1966

First blood clotting products for haemophiliacs are produced. *(The Observer, 16 April 2006)*

Focus: fight for justice

Left to die: the hidden victims of an NHS blunder

In 1991 The Observer revealed the scandal of patients infected by HIV as a result of the contamination of Health Service blood. Now, beset by illness and poverty, they are launching a final battle for justice. Lorna Martin reports

- Lorna Martin
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On a cold December morning in 1986, GRO-A woke with the worst hangover of his life. The previous afternoon he had practically skipped into Glasgow Royal Infirmary for a routine check-up, feeling healthier, more energetic and more indebted to the NHS than he could ever have imagined possible. He felt like the luckiest man in the world.

Back then the prognosis for people with leukaemia, which he had been diagnosed with the previous year, was not good. Bone marrow transplants were in their infancy. But chemotherapy and a transplant from his sister seemed to conquer this aggressive blood cancer.

'When I was told I had leukaemia I just assumed I was going to die,' he recalled. 'I knew of people who'd had it and they had all died. So when it looked as if the transplant had worked, I felt I'd been given a second chance. Because I'd come so close to death I realised how precious life is. I was cherishing every moment.'

GRO-A, then 23, had been cured of leukaemia against all the odds. But that December afternoon his consultant delivered devastating news. During his operation he had been given a contaminated blood transfusion. He had contracted HIV, a virus which destroys the body's immune system and for which there is no cure.

There was a long silence. 'If you want to cry, it's OK,' his father, sitting with him, said. GRO-A did, and so did his dad.

HIV and Aids were little understood in the mid-Eighties and they were surrounded by a huge stigma. Many people thought the viruses affected only gay men and drug addicts. GRO-A was neither.

'One minute I was feeling elated about being cured of leukaemia, thinking I had my whole life ahead of me again. The next I was told I was HIV-positive and my world came crashing down. I was too ashamed to tell anyone. I asked my dad, who'd come with me to the hospital, not to tell anyone and I went to the pub on my own and drank until I passed out,' he said.

Although he felt isolated that night, he soon discovered he was not the only victim of what has since been described as the worst treatment disaster in the history of the NHS. Thousands of people in the UK received blood contaminated with potentially deadly viruses during the late Seventies and Eighties. Much of it was imported from the United States.

Although doctors first became aware of a possible link between Aids and blood transfusions in December 1982, it took another four years before safer, heat-treated products reached Britain.

Most of those infected with HIV in that way in this country were men suffering from haemophilia, a genetically acquired disease in which the blood does not clot properly. To treat the condition they took products known as Factor VIII and Factor IX concentrates, which were made by distilling and concentrating the plasma of large groups of donors, sometimes as many as 25,000.

It was a cruel irony that for thousands of haemophiliacs across the world, the same 'miracle substance' they were being given to prolong their lives also handed them a sentence of prolonged illness and probable death. The vast majority have now succumbed to the disease.

Following a public outcry and on the recommendation of a High Court judge, the UK government announced plans in 1988 to compensate the 1,200 haemophiliacs who had been infected with the life-threatening viruses. It was a hollow victory and excluded people such as GRO-A

He became one of the forgotten NHS Aids victims, one of an estimated 150 non-haemophiliacs in the UK who became HIV-positive as a result of receiving tainted blood but whom the Department of Health refused to help. Fifteen years ago The Observer launched a campaign to highlight their plight. Virginia Bottomley, then Health Secretary, initially rejected the demands for justice, despite protests from MPs of all parties.

There were 'special and tragic circumstances' surrounding the haemophiliacs' cases, she repeatedly stated, mentioning their 'double disadvantage' of hereditary illness and HIV. She said no comparison could be made between them and the scores of children, pregnant women, accident victims and cancer patients such as GRO-A who had been infected from blood transfusions during surgery.

'It was never explained to us why the hereditary nature of the illness made a difference,' GRO-A said. 'We all became HIV-positive or contracted Hepatitis C because we were given contaminated blood by the NHS. They spoke about it opening the floodgates. They hoped we would be silenced and go away. But the Observer campaign gathered so much momentum, public and political pressure intensified, and the government had to do something. The injustice was so glaring.'

As a result of the campaign, the government eventually relented and extended its compensation scheme. The Eileen Trust, which provided one-off payments, plus small monthly sums, was established in 1992. The creation of these trusts was a first for the NHS, the only time in its history that it made an exception to the principle that it does not pay compensation without legal liability first being proved.

The rationale for this exception was linked to a presumption at the time that HIV would inevitably and swiftly progress to death. In addition, while no one was prepared to accept responsibility, it was nevertheless becoming increasingly difficult for ministers not to concede that a horrendous mistake had been made. In government-speak, 'an unavoidable inadvertent systematic failure' had occurred.

Victims were subjected to significant social problems. Many were treated as lepers. They had their doors daubed with graffiti, they lost their jobs and their children were not allowed to mix with other pupils at school. They were denied the opportunity to have normal relationships. To compensate, they were awarded an average one-off payment of £45,000, plus a monthly allowance of about £300.

Faced with an impossible situation, the victims were urged, some say coerced, into accepting the money from the government. They were advised against continuing to fight through the courts, as this would have taken years. Time had become their most precious commodity, and one they were told they suddenly had very little of.

So in June 1992, six years after he received the contaminated blood, GRO-A accepted a cheque for £43,500. In return, all the victims signed to waive their right to pursue any future legal action against the government. At the time, people with HIV were expected to live between three and five years. Suing anyone or worrying about their future security were the last things on their minds.

Not surprisingly, GRO-A spent his small windfall somewhat recklessly, booking a three-week holiday in America, even though his HIV status was supposed to prevent him from entering the country, and repaying some debts. 'Like many others I decided to go out with a bang. We were told we didn't have long. I spent two weeks at a blues festival in Chicago, something I'd wanted to do all my life, and another week in New York. I tried not to get down because I thought each day might be my last. I wanted to enjoy what little time I had left.'

For successive governments, drugs companies, some doctors and the blood transfusion services, this story would ideally end here and be remembered as a tragic medical mistake in which no one acted wrongly in the light of the only facts then known. Yet for some victims the problems had only just begun.

For most of those infected with tainted blood, the predictions of an early death proved correct. Of about 1,200 haemophiliacs infected, more than 800 have now died from Aids or hepatitis-related illnesses. Around 380 are still alive, along with around 20 non-haemophiliacs. With their one-off payments long gone, their health deteriorating, crippling side-effects from the powerful drugs that keep the virus at bay and their opportunities to work virtually non-existent, many rely on state benefits and exist in acute poverty.

GRO-A is one of them. Twenty years on from his transplant and the transfusion that saved him from one life-threatening illness and infected him with another, he sits in his basic, one-bedroom flat in Glasgow, surrounded by his Bob Dylan albums, his guitar and mandolin.

'Living longer than we ever expected has been both a blessing and a curse,' he said. 'Initially, you try to get your head around the fact that you're going to die. Then it doesn't happen, but because you think every day might be your last it's difficult to plan any kind of future. I got very depressed, and I know many people who either killed themselves or drank themselves to death as their quality of life was poor. I have been unable to form a relationship and most of the survivors are in pretty dire financial straits.'

The virus has taken its toll. His once fit body is withering away. He has had numerous bouts of pneumonia, his pancreas was badly damaged by the drugs he was taking, and he has to wear a permanent cast on his foot to limit bone deterioration.

He hands me a recent newspaper cutting reporting the case of GRO-A, 64, from Birmingham, who contracted HIV from a contaminated transfusion during surgery for pancreatitis at the private Nuffield Hospital in his home city in February 1995. Last year, after a seven-year legal battle, he was awarded £750,000.

GRO-A said: 'We were persuaded to accept one-off payments ranging from £21,000 to £80,000, depending on whether we had dependants, because there was an assumption that we were facing imminent death.' Because all the victims signed the waiver preventing further legal action, they have very limited options for the future, apart from asking the government for more money.

At the end of last year a detailed case was presented to the Department of Health, requesting a rise in the annual support available to the remaining victims from £3m to £7m per year and another one-off payment. A spokeswoman said the application had been received and was being considered.

Most survivors are not overly optimistic. GRO-A is one of them. As a teenager in Wales he refused to be constrained by his haemophilia. At 18, he married his childhood sweetheart, GRO-A. In 1979, at 22, he began using 'the miracle' Factor VIII concentrate, expecting it to make his disease more manageable. The blood was contaminated.

Six years later, with two young sons, he was diagnosed as HIV-positive. He discovered a short time later that his wife GRO-A had contracted HIV from him. He had also been infected with hepatitis C which, in many ways, has even more serious consequences.

About 5,000 haemophiliacs contracted the potentially fatal liver disease from contaminated blood, as did an estimated 20,000 non-haemophiliacs.

GRO-A and GRO-A had to give up careers with substantial incomes to live on disability allowances GRO-A now 49, is incensed at the government's repeated refusal to hold an independent inquiry into the affair.

'It is beyond belief that the deaths of over 1,000 members of the British public can pass with no explanation given by the public bodies responsible for their care,' he said. 'We need this not to embarrass or point the finger of blame, but simply to find out what happened and to make sure a tragedy of this scale will never be allowed to happen again.'

It was insulting to those infected to have 'to beg' for elementary justice, GRO-A said. 'We are living under a death sentence for the mistake of having trusted in the cleanliness of NHS blood and blood products. We have suffered in the worst way possible, not only financially but by losing our livelihood and our ability to lead a meaningful life. We have all lost friends who did not survive this terrible medical and scientific blunder.'

In desperation, GRO-A and GRO-A are among a number of UK survivors hoping to sue four major US companies in the American courts, alleging negligence and fraud over the making and distribution of blood products used by haemophiliacs. If the UK government insists it is not responsible, he said, then it should do the decent thing and take the blood companies to court on the victims' behalf.

The US lawsuit alleges that the four companies sold blood products contaminated with HIV and/or hepatitis C, resulting in the deaths of thousands of people with haemophilia worldwide.

The action claims three of the firms recruited and paid donors from high-risk groups, including prisoners, intravenous drug users and blood centres with mainly homosexual donors, to obtain plasma used in Factors VIII and IX. It alleges that between July 1982, when evidence surfaced that people with haemophilia had died from Aids, and 1985 the firms acted in concert to avoid recalling the products or warning of the risks. GRO-A said the American battle was a last resort, as the UK remained the only country which had consistently refused to hold an inquiry into the affair.

In the past 17 years, he has attended more than 150 funerals for fellow haemophiliacs who received the tainted blood. His brother, a haemophiliac too, also suffers from HIV contracted through bad blood products. Worst of all is the fact that GRO-A has been infected.

'I want an explanation. I want to be able to tell my sons and my wife how this happened and why it happened and who was responsible.'

Yet in some ways GRO-A and GRO-A are among the luckier ones, because they still have each other. Most haemophiliacs given tainted blood have died, leaving angry and penniless widows. And among those infected as children, most remain isolated and alone.

GRO-A, a fellow haemophiliac, was five when he was infected with HIV and hepatitis C. His parents told him what had happened when he was 13. At 16 he was diagnosed with Aids and spent the next four years in and out of hospital. At one point he was told he had two weeks to live.

However, new treatments became available and helped him on the road to a partial physical recovery. He is now 29 and living alone in supported accommodation in GRO-A, Birmingham.

'Emotionally the toll the virus takes can be enormous,' he said. 'The social aspect starts even before the symptoms show - the relationship difficulties around how to tell people and how they react when you do, and the stigma. These are all very difficult to cope with. And when the symptoms begin to take your life apart, it is difficult to recover. There is a feeling of isolation. Many people become virtual recluses, including me.'

GRO-A spends much of his time working with the Haemophilia Society and the Macfarlane Trust, and has been helping with the court case.

'We are victims of NHS errors and in addition to living with life-threatening, debilitating illnesses, most of those who have not died are living in acute poverty. The capital payments [£21,000 in his case] have long since been spent, often on the advice of medical consultants on the basis of likely imminent death. We live on benefits and a trickle of money from the fund. It is demeaning that someone who, for instance, might need a new bed has to beg for money to buy it.'

Like many of those affected, GRO-A has found it difficult to form a relationship. After he told his first love about his infection, she left him. That brought home the stigma, he said, and it took years for him to recover from this rejection. He met another woman but three months before they were to marry she died from Aids. He doesn't feel strong enough to seek another relationship.

British victims point to the way other countries have helped their sufferers. Canada held a £1.24m investigation lasting five years into its tainted blood scandal. It concluded this 'national public health disaster' was caused by systematic failure, a blood service that recoiled from its responsibility and governments that showed no leadership. The victims were given an apology and 'set up for life' with average awards of £750,000.

Last February a trial alleging criminal negligence causing bodily harm and endangering the public began in Toronto against a pharmaceutical company and the Canadian Red Cross.

Margaret Unwin, head of the UK Haemophilia Society, said this was being closely watched. 'The UK is the only country that has not been open and honest about this,' she said. 'There has never been an apology. Many people say that's all they want. The government has continued to refuse any legal responsibility or grant an independent public inquiry. The financial hardship is difficult, and these people desperately need more support. But more than that, they need truth and justice and for someone to say sorry.'

No one expected, two decades on, that there would be any survivors of one of the greatest medical disasters in NHS history. Nor did its victims expect still to be waiting for the government to explain the 'inadvertent systematic failure' that caused this tragedy.

How could deadly tainted blood get into a system that was supposed to save lives? GRO-A GRO-A and GRO-A and GRO-A are not the only ones who think the wider public deserves an answer to that question.

Observer blog: Tell us what you think.

Contamination timeline

1966 First blood clotting products for haemophiliacs are produced.

1970 Four US-based pharmaceutical companies to distribute Factor VIII and Factor IX around the world.

1975 World Health Organisation resolution states each country should be able to supply blood and blood products.

1978 A test to determine a history of viral hepatitis in blood donors is developed.

1981 The US Centre for Disease Control and Prevention organises a task force in response to a disease later called acquired immunodeficiency syndrome, shortened to Aids.

1982 Several haemophiliacs contract Aids in America. In the UK worries grow over the safety of imported commercial blood products from the US.

1983 First haemophiliac in the UK dies from Aids.

1988 UK reveals it is relying on American imports of blood products.

1988 The government agrees funding for the Macfarlane Trust charity to assist haemophiliacs who contracted HIV from contaminated blood products.

1991 The Observer campaigns to extend compensation scheme to non-haemophiliacs affected similarly.

1992 A multi-million pound compensation package for infected nonhaemophiliacs is announced.

2004 Patients infected with hepatitis C from contaminated blood to receive at least £20,000.

2006 Trustees of the Macfarlane and Eileen Trusts urge the government to increase financial support to those patients still