

When the world stopped for 45 minutes

A family's battle to diagnose their son's epilepsy took the laughter out of their lives, writes **Liz Heron**

One afternoon 18 months ago, life suddenly turned deadly serious for the founder of Hong Kong's premier comedy club, John Moorhead was having tea with his children at home in Somerset, England, and Elliot, at age 4 the youngest, was tucking into a plate of Marmite toast. "He just said 'Maaaarmii ...' and he went still and limp and was looking up to one side," the father-of-three says. "I caught him because he was about to fall onto our kitchen floor. I was in sheer panic inside. I said to my wife, 'Call an ambulance'. We put him on the floor on his side in a first-aid position. He wasn't moving and his eyes were rapidly flickering.

"My wife was crying. We both thought that we were watching our son die. We didn't know what was going on and we just thought the worst. Eventually the ambulance came and they gave a drug called diazepam. The fit continued in the ambulance and it finally stopped after 45 minutes."

It was the classic experience of a first encounter with epilepsy, and the beginning of a harrowing 13-month struggle to diagnose Elliot's condition and identify the best form of treatment. But it did not stop Mr Moorhead continuing his international career as a comedy impresario and managing director of Wan Chai's Punchline Comedy Club and its sister venues across Asia – despite once having to rush back from Hong Kong when his son had a 1½-hour attack.

And the experience prompted him to mount a special comedy show this week to launch Epilepsy Awareness Month and raise funds for the charity Enlighten – Action for Epilepsy. Twenty per cent of proceeds from the late-night shows on Thursday, Friday and Saturday featuring popular British and Canadian stand-ups will go to the charity's Hong Kong branch, with further cash raised through the auction of a weekend for two in Sydney.

The Moorheads were planning to move to Australia, where John was born, until

Elliot's condition turned their family life upside down. Their ordeal continued for more than a year. Elliot was prescribed three different drugs but nothing seemed to stop the fits, which were exceptionally long and severe.

Initial fears of a brain tumour proved unfounded and two electroencephalograms (EEGs) showed nothing abnormal. But the doctors persisted and conducted a third EEG on Elliot in July under anaesthetic. The traumatic events of that day were like a scene from the television show *ER* but – thanks to an extraordinary fluke – produced the diagnosis needed to get the boy's condition under control.

Mr Moorhead sat in the darkened treatment room next to his son as the anaesthetist administered the drug. He watched the boy drift off to sleep. "Five minutes later I looked over at Elliot and I saw his back was rising up and down a bit," he says. "So I walked over to him and saw that he was having a full-blown fit during the EEG. His eyes were flickering."

We just want Elliot's fits to stop one day – for him, not us. I wish I could have them for him

John Moorhead, managing director of the Punchline Comedy Club and father of an epilepsy sufferer

The father rushed out into the waiting room, found the nearest nurse and said: "I've got to get my son to accident and emergency immediately." He and the nurse began wheeling Elliot's bed and running towards A&E. He rang his wife and she called the paediatrician, who also raced to A&E.

In the emergency room, the paediatrician discussed the case with the EEG doctor and was amazed to discover that he had caught the fit on film. The doctor said he had never heard of a patient having an epileptic fit during an EEG in his entire 15-year career.

"It turned out to be the best thing because the fact that he had a fit during the

EEG gave the doctors a very rare opportunity to see precisely where the fit started and what type of epilepsy he had," Mr Moorhead says.

Elliot was diagnosed with Panayiotopoulos syndrome, a rare form of epilepsy involving prolonged seizures. But the fits nearly always happen during sleep, are alleviated immediately and do not damage the brain.

"It turned out to be the best thing," Mr Moorhead says. "It is a benign form of epilepsy and the prognosis is good. There is a very good chance of growing out of it."

"Our lives have changed since that day in June 2006, when Elliot had his first seizure. We can't fly as a family. I wouldn't dream of flying with him. Imagine if you were on a 12-hour flight to Australia and he was having a fit on the plane. And my wife and I will certainly not be going on a short break away on our own, like our friends do. We would never relax for obvious reasons."

"We just want Elliot's fits to stop one day – for him, not us. I wish I could have them for him."

Epilepsy, which involves a temporary disturbance to the brain's normal electrical activity, is not usually life-threatening and many children with the condition grow out of it before they reach adulthood. In developed societies, the condition is not a barrier to a normal life. This depends upon having a strong legal framework that obliges employers and schools to accommodate people with epilepsy and respond correctly to seizures, as well as good medical services that can provide accurate diagnosis, appropriate medication and good management of the condition.

The estimated 60,000 Hongkongers who suffer from epilepsy are covered by Hong Kong's Disability Discrimination Ordinance, which makes it illegal to sack an employee or deny a child a school place because they have the condition.

Educators and employers say that they try to support an inclusive culture for people with disabilities such as epilepsy. However, enforcing the ordinance is another matter.

A spokeswoman for the Equal Opportunities Commission says: "We do believe that discrimination or harassment against people with disability in employment is not uncommon. But complaints related to epilepsy are not that numerous compared to other types of disability."

But Orla Gilroy, executive director of Enlighten, says discrimination exists both in the workplace and at school.

"We are aware of a number of cases where the employer has strategically removed the person with epilepsy. They are being side-tracked or told that their post has been deleted because of budget restrictions, or employers will try to find a fault in the work," Ms Gilroy said.



John Moorhead and his son Elliot. When the boy had his first attack, "we thought we were watching our son die". Photo: SMP picture

"We were contacted by a young man who works in a bank. He had a seizure at work, and now, when he goes to the coffee machine, everyone will walk away. And, we were contacted by an Australian guy who came to work in Hong Kong. When he told his employer that he had epilepsy, they withdrew his contract before he had even started the job."

"Some schools in Hong Kong will not take children who have epilepsy. Strictly speaking, this is against the equal opportunities legislation, but schools will get round this by saying they are denying access to a child because they have no space left."

Ms Gilroy says the social consequences of epilepsy, such as stigma, are often more difficult to overcome than the seizures themselves.

"There are some deeply rooted beliefs in Hong Kong about epilepsy and its causes, treatments and effects. The fact that the Chinese word for epilepsy – *din gan ching* – includes the word for insane, speaks volumes about people's misconceptions and fears about this

condition." She says another major misconception is that sufferers come from a poor background and have lower intelligence.

The charity has learned that some parents even removed their children from a school in Wan Chai because they believed they would catch epilepsy from other children in the school.

"There is a big awareness problem about epilepsy in schools," she says.

"It is also extremely difficult for people with epilepsy to get health insurance in Hong Kong. Expatriates with epilepsy may get health insurance in their home countries and a lot of local people simply use the public hospitals."

"The United States, Australia, the UK, New Zealand, Ireland, India and Japan all have annual national awareness campaigns supported by their governments about people with the condition and making people understand that people with epilepsy are no different from anybody else and are entitled to some respect."

"This sort of regular campaign is essential to break through the stigma attached to the condition and the Hong Kong government should support a similar awareness campaign in Hong Kong. We had one in 2005, but because of lack of funding we can't run it on the same scale as before."

The Education Bureau maintains that an effort to promote awareness and inclusion is being made.

"The Education Bureau has been promoting an inclusive culture in schools and enhancing their capacity to cater for student diversity through various means such as strengthening moral and civic education, training teachers and school heads, parent education as well as other publicity work," a spokeswoman says.

The Equal Opportunities Commission received a total of 21 complaints related to epilepsy from 2001 to September this year, of which 16 were employment-related, one concerned education, two were related to provision of goods and services and two were about government services. Most of the complaints were lodged in the past four years.

Drugged and ripped off: welcome to Wan Chai

A few drinks with friends can turn into a potentially lethal nightmare, writes **Nick Gentle**

It was a typical Friday night not so long ago that James (not his real name) rolled into a Wan Chai bar to celebrate the end of the week with a few friends. A couple of hours went by and, like most people there, he was living it up, drinking, dancing and carrying on with his friends. All of a sudden, however, he felt like he'd probably had about six drinks too many. "I just kind of went, 'My God, I feel really, really drunk ... I've gotta go,'" he says.

From that point, his memories are hazy. He says he remembers being in a taxi and a woman getting in alongside him. He told her to get out, but she refused. The next thing he knew, he woke up in the taxi as it was barreling down Gloucester Road. He sensed some time had passed and that something was very wrong.

"I was pretty sure I'd been ripped off," says James, who has heard of similar things happening to other people. "I remember being really angry and shouting at the girl and the taxi driver to stop and let me out. As I was getting out, the girl stopped me and said, 'You forgot your wallet' and handed it over to me. I knew then that I had been robbed, but I thought it was probably just what was in my wallet at the time; maybe HK\$500 or so."

It was only the following day, after

waking up feeling "not just hung over, but groggy", that James discovered HK\$20,000 missing from his bank account.

"Now that I think of it, I can kind of remember being at the ATM with the girl, who was hiding her face, and her telling me what to get. I know when I saw how much came out I freaked out."

But between that and waking up in the taxi ... nothing.

James is sure he was drugged by someone spiking his drink at the bar. He is one of a steadily growing number of expatriates who have fallen victim to gangs of thieves using drugs to sedate and then rob their well-heeled targets.

In recent years, the *Sunday Morning Post* has received numerous anecdotal reports of this practice taking place. Since 2004, police headquarters in Wan Chai have recorded a total of 44 theft cases in which the victims (mostly foreign nationals) were drugged by sex workers they met in bars. However, the real figure is almost certainly much greater, because the offence generally goes unreported to police, as in James' case.

"There are a lot of reasons why people don't report such things," one police source says. Number one among those reasons is embarrassment.

Whether it is drunkenly signing a hugely

inflated credit card bill, being drugged and robbed, or forced to hand over money to a prostitute who is threatening to scream "rape", the source says that a big question for the victim was: "How am I going to explain that to my wife?"

The victims range from tourists to top lawyers and are often successful professionals. The minuscule chance of actually getting their money back doesn't rate when compared with the potential hassles associated with admitting they had somehow been duped by a bar girl into handing over either their PIN or a thick wad of cash.

It is difficult for police to make investigating cases like James' a priority without a report being made, the source says.

"What's the point?" James asks. "I don't think I could recognise the girl in a lineup, and it was me who took the money out."

But more concerning than the fact that the crimes are going unreported, is the manner in which they are executed – people having potentially lethal drugs administered to them in an uncontrolled environment.

The two substances thought to be most commonly employed in drug-assisted robbery are the so-called date rape drugs – flunitrazepam (brand name Rohypnol) and GHB (gamma hydroxybutyrate), also known as Fantasy or liquid Ecstasy.

Both drugs are highly soluble, odourless, relatively tasteless and colourless, and work quickly to suppress



Police believe many druggings involving sex workers go unreported. Photo: SMP Picture

the central nervous systems of people who ingest them.

GHB is particularly suited to this sort of crime because it occurs naturally in the body and is relatively easy to make. In fact, because the body makes it, all that needs to be done is for a person to ingest a precursor chemical that the body turns into GHB.

As it turns out, the chemical most commonly used for that purpose is a reagent found in many household

cleaners. It can be bought in Hong Kong in bulk in 99.99 per cent pure form in quantities ranging from a single 500ml bottle to multiple 200kg drums.

A US Department of Justice report concluded that the incidence of GHB being used to facilitate crimes like rape or robbery "is likely to be unreported or unsubstantiated because GHB is quickly eliminated from the body, making detection in body fluids unlikely. It's fast

onset of depressant effects may render the victim with little memory of the details of the attack".

But memory loss is not the biggest risk with these sorts of drugs. Mixed with other drugs such as alcohol or cocaine, their suppressing effect on the nervous and respiratory systems is exacerbated. This can lead to coma or death.

In January 2003, in Hong Kong's most high-profile case to date of a drugging gone wrong, the body of Chief Superintendent Kari Juhani Koivuniemi, 45, of Finland's Ministry of the Interior Police Department was discovered in his room at the Island Shangri-La. It was reported at the time that the cause of death was a heart attack brought about by a combination of flunitrazepam and alcohol. A young woman was seen entering the hotel with him, visiting an ATM with him, and then leaving on her own about three hours before his body was discovered.

The police source hints that such incidents may be more common than reported, and that occasional, otherwise inexplicable deaths of young and healthy tourists in their hotel rooms may have a more sinister cause than heart failure.

In the meantime, the bars are still full and the good times continue to roll, although many men, like James, are now keeping a closer eye on their drinks, and the people around them.

"The thing is, I went down to Wan Chai to see my friends," James says. "I didn't go down there to get drugged."