

# Doctors facing hepatitis inquiry

## LORNA MARTIN

A NUMBER of doctors are being investigated by the General Medical. Council after complaints that they broke guidelines by secretly testing patients for hepatitis Cwithout their consent.

The GMC, which can strike off depose for malpractice, is looking into claims that clinicians knew NHS patients had become infected with the virus years before they were told.

The news comes a month after police completed their investigation into the NHS blood mix-up which left hundreds of Scots infected with HIV and hepatitis C in the 1970s and 80s. Their investigation could result in jail sentences of up to 10 years for officials responsible for the blunder.

There are believed to be about 365 haemophiliacs still alive who were infected with hepatitis C through treatment on the NHS in Scotland, and a further 800 surviving patients infected through blood transfusions.

Haemophiliacs and other patients are still fighting for a public inquiry into the affair.

Hepatitis Č is classed alongside HIV as a serious communicable disease, and medical guidelines say that doctors must get a patient's consent before testing for it. A spokeswoman for the GMC confirmed that an investigation was under way into the issue of how patients were treated for blood-borne diseases.

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"We will look at the complaints and, if we have found that there is evidence of professional misconduct, we can take it to a final public hearing. This can lead to a number of outcomes including erasure from the register," she said

GRO-A chairman of the Scottish Haemophiliacs' Forum, said it was an issue that had affected most of the people infected.

He said: "Most haemophili= acs were not told until into the 90s. From the late 70s' they were testing us without telling us, leaving us unable to make informed choices."

He has written to the Scottish Executive, urging the goveernment to stop "pussy footing" around and to implement the findings of an expert group chaired by Lord Ross, which recommended compensation of up to £89m be paid to those who contracted hepatitis C through contaminated NHS blood products.

Dr Charles Saunders, chair of the BMA's public health committee in Scotland, said: "It's certainly not right giving them the results in an insensitive way. I think you have to accept the fact that things were done differently in the past."

# 'Breakthrough' hailed by medical researchers

## James Meikle Health correspondent

Doctors believe they can cut the need for liver transplants by injecting sick patients with healthy cells instead

Operations on bables at King's College Kondon have so encouraged researchers that they are claiming two breakthroughs, the first cell transplants to treat liver disease in Britain and the first such transplant in the world to use only frozen cells.

The ability to freeze cells known as hepatocytes could mean the development of a "bank" that could stockpile cells for use as and when they are needed. The King's team sees no reason why the developments should not be adapted for adults too

Four babies, suffering three different conditions, have so far undergone the injection treatment at ages ranging from two days to three years. One was effectively kept alive until he was big enough for an organ transplant and a suit able match could be found while the hope is that the others' livers will regenerate in a way that means that further major surgery is unnecessary.

Another boy came from a family who had already lost one child because of a missing blood clotting factor normally produced by the liver, and had another son who needed a synthetic version of the substance known as factor 7 injected daily through a vein in the neck at the cost of £700 a time.

But doctors identified the lack of factor 7 in the third son before birth and gave him three injections of hepatocytes when he was six weeks old. This has so far reduced his need for synthetic factor 7 by 80% and doctors hope another injection will mean that soon the baby, now eight months, will not need it at all.

All four babies — three boys

and a girl — will still need to take drugs for the rest of their lives to combat the threat of rejection, but the long-term hope is that cells can be treated before they are injected.

Fewer than 700 people undergo liver transplants in Britain each year, about 100 of them children. There may be up to 150 people waiting for a suitable match at any one time.

The King's team, whose first successful operation was on a six-week-old boy last September, say the technique will allow far better use of donated livers, either as whole organs from people who have just died or from live donors who donate part of their liver.

Donated livers have to be transplanted within 16 to 17 hours, but using cells culled from parts of the organs that are not used in transplants should make far better use of scarce resources. In addition, putting spare cells in liquid nitrogen should preserve them for when they are most needed, 60% survive such storage at King's.

The injections, through the umbilical cord for children just a few days old or direct into the liver, only take 30 to 45 minutes instead of the six to eight hours for whole transplants. The fourth child underwent the treatment less than a week ago.

Anil Dhawan, a specialist in children's liver disease who heads the research team, said that it was too early to comment on the success of the latest operation but added. "All three babies are doing very well and without the hepato cyte injections one of the children would certainly have died."

"If the technique does prove a long-term success then 20-40 children could avoid liver transplantation each year in Britain. This could free up more donor livers and there fore increase the overall number of people who could be offered liver replacement are "The fact that we can free?" hepatocytes will also maked consult able dimension and the many patients can be treated and how quickly."

SocietyGuardian.co.uk/health

# fest results Reptsecret The Scotsman 6/5/03 Doctors stayed silent Now medics face for years, say patients investigation by GMC

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#### TARA WOMERSLEY HEALTH CORRESPONDENT

COMPLAINTS that doctors knew NHS patients had become infected with hepatitis C for years before they were told of the virus are being investigated by the General Medical Council.

The GMC, which is responsible for striking off doctors for malpractice, is looking into procedures in which patients were secretly tested after contracting the virus in the early 1980s. It is also alleged that patients

did not give their consent for the hepatitis C tests and were unaware that they were being carried out.

There are believed to be about 365 haemophiliacs still alive who were infected with hepatitis C through treatment on the NHS in Scotland and a further 800 surviving patients infected though blood transfusions and tissue transfer. The GMC inves-tigation is also likely to look into procedures for patients

who became infected with HIV. as well as asking whether counselling services were made available.

A spokesman for the GMC said: "We have received complaints with regards to the treatment of patients with hepatitis C and we are looking into the actions of doctors responsible for the treatment of blood-borne diseases

We have taken in the substance of the complaint and will be looking at all the issues surrounding it but as yet, no decision has been made.

We do have set guidelines, put in place a few years ago, that have to be followed. These have changed a lot since the 80s and we would be looking at the guidelines and standards at the time of treatment."

The GMC states that health

professionals "must obtain consent before testing for a serious communicable disease"

The guidelines continue: "Some conditions, such as HIV, have serious social and financial, as well as medical, implications. In such cases, you must make sure that the patient is given appropriate information about the implications of the test and

appropriate time to consider and discuss them.'

GRO-A 28, contracted HIV as well as hepatitis C in the 1980s through NHS blood products when he was being

products when he was being treated for haemophilia at Vorkhill Hospital in Glasgow. Mr GROA said: The same situation seems to apply right across the country, with haemophiliacs being tested with of their country. without their consent.

What seems to have. happened is that people were tested and then were not told the result for years. In my case, my mother was not told that I had hepatitis C until 1994, when I was 19 years old, but I have found out that I was first tested for it around 1985 or 1986. And although I was told that I had HIV a few years before the doctors told us about the hepatitis C, they had still known about this for some time. It seems that it was hospital policy not to tell people and this appears to have happened en masse

was probably infected when I was about five or six years old, but by not telling methat I was infected, other people could have been put at risk, for example my family or teachers at school if I had a nose bleed"

# **Doctors 'secretly tested** patients for hepatitis C'

The General Medical Council has begun an inquiry into whether doctors broke medical guidelines by testing patients for hepatitis C without getting their

It will investigate complaints that doctors secretly tested haemophiliacs for the potentially life-threatening virus but failed to pass on the findings.

The allegations come

GRO-A 55, contracted hepatitis C during a hysterectomy in 1979 but was not told she had the virus until more than 20 years later. She said: "I was tested without my knowledge and without my consent, and was not offered any counselling when I was told I had hepatitis C.

"I went to see a consultant at Inverclyde in 2000 because I had broken veins in my neck. Three weeks later, I went back and he asked me if I had ever had a blood transfusion and I said that I had one when I had the hysterectomy. Then I was told that I had hepatitis C.

"At the time I had not even heard of hepatitis C and had to go to the public library to find out information about it.

A spokeswoman for the Scottish Executive said it would be inappropriate to comment on an investigation being car-ried out by a body such as the GMC.

A report prepared by Detective Superintendent Stephen Heath, of Strathclyde Police, looking into complaints that hundreds of haemophiliacs contracted hepatitis C from infected NHS blood products, was handed in to officials at the Crown Office last month.

Prosecutors are currently deciding whether there should be a full investigation into the matter and, if so, the extent of the investigation which could lead to the questioning of doc-tors and health service officials.

The Executive has stated it is willing to pay £20,000 to people who contracted hepatitis C on the NHS, with a further £25,000 if they have developed chronic conditions such as cirrhosis or cancer of the liver.

However, it is unclear whether such payments are a devolved matter and even if the Executive was to make them, Westminster could "claw back" the money with reductions in social security benefits.

consent

from some of the 5,000 haemophiliacs infected with the hepatitis C virus through NHS blood clotting concentrates in the 1970s and 1980s.

According to the Haemophilia Society, many people were tested by doctors for the disease without consent. Many learned they were infected years later.

The GMC inquiry is likely to cover doctors in England and Scotland.

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The Scotsman 6/5/03

# 'The doctors knew that I was infected, but never told me'

### TARA WOMERSLEY HEALTH CORRESPONDENT

GRO-A 28, was a child when he became infected with HIV and hepatitis C through contaminated blood products while receiving treatment for haemophilia on the NHS.

Mr GROADS now fighting to find answers as to why the Factor 8 clotting agent he received was never properly screened, why his family was not told until he was 14 that he was HIV positive and why he was only told that he had hepatitis C when he was 19.

Although he was a bright child at school, Mr GRO-Al dropped out shortly after his O-grades and, in his words, "went off the rails".

Since then, he has, with the support of his family, managed to sort himself out and is focusing on campaigning for the justice that he believes is severely lacking for haemophiliacs infected with contaminated blood on the NHS.

He said: "I was about a yearand-a-halfold when the doctors realised that I was a haemophiliac. I was treated at Yorkhill Hospital in Glasgow and was given Factor 8, a clotting agent, that was imported from America and was contaminated.

"It is likely that I became infected when I was about five years old But I was lucky, as my health was relatively OK, and I grew up as normal child

"It was not until I was about 14 that I found out I had HIV, but the doctors knew for some time before this. They made everybody who became infected with HIV sign a waiver for compensation if any other viruses were found If one person did not sign, nobody would receive compensation, so it was emotional blackmail. I then was told when I was 19, in 1994, that I had hepatitis C, but have since found out that I was tested for it in 1985.

"I had my whole life ahead of me when I found out that I had HIV, and it was completely ruined. I was just your average

kid, but at the time there were all these adverts about AIDS on the television, which were all doom and gloom, and I just went off the rails. I dropped out of school and completely lost interest in education, because when you think you have just six months left to live, you do not care.

"My dad worked abroad and had to come home and my parents were obviously affected. When Twas then told that I had hepatitis 'G, the doctors also played it down. They told me that people lived with it for years, which yes, they can do, but it can be a fatal illness and in most cases kills people."

Mr GROA is now unable to hold down a nine-to-five job because of his health and never knows how he will feel from day to day. He is angry that doctors could have put his family at risk if they knew about his condition some years before telling him.

He said: "The whole thing is a

## 'When you think you have just six months left to live, you do not care'

GRO-A

cover up. People were tested but the thing is they were not told the results for years and this seems to have happened right across the country. And this puts other people at risk, for example sexual partners, or any children that they may have. I spoke to one woman whose husband died ten years ago but she did not find out that he had hepatitis C until earlier this year." The Scottish Executive has

stated it is willing to pay £20,000 to patients who contracted hepatitis C on the NHS, with an additional payment of £25,000 if they have gone on to develop "chronic" conditions, such as cancer of the liver or cirrhosis. However, it is unclear whether the Executive has the power to make such payments or whether

the issue is a reserved matter. Even if the payments are a devolved issue, it is feared that Westminster could 'claw back' the money by stopping certain social security benefits.

GRO-A of Wemyss Bay, contracted hepatitis C while receiving a blood transfusion during a hysterectomy in 1979 at Irvine Central Hospital. But it was not until more than 20 years later she found she had the virus when she saw a consultant at Inverclyde Hospital about broken veins in her neck.

Although she was told she had the virus once results came back from the laboratory, she said she was unaware she was being screened for the virus until she tested positive.

until she tested positive. Mrs[<u>GROA</u>] said: "At the time I had not heard of hepatitis C and had to go to the public library to find out information about it.

"In 2001, I had an AIDS fest, which was negative, prior to taking part in a drugs trial, but although I was told about the test, I was not offered counselling for either this or when I was told I had hepatitis C.

"The doctor had originally suspected I had hepatitis C because I had redness in the

palms of my hands and because of the veins in my neck. But 1 would like to have known that I was being tested so I could have read up about it before the results and prepared myself." Carol Grayson, 43, the founder of Haemophilia Action UK, worked as a nurse during the 1980s and was involved in counselling for HIV tests. She set up the action group for haemophiliacs, based in Newcastle, after her husband, GRO-A GRO-A 45, became infected with hepatitis C and HIV.

She said: "There were guidelinés put in place for HIV testing and these should have been followed for testing of hepatitis C. People have the right as to what they want to know or what they do not want to know and the implications for treatment are enormous. There is a whole human rights issue here."



# Generation 7/5/03

# **Cold virus rids mice of brain cancer**

### Tim Radford Science editor

In an experiment that may, have implications for cancer treatment, American and Spanish scientists have used the common cold virus to eradicate brain tumours in mice.

They report today in the Journal of the National Cancer Institute that they chose an adenovirus - a virus of the respiratory tract - which targets only cancerous cells, and which spreads like a wave through malignant glioma, the most lethal form of brain cancer.

They injected it into laboratory mice implanted with human glioblastoma tumours. Untreated mice died in three weeks, but treated mice survived for more than four months. When they examined the survivors, investigators found only empty cavities and scar tissues where the brain pable infection into a weapon tumours had been.

"We believe this therapy has a lot of potential, but one that needs much more study," said Juan Feyo of the University of Texas MD Anderson cancer centre. "We've never seen this kind of response before with any other treatment tested in either animals or humans."

The US National Cancer Institute is to produce a drug to test in humans late in 2004. The virus, known so far by the clumsy name of Delta-24-RGD, replicates only in cancer cells, not healthy tissue.

It reproduces itself by killing its host cells and moving on to contaminate other tumour cells. When there are no more cancer cells to infect, it dies.

As there is no successful treatment for malignant glioma, the researchers have in effect turned an unstopagainst an incurable disease.

'Cancer can be devious, in that it does everything possible to evade destruction. But viruses are equally tricky in their quest to invade cells and propagate," said Frederick Lang, one of the investigators. "In this experimental war between cancer and a viral therapy, the virus won. Of course, we hope to obtain similar results when patients are tested, but we cannot predict such success based on animal studies."

Viruses hijack their hosts' DNA to multiply. Cancer is above all a DNA disease, and the cancer genome project in Cambridge has found more than 100 genetic mutations associated with cancer. The reasoning is that if humans can identify a cancer cell by its DNA, then so can a virus.

Researchers have proposed an altered HIV virus for gene therapy in haemophilia, cystic fibrosis and heart disease. Other teams have experimented with bacteriophages - viruses that prey on bacteria - to defeat antibiotic-resistant infection. Cell biologists experimented with an altered virus to deliver growth factor to wasting muscles, and mutant common cold viruses have been used to shrink tumours in prostate cancer and head and neck cancer.

But most experiments have been with mice, and most are rated only "promising" so far. The cooperation between the University of Texas, the University of Alabama at Birmingham, and the Catalan cancer institute in Barcelona, Spain, has achieved more than that.

guardian.co.uk/medicine

TIMES 7/5/03

# SGM-Conto AN investigate 'secret testing'

### **By Shirley English**

AN INVESTIGATION under way into complaints that doctors broke medical: guidelines by testing patients. for hepatitis C without their. consent.

The inquiry is being carried out by the General Medical Council (GMC); the doctors Boverning body.ur to elsmin Whore than 100 complaints: from haemophiliacs in Newcastle, Birmingham, Manchester and Worcestershire have been submitted against named consultant haemotologists to the GMC. A further 200 complaints are expected from haemophiliacs in Scotland, who were infected with hepatitis C and HIV through infected NHS blood products in the 1970s and 1980s. It is estimated that more than 3,000 haemophiliacs were infected. GRO-A 28, from

Inverness, contracted HIV and hepatitis C as a child during treatment for haemophilia. He claims that he was secretly tested for hepatitis C in 1986, but his mother was not told that he was infected until 1994 when he was 19. Mr GRO-A said: "People were tested without their knowledge and then were not given the results until years later, which put our families at risk of infection too."

Haemophiliacs are demanding a public inquiry. In 1991 haemophiliacs infected with HIV through +contaminated NHS blood, were offered government compensation, on the condition that they signed a waiver ruling out future payments if they became infected with any other viruses. Mr. GRO-AL was one of 1,250 who signed, the waiver, anaware that he had hepatitis C. A spokesman for the GMC said: "We will look at the com-

plaints and if we have found that there is evidence of professional misconduct we can take it to a final public hearing.

This can lead to a number of outcomes including erasure from the register."

GRO-A ; 43, of Hae-mophilia Action: UK; said. "It could end up that haemotologists from every regional centre across the UK are implicated." Ms GRO-A 's husband, GRO-A GRO-A 45, has HIV and hepatitis C from contaminated blood.

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# Probe into hepatitis testing

A number of doctors are being investigated after complaints that they broke medical guidelines by testing patients for hepatitis C without their consent.



The inquiry is being carried out by the General Medical Council Infection occurred in the 1970s and 80s (GMC).

Haemophiliacs, and other patients, are fighting for a public inquiry after thousands of people were infected by contaminated blood products.

They allege they were secretly tested for the life-threatening virus, and only told they had it years later.

Hepatitis C is classed alongside HIV as a serious communicable disease, and medical guidelines state that doctors must get a patient's consent before testing for it.

During the 1970s and 1980s more than 3,000 haemophiliacs or their families were infected with hepatitis C, which can cause fatal liver problems.

### 'At risk'

About 500 haemophiliacs were infected north of the border through tainted blood products, along with some 200 other patients.

A Scottish haemophilia action group said that most of its members had been tested for hepatitis C without their permission.

Some of those involved also claim that they were not told the result for four years or more, by which time their families had been put at risk.

The GMC is now **Destigating** complaints against several doctors in Scotland and England.

I think you have to accept the fact that things were done differently in the past

Dr Charles Saunders British Medical Association

A spokesman said: "We are british heater restances and british heater restances and blocking into the issue of the way patients were treated for blood borne diseases.

"We will look at the complaints and if we have found that there is evidence of professional misconduct we can take it to a final public hearing.

"This can lead to a number of outcomes, including erasure from the register."

Dr Charles Saunders, the chairman of the British Medical Association's public health committee in Scotland, said it was a "very disturbing" story.

But he said: "I think you have to accept the fact that things were done differently in the past.

### Without consent

"Many doctors in the past would have done things that they felt were perhaps in the best interest of their patients."

He said it was "not right" for patients to be tested without consent or to receive results in an insensitive way.

Asked whether such practices had now been eradicated, he said: "I think it's very difficult to say never.

"But one would hope that with the training doctors have received and the different behaviour that patients expect these days that this sort of thing should hopefully be a thing of the past."

Earlier this month the Crown Office in Scotland revealed that it was investigating circumstances around the prescription of contaminated blood.