

Sorting the facts from the hype in science news

Every time you open a newspaper, there's another report of a miracle vitamin supplement that will make you live forever, or deadly chemical that will kill you tomorrow. So how can you tell which stories are reporting real research, and which are press releases designed to generate publicity, cause a scare and perhaps affect share prices?

Sharing the results

Science is a huge research community that is truly global. In university departments and research companies all over the world, people are setting up experiments no one has done before, asking questions no one has asked before, building new instruments to look at newly discovered mechanisms.

What they find out must be shared with the rest of the scientific community, so that time and money are not wasted 'discovering' things for the fifth time. Researchers have to publish their results. Also, being human, they'll want the world (and particularly other scientists) to know that *they* discovered the new fact or developed the new gizmo. But scientists don't just write to their local paper about it, otherwise anyone could claim anything.

Scientific journals

Instead the researcher will write a report of their findings, including their methods and conclusions, and send it to a scientific journal for publication. These are dedicated periodicals which only publish research news (and related matters such as conferences). Which journal the researcher chooses will depend on which area of science they work in, and the nature of the research. Some journals only publish groundbreaking research, and others specify a subject area (eg, the *Journal of Neurology*, or even more specific in its focus, *Epilepsia*). Not all journals carry equal prestige either. Few medical journals are household names, except possibly the *British Medical Journal*, *The Lancet*, *Science* and *Nature*.

Peer review

Peer review is the quality-control system the journals use.

Each journal sends every new research paper out for checking by independent experts in the relevant field. The reviewers ask a number of questions:

- Are the results believable?

- Are the design of the research and the methods used appropriate?
- Are the results important?
- Are the results new? Do they add to what we already know?

The reviewers will recommend that the article be published or not, or may suggest improvements to the analysis and conclusions. Not everything submitted gets published.

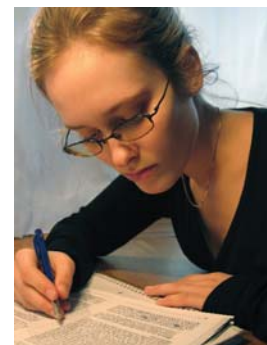
Peer review is therefore an important dividing line between scientific findings and opinion or speculation.

It's in researchers' own interests to submit their work to this searching scrutiny. Having papers published in good quality journals is a mark of prestige in the scientific field. It means a person's work is normally considered of a high standard by other scientists.

Shortcomings

Peer review can be a fairly slow process: from discovery to publication can take several months. This is used as an argument by some for bypassing the system: surely breakthroughs need to be made public as soon as possible? But if a discovery will change patient care, that's all the more reason for the results to be checked first.

Peer review also isn't designed to detect fraud and misconduct. If data has been copied or misinterpreted, then reviewers might detect this, because they know their field in depth and what has already been published. But if an author has deliberately falsified the results they report, this can't be checked until other scientists try to repeat the work independently.



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You might think that 'maverick' science is placed at a disadvantage by a system where an 'establishment' reviews all discoveries. Unusual findings are likely to be received with caution, it is true, but gifted research is likely to be recognised as such by other scientists. That's why the experts are used - they know the field after all. Journal editors like new ideas anyway, and controversy can be helpful!

So what does this mean for reading the newspaper?

You can ask one simple question about a story: is it peer-reviewed? If it is, then you know the claims in it have been checked by scientists who are experts in the field. According to the people who know the most about it in the world, the reported discoveries (and the authors' interpretation of them) are important and relevant, though typically new findings are not accepted as 'true' until they have been confirmed by independent researchers in similar studies.

The trouble is, in most short articles in newspapers, there may not be enough information to tell. The internet is a great help here! A full reference to a peer reviewed paper will include the authors' names, the title of the paper, the name of the journal, the year of publication and the volume and page details. Here's an example of work funded by the Foundation:

Scimemi A, Semyanov A, Sperk G, Kullmann DM, Walker MC. Multiple and plastic receptors mediate tonic GABA(A) receptor currents in the hippocampus. *J Neurosci*. 2005;25(43):10016-24.

A good newspaper article, while not mentioning all of this, should mention the name of the journal and the date of publication. This should be enough to find the original article, especially with the help of an online database such as PubMed (for medical articles) at <http://www.ncbi.nlm.nih.gov/entrez/query.fcgi>.

At the Foundation

Every grant we award is strongly encouraged to publish its results in peer-reviewed journals. We check the progress of publications regularly. Grant holders are also encouraged to present their results at epilepsy congresses worldwide. Every news article we now publish on our website (see <http://www.erf.org.uk/news/recentnews.htm>) is of peer-reviewed research, and will contain links to the research report itself.

Sense About Science

For more information about understanding science reported in the media, there's an outstanding website at <http://www.senseaboutscience.org.uk/>. This is run by an independent charitable trust, and carries information about other controversies and scares in the news, like genetic modification, MMR and stem cell research.

New anti-epileptic drugs on the horizon



A short article published in *Lancet Neurology* in December 2006 presented an overview of some of the new anti-epileptic drugs currently being developed.

Some are 'cousins' of drugs already in use, with largely the same chemical structures but with small, significant changes to create either greater efficacy or fewer side effects than the older drug. Others have completely new mechanisms of action. Sometimes

these are discovered by chance, sometimes by systematic screening programmes, and sometimes by deliberate chemical design, for example, making a compound to target a specific receptor.

Most of these drugs are currently in Phase 2 trials. These investigate the safety of a new drug in patients with epilepsy and its effectiveness in treating seizures. Four of the drugs are in Phase 3 trials (these are marked). Phase 3 trials compare the

new drug to the current standard treatment method. A drug can only be licensed after Phase 3 trials are successfully completed.

Drugs of the 'cousin' type currently in development include:

- Brivaracetam and seletacetam, which interact with the same protein in brain cells as levetiracetam, but more strongly.
- Eslicarbazepine, related to oxcarbazepine (in Phase 3).
- Fluorofelbamate and RWJ-333369, related to felbamate, are designed to avoid the serious adverse effects associated with the original: their breakdown process avoids a pathway which leads to a toxic by-product.
- Isovaleramide, valroceamide, and DP-VPA are related to valproic acid. They are designed to avoid the side effects seen with the original, including its potential to damage the babies of mothers with epilepsy who take valproic acid during their pregnancy.

The following drugs work in ways unlike any current drugs available:

- Lacosamide (in Phase 3) has an unknown mechanism of action. Unusually, it appears to be able to protect neurones from the effects of seizures, and may therefore be useful for treating status epilepticus.
- Retigabine (in Phase 3) acts on two potassium channels, creating a current which stabilises cells which can become over-excited, leading to seizures. This drug is structurally quite unlike any other drug in use today.
- Rufinamide (in Phase 3) has an unknown mechanism of action, but may be especially good for treating people with Lennox-Gastaut syndrome.

Other interesting compounds are:

- Talampanel, which was discovered by a targeted programme of research deliberately looking for a compound to interact with specific receptors called AMPA receptors, which are sensitive to glutamate, the principal excitatory neurotransmitter in the brain.
- Ganaxolone, which activates receptors for GABA (the major inhibitory neurotransmitter), looks promising for use in catamenial epilepsy and infantile spasms.
- Stiripentol's use is limited at present by apparently significant interactions between it and other drugs, but it has shown remarkable efficacy treating patients with severe myoclonic epilepsy of infancy, which is otherwise difficult to treat.
- Safinamide may have several mechanisms of action, and is also under investigation for use in Parkinson's disease.

Not all these compounds may ever be widely used in people with epilepsy, but they do represent hope for the 30% of people with epilepsy whose seizures are not controlled with currently available drugs.

It seems paradoxical that despite highly rational scientific programmes for discovering these drugs, many of their mechanisms of action are still mysterious. However, this is also the case for many AEDs already licensed.

Other current avenues of AED research include the influence of a person's own genes on the efficacy of drugs they take, and the development of substances designed to prevent the development of epilepsy in high-risk patients.

Epilepsy and memory



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Many people with epilepsy complain of having problems with their memory. Seizures themselves, anti-epileptic medicines, mood changes and any underlying brain condition can all disrupt memory, especially if they affect the temporal lobe, the part of the brain which coordinates the storing of new memories and the retrieval of old ones.

Disruption to the temporal lobe can affect either short- or long-term memory, or both. It can affect particular types of memory but not others. One person with epilepsy may not remember what happened last week, but clearly recall their schooldays; another may often forget specific words, but remember events well; another may keep forgetting where they're going and why.

There is a form of temporal lobe epilepsy where the main sign of a seizure is a 15- to 30-minute period of forgetting. This is called transient epileptic amnesia (TEA). This type of epilepsy mainly affects middle-aged adults. Seizures occur about once a month. People with TEA often find they forget recent memories quickly, but they also forget important episodes in their own lives, often from years before they developed epilepsy. This is called autobiographical amnesia and is an especially upsetting aspect of this form of epilepsy, affecting patients' sense of personal identity.

Researchers at the Peninsula Medical School, University of Exeter, have already carried out a series of clinical and imaging studies of 50 patients with TEA, to establish the nature of their epilepsy and the way it affects their memory. In this project, **Professor Adam Zeman, Dr Catherine Haslam and Ms Dominika Pindus** will now focus on autobiographical memory loss, in about twenty patients with TEA and twenty comparison patients who do not have TEA.

They will look at the underlying biology of the brain that contributes to this effect, and the exact nature of what gets forgotten, for example:

- Which sorts of episodes are forgotten, e.g., public or personal; dating from childhood, adolescence or adulthood?
- How quickly does this memory loss occur?
- Does the age of onset of epilepsy make any difference?
- Do any psychological or social factors predict this form of memory loss?
- Why are some memories spared?

They will also look at the effect of autobiographical amnesia on social interactions and psychological health, how TEA should be treated and how it might be prevented.

This project, entitled **The impairment of memory in epilepsy: the significance of autobiographical amnesia** is funded in collaboration with the Economic and Social Research Council (CASE Studentships programme). The Foundation will contribute **£18,000** over three years and the ESRC will contribute approximately £60,000.

We would like to thank everyone who responded to our appeal last year enabling us to support this project.

Fundraising runners

Since the summer, Foundation runners have continued their energetic fundraising for the Foundation, raising over £18,000 from the following events. Our thanks go to all for their dedication both in training and in pursuit of their sponsors!

Buenos Aires Marathon Amy Harland
Edinburgh Forthside Half Marathon Michael Swinburn
Hydro-Active Women's Challenge Susan Allen, Ranjit Basrai, Michelle Cha, Alice Fox, Helen Sawyer,



Team Xtreme at the Great North Run

Great North Run Paul Bevin, Samantha Cund, Rhonda Flanagan, Graham Hagger, Patrick Hepplewhite, Andrew King, Paul Mackenzie, Jonathan Moody, Helen Austin, Pietro Borrelli, Wesley Guy, Julie Hagger, Russell Harvey, Mark Jackson, Keith Jackson, John Johnston, Heather King, Madhumati Manjadar, Stuart Matthew, Becky Newman, Jonathan O'Dea, Patrick O'Kane, Thomas Pate, Nick Popham, Vicky Reed, Yvonne Reid, Barry Smith, Chris Spellman, Ron Spellman, Ruth Torrance, Emma Warwood, Roger Weldhen, Arron Williams, Barry Williams, Mark Woolerton

Great South Run Nicola Blake, Helen Chapman, Neil Chapman, Mark Elliott, Cathryn Fursessedonn-Coates, Heidi Harrison, Nathan Leavold, Christine MacCuish, Toby Meredith, Julie Meredith, Neil Vickers

New York Marathon Stephen Griffin, Cameron Wilson

Windsor Half Marathon Liz Hartnett, Vicki McGregor, Sarah Milne

Fundraising events

This year some of our supporters are taking on exceptional challenges to raise much needed funds for research. As well as giving their time and energy to train for and undertake these expeditions, they are covering all their own costs. If you would like to show your support by sponsoring them, please send your donation to the Foundation's office or visit their online sponsor pages at justgiving.com.



Chris Spellman

Chris Spellman is setting out on the Marathon des Sables, 'the toughest foot race on earth', at the end of March. This 6-day, 155-mile endurance race across the Sahara Desert is a real test of stamina and mental fortitude. Competitors run the equivalent of six marathons in as many days, across the most hostile sands in the world, carrying all their supplies on their back. Chris is running for the Simon Warwood Memorial

Fund. www.justgiving.com/spellmanc

Joey Mezzetti, Andy Kett, Rob Bacon, Mark Claxton and Matt Willimott are cycling from Land's End to John O'Groats for the Ellen Mezzetti Memorial Fund. They have set themselves a tough target of cycling the 1,000 mile route in just seven days, so will be covering an average of 140 miles each day. www.justgiving.com/mezzetti



Matt Willimott, Rob Bacon, Joey Mezzetti, Andy Kett and Mark Claxton

Safely returned from a Kilimanjaro summit climb are Simon Rumble, John and Matthew Smith, Roger Baker and Laurence Brown. Their arduous trek took them from dense jungle to the icy summit of Kilimanjaro at 19,341 feet. Our thanks to the team for taking on such a tremendous challenge and raising a magnificent £15,118 for research.



The Jade Cronshaw Memorial Fund continues to be strongly supported by Jade's family, friends and local community. Their annual charity night raised £500 and Chipping Young Farmers donated £500 from carol singing and other events. The Insurance Broker made a donation of £500 instead of sending Christmas cards to their customers, and staff on Ward D at Blackpool Victoria Hospital donated £85 instead of sending each other cards. Further donations following the LUMPS '20 mile, 20 pub' walk brought the grand total raised from the walk to £8,210.

Tamsin Cummings' family and friends gathered together on the beach in Oman to honour her memory, and generously donated over £1950 to her memorial fund.



Julian Reed presents a cheque to Foundation trustee Dr John Mumford

Family and friends of Kasia Gonzalez held another strongly supported Swimathon at the Splash Leisure Centre, Rushden raising £3,000 for Kasia's memorial fund. The City of Milton Keynes Masters Swim Team donated £750 in memory of Louise Dempsey from their Masters Swim Meet.

The John Morton Memorial Fund received £1062.40 as a co-beneficiary of a charity golf day at St Thomas' Priory Golf Club, Rugby. Thanks to all involved.

Thanks to the generosity of Le Creuset and their employees a further £2247.50 has been contributed to the Samantha Pennicott Memorial Fund from 'le Tour de Store' cycle ride.

Our thanks to Stan Quinn, Brenda Lennox and supporters in Lytham St Anne's for organising a charity football match and 4 Piers sponsored walk to raise over £2,500 for the Jane Quinn and Natalie Walmsley memorial fund.

New donation form

You will have noticed that we've replaced the donation box that used to occupy this corner with a separate form. We've done this for two reasons. Firstly, as ever more people are supporting the Foundation, we have been struggling to find room on the back page to thank them all. Secondly, cutting out the old form meant losing whatever was printed on the reverse. We hope, therefore, that the new form is more convenient for anyone wishing to make a donation.

Our thanks to West 4 Harriers for their donation of £500 following the 2006 Fuller's Thames Towpath 10.

Well done to pupils at the Hundred of Hoo School, Rochester for donating £546 following a concert they organised in memory of Shanice Chrystie. Mountain Lane Primary School once again chose to support the Foundation at their Christmas Carol service with a generous collection of £245 for research.

Alec and Pippa Horn dipped their feet and tandem wheels in the Pacific Ocean at the end of a sponsored coast-to-coast cycle across the USA, raising £650 for research.



Sally Davis asked family and friends to make donations to the Foundation in lieu of buying her Christmas presents, resulting in donations of £130 for our work. By making cards for all occasions and selling them to family and friends Mrs Loach was able to donate £130.

Matched funding from your employer is an excellent way to increase the value of individual fundraising efforts. The £201 raised by Jane Head from her entry in a Ladies Driving Challenge was matched by Barclays' Community Programme giving a total contribution of £402. Following the Mili jewellery sale, Lindsey Henry donated £430 from commission on sales.

Our heartfelt thanks go to all our supporters for their generous personal donations and their enterprise and effort in raising funds for research. All donations are valuable to us whatever their size. Every pound you raise helps to increase the amount of research we can fund.

In memoriam donations and bequests

Since the last newsletter new memorial funds have been set up in memory of Peter Blayney, Catherine Ann Jarvis, Debra Leonard, Carl Newell-Hill, Helen Richardson and Richard Shimell.

Donations have been received in memory of:

Katie Almond, Audrey Ashworth, James Atkinson, Nicola Bassey, Jonathan Bevan, Beryl Billet, Joan Brailsford, Alexander Buckman-Drage, Jamie Chivers, Dennis Cole, Mark Collins, John Cosens, Jade Cronshaw, Tamsin Cummings, Nathan Darragh, Roby Jay Dowry, Wayne Duffy, Kevan Elliman, Ian Ferguson, Sarah Fogg-Elliot, Kasia Gonzalez, Catherine Jarvis, Daisy Jefford, Evelyn Keating, Tania Knight, Stephen Lang, James Latham, Pearl Lovett, Joyce Mannion, Edith Matthews, Ellen Mezzetti, Jake Morgan-Hewer, John Morton, Rosa Payne, Brenda Mary Peck, Samantha Pennicott, Mr Perry, Rebecca Potter, Jamie Powell, Jane Quinn, Michael Ruff, Mark Scotchmer, David Scourse, Carl Simon, Jill Sloan, John Sloper, Marie Smith, Katie Stallard, Jenny Sykes, Jonathan Vaughan, Brenda Walley, Natalie Walmsley, Joy Walters, Steven Webster, Graham Whitmore, Albert Wilkinson and Beryl Wright.

We are grateful to have received a bequest from Mr William J Burns.

Our thanks go to all who have chosen to remember their loved ones by supporting our research.

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