

Anti-epileptic drug (AED) Withdrawal Registry

The **EpiNet** AED Withdrawal Registry is a multi-centre registry that has been established to follow patients who are discontinuing all AEDs because they are seizure-free.

We hope that it will be used to systematically record information on all patients who are withdrawing from their final AED **because they are seizure-free**. If a patient has been on polytherapy, and a drug is being discontinued, but the patient will still be taking at least one AED, the patient should NOT be entered into this registry.

We would like investigators to do the following:

- create a record for the patient in **EpiNet** in the standard way, and select "AED withdrawal registry" on the demographics page;
- record the type of seizure(s) the patient had previously experienced;
- update the record whenever the investigator sees the patient again; in particular we would like investigators to record:
 - the result of the most recent EEG;
 - whether the patient has an EEG prior to the decision to withdraw the AED, or following the commencement of AED withdrawal;
 - whether the patient has further seizures;
 - whether the patient starts an AED once again;
- update the record at least once per year.

As with all records in **EpiNet**, the individual patient data will be controlled by the person who is listed as the Primary Investigator for that particular patient (usually the person who created the record.) Each investigator will be able to extract data for their own patients at any time. However, the registry has been established so that "real-world" data from large numbers of patients can be analysed. Only de-identified data will be shared with other investigators. This de-identified data contained in the registry will be able to be analysed at various times. All investigators who have contributed patient data will be acknowledged in any publications that result from these studies.