

PARTICIPANT INFORMATION SHEET AND CONSENT FORM

Study Title: The EpiNet project; an open-ended, observational study of epilepsy (continuation of previous study; An International Pilot Study of an Internet based platform to run epilepsy trials (Epinet).

Chief Investigator: Dr Andrew Bleasel
Department of Neurology, Westmead Hospital

WSLHD Human
Research Ethics Committee

APPROVED
Date: 21.8.13

Invitation

You are invited to participate in a research study about epilepsy and seizures. In this study, information will be collected and entered into an internet database. The study is being conducted by:

Dr Andrew Bleasel, Department of Neurology, Westmead Hospital

Dr Chong Wong, Department of Neurology, Westmead Hospital

The study is part of an international collaborative study coordinated by Dr Peter Bergin, Department of Neurology, Auckland City Hospital, New Zealand.

Before you decide whether or not you wish to participate in this study, it is important for you to understand why the research is being done and what it will involve. Please take the time to read the following information carefully and discuss it with others if you wish.

What is the purpose of the study?

There are many drugs which are available to treat seizures in patients with epilepsy. Although these drugs have been shown to be effective in reducing the likelihood of seizures in patients, they do not prevent all seizures in all patients. Indeed, some drugs seem to have very little effects in some patients. Unfortunately, doctors often cannot predict which drug will work best for a particular person.

We hope to undertake studies to learn more about which of the various anti-epileptic drugs work best for which kind of seizures. This can be done by using the internet to gather information and coordinate drug studies. To do this we have created an internet based database which collects and compares participant's clinical information. This study's focus is to register participants and following them via the internet. Follow on studies can potentially use the system to arrange studies in which drugs are directly compared with one and other. Further consent will be sought if a follow on study is suitable for you.

Who will be invited to enter the study?

You are invited to participate in this study by your study doctor because you have been diagnosed with epilepsy and have seizures.

Do you have a choice?

Participation in this study is voluntary. It is completely up to you whether or not you choose to participate. If you decide not to participate, it will not affect the treatment you receive now or in the future. Whatever your decision, it will not affect your relationship with the staff caring for you.

New information about the treatment being studied may become available during the course of the study. You will be kept informed of any significant new findings that may



