

Dear Colleagues

As some of you may remember from my presentation at the ESA meeting in Sydney last November, my colleagues and I have been developing an on-line research tool to determine optimal treatment for patients with epilepsy. We have conducted a pilot study in New Zealand (see below), and we are now moving to the next phase of the project. We are looking for clinicians who are interested in testing the interface. We've included some information below about the project and how to get involved, and hope that you will consider participating in the project.

Objectives

This research is driven by the view that the best way to determine the optimal treatment is through randomised controlled trials. The ultimate goal of this project is to create a culture where epileptologists will automatically seek to enter patients into randomised controlled trials where there is uncertainty regarding the optimal treatment. We want to develop a platform that facilitates investigator-driven studies.

How it works

Doctors would log on to the website whenever they are unable to determine the optimal treatment for a patient with epilepsy. The website guides the doctor through a series of checklists that would determine whether or not the patient meets the criteria for any of the randomised controlled trials linked with the project. If so, the patient would be entered into the trial immediately. If not, information would be collected into a prospective register. Alternatively, the doctor might be directed to websites for independently run research trials.

The database will store information about the patients, so that each doctor would be able to access information for any patient they have entered. De-identified information would be available for review by investigators participating in studies, and participating doctors would be able to propose trials.

Pilot study results

The pilot-study was approved by the New Zealand multiregional ethics committee and a database and website were set up. Sixteen neurologists and paediatric neurologists with an interest in epilepsy registered 137 patients on the website over six months from June to December 2007. Over 100 patients were deemed by the registering doctor to be suitable for randomised controlled trials in general. In this pilot study, patients who had failed to respond to a first antiepileptic drug were randomised to one of three alternative drugs, depending on the seizure syndrome and the drug they had previously used. Fourteen patients fulfilled the criteria for this randomised controlled trial, and were successfully randomised to a different drug.

Obviously no real scientific questions can be answered with such a small sample, but the study showed that this approach could be successful on a larger scale.

The next phase: how you can help

We have now upgraded the database and website so that it is more user-friendly, and so that it will be able to be accessed internationally. We now need clinicians in different centres and different countries to test the platform and interface. We would like to get feedback from as many people as possible so that we can make sure the system really is user-friendly.

While awaiting approval from ethics committees, participants will be able to enter fictitious patients. Entering the data should take no more than ten minutes for each patient.

If you would like to participate in the next phase of this project, or would like more information, feel free to email me at PBergin@adhb.govt.nz. I would also be happy to send you a copy of the article we published last year in *Epilepsia*, and the document we submitted to the NZ Neurological foundation to obtain the grant for this project.

With best wishes

Peter Bergin

President, New Zealand League against Epilepsy