



TODAY we begin a major series on AIDS. Echo writers have been speaking to sufferers and potential victims and assessing the claim for compensation by haemophiliacs who have been infected via blood transfusions.

Newcastle's Dr. Peter Jones, who leads the campaign, explains why he believes their cause is just, and virus carrier GRO-A tells his story.

Man who waits as the clock strikes fear

VIL servant GRO-A is waiting for the clock to tick away a next five years.

GRO-A, 42, is a severe emphyliac and has entered pain and heartache all life.

ut now he faces a greater threat after being confirmed as AIDS carrier.

le came into contact with the PS virus after receiving contaminated blood during the frequent nsfusions he needs to stay alive.

He now faces an agonising five-year wait to see if the disease develops.

GRO-A has been able to cope due to his own remarkable courage and the support and understanding of colleagues and friends, including the 21-year-old girl he may marry.

He began suffering from birth — his blood contains no Factor VIII, the vital ingredient needed to make it clot and prevent bleeding.

Now, every time he feels particularly unwell or tired, he wonders if AIDS, the disease which has spread fear throughout the world, is about to strike.

He said: "The symptoms of AIDS developing are extreme tiredness, a

dry hacking cough and acute diarrhoea. Whenever anything like that happens you start thinking 'Is this it? Even if you have a rotten curry you worry.

"If it comes, I don't know how I'll react. You always like to think you'd cope, but you never really know until you're there. I try to push it to the back of my mind and stay cheerful."

Diverces GRO-A, a charming, articulate man, was speaking with great frankness from his office in Moorgate, North London, where he works as a higher executive officer in the official receiver's department.

As a child, the slightest accident, such as knocking his knee against a chair or being bumped by a toy, would lead to internal bleeding, swelling and "excruciating" pain.

It happened so frequently, he missed a third of his schooling — but managed to pass eight O-levels. A-levels proved too much of a strain, and he joined the Civil Service when he was 19.

He missed a lot of work at first, but his attendance improved as treatments developed. He now keeps a portable haemophiliac kit with him at work and doesn't lose more than ten days a year.

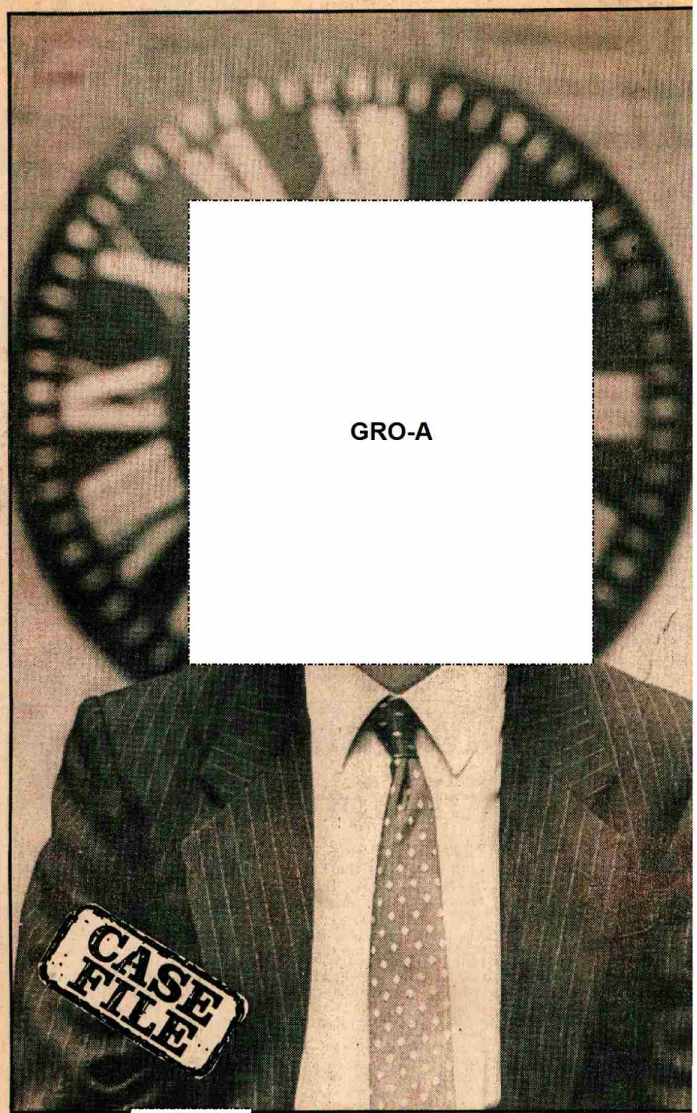
GRO-A had 32 "bleeds" last year, but he is able to give himself emergency transfusions at work or home with the kit, which contains freeze-dried supplies of Factor VIII. He just adds water and injects himself. It takes no more than half an hour.

The illness has left an obvious legacy. GRO-A, who lives in a flat, struggles to walk because his joints have been damaged over the years by swelling.

But it was an illness he had conquered until a new horror emerged nearly two years ago. During routine tests at St. Thomas's Hospital on the Thames embankment, it was discovered he had gone "anti-body positive."

"To be honest, I wasn't surprised. I'd had such a vast quantity of blood over the years, I knew the odds were in favour of my coming into contact with the virus."

He knew some of the blood he had



GRO-A

GRO-A

"If it happens I don't know how I'll react."

Tragic costs for suffering families

FAMILIES in the North-East suffer great hardships because the AIDS risk — and the biggest worry for many is the cost of funerals.

Pauline Sanderson, secretary of the strong northern group of the emphyliac Society, said: "The sole lifestyle of a family can break down and it's often heart-breaking."

I know of families now who are going through an awful lot of pressure, emotionally and financially. AIDS victims need intensive care and are often unable to work so family incomes are slashed.

"Everything suddenly becomes expensive, such as special diets, increased hygiene costs, and their less energy coming in to pay it," said GRO-A.

It's the younger ones I feel sorry for. It hits them as they are trying to build a life and suddenly everything is ruined.

There are some allowances available, but they go nowhere near

compensating for the problems. A big worry for some is how they are going to pay for funerals.

"Something must be done to help because families simply can't cope. The possibility of setting up a trust fund would certainly be examined."

GRO-A, who has a 13-year-old son with mild haemophilia, said many haemophiliacs had "gone underground" since the advent of AIDS.

At one time you could always get a haemophiliac to admit their illness, but not any more. The effect of being linked with other high-risk groups, such as drug users and homosexuals, has had a devastating effect," she said.

Another anxiety is the problems haemophiliacs now face obtaining life insurance and mortgages.

A British Insurance Association spokesman said: "Haemophiliacs have always been a high risk but now are even greater."

"We have no official line on it. Whether insurance is given is entirely at the discretion of companies."

People who must NOT give blood

Men who have had sex with another man at any time since 1978.

Drug abusers — men or women — who have injected drugs at any time since 1978.

Haemophiliacs who have received untested blood products at any time since 1978.

People who have lived in visited Africa south of the Sahara since 1978 and have had sex with men or women living there.

Sexual partners of people these groups. This includes regular as well as casual relationships. Further information is available from family doctors, transfusion centres and sexually transmitted disease clinics.

Know the facts

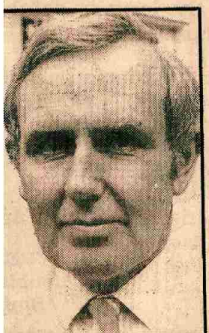
Myth: AIDS is easy to catch.
FACT: AIDS is very difficult to catch. It is caught by coming into contact with the blood of, or by having sex with, someone who already has AIDS.

Myth: There is an AIDS plague.
FACT: By November 1986 there were only 599 reported cases and deaths in the UK.

Myth: AIDS is a gay disease.
FACT: AIDS is a heterosexual disease that is epidemic in Central Africa. At present gay men are the largest affected group in Europe, USA and Australia, but heterosexuals have contracted AIDS there too.

Myth: AIDS can be caught everyday social contact.
FACT: You cannot get AIDS shaking hands, embracing or kissing an infected person. You cannot catch it from toilet seats.

Victims who cannot help their plight



Dr Peter Jones.

NEARLY half the North's known AIDS virus carriers are haemophiliacs who were infected by contaminated blood transfusions.

Now, one of the world's top haemophilia experts, North East based Dr Peter Jones, is calling for a special trust fund to be set up for haemophiliacs who catch the dreaded disease.

Nationally, there are about 7,000 haemophiliacs. According to government figures, 2,941 have been tested for AIDS and 937 were found to be carrying the virus, or 31.6 per cent.

Figures released by the DHSS this week show there have been 25 haemophilia/AIDS cases out of a total of 610. Nineteen of the haemophiliac victims have died out of a total death toll of 293.

In the Northern health region, there are between 500 and 600 haemophiliacs. About 90 have been positively tested for the AIDS virus, "a handful" have developed the

disease and most have died.

There have been 18 deaths from AIDS in the region, and haemophiliacs account for about a third of them.

The first reported case in the Northern region was in November 1984 when GRO-A died at his home in Lanarkshire after haemophilia treatment at Newcastle's Royal Victoria Infirmary.

In May 1985, telephonist GRO-A, 64, of Sedgfield, died after being treated at the same hospital.

'Patients die through no fault of their own leaving dependants unable to cope.'

And the following June, GRO-A, 62, of Billingham, died after receiving a blood transfusion at the RVI.

Of those severely affected by haemophilia, 60 per cent have caught the AIDS virus from transfusions and between one and five per cent of those have developed the disease.

Dr Jones, who is based at the RVI's haemophilia centre, said: "Haemophiliacs are different from other AIDS categories. Their actual treatment can cause AIDS. Therefore, it seems just that we provide them with some means of compensation."

"When patients die after catching a disease through no fault of their own, they leave dependants who need a financial safety net. That is not there at the moment."

Dr Jones believes there are two ways in which the Government could help:

First is that the Government pays direct to families, with compensation based on material loss, such as lost earnings if a victim has to quit work.

Secondly, if that proves legally difficult, he wants a special government trust fund. Families in hardship could apply and applications would be properly administered.

Dr Jones sees the fund operating like the Joseph Rowntree Trust in York, which was established to help families in need.