

**UK JIA Biologics Register Champion** – Ellen Lacey, Children’s Research Clinical Trials Assistant, University Hospital Southampton

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Ellen is a children’s clinical trials assistant who has been working on the UK JIA Biologics Register for the last two years at University Hospital Southampton, where Dr Alice Leahy is the Principal Investigator.

Ellen’s fantastic efforts in both recruiting participants and submitting scheduled follow-ups have earned her the title of ‘Register Champion’; this highlights her commitment and impact on this long-term study.

We recently spoke with Ellen to find out how she works so effectively on this study.

### **How do you identify eligible participants?**

We have established a really positive working relationship with our rheumatology team and have monthly meetings with the nurse specialists to discuss upcoming or patients who have recently started biologic treatment. They are a great source, and will also prime families for my approach once they know treatment will be changing. I have also found that posting the family the information sheet before the scheduled appointment really helps, as they are then able to digest the information and give a quick ‘yes’ or ‘no’ to joining, or ask any further questions on the day of consent.

### **How do you keep on top of follow-up data submission?**

The follow ups can be time consuming depending on a few factors: how well established they are on treatment; whether it is IV or SC; and the number of adverse events they have contacted the team about.

More recently, I have been trying to prioritise the follow ups that are within the initial five year follow-up period, and have found scheduling allocated times for specific follow ups helpful.

### **Do you have any other hints or tips about working on the study?**

A good working relationship with the rheumatology team has been helpful. I also like to reassure families that any bloods will be done alongside clinical ones, and that their input in the study can be as minimal as they choose, which has been a big selling point to families with lots of medical appointments and potentially having different diagnoses to think about. The annual questionnaires have been able to be completed before going in for appointments and therefore not added any additional time.

**Thank you to Ellen and the team at Southampton!**