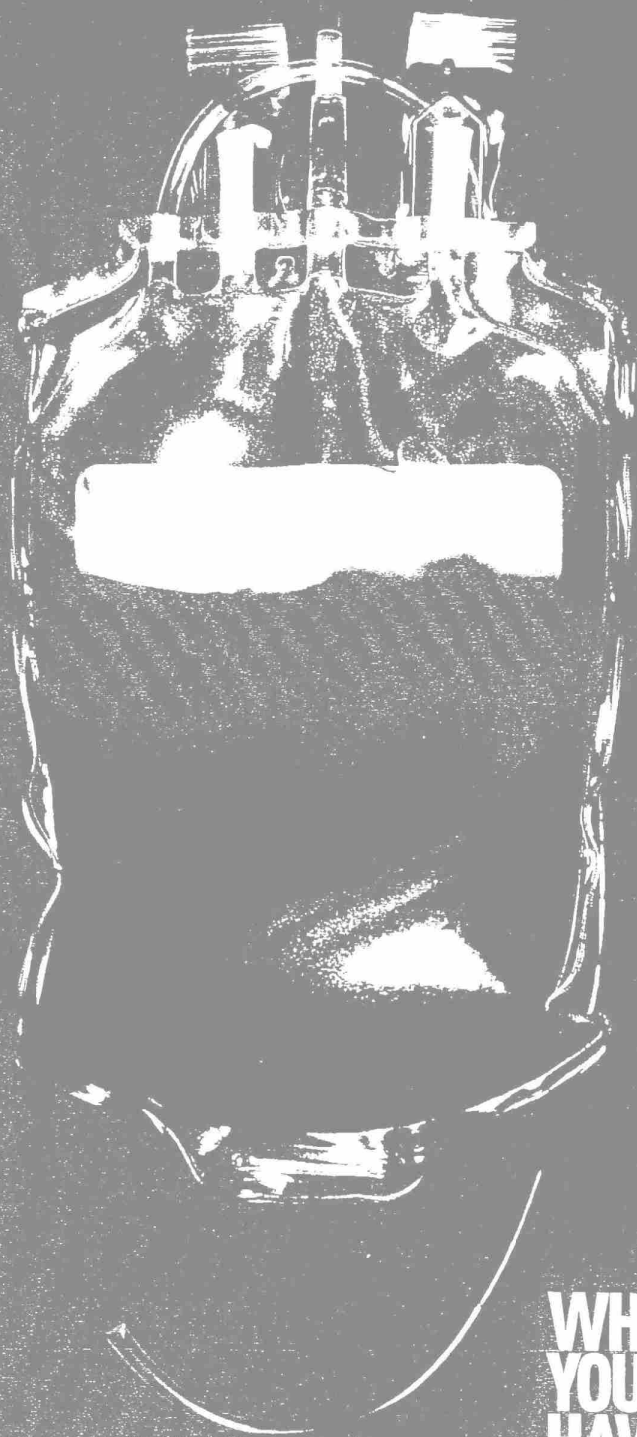


# The Herald Magazine

BRITISH SUPPLEMENT OF THE YEAR

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**WHEN YOU'RE GIVEN BLOOD  
YOU EXPECT TO LIVE. SO WHY  
HAVE THOUSANDS OF SCOTS  
BEEN LEFT TO DIE ALONE AND  
IGNORANT OF HEPATITIS C?**

# **In 1982 this woman contracted hepatitis C after giving birth. It killed her husband, and it is killing her. Yet she was only told she had it three years ago. Why?**

Investigation by Eamonn O'Neill Photographs by Simon Murphy





## COVER STORY

**A**t a quarter to three on a cold Tuesday afternoon, the 45-year-old woman slips into her lawyer's office. Two secretaries work the telephones nearby. "Hello, Thompsons," they sing every minute or two. She sits next to them in silence. She is soon joined by her daughter, and they whisper to each other for a moment before settling back into stillness.

The solicitors' offices smell of fresh paint. Glass-fronted rooms – large cubicles, really – greet the two women. They can see other clients inside having soundproofed conversations, like fish gulping for oxygen. After five minutes their lawyer, Frank Maguire – a 6ft 5ins solicitor-advocate – arrives and shows them into the larger conference room nearby. His wide build and almost Olympian arms are in stark contrast to his gentle manner.

Ten minutes later, after they have been legally briefed and prepared, I am led into the room and introduced to GRO-A, from Dumbarton, near Glasgow, and her namesake 20-year-old daughter. We sit looking at one another in the clinical lighting of the office setting. Both GRO-A are pretty and shy. GRO-A has taken a bit of time to build up to this encounter with a journalist. What she has to say isn't easy.

For the past 20 or more years she has been suffering from hepatitis C. But the labyrinthine world of medicine in Scotland didn't impart this hammer-blow news until just over two years go, so, in a sense, talking about it now is still new and different. Consequently, when she starts to speak, the words flow out like a shamed confession.

"In 2002 I started feeling unwell, having headaches and being sick, and my stomach was bloated. I looked as if I was expecting triplets," she says. "I went to the doctor and at first he couldn't explain it. Then I went back and he felt my stomach and he said my liver was really enlarged and asked if I drank a lot."

She glances down at her hands, then begins kneading her knuckles like a baker working knotted dough. She peeks at her daughter – the first of many such glances. GRO-A stares at the surface of the conference table.

"I said that I did drink, but not any more than anybody else. So he said they'd send away some blood samples. Then he did some more, and when they came back he said it was hepatitis."

The atmosphere in the room is brittle. Secret information – mere testimony to professionals, but something else for private citizens – is being imparted here. It is the kind of information that changes lives.

Eventually the source of GRO-A's hepatitis was tracked down to a single event: the birth of her daughter GRO-A in 1982. "I had a blood transfusion. The afterbirth had come away and caused a lot of bleeding, and I had to be rushed into theatre to get the afterbirth removed and to get a transfusion as well. They said that was where the hepatitis came from. I was in the GRO-A Hospital in GRO-A."

She knew she was sick, but this revelation floored her. "I had no appetite, and if I ate something I was just throwing it up. I had headaches and I was tired. I had swelling on my face. I was in a terrible state. I said to the doctor, 'There must be something you can give me for this?'"

GRO-A's eyes narrow as she speaks. Her hands are rubbed raw. She tightens up in the chair at the memory of her body's state. As she pauses, her daughter's voice jumps in from the other end of the table: "You had blood clots as well, Mum. Remember?"

GRO-A nods. "That's right. I was waking up through the night choking, and it was big clots of blood. It was terrible. The doctor said it was the hepatitis and the liver disease causing varicose problems in the gullet."

Mother looks at daughter; daughter stares at her face and then, finally, at the table again.

GRO-A looks back at me. She smiles softly and shrugs, as if to say, 'Sorry for my pain.' She starts kneading her hands for the umpteenth time.

**Y**ou and I shouldn't really know anything about GRO-A. She was off the official radar. Nobody came to find her to tell her she was possibly suffering from hepatitis C – a blood-borne disease of the liver that can lead to serious damage of the organ and, in many cases, death. More than 80 per cent of those who are infected will progress at some stage to chronic liver disease. But GRO-A wasn't tracked down. Only when she became extremely ill and made the first move did her condition come to light.

The hepatitis C "scandal" in Scotland has become ubiquitous and almost passé. Like media wallpaper, it has faded into the background of everyday life. It's the medical version of Lockerbie: everybody knows a bit about it, but few know all the details. Most have long forgotten how to get outraged about it, or why outrage is an appropriate emotion in the first place. Instead we worry about bird flu or other nasty pandemics that could wipe us all out. Yet, as you read this, up to 35,000 people could be under serious threat. That's how many people in Scotland are thought to have hepatitis C – and only a fraction of those who have it actually realise they've got it. That's why you don't see many people running down the street screaming.

But that's what GRO-A feels like doing. "I was crying all the time. I was depressed," she says. "What have I done to deserve this? That's the first thing that goes through your mind."

The statistics of which GRO-A is now a part are a mess. No-one is really sure of anything. But some numbers stand out. As far back as 2002, the British Liver Trust warned that the number of potential victims across the UK could be as high as half a million. And last year the Hepatitis C Trust commissioned a study showing that 18,000 people in Glasgow alone could have the disease. It has been estimated that, by 2035, it will cost the NHS £1.6bn across the UK to manage it.

Two groups of potential victims emerge through the fog. Firstly, haemophiliacs who were treated with blood products in the 1980s and 1990s to help with clots, and secondly, an unknown number of people who were given blood transfusions during the same timeframe. It's estimated that 5,000 British patients, most of whom were haemophiliacs, contracted some form of hepatitis – of which type C is generally considered the most serious – through blood treatment, and it is believed that more than 1,000 subsequently died from associated liver problems.

Many of the 35,000 Scots with hepatitis C will be intravenous drug users who contracted through needle sharing. But many others will be ordinary people; people who unknowingly received blood from the NHS. Some were haemophiliacs being treated with clotting agents; others, like GRO-A, received infected blood transfusions.

Scotland was not self-sufficient in producing its own blood products until the 1990s. Much of the infected blood was imported from America: inmates in US prisons were paid to donate blood regularly, as

GRO-A

GRO-A



Main picture and previous page GRO-A, who contracted hepatitis C from a blood transfusion after giving birth in 1982. This page, from top GRO-A with her husband, GRO-A, who died from the disease; campaigner GRO-A; GRO-A outside the Scottish parliament; Frank Maguire, the solicitor who refuses to let such cases drop

were members of the military. It is believed some of the infected blood came from prisoners in British jails – and that some of it was also infected with HIV.

Questions have been asked as to when the relevant authorities, such as the Department of Health, knew the products were risky, and how quickly action was taken to safeguard lives. A Scottish Executive report claims the medical community did everything in good faith, and used standard existing practices until effective heat treatment to make the blood safe was introduced in 1987 – some 18 months after it had been introduced in England.

Against this backdrop, GRO-A knew nothing. She simply didn't realise she was infected. Nor had she any reason to be



GRO-A

worried, since she wasn't a haemophiliac or a drug user. Even if there had been a safety net, she'd have slipped through it – although in fact there was nothing.

"I started to attend GRO-A in Glasgow," she tells me quietly, "and they were doing all kinds of tests to see how bad my liver was. For 20-odd years I'd been walking about with this disease I didn't know I had."

Doctors put her on the drug interferon, which is used in hepatitis cases, but she had a bad reaction and was taken off it. Now she is on experimental drugs instead, and says she is part of a blind study. She assumes she is being given the real drug rather than a placebo because she has been doubled up with cramps from its effects. "The family still don't like it.

But I am trying to find something that's going to help me. And it's not just me – there are thousands of people out there. It's a shame." The sense of understatement is enormous.

The Scottish parliament's health committee has considered demands from campaigners seeking a full public inquiry. Frank Maguire is handling hundreds of cases like GRO-A's across Scotland. Before giving evidence to the health committee, he told me: "No-one is taking responsibility for this. No-one is taking charge of it and saying, 'This was a disaster and we need to look at it and find out what went wrong, why it went wrong, why we didn't do as much as we should have done, and what we can still do about it.' No-one has done that. That's what an inquiry will do."

**'Why didn't they tell people? I could maybe have been cured'**

But when the health committee hearings were held earlier this month, Andy Kerr, the health minister, said he wasn't convinced of the need for an inquiry. He believed it would be costly and pointless, and that after this length of time it would never uncover the full story or bring about "closure" for the victims. It has been alleged that the UK Department of Health knew as early as 1981 of the potential hepatitis risk, but that imported blood was still used. Kerr, however, reiterated what the Scottish Executive had already said: that all treatment was carried out in good faith.

As Kerr spoke, Frank Maguire sat with an expression of open incredulity. GRO-A, a well-known haemophiliac campaigner from Inverness, said: "I can't listen to this any more," got up and walked out.

After the hearing, Maguire's response to the Scottish Executive's "good faith" line was unequivocal: "It doesn't matter if it was in good faith. You can do anything in good faith and it can be a disaster. You can be a complete idiot and do it in good faith. The question is whether it was negligent or was not best practice. Was as much as possible done to make sure these people were not infected at that time? If you have a situation where people cannot be traced and are not traced – if that's the kind of attitude they have to that position, what kind of attitude did they have regarding the infection in the first place? There's organisational defects in there – passing the buck and running for cover. Did that culture exist which gave rise to hepatitis C infection in the first place?"

During the hearings, a Scottish Executive legal official was asked if the people who received infected blood transfusions could be traced in any way. He hesitated, stuttered a little bit, then said: "My understanding is no."

At first, says GRO-A, she didn't want to tell me her story. Her suffering was private, and she was still struggling to come to terms with what had happened to her. Every morning she looks at both life and death in the mirror.

Just as she was starting to cope with her own condition, another punch was delivered. Her husband, GRO-A, also developed hepatitis C, through secondary contact with GRO-A. "We were frightened to go to the doctors," GRO-A says. So she and GRO-A alone and felled by an illness neither of them understood, sat at home and slowly became more ill. GRO-A was plagued with self-loathing and guilt because GRO-A had contracted it from her. "I just wanted to die," she says.

They realised she had probably passed the disease on because GRO-A, a diabetic, occasionally tested his blood-sugar-reading equipment on her. That prick of the thumb to draw blood would do the trick, she says. But she still hated herself, even though GRO-A told her not to worry; that it wasn't her fault; that it was just one of those things.

She still feels guilty. They'd been together for 14 years, and married for three. "They told me it was life-threatening," she says. "They told me I could never drink alcohol again. Not even one drink. They said it would kill me. You've got to watch what you're taking: tablets for headaches and things like that, because it might affect your liver. It changes your whole life. It's a horrible experience. Really horrible. You feel dirty."

GRO-A shrivels when she says "dirty", as if she could have somehow cleaned herself and prevented this situation. "Since my husband died I've got my daughter staying with me, and I won't even keep my toothbrush in the

## COVER STORY

► bathroom. I don't want it anywhere near hers. I've been taking it into the bedroom with me. That's the way it gets to you."

GRO-A looks up. "She knows it can't be contracted from saliva. But she's always really paranoid."

"I just feel really, really dirty," says GRO-A again, forcefully. "Sometimes you just sit down and have a wee cry to yourself and think, 'Have I ever been that bad a person that I deserve this?' That's the stupid thing that goes through your head." She turns to her daughter. "I think I've been a good mother?" GRO-A nods in agreement as her mother keeps talking. "I mean, I have been a good person really, and I don't deserve it. But you've got to think about these things yourself, because if you don't analyse your own life, and tell yourself, 'Well, I haven't done anything to deserve this,' then you'd break down. It's a horrible, horrible feeling."

The room falls silent. Then GRO-A tells me that one doctor to whom she was referred spoke to her "like I was trash" and kept his distance "like I was a leper". She suspects he thought she and GRO-A were drug users.

GRO-A deteriorated rapidly. His stomach swelled up like a football and his mind started faltering too. He'd go into the kitchen for fruit, then inexplicably throw it in the bin. "Eventually he was screaming with the pain," says GRO-A. "He'd have to go to the hospital to get something for the spasms. But this wasn't parts of his body - this was his whole body."

The tears start to fall, but her voice doesn't catch. "I took him home again but I couldn't handle him. It was breaking my heart. He was needing help and he was dirtying himself. He was only 39. When he started dirtying himself, I couldn't get him into the bathroom because

he was a big man, even though he'd lost a lot of weight. His mother offered to take him to his family because he had brothers who could help him into the toilet. He was only over there three days and I got a phone call from his mum. She said he was in the hospital, he was really bad. I went to see him and he was lying there like a frail old man." On top of the hepatitis C, GRO-A was also suffering from an MRSA infection.

He was allowed out of hospital a week later and returned to his mother's. His condition worsened again. "I went over and the doctor was there," says GRO-A. "I said I knew GRO-A was dying and that I'd known before he came out of the hospital. The doctor said, 'We're going to give him some morphine patches,' and I said, 'What's the point of giving him that now? When he was in all that pain, you wouldn't give him anything.' He died the next morning." It was four days before Christmas last year, 2005.

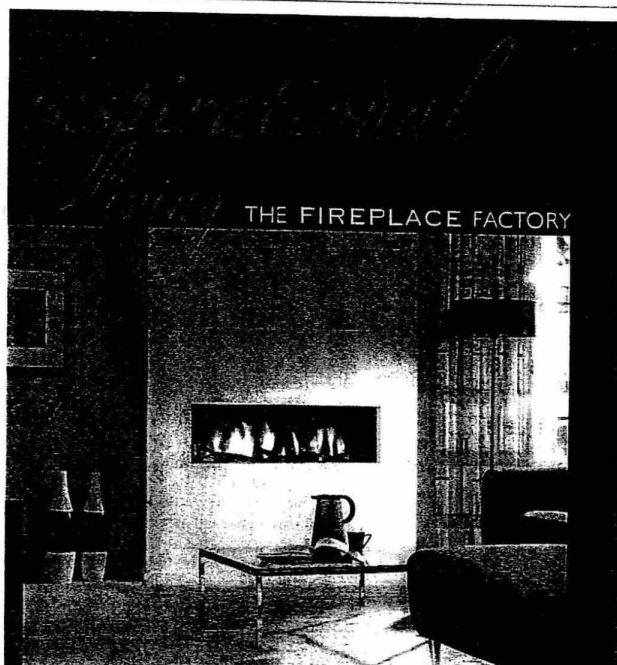
GRO-A's face is soaked with tears. She smiles weakly and rubs it with the stub of a hanky. Her daughter sits quietly, obviously distressed. They are only speaking out now to make people understand that it was a routine transfusion, nothing else, that led to GRO-A's illness and her husband's death. Some members of their family aren't sure that speaking out is a good idea, but mother and daughter have made up their minds and they're here to do it.

The illness is probably too far gone for GRO-A to be cured. "I blame the government," she says, "because it was up to them to call people back and let them know about all of this. But they haven't done it. They've not played their part. They've just let people get sick and die before they discover they've got


GRO-A

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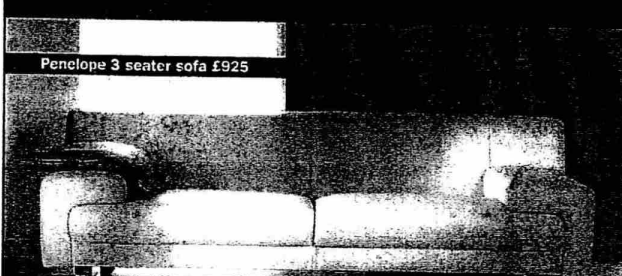
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GRO-A

## 'I took him home but I couldn't handle him. He was in pain and it was breaking my heart'

this. I mean, think about it. If I'd known after it happened, or even ten years down the line, I could maybe have been cured. But that was me only finding out three years ago. So why didn't they come back and tell people?"

That's the question Frank Maguire is fighting to have answered.

**T**he Scottish Crown Office's own rules, dating from November 1998, state that every death from hepatitis C should be investigated by the local procurator-fiscal's staff. Yet, according to Frank Maguire, this is not happening – and no-one seems able to explain why. Maguire has asked why the deaths aren't being investigated – but so far, he explains, all he has found is "a bureaucratic paper trail".

GRO-A has received £45,000 from the Skipton Fund, a trust set up to administer payouts to people in her position. In Scotland, that is all she is entitled to by way of compensation. In the Republic of Ireland, payments of £350,000 are not uncommon. "I think it's ridiculous. £45,000 for my life?" says GRO-A. "I think I'm worth a bit more than that. I think everyone that's got it is worth more than that. If someone was to come up to you and say, 'I will give you £45,000 and I will take your life,'

what would you do? You'd want your life, not the £45,000." Nobody knows how many more GRO-A and GRO-A there are in Scotland – and, at the time of writing, nobody is trying to track them down and tell them they might need help. They are being left to die. Abandoned to become like the bruised woman I meet today. Expected to find their own "closure" without official help.

Yet the biggest thing GRO-A wants is an explanation of what happened and why. That's all. Everything else is secondary.

After the interview ends, GRO-A says she hopes people will understand her predicament and not think badly of her. I simply don't know what to say. Then she confides that the only other member of the Scottish public who knew her story until now was another woman from Dumbarton – someone she would meet every so often when she was walking her dog in a park. They weren't friends as such, merely passing acquaintances. But one day GRO-A plucked up the courage to tell this lady she had hepatitis C. She's not sure why she chose her, but she did. She reached out to another soul and spilled out her truth.

To her delight, the woman wasn't shocked. GRO-A told her the problem was the stigma that went with the condition, especially from people who didn't understand it. "Listen," the woman told her, "those people aren't worth knowing."

GRO-A smiles at the bittersweet everyday picture in her memory. There they were, two ordinary Scottish women, two relative strangers sitting on an anonymous park bench, sharing secrets and a momentary oasis of common decency in a cold world. They could have been anybody's mothers, daughters or sisters.

But we already know that, don't we? ■

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