

A-T Nest inter-observer reliability and training video study



Why is this project needed?

- The neurological symptoms (problems with movement) of A-T are complex and varied. They are different from the symptoms of other conditions.
- In order to carry out effective clinical trials for drugs to treat A-T, we need to be able to measure accurately someone's symptoms before and after treatment.
- A group of international specialists has developed a scale to provide a standard neurological examination for A-T patients.
- This is called the AT-Neurological Examination Scale Toolkit (NEST).
- Before it can be used, the scale needs to be tested to ensure it is accurate and reliable.
- A training video will help ensure that neurologists use the scale consistently.

Summary:

The project aims to film 12-18 children each day undergoing an examination using the A-T NEST. We aim to recruit a wide range of patients with a wide range of abilities and scores.

The A-T Society will recruit patients, each child / young person for a half-day session at the clinic in Nottingham, in which filming will take 30 – 60 minutes.

Once edited, the films will then be used to conduct validation studies, which will test that different neurologists give the same scores to the same patients, and also that individual neurologists are consistent in how they score different people with the same level of disability.

The films will also be used to make a training video.

Status of the project:	Looking for funding
Main Researcher:	William Whitehouse, University of Nottingham
Total costs:	£12,000
Start date:	The project can be carried out as soon as funding is available