the legal argument had only been received in letters today he needed time to consider it before making any comment.

06.05.04
Radio Scotland
Newsdrive
1740 hrs
2 mins 55 secs

Ordered by: Ken Stein

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Serial no: 450011

Legal challenge over Hep C cases

Bereaved families of Hepatitis C victims who contracted the disease through contaminated blood, are taking action against the Scottish Executive.

The families want judges to rule that Scottish Health Minister Malcolm Chisholm is breaking human rights law by refusing to hold a public inquiry.

At least 550 Scottish NHS patients were infected by the virus in the 1970s and 1980s.

Mr Chisholm said he would consider the legal argument before making comment.

The lawyer for the bereaved families, Frank Maguire, said the action was necessary as there are still many unanswered questions.

Referring to the system which administered blood products, Mr Maguire called for a public inquiry to clear up doubts.

Inquiry call

He said: "Does it have systematic faults? Does it have institutional problems? How does it communicate with each branch of its service.

"Has something gone wrong there which may occur in the future with CJD or HIV? We don't know.

"If there is a systematic failure or institutional failure and a lack of communication and a lack of action by these authorities, then that is of public interest."

To date there has been an internal inquiry into how contaminated US blood products came to be used in the NHS.

But victims said that this had not answered key questions on why blood products in Scotland were treated differently to those in England.

The victims also said that it was unclear what Scottish doctors did when they knew there was a problem and why victims were not told about infection until years later.

Mr Chisholm has stated that he will not sanction another inquiry unless new evidence comes forward.

On Thursday, Mr Maguire said that, legally, the health minister does not have that choice.

Story from BBC NEWS:
http://news.bbc.co.uk/go/pr/fr/-/1/hi/scotland/3691583.stm

Sunday Herald 9/5/04

Hep C victims use payouts for new legal fight

John Reid faces court battle over 'bad blood' scandal

By **Liam McDougall**
Health Correspondent

GOVERNMENT payments to patients who contracted hepatitis C through NHS blood transfusions will be used to fund the legal campaign for a public inquiry into the scandal.

Lawyers acting for patients said yesterday that they are prepared to take UK health secretary John Reid to court if he refuses to call an inquiry.

Frank Maguire, a solicitor with Thomsons Scotland, has already threatened a legal move against Scottish health minister Malcolm Chisholm. He believes both Chisholm and Reid would be acting illegally if they refused to order an independent judicial inquiry into how thousands of haemophiliacs were infected with the deadly virus through contaminated blood products.

It is thought that more than 5000 people – including at least 550 in Scotland – were infected with hepatitis C through transfusions and other blood products in the 1980s. More than 1000 have since died.

Ministers have consistently refused to grant an inquiry unless fresh evidence came to light, but the new legal challenge warns that both health ministers are obliged to hold an investigation under article two of the Human Rights Act. Lawyers now plan to take a civil case to the Court of Session in Edinburgh to force ministers to back down.

Maguire said: "We believe Malcolm Chisholm is required by law to hold an inquiry and this applies equally to John Reid. Thomsons are in the process of co-ordinating UK cases and are prepared to take Reid to court if the families are not granted an inquiry."

Scores of patients have agreed to apply to the government scheme, offering ex-gratia payments to victims, and then plough part of their compensation into a "fighting fund" to pay for the court battle.

The payment, announced by Reid and Chisholm in January, was to be given to victims "on compassionate grounds" as the government has refused liability for the tragedy. Under the scheme, they would be entitled to £20,000, with a further £25,000 for those who have then developed chronic conditions such as liver cancer.

However, many will now use the money to force the government to reveal the truth about what it knew and the reasons behind their infection. They also hope an inquiry will push ministers into a U-turn over their decision not to compensate the relatives of those who died before August last year.

Only relatives of those who died after August 29 – the date Reid confirmed the Scottish Executive had the powers to operate the scheme – will receive payment. Campaigners are also furious about a similar scheme in Ireland that paid out at least £300,000 to each victim and agreed to compensate the bereaved of those who died.

Philip Dolan, chairman of the Scottish Haemophilia Groups Forum, said he would not be applying for the government payout on a point of principle, but added that many of those infected had agreed to use the fund to pay for the court case.

The campaigners aim to raise at least £15,000 to take the case forward. The money is being held in a special account set up by the law firm.

Dolan said he would be putting his own money into the fund. He added: If the government says it does not accept liability for this tragedy and has nothing to hide, why should it fear a public inquiry?

"I believe a contribution of £150 towards this case is a small cost when, if we're successful in getting an inquiry, it will provide us answers to the questions we've been asking for years."

Bruce Norval, from Fortrose, a haemophiliac who was infected with hepatitis C, said: "I will be applying to the ex-gratia fund. If I get £20,000 I'll give £1000, if I get £45,000 I intend to give £5000. Many others are willing to do the same.

"This is the biggest medical disaster the NHS has ever known. An inquiry is crucial."

The legal move was welcomed by SNP health spokeswoman Shona Robison. She said: "I support the campaigners' bid for a judicial review, given so many doors have been closed to them. I hope a judicial review will give them the opportunity to get some answers about how they came to be infected and also to raise questions about compensation."

David Davidson, the Tory health spokesman, believed the matter should be dealt with by the courts, not a public inquiry. He said: "We've all seen what public inquiries can be like under Labour."

An Executive spokeswoman said the health minister would consider a public inquiry "if new evidence came to light". But she added: "As things presently stand nothing useful would be achieved."

Herald 7/5/04

Hepatitis C families planning legal action

FAMILIES of people who contracted hepatitis C through blood transfusions are to take legal action against the Scottish Executive. They say that Malcolm Chisholm, health minister, is breaching human rights law by refusing to hold a public inquiry.

Frank Maguire, lawyer for the families, told BBC Reporting Scotland last night that the action was necessary as there were too many unanswered questions.

He said: "Does it have systematic faults? Does it have institutional problems? Has something gone wrong which may occur in the future with CJD or HIV? We don't know. If there is a systematic failure or institutional failure and a lack of communication and a lack of action by these authorities, that is of public interest."

As many as 550 Scottish NHS patients were infected by the virus in the 1970s and 1980s through the use of US blood products. There has been an internal inquiry but victims said the inquiry had not shown why blood products in Scotland were treated differently to those in England.

Mr Chisholm has said that he will not sanction another inquiry unless new evidence is presented.

No inquiry into hepatitis infection via NHS blood, minister says

The Scotsman 5/5/04

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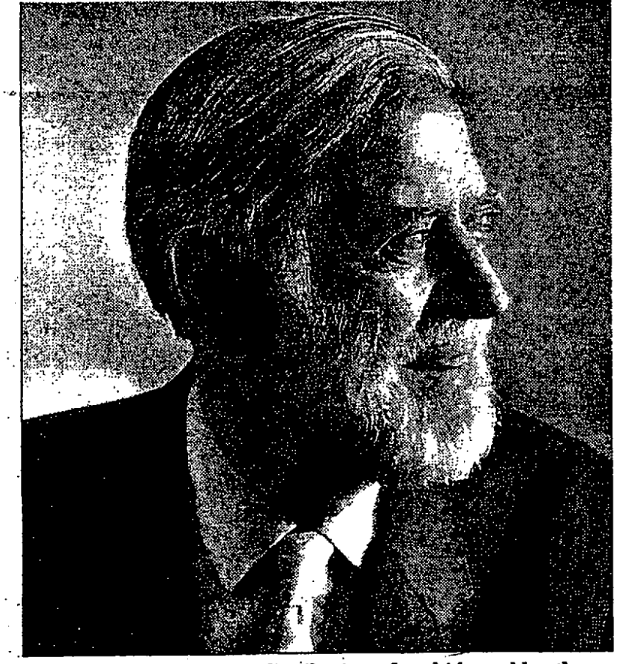
D. Telegraph 3/5/04



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Ingram went on to study clinical medicine at St Thomas's Hospital, London, qualifying in 1944. Within a year he had passed the membership examination for the Royal College of Physicians.

As a house physician at St Thomas's, Ingram developed an interest in the newly-arrived penicillin, which led to the drug being the subject of his subsequent MD at Cambridge. He went on to study medical statistics at the London School of Tropical Medicine, and then took up an appointment at the Hospital for Nervous Diseases in London. Whilst there, he had what was to be the worst recurrence of his pulmonary tuberculosis.

Following lengthy treatment, in May 1948 he became acting medical superintendent at a sanatorium in Switzerland for British patients with tuberculosis. There he met Patricia Forbes Irving, a Nightingale ward sister recently arrived from England, and they married in Montana in September that year. On his return to Britain in 1949, Ingram was awarded a Wilkie Research Fellowship to work for six months in Oxford under Professor McFarlane and Dr Rosemary Biggs.

There he studied haematological techniques before going on to work under Sir James Learmonth, Regius Professor of Surgery at Edinburgh University. With Learmonth, he developed his particular interest in abnormal bleeding syndromes, of which haemophilia is the classic example. His research led to important papers on the underlying mechanisms of bleeding disorders. In 1956 he was appointed to the Jenner Laboratory at St Thomas's Hospital, London. He was based there until he retired in September 1979.

In 1960 Ingram was awarded a Wellcome Research Travelling Fellowship which enabled him to spend a year in the University of North Carolina with Dr John Graham, studying canine haemophilia. Studies with Graham and others led to the overturning of a leading theory concerning blood coagulation. Ingram also contributed significantly to the understanding of the effects of exercise and adrenergic drugs on blood coagulation.

Ingram's time at St Thomas's was notable for the substantial advances he made in the clinical care of haemophiliacs and in developing programmes of self-treatment. He became Director of the Supra-regional Haemophilia Reference Centre and the Supra-Regional Centre for the Diagnosis of Bleeding Disorders based at the hospital. He was also a member of the external staff of the Medical Research Council and a founder member of the Royal College of Pathologists in 1963, becoming a Fellow in 1969. In 1972 he became a Fellow of the Royal College of Physicians. In 1979 he received the McFarlane Award of the Haemophilia Society (of which he was to become a vice-president). Much later London University conferred on him the title of Professor of Experimental Haematology.

Shortly after his retirement, Ingram was confronted by the appalling news that many of his patients had been treated with Aids-contaminated blood products. He did what he could to help, and was effective in persuading John Major's government to pay some compensation to patients and their relatives.

Ingram had a life-long passion for natural history and, on retirement, became warden of Yockletts Bank Nature Reserve in Kent, famous for a number of wild orchid species. He published several papers on the distribution of orchids and surveys of ground beetles. In 1989 he was elected a Fellow of the Linnaean Society of London.

Ingram was also a keen poet, publishing a collection of his work in 2002.

Ilsley Ingram died on April 12; he is survived by his wife, Patricia, and by their son and two daughters.

UK hepatitis C campaign – a victory for volunteers

Richard Andrews
WFH Communications Officer

The U.K. government's recent decision to offer compensation to people who caught hepatitis C (HCV) from contaminated blood was a victory for hemophilia association volunteers, says Karin Pappenheim, chief executive of the U.K.'s Haemophilia Society.

Some 5,000 people with hemophilia in Britain were infected with HCV through blood clotting concentrates in the 1970s and [illegible]s before viral inactivation processes were introduced. One in four was also infected with HIV. The infected concentrates were part of the treatment supplied by the National Health Service

Pappenheim welcomed last August's government announcement of a payment scheme for the HCV victims, but says the battle is not yet over.

"We've been campaigning from the mid-1980s about the contaminated blood disaster. Initially the focus was on people dying at that time from AIDS. In 1987, the government agreed to set up a special payment scheme for those with HIV, but people with hepatitis were excluded. In 1990, anyone who accepted HIV compensation was obliged to sign an agreement saying they would not seek any further money for other infections, including h[illegible]atitis. The move created a great deal of anger."

This anger, combined with a growing awareness of the death and serious harm caused by HCV, spurred on the Haemophilia Society to seek government compensation. Met by repeated refusals and broken promises, the society embarked on a serious lobbying campaign in 1998, the year Pappenheim joined the organization.

"It was a big investment for us. To increase our campaigning power we had to pay for professional public relations support.

"But at the end of the day, the campaign would have been nothing without the dedication of so many of our members. They lobbied local politicians, organized demonstrations, and staged protests outside the houses of parliament."

Pappenheim says the campaign involved much activity centred on human interest stories in the local and national media. "Credit should go to people with HCV who were brave enough to talk publicly about what the virus had done to their lives. Media opportunities also included a picket of the Scottish parliament. Our members stood outside for weeks on end, stopping members of parliament and talking to them about the issues."

Other activities were less dramatic, but just as important, she says. "The government argued that nothing could have prevented these infections and it had done the best it could, given the state of knowledge at that time. To challenge that claim, volunteers spent much time on research and digging around for old minutes. We were also fortunate to win the support of some members of parliament who fired questions at ministers.

"A group of only 5,000 people out of a population of 56 million represents few votes for politicians. Also, HCV is not the huge public health issue that HIV was and still is. The HCV infections happened a long time ago and it's difficult to maintain interest among journalists. It was a huge amount of work over the years, however the volunteers' refusal to give up and take 'no' for an answer led to some success."

The ex gratia payment scheme is based on compassionate grounds, where the government admits no legal liability. Pappenheim says the compensation does not cover those who suffered the loss of a family member, therefore, the society is continuing the campaign.

Pappenheim says any other hemophilia association contemplating similar action should not do so lightly. "Define your goals very clearly. Do your research and gather your evidence. It's all in the planning before you start. Be aware of the implications for your association's resources and relationships with government, doctors and any other key bodies you're seeking to influence. If you can't afford a public relations agency, you will need to base your campaign on volunteers. Our members have shown just how much can be done through volunteer effort." ■

Further details are available on *www.haemophilia.org.uk*

British parliamentarians carry white lilies in support of HCV victims

Sunday Herald 25/4/04

Launch of hepatitis C trust fund in disarray

By **Liam McDougall**
Health Correspondent

THE head of a trust overseeing government payouts to thousands of dying patients mistakenly infected with hepatitis C has admitted to serious delays in launching the scheme.

Martin Harvey, chief executive of the Macfarlane Trust, confirmed that hold-ups in setting up the fund for patients who contracted the deadly liver disease through infected NHS blood products would mean they would be unable to claim their cash for months.

Informed sources have also said those behind the ex-gratia scheme – which health ministers John Reid and Malcolm Chisholm promised to launch this month – have not even finalised the application form that patients will use to receive the £20,000 lump sum.

They paint a picture of stifling bureaucracy within the department of health in Westminster, which will hold up the scheme until June at the earliest. A website set up to publicise the scheme, to be called the Skipton Fund, has also lain dormant for weeks.

A source said: "We pressed for an April start and then a May start. But the department of health in London has not been very forthcoming in helping to process this. We could have been where we are now three months ago had they done what they were supposed to do. If they had any sense they would not have said it was an April launch. April was a pipe dream."

He added that despite pressure from patients groups, civil servants have been reluctant to prioritise the fund. "You have to get forms out to people

Malcolm Chisholm's April deadline will be missed

because they are bloody well dying. There are people who are relying on this money to see them through. The procrastinations of civil servants should not be a barrier to this."

The Sunday Herald understands that relations among those administering the scheme have reached such a low that Harvey has told the department he will launch the fund on June 1 himself, whether ministers are ready to hand out the cash or not.

The source warned: "The feeling is so strong that the fund will open for business on June 1 in the hope that it galvanises the departments of health in England, Wales, Northern Ireland and Scotland into action. It's a message to them saying they had better get their act together."

Harvey admitted to the delays, but said the trust "wanted to get it right".

"Progress has been slow because it's been important to get the detail correct. It affects a very large potential constituency and if we were to rush the matter we may not fully reach those who qualify for an ex-gratia payment. Having said that, we do need to progress matters as quickly as possible. We know there are people out there who desperately need this money.

"Our main aim is to get the ex-gratia payment – whatever people think about the rights and wrongs of the amount – to those who require it."

Patients who contracted hepatitis C will received an initial £20,000. Those who have developed advanced forms of the disease will receive another £25,000. However, payments will only be made to patients infected before September 1991 and who were alive on August 29 last year.

Michael Connarty, Labour MP for Falkirk East and chairman of Westminster's all-party group on haemophilia, said he would campaign for the inclusion of widows and widowers of those who died before August 2003. "In many cases those who died were the main breadwinner in families that have suffered terribly," he said.

Asked about delays in the fund, Connarty said they were "to be expected".

A spokeswoman for the Haemophilia Society said: "We want it to go through as quickly as possible for our members so they can apply. It should go through as speedily but as accurately as possible."

The department of health refused to comment, but a Scottish Executive spokeswoman said Scotland's health department was working on the fund: "An April start date is no longer possible but we still hope that operations will start as soon as possible. We regret this delay, however it is crucial that we get this right."

liam.mcdougall@sundayherald.com
www.skiptonfund.org
www.haemophilia.org.uk

GIG Today "Spring 04"

Haemophilia Society News

The Haemophilia Society has recently made five small grants covering a range of issues from pain management in haemophilia and the Factor VIII gene, to testing of young carriers and information provision for siblings of children with chronic health conditions. Launched in 2002 in adherence with AMRC guidelines, the Society's new research fund was made possible thanks to the Society's acceptance as a guest charity of Jeans for Genes.

Jeans for Genes, a national appeal organised by four main national charities and partnered by four guest charities, raises funds for research into serious genetic disorders affecting thousands of children. Donations also help to fund valuable advice and support services for families. The idea is simple: wear your jeans and pay £1 for the privilege.

Members of the Haemophilia Society were keen to get involved and have helped raise awareness of bleeding disorders, as well as other genetic conditions, by acting as case studies for education packs, talking to their local media, and even presenting directly to schoolchildren about their experience of living with a long-term medical condition. Many came up with some innovative and exciting ways of raising extra funds on the day too!

The deadline for the Society's next round of small grants for medical, scientific and psycho-social research studies in the UK is 29th February 2004.

For more information visit www.haemophilia.org.uk or www.jeansforgenes.com.

Eastern Daily Press 22/4/04

Firm launches haemophilia drug

Baxter Healthcare, which employs almost 600 people in Thetford, has launched a treatment for haemophilia in the UK.

Advate, made at Baxter's biotechnology facility in Neuchâtel, Switzerland, is said to be the first and only factor VIII therapy made without the addition of any human or animal proteins. This eliminates the risk for transmission of infections that could be carried in these proteins.

The new treatment is a blood-clotting therapy that helps people with haemophilia A prevent and control bleeding episodes. Infused directly into the bloodstream, Advate works by temporarily raising the level of factor VIII in the blood, thus allowing the body's blood clotting process to function properly.

Irish Times (Dublin) 21/4/04

Blood product safety project hailed

JOE HUMPHREYS

Blood products used by haemophiliacs will be electronically tagged for the first time under a safety project aimed at minimising the risk of infections.

The quality initiative, the first of the kind internationally, has been hailed as a major breakthrough by clinicians and patients eager to avoid any repetition of the HIV and hepatitis C infection tragedies of the 1980s.

Under the €1 million project, all blood products will be labelled with a bar-code that can be checked against patient records, thereby allowing a more efficient recall if a safety concern arises.

Dr Barry White, director of the National Centre for Hereditary Coagulation Disorders at St James's Hospital, said the scheme "will set a new standard for safe administration of haemophilia treatment". As well as being the first electronic tracing system in the world for haemophilia, it was the first time such technology had been used for prescriptions and treatment assessment in an Irish healthcare context.

St James's is planning a similar scheme in cancer treatment.

Dr White said the project should be seen in the context of the introduction in 1997 of synthetic, or recombinant, products for the treatment of haemophiliacs, which further sought to eliminate the risk of infections. "We always assume risk with medication, and we plan for it."

Mr Brian O'Mahony, president of the World Federation of Haemophilia and a representative of the Irish Haemophilia Society, said, in introducing the scheme, "medical practice is catching up with what supermarkets have been doing for years" as regards tracing.

Some 600 people with haemophilia will benefit from the initiative, which is being rolled out next month on a pilot basis at St James's. Some 200 patients who treat themselves at home will be supplied with hand-held computer devices to ensure all treatment information is recorded on an ongoing basis.

HEP C PATIENTS SUE FOR CASH

by HELEN PEARSE
Health Reporter

Law firm is briefed to make claims

PLYMOUTH haemophiliacs who contracted hepatitis C in an NHS blood blunder are to sue the Government for thousands of pounds in compensation.

But the £20,000 they have been told they can claim has been described as 'paltry' by angry sufferers who say it is not enough to make up for the pain, and anguish they have endured.

After a change in the law the Government said one-off lump sum payments of £20,000 can be claimed by haemophiliacs who can prove they contracted the potentially lethal disease through contaminated blood products.

Two city men today told the Herald they will make claims directly from the Government, with help from the Haemophilia Society, and Plymouth-based law firm Foot Anstey Sargent has been instructed to handle the claims of other haemophiliacs.

Sufferer GRO-A who has battled for compensation for victims since 1994, today said he would claim the cash but the cash available is a 'drop in the ocean'.

He said: "It is a paltry amount considering what we have had to go through. It won't make us better off financially month by month; it's just a drop in the ocean."

Mr GRO-A from GRO-A discovered he was infected with hepatitis C in December 1994. He was given the all-clear from the virus in 2001, after a painful treatment programme.

But as a teacher he was forced to go on sick leave during his treatment and has since retired on health grounds, partly because of the effects of hepatitis C. He will continue to fight for a more substantial pay-out for others.

A special ex-gratia payment scheme was set up in January by the Department of Health to compensate people infected with hepatitis C from blood or blood products. The scheme comes into effect this month, and haemophiliacs will claim payments. They say the compensation is not enough.

Under the scheme they can claim a lump sum of £20,000 if they have or have had the hepatitis C virus. Those who go on to develop cirrhosis or liver cancer or who have received a liver transplant can claim a further £25,000.

Payment will be made to the families of patients who have died since August 29, 2003, but no money will go to families of sufferers who died before that date.

Mr Waring said: "The bereaved families are still not included and that's very sad, and for that reason I will carry on campaigning.

"They are just going for a minimum level of payment for people such as myself, and another £25,000 for those with cirrhosis or liver cancer.

Claimants will be asked to sign an undertaking not to institute future proceedings against the NHS in relation to their infection with hepatitis C, something Mr GRO-A is unhappy about. He added: "I don't want to feel that if something else comes up in the future we will be prevented from taking action. That's totally wrong.

"Whilst the recent offer of payments is a welcome major step forward in what has been a nine year battle for me, it falls a long way short of what should be done.

FIGHTING ON: Hepatitis C sufferer Richard Waring

"Many people have incurred huge financial losses as a result of this tragedy not to mention the terrible suffering. Those who have lost family members have paid the highest price and will be left out of the scheme. This cannot be right."

Mr GRO-A said haemophiliacs were expecting to get at least £40,000, whilst the Haemophilia Society hoped for sums of up to £140,000. Mr GRO-A said: "It's not a fair package."

Haemophiliac GRO-A 63, from GRO-A was diagnosed with Hepatitis C in 1992. He now has cirrhosis of the liver so will claim the additional payment.

He is angry that the sum offered is below that claimed by sufferers in other countries. He said: "Canada have got £100,000 payments and we have had nothing yet.

"I will apply for the extra £25,000 as I have had all sorts of health problems because of Hep C."

"We will continue to campaign."

At Foot Anstey Sargent, Jonathan Green said: "We are notifying the Department of Health of potential claims."

down, two to go!

However, I still had to overcome my denial of HCV, and acknowledge that this virus was potentially lethal too and even more so in conjunction with HIV. During my first interview with the doctor I held back the tears while repeating my story all over again. At the end of the visit, I was told that after some preliminary tests I should have a liver biopsy, and possibly start treatment for HCV.

I had seen friends on HCV treatment – peglyated interferon (peg-interferon) and ribavirin – going through incredibly tough side effects. I knew a lot about genotypes and how they affected prognosis and length of treatment. I had made my mind up that if I had genotype 1, the hardest to treat, I didn't want to go through the pain of HCV treatment. I already had enough with over four years of HIV treatment! So I asked to have at least the genotype test done before deciding whether to have the biopsy. I was told it was not possible because the hospital did not have enough money. The biopsy was the most important exam to assess liver damage, and they would do that first. So against my wishes I booked myself in for a biopsy. The waiting list was long, more than two months.

As the date of the biopsy approached my doubts grew. I was scared because I had heard quite painful tales of liver biopsies. Moreover, I was not convinced this was the right procedure. After many discussions with other women at PW I was told that there was a hospital in north London where I would have had my HCV genotype and viral load done first, as routine, and then I could choose whether to have a liver biopsy. In this hospital they had a co-infection clinic and you didn't have to leave the HIV clinic to have the hepatitis treated.

The choice of changing hospital was a very difficult one. First of all, it would take me over an hour from my home in deepest south London to travel to a hospital in the posh North. Secondly, I was worried I would have to wait another six months if I needed a liver biopsy. However, a week before the biopsy the fear won. I made my mind up and I called the north London hospital. They confirmed that they would do all the possible blood tests before doing 'such an intrusive procedure as a liver biopsy' (their words), including HCV genotype. I was so happy to have a professional agreeing with me! I quickly cancelled my appointment for the liver biopsy and I booked myself in at the new hospital.

On the first day in the north London hospital, my blood was taken and I was tested again for HIV and HCV (just in case there had been a mistake). On my second blood test, without a need for lengthy referrals (and to my delight), I was tested for HCV genotype and viral load! In a matter of few weeks I had seen a co-infection specialist and I had received the good news that my HCV genotype was one that responded very well to treatment.

Relieved, I finally consented to a liver biopsy and I had it performed at the beginning of October. Things worked fine for me and I feel optimistic I have enough support around me to deal with going on HCV treatment.

I think it is quite clear from this last part of my story that one of the things that most helped me in making decisions around how to deal with my co-infection has been support from other people living with HIV and HCV.

What has left me with a feeling of malaise (that is not caused by my liver) is the following thought: how can standard of care be so different between two hospitals that are separated only by a few miles? Shouldn't all people in the UK who are living with two life threatening viruses such as HIV and HCV, be entitled to equal standards of care?

Silvia

Babs, who organised the conference

HBV, HCV, HIV one

GRO-A

GRO-A

In this article, GRO-A tells of her experience of co-infection. Originally, this was part of the speech that she presented at The Haemophilia Society HIV and Hepatitis Co-infection Conference 2003. It tells her personal story of diagnosis and experiences within the medical system as a woman co-infected with the HIV and hepatitis viruses.

I am going to talk about my experiences with three blood-borne viruses: Hepatitis B (HBV), Hepatitis C (HCV) and HIV. Acquiring those viruses is deeply linked to difficult and painful moments in my life, but instead of getting lost in explanations on how and why, I will instead try to just highlight how those viruses affected me and what helped me, or did not help me, to deal with them.

HBV

I was only 16 when I got Hepatitis B (HBV). I won't go into the details of my precocious drug use. However, this disease gave me an early insight on how precious the liver is. I spent four weeks in hospital, with a transaminase count of 1,600, yellow like a lemon. It was not fun, especially as a teenager. If I have to think what helped me, I can't say – probably being so young! After six months my antigens became negative, and that was it. One down!

HCV

I was 27 when my GP in Italy advised I get tested for Hepatitis C (HCV). I had gone for a check up and there were some abnormalities in my liver tests. My GP gave me the results over the phone. It was confirmed; I had HCV. He also advised me not to have children because of the risk of pre-natal transmission. Nothing more. No further explanation or counselling was available. I was shocked, and didn't know what to do.

I decided to contact a couple of friends who I knew had HCV as a souvenir from their drug use and who were crippled by chronic fatigue. When I talked to them, they advised me not to go on the interferon, which was the main therapy at the time. One of them had tried it and said, 'under its effect, I considered going back to opiates'.

How did I cope? I opted for denial. I just didn't think about it. I was lucky because I didn't have any strong symptoms. However, at least I had been able to get support and advice from other people in the same situation and that had helped me in my 'choice' of no-action.

HIV

In 1997, three years after HCV, I was diagnosed with HIV. One would think that because of my life experien I should have been prepared. I wasn't. Shock, terror and tears came with my diagnosis. When I managed to ask doctors about how HCV would interact with HIV, I was more or less told that since HCV was a slow developing disease, it would not have time to affect me. I would have died of AIDS first.

Unlike with Hepatitis C, I did not feel like I could talk to anybody who could fully understand and empathise with me. I did not know anybody who was open about their HIV status. In Italy, as in most of the world, stigma and discrimination around HIV is rife. I felt terribly isolated. Having to think about dying at 30, when most of my friends were planning babies, was very hard but it meant I had to think clearly about how I really wanted to live.

I made a plan. I love books. Books are what saved me from addiction. I decided to come back to London, where I lived during my early 20s and study for a Postgraduate Degree in Development Studies. I dreamt of working for an NGO.

HCV + HIV

When, in 1999, I finally arrived in London, my HCV was still not addressed for a couple more years. Then finally, more than a year and a half ago, the doctors decided it was time to deal with my Hepatitis C. I was attending an HIV clinic in south London, and they referred me to the liver clinic that was in a totally different department of the hospital. I had to wait four months for an appointment, and when it came it was very difficult. I had become more relaxed towards HIV, as I was confident that HAART would allow me to live much longer than I expected at the time of my diagnosis.

P.T.O.

SUNDAY HERALD (GLASGOW) 4/4/04

Blood money

I WAS disgusted but not surprised that the proposed hepatitis C financial settlement announced by Malcolm Chisholm involves a legal waiver, requiring that haemophiliacs give up any rights to take future legal action against government ministers and the NHS in respect of their contamination (News, March 28).

The award is paltry; barely 10% of the payment received by the Irish scheme, which also included widows, partners, and dependents.

My husband GRO-A a severe haemophiliac, was made to sign a similar hepatitis waiver in 1991 in order to receive an HIV ex-gratia payment from the Westminster government. Haemophiliacs were then told that hepatitis C was "nothing to worry about". We now know this was totally incorrect.

My husband mounted a legal challenge to this waiver and the advice from a QC was that if the case went to court, Peter would very likely win his case and the waiver would not stand. There was, however, one problem: my husband would be unable to secure legal aid funding as the cost of taking the case to court would be greater then any damages awarded. The only way around this would be as a class action involving all the original HIV litigants.

We would ask haemophiliacs to question the legality of any proposed waiver, and refuse to sign a waiver as part of the hepatitis C government financial scheme.

Why would any government that refuses to accept legal liability and claims there is no evidence of negligence in relation to haemophiliacs' hepatitis C infection, be so desperate for haemophiliacs to sign away their legal rights?

Carol Grayson
Haemophilia Action UK
Newcastle

Aberdeen Press & Journal 2/4/04

Payments waiver on bad blood dropped

by Paul Gallagher

FIRST Minister Jack McConnell has backed down over plans to make people who caught hepatitis C from NHS blood products sign away their right to legal action before gaining compensation.

A Scottish Executive guidance paper stated that anyone who contracted the disease through contaminated products would have to sign an undertaking not to sue ministers or the health service. Any payments the patients received would have been conditional on them putting their names to the waiver. The ex-gratia payments, worth up to £45,000, were announced last year.

But at first minister's questions yesterday, Mr McConnell announced that the waiver would no longer apply.

The question was raised by Dundee East MSP and SNP health spokeswoman Shona Robison.

Mr McConnell answered that people receiving awards from the Skipton Fund, set up to administer the payments, would not be required to sign any such undertaking.

Ms Robison then asked: "What action, given the alarm among those who contracted hepatitis C, will the executive take to reassure them they will not be debarred from seeking compensation through the courts?"

Waiver

Mr McConnell replied: "The best action to take is the decision I have announced, to make sure there is not a waiver. There will not be a waiver people will be required to sign. We have agreed to withdraw that particular document and ensure new guidance is circulated to those affected.

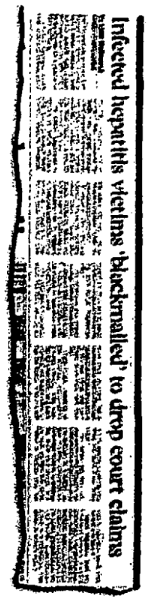
"Members across the chamber will be pleased there will be no requirement on anybody to sign a waiver in this way."

Bruce Norval, of GRO-C in Easter Ross, a haemophiliac who contracted hepatitis C through contaminated blood products, believes Mr McConnell's announcement should be "the first of many reversals".

He said: "This is a significant step forward but the next reversal I would like to see in their decisions is in the refusal to pay widows.

"I think the current compensation scheme is an attempt to try and defuse any bad publicity that may come if someone proves their case."

Philip Dolan, chairman of the Scottish Haemophiliac Forum, said: "I obviously welcome the fact this waiver has been withdrawn but it should never have been there in the first place. If they're making an ex-gratia payment, it shouldn't affect any other benefits. There are other issues which still need to be reviewed. We would still maintain the amount of money they are talking about is derisory and there's an urgent need for an independent public inquiry into the safety of the blood."


Infected hepatitis victims 'blackmailed' to drop court claims

How the Sunday Herald broke the story last week

New call for probe after McConnell U-turn on hepatitis

By **Liam McDougall**
Health Correspondent

JACK McConnell was last night under mounting pressure to order a judicial inquiry into how hundreds of haemophiliacs contracted hepatitis C from NHS blood products.

The First Minister faced fresh calls to announce an investigation just days after he appeared to overrule his health minister by reversing a decision that would have stopped victims from suing.

The move followed the Sunday Herald's publication of leaked papers last week showing how health minister Malcolm Chisholm planned to withhold ex gratia payments to victims unless they signed a waiver preventing them from taking legal action against ministers and the NHS.

It has fuelled speculation in the Scottish parliament that Chisholm's position as health minister may be under threat.

On Thursday, McConnell said: "Following discussions yesterday, the minister for health and community care and I have agreed to withdraw that particular document ... there will be no requirement for them to sign a waiver."

But McConnell's U-turn has led to demands that he now does what is "morally right" and agrees to an inquiry.

Frank Maguire, the lawyer representing around 140 victims in Scotland, said: "Now that Jack McConnell's involved and not just the health minister I'd like to have some sense and fairness injected into this.

"They are still missing the crucial thing that these people want, and that is an inquiry. They want to know why this happened and what was done about it."

More than 500 Scots are believed to have contracted hepatitis C during transfusions and other blood treatments in the 1980s before proper screening was introduced in 1991. But Maguire said patients were coming forward who had contracted the condition from blood treatments as late as 1995. The claim means people were still getting the disease after the NHS knew that heat-treating would kill the virus.

Philip Dolan, chairman of the Scottish Haemophilia Groups Forum, who contracted the deadly liver disease through a blood transfusion, said: "I welcome this change of mind on the waiver but there is still an urgent need for an inquiry if there is no blame then the government should not be afraid to have an inquiry.

"There seems to be an endless amount of money to have an inquiry into the Scottish parliament building, so why can't we have one for the more than 560 people in Scotland who have been injured or killed through NHS treatments?"

But as the pressure mounted on the Executive to order an inquiry there was further outrage that ministers would still refuse to compensate the relatives of those who had died before August of last year.

Under the award, announced in January by health secretary John Reid and by Chisholm, victims would be entitled to £20,000, with a further £25,000 for those who have gone on to develop chronic conditions such as liver cancer.

Only the relatives of those who died after August 29 – the date Reid confirmed the Executive had the powers to operate the scheme – will receive payment. Fury has erupted among campaigners, politicians and relatives of those who have died who say a similar scheme in Ireland paid out at least £300,000 to each victim and agreed to compensate all widows of those who died.

Dolan said: "The widows' situation is simply scandalous. What is the difference if someone dies on August 29 last year or the day before? How can they say they will give money to one and not to the other?"

Opposition politicians also condemned the move. SNP health spokeswoman Shona Robison said: "It is scandalous that the families of those who died before August 29 will not benefit from this. This anomaly needs to be addressed."

David Davidson, the Tory health spokesman, added: "I think it is quite unjust that the government should use this arbitrary date to exclude people from receiving payments. An ex-gratia payment should be made on an unconditional basis."

However, a spokesman for the Executive said: "There are no plans to review any other aspects of the scheme."

liam.mcdougall@sundayherald.com

SUNDAY HERALD (GLASGOW) 4/4/04

Daily Telegraph 30/3/04

Genetic surgery in the womb moves closer

British scientists lead in the use of HIV to deliver a pre-birth cure after successfully treating blood clotting in foetal mice, reports **Roger Highfield**

BRITISH scientists are preparing to conduct genetic surgery on an unborn child. The team reported yesterday that it is the first to use gene transplants in the womb to cure an inherited disease – the blood clotting disorder Haemophilia B.

Success in using a "tamed" Human Immunodeficiency Virus to implant corrective genes to cure foetal mice was reported to the British Society for Gene Therapy in Keble College, Oxford, by Dr Simon Waddington and colleagues from Imperial College London.

Consultations on conducting transplants on unborn children are about to start, along with discussions with the Gene Therapy Advisory Committee, which supervises human trials.

Gene therapy in the womb has been studied for a decade by Imperial's Gene Therapy Research Group, headed by Prof Charles Coutelle. This first application was funded by the Medical Research Council and a charity, the Katharine Dormandy Trust for Haemophilia and Allied Disorders.

The approach was advancing to where it could be considered on patients in special circumstances, said Dr Waddington, notably when a hereditary disorder was diagnosed during pregnancy and the parents, for religious or personal reasons, refused a termination even though the baby might die soon after birth.

The group has joined with Prof Charles Rodeck at University College and the Royal Free Hospital, London, to explore the safe use of gene therapy on a human foetus. Dr Michael Themis of Imperial is assessing the safety of the adapted Human Immunodeficiency Virus used for the transplants.

The team will also consult doctors and patient groups to explore ethical dimensions. The advance is likely to stir debate since a method to correct diseases could also be used to create "designer" babies.

These investigations were likely to take several years, said Prof Coutelle. If shown to be efficient and safe in larger animals, such as sheep, an injection of virus-derived medicine offers the promise of a cure for diseases such as enzyme deficiencies, perhaps even muscular dystrophy and cystic fibrosis.

There are reasons to think gene transplants will be more successful in the foetus than in children or adults, among them the better access to cells that need to be corrected before the disease develops, and fewer immune reactions.

Inefficient gene transplants have caused problems, along with immune reactions.

Despite huge promise, human trials have only worked convincingly after birth in treating immune deficiencies, when so-called "bubble babies" are stripped of the ability to fight infection.

Other issues are raised by foetal gene therapy, notably whether transplanted genes can end up in eggs and sperm. However, a screen of the sperm made by mice in the Imperial experiments did not reveal genes transferred this way.

Prof Edward Tuddenham, of Imperial, who is working on adult gene therapy for haemophilia, said there was often knee-jerk opposition to foetal gene therapy.

Half a dozen trials have been conducted in America on patients. These trials implanted either factor VIII or factor IX genes, but only at levels that would reduce dependence on treatment.

One trial detected the virus used for the transplant in semen, raising concerns about germ-line transformations. All but two are discontinued.

As more patients use more expensive biotechnology-manufactured clotting factors, lifetime treatment costs may rise to £5 million.

"No wonder most of the world's haemophiliacs receive no treatment at all," said Prof Tuddenham. "Gene therapy offers the hope of freeing patients from a lifetime's dependence on the needle."

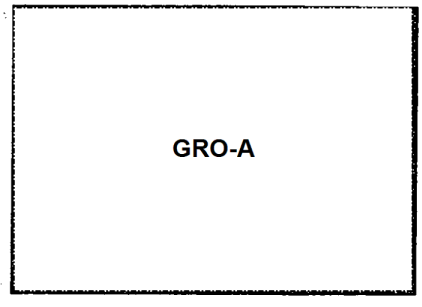
● Gene therapy research is to be given a £4 million injection, the Health Secretary, John Reid, said yesterday.

Around £1 million will be spent on safety studies, including of the viruses used for gene transplants, such as HIV. Another £500,000 will be given to Dr Kyriacos Mitrophanous of Oxford BioMedica for research on Haemophilia A, caused by a lack of factor VIII, marking the first British gene therapy haemophilia trial.

The Muscular Dystrophy Campaign is awarded £1·6 million for research into the fatal muscle-wasting condition.

Headed by Prof Francesco Muntoni of Imperial, the research aims is to insert a "molecular patch" to fix the underlying genetic error in a trial that will also mark a British first.

Another £900,000 is awarded to Dr Robin Ali of University College London to treat childhood blindness.



success

'Safe' virus held the key

TO carry out the pioneering gene therapy, the team used a stripped-down Human Immunodeficiency Virus, designed to be safe and to implant corrective genes into the liver of the foetus.

The virus was used to deliver the gene responsible for the human blood clotting factor IX to normal and haemophiliac foetal mice via the yolk sac blood vessel, which flows into the umbilical cord.

Haemophiliac mice lack the factor and can bleed to death after injury. However, after treatment, they made human factor IX and were all born with blood that was able to coagulate normally.

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'I am not sure about the long-term effects'

By Roger Highfield

THE GRO-A family has mixed feelings about using gene therapy in the womb to treat haemophilia, which causes uncontrolled bleeding.

GRO-A 35, a consultant engineer, and her husband Chris, 36, an executive in financial services, have no history of the disease in their families so it came as a shock when their son was diagnosed with severe haemophilia A.

A few hours after GRO-A s birth at Queen Charlotte's and Chelsea Hospital he collapsed with bleeding into his abdomen and had to be resuscitated in intensive care.

"It was touch and go for a while," said Mrs GRO-A GRO-A was found to have less than one per cent of normal levels of factor VIII and diagnosed with the bleeding disorder. He bruised easily while crawling at home in GRO-A although the family was spared serious bleeding that would have meant hospital.

"Though it is serious, 98 per cent of the time we could treat him just like we do our daughter," said Mr GRO-A Since the end of last year, the one-year-old has had three injections of the missing factor each week "which makes a huge difference and should prevent him having a joint bleed", said Mrs GRO-A

His diagnosis raises the possibility that GRO-A and her four-year-old daughter, Helen, are carriers of the faulty factor VIII gene that causes the disease. Would she consider gene therapy if her unborn child were diagnosed in pregnancy?

So long as the risks and side effects of the technique were fully explained along with the benefits, Mrs GRO-A felt it was worth considering.

"The idea of gene therapy is fine and not meddling too much, so long as it is well controlled."

She added that foetal gene therapy should be considered only for medical uses, not to enhance a child's intelligence or for cosmetic reasons to create a designer baby.

"There has to be tight control of this technology."

Her husband said if gene therapy in the womb were viable, potentially it could b effective, as haemophilia A was caused by a single component and affected onl clotting.

But he would prefer conventional gene therapy i which corrective genes are introduced at intervals over a lifetime to correct the condition.

He is sceptical about how easy it will be to use gene therapy to treat more complex conditions.

"I am not sure we know what the long-term effects of genetic modification will be," he said.

GRO-A

The GRO-A at home in Fulham with Helen and Alexander. They have mixed feelings about using gene therapy in the womb to treat haemophilia

Guardian 30/3/04

DoH cash for gene therapy firm

Heather Stewart

Biotech group Oxford Biomedica is to profit from a government drive to kick-start innovation in gene therapy, with a £500,000 research grant to test a potential treatment for haemophilia.

Oxford Biomedica was the only private sector winner from a £4m funding round announced by the Department of Health yesterday, aimed at bringing the benefits of genetic research to NHS patients.

"It's a bold step for the Department of Health to be committing to use this approach to treatment. They're usually a follower rather than a leader," said Nick Woolf, Oxford Biomedica's head of corporate strategy.

"Investment saves lives — that is why it is vital that we fund research into the latest cutting-edge treatments such as gene therapy so that Britain remains at the forefront of medical research," said the health secretary, John Reid, announcing the funding.

A DoH spokeswoman yesterday admitted that it was unusual for profit-making firms to receive such grants. The government was committed to spending £50m on gene therapy by 2006, she said.

Haemophilia A, the target of Oxford Biomedica's research, affects about 400,000 people, who now have to be injected with a blood-clotting factor about three times a month. Oxford Biomedica believes it can adapt its LentiVector technology — which uses a virus to deliver genetic material into cells — to correct the underlying defect stopping people with haemophilia producing their own clotting factor. They would then probably only need to be treated once a year. "It's as close to a cure as you can get," said Mr Woolf.

Oxford Biomedica had put its haemophilia research on hold to concentrate on developing treatments for cancer and central nervous system disorders such as Parkinson's, which are closer to completion and where the potential market is larger.

"This grant will directly fund this programme, so we can take the research off the shelf," said Mr Woolf. It could be two years before the treatment starts clinical trials in humans, but the DoH cash will bankroll the project until then.

Multi-million pound funding from charities and other non-profit groups has already boosted Oxford Biomedica's coffers as it moves towards bringing genetic therapies to the market.

Non-profit investors such as Cancer Research UK do not ask for a financial return from their donations — they simply want to speed up the search for a cure.

Other beneficiaries of yesterday's government funding round included researchers at Imperial College, London, studying Duchenne muscular dystrophy, and a project on childhood blindness at University College, London.

Financial Times 30/3/04

Gene therapy to be given £4m injection

Gene therapy is to be given a £4m boost by the Department of Health as part of a £50m plan to harness the benefits of advances in genetics. Most of the cash will go to fund three human trials of experimental cures for muscular dystrophy, the degenerative disease, haemophilia, the blood clotting disorder, and inherited childhood blindness. However, £1m will be used to fund studies into the long-term safety of the introduction of genetic material into patients' cells. Gene therapy, which involves the introduction of genetic material into cells, offers the possibility of curing inherited diseases by repairing or replacing faulty genes. But there has been little progress despite more than 70 clinical trials involving 900 patients.
David Firn

Sunday Herald 28/3/04

Infected hepatitis victims 'blackmailed' to drop court claims

By **Liam McDougall**
Health Correspondent

DYING patients infected with hepatitis C will be forced to sign a waiver preventing legal action against government ministers and the NHS before being eligible for a payout for their suffering.

A leaked document reveals that more than 3000 people in the UK, including 550 in Scotland, who contracted the deadly liver disease through contaminated blood products will have to give a written promise not to sue or they will lose their claim to a £20,000 government payment.

The award, announced in January by Health Secretary John Reid and Scottish Health Minister Malcolm Chisholm, was said at the time to be an "ex-gratia payment" given "on compassionate grounds".

However, the internal Scottish Executive briefing paper reads: "People who receive payments under the scheme will be asked to sign an undertaking not to institute proceedings against the NHS or ministers in relation to their having been infected with hepatitis C from blood, blood products or tissue received from the NHS before September 1991."

The revelation has caused outrage among campaigners, politicians and lawyers acting for hundreds of sufferers who are poised to have their cases heard by the courts.

The campaign for compensation has been running for more than 20 years. Since patients were infected through contaminated blood products in the late 1970s and early 1980s, more than 1000 have died.

Philip Dolan, chairman of the Scottish Haemophilia Groups Forum, who contracted hepatitis C, said many campaigners would refuse to sign the waiver. "I for one will not be signing anything that stops the facts from being heard."

The waiver was also condemned by Frank Maguire, the lawyer who is acting for around 140 sufferers in Scotland. He said: "It's very convenient for politicians because it closes up any more civil claims. If it succeeds, the issue will not be looked at because they will have bought them all off. They are trying to bury it."

David Davidson MSP, the Conservatives' health spokesman, branded the situation "scandalous". He said he would be writing to Chisholm to demand an explanation for the action. Shona Robison, the SNP health spokeswoman, added: "It is outrageous. This cannot be morally right."

AFX (Premium Wire) 30/3/04

Bayer's Wenning says has shortlisted bidders for up-for-sale plasma ops

FRANKFURT (AFX) - Bayer AG has shortlisted the number of bidders for its

plasma business, which is in the process of being sold, chairman Werner Wenning

said at today's German Corporate Conference hosted by Deutsche Bank.

'We have put together a shortlist,' Wenning said.

At the company's annual news conference two weeks ago, Wenning said the

divestment of the plasma operations may run into 2005 because the new owner of

the business must submit an application with the US FDA to gain a license for

the products it is buying.

Bayer just has one license for its biological products division, but has

decided to sell the plasma business and keep the haemophilia treatment Kogenate,

and is therefore keeping its license.

The plasma business posted sales of 613 mln eur in 2003. Australia's CSL Ltd

was reported last year to be interested in buying Bayer's business.

A planned blood plasma joint venture between Bayer and Aventis SA fell

through last year due to a disagreement over the value of the deal.

The Herald 30/3/04

LETTERS TO THE EDITOR

200 Renfield Street, Glasgow G2 3QB
e-mail: letters@theherald.co.uk
Fax: 0141 333 1147

New low in dealing with hepatitis C victims

THE latest revelations on hepatitis C show that the Scottish Executive has sunk to a new low in how it is dealing with this vexed affair. On the one hand it is making a derisory financial offer to haemophiliacs which does not admit to any legal responsibility for their being contaminated through NHS blood products with this sometimes fatal virus. On the other hand it seeks to deny haemophiliacs their future legal rights should it be found that they collectively or individually have a case against the executive.

The only logical conclusion, therefore, is that the executive is aware that haemophiliacs might have a legal case against it. Otherwise, if it is so certain of its innocent position, why build in the clause that signs haemophiliacs' rights away? The executive has, of course, also denied legal aid to those affected.

Most living haemophiliacs could have received at least £50,000 under the recommendations of the ministerial-appointed expert working group chaired by Lord Ross. They will now have to decide whether they not only settle for the Westminster-controlled offer from the health minister, Malcolm Chisholm, which for many is less than half of what Lord Ross recommended, but also sign their life away.

GRO-A