

THE HEP C BUYERS' CLUB

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Sean Reddin, a hep C patient, joined the Australian FixHepC Buyers' Club last year and flew to Hobart for generic medication. It cost him about €1,000 and he was declared free of the life-threatening virus last month

Bryan Meade

Hepatitis C can now be cured, but at a hefty price. Irish patients are circumventing the pharmaceutical industry to find cheap and life-saving drugs overseas, even if that means flying to the other side of the world



Susan Mitchell
Health Editor

In the 1980s, the Dallas Buyers Club became famous for smuggling illegal drugs to Aids patients in the US, and was the subject of a recent movie.

Now a buyers' club set up by Australian doctors James and John Freeman is challenging the pharmaceutical establishment by delivering life-saving drugs to patients with hepatitis C for a fraction of the cost.

The medics source cheaper drugs that are not usually available in richer countries such as Australia and Ireland.

Irishman and HepC patient Sean Reddin, 56, joined the Hobart-based

FixHepC Buyers' Club last year. In October, he boarded a plane for Australia and returned to Ireland with a generic form of the medication, which cost him about €1,000.

His GP, Dr John Fleetwood, declared him free of the life-threatening virus last month.

“I used to feel like I had a ticking time bomb inside me. Now, I can look forward to another 30 or 40 years,” Reddin said.

Had Reddin been in Ireland, he would have had to pay €80,000 for the same treatment regimen. Like many of the people in Ireland who have been diagnosed with hepatitis C, he could not afford that large sum of money.

Reddin credits the FixHepC Buyers' Club with saving his life and giving him peace of mind. Chronic hepatitis C is a serious condition that can result in long-term health problems, including liver damage, liver cancer, liver failure, and death (see panel).

It is believed that hepatitis C, which is a viral disease, affects around 30,000 patients in Ireland. Only 12,820 have been diagnosed since 2004. Many people are unaware that they have been infected as the majority of patients are asymptomatic until the liver becomes severely damaged, often decades after exposure. The disease is often dubbed the “silent killer”.

New pills: the magic bullets

Until 2013, the most common treatment available to patients with hepatitis C involved injected interferon and twice-daily tablets (called Ribavirin). The list of side-effects was long and gruelling. As few as one in 20 patients were eventually cured, but some patients showed little or no response.

Then along came new drugs called Direct Acting Antiviral Drugs, or DAAs. These DAAs – Sovaldi and Harvoni – were dubbed a game-changer by doctors. Treatment typically takes 12 weeks, is largely free of side-effects and delivers a 95 per cent cure rate.

The problem is that they are ruinously expensive.

Gilead launched the 12-week course of Sovaldi in the US with an \$84,000 price tag, or about \$1,000 a pill. However, in Egypt and India, it priced a 12-week course of Sovaldi at \$900 per patient – or \$10 per pill. Patients and politicians in the US were incensed by the price of these life-saving fixes.

The Irish government agreed to pay Gilead approximately €45,000 per patient



Gilead chairman John Martin (above) stepped down earlier this year as chief executive of the company. In 2015, Martin was dubbed the \$600 million man as his stock and options were so valuable.

The Harvard Business Review singled Martin out in 2014 “for delivering a staggering 7,000 per cent industry-adjusted shareholder return”.

Gilead has attracted much criticism from campaigners for better healthcare.



Dr James Freeman of the Australia-based GP2U



“What we are doing is slightly naughty, but what Gilead and these guys are doing is just so wrong and so greedy”

for a 12-week course of the medications – or €535 per pill. Because Sovaldi is used in conjunction with another new medication, it brings the price tag to almost €80,000 for a 12-week course. The cost ramifications to the state – because of the high numbers infected with hepa-

titis C – are enormous and would have run to hundreds of millions of euro if all patients registered were treated. So the Irish state agreed to treat patients on the basis of need.

Women who were infected through blood products supplied by the state were prioritised. So too were patients with cirrhosis, which is the severe scarring of the liver and poor liver function seen at the terminal stages of chronic liver disease. Other patients just have to sit it out until they are sick enough to become eligible. Ireland is not alone in this approach.

Gilead's pricing has forced private and public healthcare providers in developed countries all over the world to engage in outright rationing, reserving coverage of the drug only for patients with the most advanced disease.

The state – via the HSE – has covered the cost of these new drugs for about 500 patients in Ireland since the treatment programme started in 2014. But many Irish patients remain in limbo. Their conditions are deteriorating and they worry they will not get the drug before they end up on the liver transplant list. Reddin said he was not deemed sick enough to get the drug. Neither was another patient who spoke with this newspaper.

“I'm not willing to wait and there was no definite promise that I would even get it anytime soon. My condition has deteriorated a lot,” this patient said.

He, like Reddin, sourced his medication through the FixHepC Buyers' Club. But instead of travelling to Australia, he had the medication posted to a relative in Britain. He is now a few weeks into his treatment, but did not want to go public at this stage.

Taking matters into their own hands

The central character in the Dallas Buyers Club film, the HIV-positive Texan hellraiser Ron Woodroof, was willing to break any laws to get hold of the drugs he and others needed to stay alive.

Dr James Freeman, who is part of the father-and-son team that set up the FixHepC Buyers' Club, is far from a buccaneering rebel.

In fact, Freeman said he was nervous about setting up the organisation.

“You have this dreadful fear in medicine that if you stick your head up and be alternative, you get it shot off,” Freeman said.

He said he was alerted to the existence of generic drugs by one of his own patients who was infected with hepatitis C. Freeman agreed to prescribe the drug on the condition that it would be tested on arrival in Australia before he allowed his patient to take it. The generic drug worked. The patient was cured. And word

spread. James and his father, Dr John Freeman, began to source and test generic versions of Gilead's drugs from manufacturers in China, India and Bangladesh.

A number of manufacturers in these countries are making generic versions of the drugs. This is being done legally, as these countries often refuse to grant large pharmaceutical companies a patent for life-saving medicines. Gilead even agreed to team up with generic manufacturers in some of these countries to manufacture the medicines locally. Soon liver specialists in Australia began to prescribe the generic drugs that the Freemans were helping to source.

A number of other organisations facilitating access to generic hepatitis C drugs have also sprung up. Freeman said the FixHepC Buyers Club has helped to source the medication for thousands of Australians and hundreds of Europeans. The drugs are clinically tested, Freeman said. The website, FixHepC.com, spells out the process in layman's terms.

“Although the asking price in many countries is \$1,000 a tablet, these medications are available overseas for far less. For example in Egypt, China and India, Sofosbuvir is available for under \$10 a tablet,” it explains.

Freeman said it was legal for “a patient to import a 12-week supply of medication into Australia” as well as many other countries including Britain. “Doctors here [in Australia] were sceptical at first. But then they started sending their patients to us directly,” said Freeman.

Dublin-based liver specialist Dr Diarmaid Houlihan said the issue of Irish patients procuring generic hepatitis C cures was raised at a recent meeting of ICORN (the Irish Hepatitis C Clinical Outcomes Research Network).

“More and more people are doing this,” said Houlihan. Houlihan said some were using the buyers' club, but that he also had patients who were flying to countries such as India and getting the medicines themselves.

Many are accessing original branded drugs in this way. Houlihan said there was a very real prospect that there could be an “exponential growth” in numbers procuring the medicines from underground channels as patients begin to hear about the experiences of other patients.

“We can't stand over the quality of these drugs ourselves, but I do know that this doctor in Australia is considered very reputable,” Houlihan said.

World-renowned liver experts will gather in Barcelona in April for the annual conference of the European Association for the Study of Liver (EASL).

Dr James Freeman has submitted an abstract on the success of the generic hepatitis C drugs and hopes to present his findings. Freeman said he was operating within the law.

It is unclear whether, or how, Gilead will respond.

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What is hepatitis C?

Hepatitis C is a blood-borne virus that causes inflammation of the liver. The virus is present in the blood of an infected person and can be spread through blood-to-blood contact.

In Ireland, over 1,000 women were infected with contaminated blood products given to them during childbirth. Hundreds of haemophiliacs were infected with both Hepatitis C and HIV from products

they used to try and help their blood to clot. It is also commonly spread through sharing unsterile needles, syringes and other injecting drug equipment.

A recent study estimated that there were between 20,000 and 30,000 people with Hepatitis C in Ireland. It can be fatal and can lead to conditions like liver cancer and cirrhosis, or scarring of the liver; this is one of the main reasons why people get liver

transplants.

Until recently, treatments for hepatitis C were problematic. They had poor cure rates; required prolonged treatment times that involved regular injections; and triggered extremely unpleasant side-effects, leading many who have been treated to describe the treatment as being worse than the disease. New drugs offer a 95 per cent cure rate, but at a huge cost.



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