# Enceph-IG Lay Summary Results

Autoimmune encephalitis (AIE) is inflammation and swelling of the brain caused by the body's own immune defence system. The symptoms can include sleep disturbance, autonomic dysfunction abnormal behaviour and movement, memory problems and epileptic seizures. Some patients recover completely, but in others it can cause death or severe disability from brain injury.

Autoimmune encephalitis is often treated with drugs called steroids, which reduce brain inflammation and swelling. If patients are not improving, intravenous immunoglobulin (IVIG) is sometimes also given. IVIG is an extract of many antibodies in liquid protein form produced from the blood of healthy donors.

Some doctors think that if IVIG were used from the start of AIE treatment, patients might recover more quickly and have fewer long-term effects from the illness. Whilst IVIG may help patients, it can also have side effects including blood clots or allergic reactions. It is also very expensive, and we do not know whether it truly helps recovery. The ENCEPH-IG trial (Intravenous immunoglobulin in autoimmune encephalitis in adults) looked at whether early treatment with IVIG improves recovery from AIE.

**Aims**

The aims of the trial were to:

1. Work out whether, in adults with autoimmune encephalitis, early treatment with IVIG leads to a quicker time to recovery and reduces the long-term effects of autoimmune encephalitis.

2. Carry out scientific studies to understand the way in which autoimmune encephalitis affects the brain, and how IVIG affects this.

**Design and Methods**

In the ENCEPH-IG trial, adults with autoimmune encephalitis were randomly assigned to be treated with either IVIG or with a placebo (a dummy drug of IVIG). Patients, staff treating the patients and the trial team did not know which participants received the IVIG and which received placebo. Alongside this, all the participants received the standard treatment of steroids. After treatment, participants (or carers) completed an assessment of their level of functioning in everyday life (the Glasgow Outcome Scale Extended). The time to recover the ability to live independently was compared between those who received IVIG and placebo. In addition, we collected a range of other information about their progress and recovery, as well as samples and scan images.

**Results and Discussion**

The trial was slower to recruit participants than expected, and for this reason it was stopped after 21 participants were recruited. Because of this, it was not possible to decide whether IVIG is an effective treatment for autoimmune encephalitis or not. Nevertheless, the participants who did join the trial have provided some valuable information about autoimmune encephalitis, as well as samples for further studies. We were also able to learn some important lessons about designing trials in autoimmune encephalitis, and in rare diseases in general. This will help other studies in these diseases to answer the questions for which they were designed.