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From a couple of seizures a week to none: how medicinal cannabis is helping Ethan

DC By Damon Cronshaw April 1 2025 - 11:30am



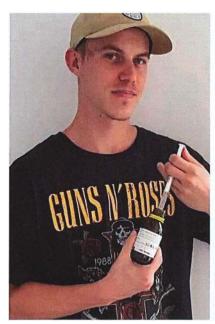


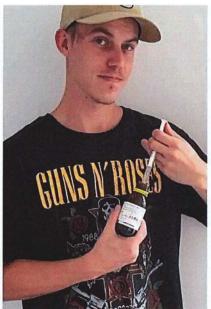


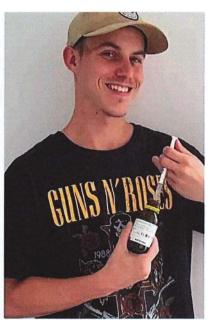












Ethan Stewart with Epidyolex medicine, a CBD oil. Pictures supplied

Ethan Stewart began taking <u>medicinal cannabis</u> four months ago in a Newcastle-based <u>clinical trial</u>. Since then, he hasn't had an <u>epileptic seizure</u>. His mum Angela Stewart said "it's incredible".

The clinical trial is being done through the University of Newcastle and Hunter New England Health.

It aims to determine the safety and efficacy of Epidyolex, a form of CBD oil, for people with developmental and epileptic encephalopathy (DEE).

Researcher Linda Truong, who is leading the trial, said Epidyolex was classified as a "pharmaceutical-grade product".

Ms Truong said it was "considered more effective than standard CBD oils available for legal purchase in Australia".

Dr John Lawson, a paediatric neurologist, said "cannabis medicines are showing promising results".

"Trials of this kind give hope to families and will potentially shape the way we work with patients," Dr Lawson said.

Ms Truong said the trial was open to 20 children and adults <u>suffering</u> <u>seizures</u> caused by DEE. Ethan, 24, has lived with this condition since age one, as part of the genetic disorder tuberous sclerosis. Before he tried Epidyolex, he was having at least a couple of seizures a week.

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"He was hospitalised occasionally with major uncontrollable seizures," Ms Stewart said.

While taking the CBD medication, "he hasn't had one seizure".

His seizures are caused by 14 tumours in his brain.

"He had brain surgery at age 10," Ms Stewart said.

"Seizures can be deadly. They cause brain damage every time they happen"

She said Epidyolex had "a varied and wide benefit with no drawbacks".

Ethan, a Port Macquarie musician, said the CBD oil had "changed my whole life".

"I used to be very anxious Any decision I had to make, it'd be a mountain to get through," he said "Ever since I've been taking the medication, day and night, I feel more at ease and confident in my abilities"

He has taken anticonvulsant medication since age one, but hopes to reduce it. "It takes its toll on my internal organs, so it's good something more natural is working for me."

He hopes to stay on the CBD medication in future.

One 100-millilitre bottle of Epidyolex lasts Ethan about nine days, but he doesn't have to pay for the drug in the clinical trial.

Sydney-based Jazz Pharmaceuticals, which manufactures Epidyolex, is funding the \$755,000 clinical trial up until next year.

The drug is listed on the PBS for patients with severe myoclonic epilepsy in infancy (Dravet syndrome) and seizures from Lennox-Gastaut syndrome.

University of Newcastle Professor Jennifer Martin, a clinical pharmacologist, said a case could be made to list Epidyolex on the PBS for DEE patients.

But this would depend "if it is more cost-effective than other comparable therapies", Professor Martin said.

She said the company could "make it more cost-effective by lowering the price".

Epidyolex is one of only two cannabis medicines registered with the TGA. Other medicinal cannabis products available in Australia are "unapproved", but can be accessed with a prescription.

More than 3350 applications for medicinal cannabis use for epilepsy patients have been approved since the national medicinal cannabis scheme began in 2016.

For more information about the clinical trial, email Linda. Truong 1@health.nsw.gov.au.