

ETRAVIRINE – POSITION STATEMENT

Euro-ataxia is aware that research into the re-purposing of an HIV antiviral drug for Friedreich's ataxia (FA) has sparked understandable interest among the ataxia community. This research has shown that frataxin, the protein which is depleted in FA, is increased in cell cultures following treatment with the antiviral Etravirine¹. Whilst this is exciting research, the community should be aware that this is early stage research, which has been carried out in laboratory cell cultures. There have been no clinical trials in people with FA.

There is urgency to develop effective treatments for FA, and indeed we are actively supporting researchers to ensure FA trials take place. However, we believe that potential treatments for ataxia should be offered on the basis of the results of rigorous trials in patients that assess both the risks and benefits of the intervention. Although this treatment has been through clinical trials in HIV+ patients, it has not been formally tested in trials of people with FA yet. There are a number of potential side effects, for example, that would need to be carefully evaluated as they involve some issues of importance in FA.^{2,3} Trials to test the effect of etravirine in people with FA are currently being organised, and we are working with the parties involved to see where we can best support these efforts. At this stage we are not able to recommend that people take this medication outside of a trial.

We would strongly advise anyone wishing to pursue any treatment using medication not currently approved for ataxia to get a full clinical assessment from a specialist neurologist with an interest in ataxia before, during and after any treatment so that any safety concerns can be accurately measured as well as any potential beneficial effects. It is important to discuss dosage to be used and any potential side effects.

May 2019

¹Alfedi G, Luffarelli R, Condo I, *et al.*, Drug Repositioning Screening Identifies Etravirine as a Potential Therapeutic for Friedreich's Ataxia, *Movement Disorders*, 2019, 34(3):323-334.

2. <https://bnf.nice.org.uk/drug/etravirine.html>

3. https://www.ema.europa.eu/en/documents/product-information/intelence-epar-product-information_en.pdf