

# Epilepsy charity asks Department of Health to reconsider drug substitution plans

From January 2010 pharmacists will be obliged to substitute expensive branded drugs with a cheaper generic version. Although essentially the same, there are subtle differences in how different generic forms of a drug are made up and for people with epilepsy those differences could have a catastrophic effect.

Professor John Duncan, NSE's medical director, said, "Epilepsy is different from other conditions. A single seizure has severe consequences. It impacts on the ability to drive, employment, well being and increases the risk of injury and harm. The cost saving on the drug budget is not worth the potential harm caused and the cost of dealing with seizures."

The Department of Health's plans are part of the 2009 Pharmaceutical Price Regulation Scheme. NSE's communications manager Amanda Cleaver said, "The Department of Health appears not to have consulted with patient groups on this decision. As the UK's leading medical epilepsy charity our message is clear – anti epileptic drugs must be exempt from the scheme." NSE has submitted to the Department of Health recommendations from a round table discussion with key representatives from the pharmaceutical industry who unanimously agreed with NSE's stance. The full report and recommendations can be found at [www.acnr.co.uk/epilepsy](http://www.acnr.co.uk/epilepsy)

## Tell us what you think

Do you agree that epilepsy drugs should be exempt from the 2009 Pharmaceutical Price Regulation Scheme?

Take part in our 10-second survey on the website at [www.acnr.co.uk/epilepsy](http://www.acnr.co.uk/epilepsy) or email your comments to [Rachael@acnr.co.uk](mailto:Rachael@acnr.co.uk)

## The NSE's letter to the Department of Health

Andy Burnham MP, 10 Market Street, Leigh WN7 1DS  
July 20 2009

Dear Mr Burnham  
Re: generic substitution

I am writing to you in response to the 2009 Pharmaceutical Price Regulation Scheme and the proposal of generic substitution from January 2010. As far as I am aware, there has not been any discussion with patient groups regarding this decision. As Chief Executive of the National Society for Epilepsy I would like to highlight to you the particular issues which face people with the condition. Epilepsy is different from other conditions. A single seizure has severe consequences. It impacts on the ability to drive, employment, well being and increases the risk of injury, harm and death. Adverse side effects can also have a high impact on day to day living. The cost saving associated with generic substitution is not worth the potential harm caused.

Anti-epileptic drugs have a narrow therapeutic index – differences between the minimum toxic concentration and the minimum effective concentration are slim. As the UK's leading medical epilepsy charity we recently initiated a round table discussion with leading pharmacists, pharmaceutical companies and representative bodies to gauge industry views on this important topic.

The unanimous message from that meeting is that anti-epileptic drugs should be exempt from the scheme. Tick in, or tick out, options on prescriptions, which I understand have been suggested, are simply not clear enough.

Enclosed are key points for consideration, a full report of the round table discussion and the presentations made by Professor John Duncan, Medical Director NSE, Professor Phillip Patsalos, Consultant Clinical Pharmacologist NSE and Frank Widdowson, a patient affected by drug substitution.

I have also enclosed a statement from Dr Henry Smithson, GP and Deputy Head Academic Unit of Primary Medical Care School of Medicine University of Sheffield who was unable to attend and letters from the Association of the British Pharmaceutical Industry and Beacon Pharmaceuticals who were also unable to be present.

I really hope you find this report useful. Please do not hesitate to contact me if you would like any further information and I look forward to receiving your response.

Yours sincerely  
Graham Faulkner, Chief Executive  
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## Epilepsy Action Research Grants Programme 2008-2009



Epilepsy Action invites applications from researchers and students interested in carrying out non-laboratory research into epilepsy. Research project grants, PhD studentships, postgraduate bursaries and travel bursaries are available. Researchers and students working within the British Isles, including Eire, are eligible to apply for funding.

Epilepsy Action is the largest member-led epilepsy organisation in Britain. It acts as the voice for the UK's estimated 456,000 people with epilepsy, as well as their friends, families, carers, health professionals and the many other people on whose lives the condition has an impact.

**Closing date for applications is 9 October 2009**

Further information can be found on Epilepsy Action's website <http://www.epilepsy.org.uk/research/awards.html> or by contacting Margaret Rawnsley on 0113 210 8800, email [research@epilepsy.org.uk](mailto:research@epilepsy.org.uk)

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