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INFECTED BLOOD INQUIRY

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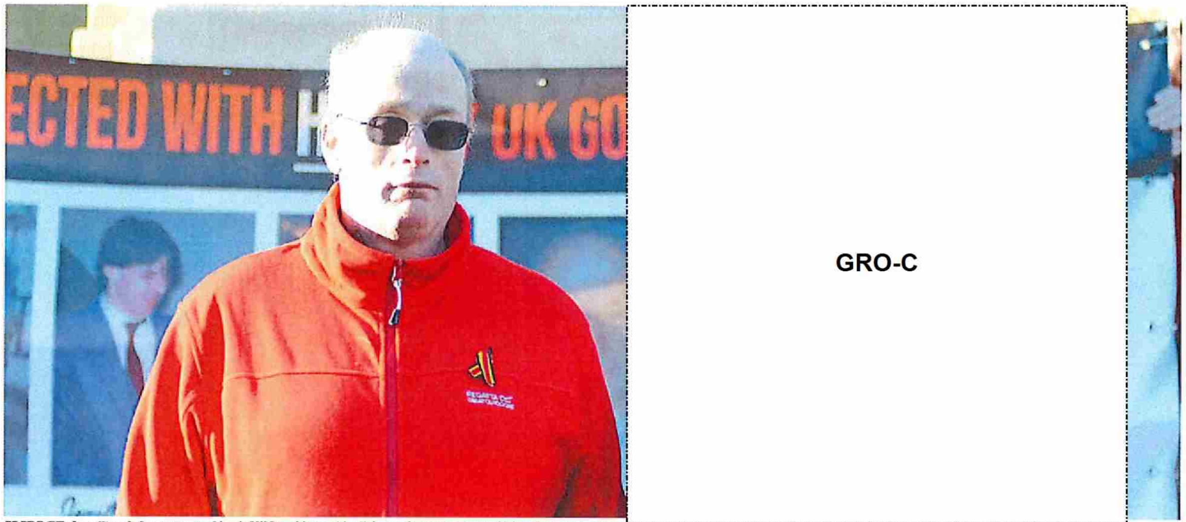
GRO-C

IMPACT: Lee Stay, left, contracted both HIV and hepatitis C through contaminated blood, resulting in a string of health problems. Steve Dymond, right, suffered from hepatitis C.

Contamination victims' anger at government payment changes

Chris Britcher on the latest blow to those seeking justice and compensation for bad blood infections

VICTIMS of the blood contamination scandal say proposed changes by the government to support payments "is nothing short of a cyenical ploy to rob Peter to pay Paul".

The government unveiled a major shake-up of how those infected with either hepatitis C or HIV last July would receive cash, pledging an extra £125 million for beneficiaries.

But a consultation into changes to those payments ends soon after it transpired it was on track to see the Department of Health overspend the budget by between £76m to £123m.

During the 1970s and 80s, thousands of people - primarily haemophiliacs who need treatment to help their blood clot - were administered by the NHS with infected blood products.

With companies sourcing blood from prisons, drug addicts and others, particularly in the US, many patients became infected and many have since died.

Prime minister David Cameron apologised to the victims in March 2015 but calls for a Hillsborough-style public inquiry into the circumstances around the scandal in England have fallen on deaf ears. Survivors, who have seen their lives so damaged, are demanding justice - and answers to just what officials at the time knew of the risks.

But after their calls for compensation lump sums to be paid were rejected, they are now fuming at the risk of losing money they thought they have been promised. In particular, those who are co-infected with HIV and hepatitis C are set to be hit in the pocket.

Announced last July, the payments would see those with chronic hepatitis C infection - known as stage one infection - receive payments, with those with an advanced condition - stage two and HIV - receiving an increase.

However, an increase in the number expected to claim for that has meant a consultation into changes for other payments to prevent it running over budget.

Lee Stay, from GRO-C, was given infected blood as a teenager. He discovered he had contracted HIV when he was 16 in 1986 - when diagnosis was a death sentence - and told he could expect to live another 10 years. He also was infected with hepatitis C which damages the liver. He revealed his condition, exclusively, to KoS last year.

Now 47, he explained: "Whilst I welcome the fact that the government recognises that many of those currently infected with hepatitis C at stage one will require the additional financial help that stage two provides due to ongoing deterioration of their health, I am appalled that rather than increase the overall funding of the scheme, this change is to be paid for by removing the future fixed increase previously proposed for all existing scheme recipients in 2018/19 and replacing it with increases in line with the consumer price indext (CPI) - a much smaller amount.

"On top of this, there is much uncertainty regarding discretionary payments, which many recipients are dependant on to sustain any kind of normal life they would have lived if they had not been infected.

"It seems the amout of money available for this discretionary support will be more than halved to fund the change to the scheme.

"As one of only around 250 co-infected with HIV and hepatitis C still alive, relying on discretionary support, this will affect me the most. How can those most affected by this disaster, suffering decades of ill-health due to multiple illnesses - in my case pneumonia, liver failure, lymphoma - caused by several viruses being present in contaminated blood through no fault of my own, finish up losing out more than anyone else?

"It is not fair the government are determined to fund the scheme out of the NHS budget, deliberately provoking opinion by saying that any increase in budget would take money away from patient care. Surely the funding should come directly from the Treasury? This disaster was caused by government decisions made decades ago - why should today's NHS budget be affected to right a wrong back in the 1970s and 80s?

"It is exactly two years since David Cameron apologised for this disaster, yet most of the worse affected are barely better off today - in fact many expect to be worse off despite government promises to the contray due to the proposed changes in the discretionary payments.

"They should hold their hands up, admit that this disaster could have largely been avoided at the time and now compensate all those affected properly."

Steve Dymond, 60, from GRO-C was infected with hepatitis C. He added: "In January 2016, the Department of Health launched a consultation on improving how support was provided to victims of contaminated blood. It closed in April and the final policy decisions were announced last July - and extremely unsatisfactory they were.

"Earlier in March this year, the junior health minister Nicola Blackwood issued a statement launching a new consultation. Somewhat ironically the consultation process closes on World Haemophilia Day, April 17.

"Facing legal action for discriminating against certain victims who contracted hepatitis C from contaminated blood products, the Department of Health have decided to spread the inadequate contents of this meagre pot even more thinly.

"It is in effect nothing short of a cynical ploy to rob Peter to pay Paul.

"All of this contradicts the pledge made by David Cameron when PM that no one should be worse off under any reformed system. It is yet still further away from any full and proper settlement which would enable victims and their families to live their remaining years with some modicum of security and dignity."

In a letter to health secretary Jeremy Hunt, campaign group Tainted Blood added: "The brevity of the consultation in no way reflects the gravamen of the situation the victims are in through no fault of their own. We believe it is wrong, and more than likely, unlawful, to deprive vulnerable beneficiaries of what is a significant annual increase to their regular payments, which you unequivocally promised, both verbally and in writing, and was also made plain directly to our group as part of the hard-and-fast policy of July 2016.

"We believe it would be unconscionable for you to go through with your proposed move.

"It is clear that from a legal perspective you believe you are acting correctly, but it cannot be morally right to undertake an action which further damages people simply in order to avoid being challenged in court.

"In fact, our most recent advice suggests that your proposed action – if it becomes policy – could well result in further legal challenges as it would be inherently unfair."

In a statement, the Department of Health said: "This was an unprecedented tragedy, and we are continuing to work closely with those affected to make sure the right support is in place for them.

"We have more than doubled our annual spend on payments to people affected since 2015, committing an additional £125m, as well as providing an annual payment to all infected individuals. This is significantly more than any previous government has provided for those affected by this tragedy.

"We will continue to listen and are currently consulting on new measures to extend the group of individuals who benefit from higher annual payments."

It reiterated claims no-one who currently receives an annual payment will be worse off than they are now and said many beneficiaries, namely those with chronic hepatitis C infection, may benefit from an increase in annual payment. The consultation can be found on the department's website.

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East edition No 740

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One man's brave story to make you stop and think

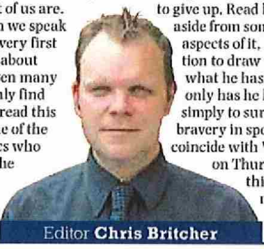
I THINK we all know folk who allow health concerns to define everything they do. They apply the label themselves and then allow everything to be filtered via their condition.

It's hard to blame them, of course; health is something which can play a significant role in our lives, influencing what we do and how we do it.

But sometimes you meet someone who has been dealt a hand which almost defies belief. Whose health conditions make almost everything else pale into insignificance and makes you stop and take stock of just how fortunate most of us are.

Inside this edition we speak to Lee Stay. For the very first time he has spoken about living with HIV - even many of his friends will only find out first when they read this newspaper. He is one of the many haemophiliacs who were caught up in the blood contamination scandal, of which many readers will be familiar - we've campaigned on behalf of the victims for many months. He was infected with HIV and Heptatis C when a teenager through blood products he was administered by the NHS. That subsequently led him to pneumonia, a liver transplant, an agressive blood cancer, the loss of his job and breakdown of his marriage. Yet he remains positive and refuses to let his condition rule his world - despite its best efforts.

He is a man who has faced a life of challenges and hurdles and refuses to give up. Read his story and aside from some of the horrific aspects of it, there is inspiration to draw from him and what he has experienced. Not only has he had to fight simply to survive, but his bravery in speaking out, to coincide with World AIDS Day on Thursday, is something which should make you compelled to hear his story.



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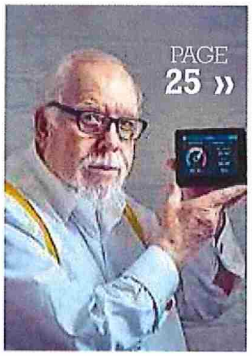

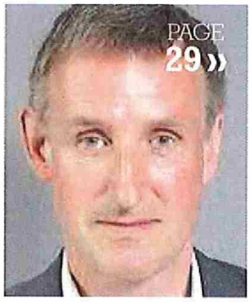

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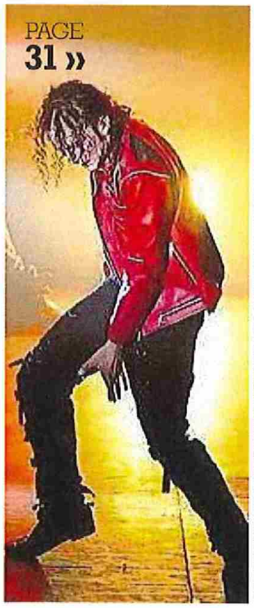

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ARCHANT

STRIKING: An image to promote World AIDS Day and the struggle many continue to face

'I was infected with HIV at school'

In a remarkable interview to coincide with World AIDS Day, Lee Stay goes public for the first time about how he was infected with HIV as a teenager through the contaminated blood scandal at the very height of the epidemic's terror and the chain of health crises it sparked. **Chris Britcher** reports...

IT WAS 1986. The height of the fear over the AIDS epidemic and the world was gripped by the emergence of an illness which was spread, primarily at least, through sexual contact.

Lee Stay was just 16 at the time. A haemophiliac, a condition which prevents the blood from clotting normally, he attended a special school where his condition could be monitored and treated carefully, having been sent there by his local authority at the age of 11.

Treloars College in Hampshire was a boarding school which specialised in providing an education for the disabled. In addition, it had a specialist unit attached to it for haemophiliacs.

When Lee had joined the school, he was among around 50 other youngsters there who suffered from the condition. The most common treatment was the injection of a blood product called Factor VIII. Formed by donors' blood, it provided the 'factor VIII' needed for the blood to clot for short periods of time. It was a common treatment and allowed haemophiliacs to live a relatively normal life.

But on a fateful day in 1986, Lee was told something which would change his life forever.

"I was having bleeds on average once a week," he explains to KoS, "and every time I needed treatment I was having Factor VIII. I must have started on it back in the late 1970s, and that continued at Treloar's.

"But then, when I was around 16, the college called me in and said I was HIV+. They thought I had been infected in 1983."

He, along with almost all of his fellow haemophiliacs at the college, had been infected. Victims of the blood contamination scandal.

Caused by drug companies responding to a relentless demand for Factor VIII, donors were sought wherever possible. Often sourced in the US, prisoners, drug addicts and the homeless were frequently used. The result was that infected blood was then used and illnesses spread. Most notably, HIV and Hepatitis C. Infected blood was used throughout the 1970s and 1980s before the dangers finally saw tighter safety introduced. Far too late, however, for many.

"I'd seen the campaigns and knew all about HIV and AIDS," explains Mr Stay, who has lived in Kent for many years, first in GRO-C and now in GRO-C.

"I was shocked. Basically you're told it's not affecting you at the moment, but that you were not expected to live more than 10 years.

"At that age, you think about how it's passed on. Having sex with other people and forming relationships go out of the window because it's put you in a position to infect others.

"We were told how we had become infected. I was told when there were very few in the college at the time. I subsequently discovered there were a large number of haemophiliac pupils infected in the same way.

In 2015, we knew that 64 at that centre had died, since then we know that total is now at least 72. Most of my haemophiliac friends at the college are now dead; I think I'm the only one from my year who survived. Most died in the early to mid 1990s."

It is believed some 1,274 haemophiliacs were infected with HIV through contaminated blood. Of whom, just 256 still survive today. But they carry some heavy scars.

The fact that Mr Stay, now 47, is still here today says much about the treatment for the illness – but perhaps more about his remarkable ability to be taken to the brink of death over and over again and somehow survive to fight another day.

Because HIV has been just the tip of an iceberg for a man whose life may have become defined by his illness, but whose positive outlook and mental attitude makes him determined not to have become a victim of it.

He has been forced to have a liver transplant, narrowly avoided death after pneumonia ravaged him, spent months undergoing gruelling chemotherapy for cancer, lost his job and his family. And all as a direct result of blood contamination caused by a product that was provided by the NHS.

He has never spoken publicly of his HIV be-

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fore – even some of his closest friends are unaware. But he is now keen to highlight not only that those with the condition can now control it and live good lives, but also to add his voice to the growing chorus of those infected by contaminated blood and a desire for proper compensation and an openness into just how such a calamity could befall so many.

Yet he refuses to let his challenging life slow him down or lessen the "positive attitude" he says is embedded within him.

He left college facing a death sentence, but continued to university where he completed a degree at Portsmouth and, in 1992, started work for the ferry firm P&O as a trainee before moving up through the ranks.

"Because of the stigma around HIV I didn't want to shout about it – only close family know. There is, even today, still a stigma attached."

After altering the way generations conducted their sex life through the 1980s and 1990s, and riding on the back of a huge wave of publicity, today having HIV is controllable courtesy of what is known at antiretroviral therapy (ART).

It's not a cure, but the combination of medicines can control the virus so sufferers can live a longer, healthier life and reduce the risk of transmitting HIV to others. It should also prevent the onset of AIDS.

World AIDS Days takes place on December 1 – an annual global event for raising awareness, trying to shrug off that stigma, and tackling the challenges elsewhere in the world, where it continues to be a major problem.

The condition weakens the immune system and leaves a victim unable to fight off infections.

"Around 1995 I became quite ill and had to go to hospital," Mr Stay recalls, "and it turned out I had contracted PCP – a severe form of pneumonia caused by HIV infection.

"I was very ill at this time. Drugged up to the nines on steroids, in hospital for weeks.

"Of course, I know now that many others must have died from this same condition around that time. I survived it and they put me on a combination of drugs which have kept it at bay ever since."

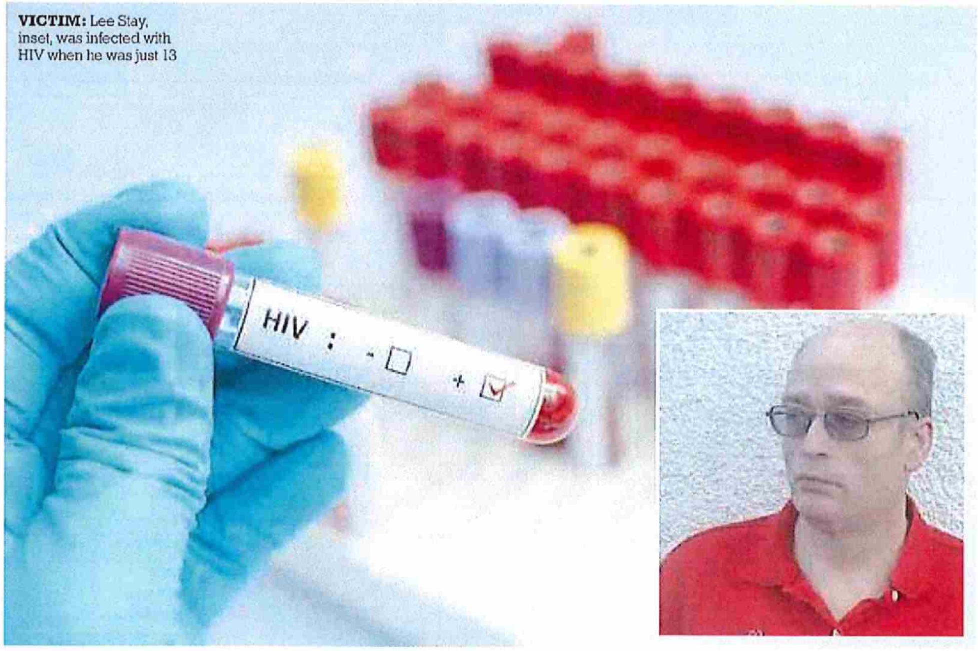
For Mr Stay, however, HIV is just one part of a complex jigsaw of health problems caused by that batch of contaminated blood he was administered as a teenager.

Like many other haemophiliacs treated with blood products, he also received Hepatitis C, a condition which attacks the liver.

By around 2003, P&O shut its Portsmouth operations and Mr Stay sailed off to a new role at its [redacted] base, gaining a promotion and becoming a specialist in stock control systems shoreside.

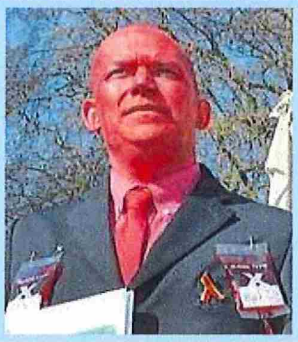
"I saw a haemophilia specialist in Canterbury who told me that at some point something needed to be done about my liver. He sent me to Kings in London for blood tests and within an hours of those results they told me I need urgent treatment. The only option was a liver transplant."

After around two years on the waiting list, he finally secured a donor and the transplant took



VICTIM: Lee Stay, inset, was infected with HIV when he was just 13

PROTEST FOR WORLD AIDS DAY



WORLD AIDS Day takes place on Thursday, December 1, with a series of events taking place across the world to mark the occasion.

Outside Westminster, there will be a protest taking place from 11am where members of the haemophiliac community will be raising awareness of the impact of contaminated blood and HIV infection.

A candle will be lit for all of those haemophiliacs who have died.

Lee Stay will be among those travelling to London to take part.

He explains: "World AIDS Day is a reminder of the haemophiliacs and friends we've lost over the years. I used to be in a pop group in school and someone found a picture of six of us and I'm the only one still surviving. That brings it home."

place in 2007 – keeping him bed ridden, and off work, for several months.

The year before, he had started seeing a woman with a number of children from previous relationships. She was aware of his condition.

The internet had allowed him to chat to women and be open and honest about his condition.

He explained: "I was always clear and told them about my infection before meeting anyone. If they said no at that point then that was fine. There was a safety by being online.

"My partner knew the risks at the time, felt she could handle it, but then she worried and we split up. After the transplant we got back together and married in 2008."

As is so often the case, it is the weight of pressure on the shoulders of loved ones that can have the biggest impact on the victim. And Mr Stay had little family to fall back on.

"My mother passed away in 1985, so before it cropped up," Mr Stay remembers, "and my father died in 1989 when I was 19. Dad was aware of the HIV but we never really spoke about it to be honest. There wasn't much else to discuss."

Life had more hurdles just around the corner.

In October 2008, he was made redundant and left with a pay-off which kept him afloat for around a year. He threw himself, instead, into family life.

However, ill health plagued him and he has not held down a full-time job since.

"Obviously money started becoming an issue," he says of life after redundancy. "There was a lot of pressure on the relationship and it became a struggle. We split up late 2009.

"We stayed closed, and when my home in GRO-C GRO-C was repossessed, and she couldn't look after the kids on her own, I moved in with her at her home in GRO-C, but just as friends as we still got on well."

Now divorced, she has now moved out of the county, but he remains close to her children; one of whom continues to live with him.

His income today comes from the modest sums paid from organisations to help those caught up in the blood scandal and benefits.

However, having lost his job and relationship, more problems lurked around the corner.

"In around December 2013," he says, "I had been feeling ill and had been since about the October. But I couldn't pinpoint what it was. I was getting a pain down the right side so I went to the doctors. They had recently changed my medication. The consequences of switching meant far from making me better it made me worse.

"I went for tests to try and work out what was wrong. They discovered my kidneys were severely affected and found this mass attached to the tube between bladder and kidney."

The diagnosis was Burkitt Lymphoma, a very aggressive form of blood cancer – caused by the HIV– sparked by a low immune system.

He was sent back to Kings where they started on an aggressive form of chemotherapy. It involved him having to stay in hospital for treatment on a daily basis and often over 24-hour periods. He would spend four months receiving the treatment.

Ironically, the liver transplant had solved the haemophilia problem. However the chemotherapy reduced the platelets in the blood which then made it unable to clot naturally again.

While in hospital he knocked his head and suffered a major bleed on the brain. He had to have a hole drilled in his skull to ease the pressure.

"You really couldn't make this up," he says with a wry smile. He finally returned home in June but needed twice-weekly trips to hospital during which he had frequent blood transfusions. Any hopes of holding down a job were further eroded.

"At the end of August 2014 they called and said they thought the mass had got bigger – so worse rather than better.

"At that point they said there was nothing else to do.

"But then they sent me to St Thomas' in London and they checked again and came to the conclusion it was actually getting a little smaller."

Referred back to Kings, it continued to shrink. Incredibly, he had escaped another killer illness. Today the lymphoma is undetectable.

Remarkably, his HIV is now so well controlled that too is barely detectable in his body. He was given early access to a pioneering new Hepatitis C drug and that has proved successful too – also now undetectable.

With the liver transplant solving the haemophilia he is, today, perhaps in better condition than ever before.

"I do feel better in myself," he says. "It's been a very long road with plenty of knockbacks, and you never know what's round the corner. I've had so many traumas you can never feel confident going forward.

"It is a lot for one person to cope with and plenty of other people may have given up a long time ago, but life goes on. You get knocked back by something, you climb back up, and then something else knocks you back. The only way I can deal with it is put it to the back of my mind and fight on.

"What makes it hard is that none of this was my fault. I would have had none of it if it hadn't been for the contaminated blood.

"The thing is all these things in combination has finished up with me having no relationship, no job and struggling to get by.

"Yes, there is some anger there especially as things have emerged that the authorities were aware of the risk before I got HIV. That things could have been dealt with a lot earlier. That creates a certain amount of anger.

"But I can't let the anger dominate because it will have a detrimental effect on my health and it would just take over my life.

"But life has been a constant struggle. I was in a £30,000 job up to transplant to have that taken away, to have gone through a divorce, and I don't feel confident about having a relationship now.

"I don't want to go there now. I'd rather just get on with life."