

Route opens to hep C hope

Trip cuts lifesaver drug cost

STEPHEN BURKE

IT IS the breakthrough drug that thousands of Australians with liver disease have been praying for, but at \$90,000 the treatment is cruelly out of reach for all but a wealthy few.

Now a Tasmanian man diagnosed with hepatitis C has given patients around the world new hope by opening the door to an affordable source of the lifesaving drug in India.

Historian and author Greg Jefferys, 61, faced a bleak future of chronic liver disease, serious illness and a life cut short because he could not afford the most effective hep C treatment.

In Australia only hep C patients with the most advanced stages of liver disease are given subsidised treatment with sofosbuvir, a drug that has a 95 per cent success rate and minimal side effects, but costs \$90,000 for 12 weeks' supply.

Last month Mr Jefferys travelled to India and bought a

generic version of the drug for just \$900. Three weeks after beginning treatment back in Tasmania, blood tests reveal he is already well on the road to recovery.

"Before it was like walking around in a fog. That feeling has just totally gone," he said.

His case has highlighted the dilemma for 230,000 people nationwide with hep C.

They face a gruelling 44-week treatment using the drug interferon, which has a raft of serious side effects and is only about 60 per cent effective, or they can wait until they develop severe liver damage and hope to be included in a subsidised program for sofosbuvir.

Despite the difficulties involved, including fears about whether the drugs he bought would be genuine, Mr Jefferys said he would not hesitate in recommending other hep C patients follow his lead.

"What are your choices? One is to wait to get cirrhosis

and get real sick, or go to India and get the medication," he said.

Medical experts estimate that if sofosbuvir were available to all hep C patients through the Pharmaceutical Benefits Scheme, it could wipe out the virus in Australia and reduce the waiting list for liver transplants by a third.

In April the Pharmaceutical Benefits Advisory Committee recommended it and another drug, Harvoni, be included in the PBS, but federal Health Minister Sussan Ley will not grant approval unless a better price deal can be reached with patent holder Gilead.

A request for comment from Ms Ley was referred to the federal health department, where a spokeswoman described the PBAC recommendation as "a very important step in the listing process". "However, other steps need to be taken before a (PBS) listing is achieved, such as pricing negotiations with the product's sponsor," she said.

THE KEY TO HELPING KIDS WITH DISABILITIES



SMILING: CMI Portside CEO Steven Thomson and Living Without Limits co-founder Phillip de Pinto with the Yaris to be raffled.

ADELAIDE motoring industry identity Phillip de Pinto is driving a cause close to his heart.

With help from his business friends at CMI Toyota, the manager of Universal Motor Auctions is on the way to realising his vision to build a holiday home "of respite" for families caring for children with disabilities such as autism and cerebral palsy.

"I have an autistic son so I know what parents of these children are going through," said Mr de Pinto, chairman

of the Living Without Limits Foundation. He founded the charity in 2012 with friends Steve Maras, CEO of the Maras Group, and BDO Adelaide partner George Yatzis.

CMI Toyota has donated a new Toyota Yaris as the major prize in a raffle to help LWL's fundraising.

"They've been fantastic. They did not hesitate when I approached them," Mr de Pinto said.

He said if LWL achieved their fundraising goal of \$150,000 this year, it could

have the holiday home open within 12 months.

"It would allow 50 to 60 families a year to enjoy a free holiday by the sea," he said.

"We want to provide a place somewhere near the beach where families can get away and reconnect with each other in a holiday atmosphere."

The 400 car lottery tickets, which cost \$100 each, are being sold through the charity's website lwl.org.au. The winner will be announced at a gala dinner on July 18.

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