

PARROT Study Trial Management Group Meeting

13th July 2021 10:30- 12:30 on Zoom

Attendees: Sarah, Hayley, Nawal, Kirsty, Laura, Julia, Helen Eccleson, Paul McNamara, Bel McDonald, Chris Morris, Fleur Boyle

Key points:

Background: There are currently no NICE guidelines for using prophylactic antibiotics in this way. This is the biggest trial on children with neurodisability. Around 500 children are taking part in Australia and UK.

Possible side effects: Bowel upsets, build up of antibiotic resistance. This may cause concern for parents. Add to FAQs on website, parents to contribute to this. (Helen)

Eligibility: Children with a neurological condition who:

- have had one or more chest infections that have needed hospitalisation in the past year or
- are already on azithromycin, or
- have needed two courses or more of antibiotics for a chest infection in the past year.

There may be a shortage of eligible participants initially due to fewer infections recently due to lockdown.

Pandemic changes:

- Parents can now do nasal swabs at home rather than coming into hospital. Pre-pandemic: some parents appreciated coming into hospital to interact with the research team. Many children had fewer infections during lockdown. Doctors are anticipating a big increase in infections this autumn.
- The trial protocol has been amended to include video conferencing or phone calls instead of face to face visits. Children could be weighed at school rather than in hospital. Medications sent in the post from central pharmacy. There still will be a face to face visit to talk through consent process.

Promoting the Study:

- Hospitals and Community Trusts.
- Social media: Twitter and Facebook. e.g. WellChild, Together for Short Lives, Children's Hospice, Cerebra, Contact, CDC, Heartline, Disabled Childrens Partnership, Encephalitis Facebook group, Mumsnet. Facebook tends to be used more than Twitter for parent carers. Could have our own Facebook group. (Helen)

Bereavement:

- After a child dies the most important thing is to reassure parents that involvement in the trial wasn't responsible for the death. If a child received the placebo this could raise concerns. It's important to give good support.
- If there is a commemorative page, it needs to go up at the end of the trial so not to deter recruitment.

Going forward: Recruitment is due to start in September. Follow up meeting for this group in November.