

UK JIA Biologics Register Champion – Danielle Miller
Making research a normal part of everyday clinical practice

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Danielle is an experienced children’s research nurse who has worked on the UK JIA Biologics Register for a number of years at Nuffield Orthopaedic Centre (Oxford), with Dr Kathy Bailey as the Principal Investigator at this site.

Danielle’s outstanding contributions to the UK JIA Biologics Register in both recruitment and follow-up have earned her the recognition of ‘Register Champion,’ a testament to her dedication and impact on the study’s success.

We asked Danielle some questions to learn more about her approach to working on the study.

How do you identify eligible participants?

I attend every rheumatology clinic and all of the team meetings. This means I learn about when we start new patients on biologics/switch biologics for patients who have been previously missed as soon as the decision is made. Because of this, I am able to ensure that these patients hear about the study at this point, and receive the information sheet to read. I am then able to follow them up at their next clinic appointment, meaning I can catch them within the window for consent.

I also try and utilise opportunities outside of routine clinical appointments to see the eligible patients. I am lucky enough to be able to be pretty flexible with my hours, so if a patient needs to come back to the hospital for a blood test etc. (such as a TB test prior to starting on biologics) I can often book them in with me to do that; this not only takes some of the clinical pressure off, but also allows the family to choose a time and date that works well for them – which may not be possible when booking through the standard service. I use that time to talk to them about the study.

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

As I attend each clinic and meeting, I am able to check and plan to see if a follow up is due. I like to keep the amount of work the rest of the team needs to do for research to a minimum, as they are all already so busy with the clinical demands of the service. As I am there in clinic, I can ensure that any relevant paperwork is given to the families, and patients remain happy to be in the study.

When it comes to the data, I usually check on the database about once a week to enter all the outstanding visits I can as soon as the doctors have written their letters with the relevant information I need on it.

I love the filter options on the database, which allows me to quickly go through all the outstanding visits, and check against our records to see if a patient has had a recent visit and the letter is written.

For me, the biggest thing that makes a difference is having the doctors who see the patients document the core data as part of their routine clinical assessment (which all of the consultants here at Oxford now do). This means, even if I'm not able to come to a clinic for some reason, the data is still available for me to do my data entry from.

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

I have been working in research for over a decade, and with this team for 8 years. Over that time, I have tried to make research an integral part of the service, and not something separate that happens and creates more work for everyone. I am very passionate that every child eligible for any study has the opportunity to take part in research, if they wish to.

All of the team know what studies we have and know to tell me when a patient is eligible for a study so I can approach them, if they haven't already been highlighted as eligible in one of the team meetings.

We're quite lucky here that the rheumatology team has a dedicated research nurse, which means making sure all the rheumatology studies run smoothly is pretty much my entire job. I can be there in clinics and at meetings to keep research part of our team's practice.

This is pretty much the biggest tip I can give - having research be a normal part of everyday clinical practice.

Thank you to Danielle and the rest of the team for all your hard work!