World focus: China
Professor Ley Sander, a leading neurologist at the National Society for Epilepsy, has won a top award for his research into epilepsy in developing countries. Here we look at how his flagship project established a blueprint for epilepsy services in China.

In 2000, when an ambitious project was launched to improve the care and treatment of people with epilepsy in rural China, the outlook for those with the condition was bleak. People with epilepsy were stigmatised. Epilepsy was seen not as a medical condition but as a mental disorder bordering on insanity. Studies showed that most people would object to their seizures and worrying or even playing with someone with epilepsy. Half the population believed people with epilepsy should not be employed.

The four-year project, Epilepsy Management at a Primary Health Level, set out to dispel these stigmas while at the same time training health professionals and increasing the number of people with epilepsy who were being given appropriate treatment. The aim was to develop a model for epilepsy care for the whole health system.

Jointly launched by the World Health Organisation (WHO), the International League Against Epilepsy (ILAE) and the International Bureau for Epilepsy (IBE), the project was piloted in six provinces across rural China. Free treatment with AEDs was distributed through local health centres. Epilepsy is now a national health priority.'

Ley Sander was awarded the 2009 Epilepsy Research Recognition Award for Clinical Science by the American Epilepsy Society. Next issue: Africa

Make your views count
A major survey to find out what people with epilepsy – and those close to them – most want and need to make a difference to their lives, is being carried out by the National Society for Epilepsy (NSE).

To take part in the online survey go to www.epilepsysociety.org.uk

Out of step?
Dancer Rita Marcalo has defended her decision to try to induce a seizure on stage during a 24-hour performance at Bradford Playhouse.

'As an artist I am interested in autobiographical work which explores who I am. Epilepsy is part of who I am: it is part of my body, my identity, the way my brain works,' said Rita who has had epilepsy since she was 17. 'My performance was a lot safer than the situation I and many epilepsy people find themselves in when they have seizures, especially if, like me, they take themselves away to a toilet.'

The Portuguese dancer stopped taking her anti-epileptic drugs prior to performance, involuntary Dances, in the hopes of triggering a seizure that could be recorded by the audience on their mobile phones.

Although Rita remained seizure free during the performance, she still feels the project did much to help raise awareness of the condition, and intends more performances.

'Twelve hours into the performance I started to worry that I was not going to have a seizure and at first I felt guilty that I had short changed people,' continued Rita. 'Then I actually felt quite angry at my epilepsy. This was supposed to be the one instance in my life when I was going to take control of it (instead of it taking control of me) and have a seizure on my own terms. How dare it not behave as I had expected?'

'But towards the end of the 24 hours, I began to consider how much discussion around epilepsy the event had generated.'

While supporting Rita’s freedom of expression, the National Society for Epilepsy (NSE) – and other epilepsy charities – had spoken out about the risks she was taking, expressing concerns over the safety of coming off medication without medical supervision.

NSE neuropsychologist Sallie Baxendale said: ‘The danger of coming off medication is that sometimes when you go back to the same level as before, your seizures are not controlled any more. You play about with your medication at your peril.’

Rita Marcalo: mixed reaction
‘What Marcalo is doing is terrific – well conceived, witty and thought provoking. She is drawing attention to the fact that on YouTube it is easy to find mobile phone footage of people having fits – mostly taken without their consent. Marcalo’s performance implicitly said: “It’s just a fit. Get over it.”’

Allan Sutherland, The Guardian

‘Persons diagnosed with epilepsy have enough to contend with without being used as a theatrical stunt.’

Julia Dunning, Yorkshire

Sleep soundly
A new generation sleeping device, designed to raise the alarm and summon help if breathing stops, has won a top award. The Apnoea Detection Device prototype took first prize in the information technology section at the 2009 Institution of Engineering and Technology Awards.

The miniaturised device has been developed by NSE’s medical director Professor John Duncan and Dr Chen Guangwei and Dr Esther Rodrigues of Imperial College. It is hoped it will help to prevent some instances of Sudden Unexpected Death in Epilepsy (SUDEP) in the future.

Dear diary
Day By Day by Me, a new seizure diary especially for children with epilepsy, is available free to children with the condition through epilepsy specialist nurses. The diary, produced by the National Centre for Young People with Epilepsy (NCYPE), is full of pictures and cartoons by famous illustrators including Nick Sharratt.

EDITOR’S CHOICE
VINCENT VAN GOGH – was he a frenzied artist with wild colours, turbulent and turbulent paintings were the result of his epilepsy and mental torment, or was his visual revolution a considered campaign in the world of art? For the first time, a new exhibition allows the artist to speak for himself, not just through the medium of art but through his collection of compulsive and eloquent correspondence.

The Real Van Gogh: The Artist and His Letters. The Artist and his letters challenges the theory that Van Gogh was an erratic genius by allowing us a rare insight into his artistic process through often intimate and detailed correspondence.

Van Gogh was a prodigious letter writer and this collection, edited from 819 letters written by himself and 93 written by his brother Theo and artists including Paul Gauguin, charts the artist's torment from his epilepsy and mental breakdown through to his loneliness.

The collection is supported by some of Van Gogh’s most celebrated paintings including many painted in his trademark buttery yellows and limes greens. It has often been said that Van Gogh’s use of yellow was a result of his suffering from Xanthopsia, a condition that causes the person to see everything as though through a yellow filter. Xanthopsia was a side effect of digitals, often used to treat epilepsy.

Van Gogh’s Chair, December 1888. The National Gallery, London