Welcome to our autumn newsletter. Time is flying, I can’t believe that it is already the end of October and the year is nearly over. Let’s look back at what has happened in the study during the last 4 months. After a long wait we finally rolled out amendments 7.0 and 7.1 on the 26th August 2015. Cimzia is now an eligible drug, recruitment has been extended until December 2016 and follow-up until December 2017. During the summer months recruitment was exceptionally poor, partly because of the holiday season and partly because many sites have now approached all existing patients at their sites. To boost recruitment again, we have taken on a few new sites. I would like to extend a warm welcome to our new sites: the rheumatology teams of The Pennine Acute Hospitals NHS Trust, Peterborough and Stamford Hospitals NHS Foundation Trust, University Hospital of South Manchester NHS Foundation Trust, Royal Liverpool and Broadgreen University Hospitals Trust and Luton and Dunstable University Hospital NHS Foundation Trust. We are hoping for another 6 sites to join us before the end of December.

In this edition of the BSRBR-AS newsletter, we have much pleasure in including a summary of the first results from the study.

Claudia Zabke
Study Coordinator

First Cimzia Patient

We are very happy to report that the first Cimzia patient was recruited in sunny Scotland by the NHS Fife Spinal clinic team, shortly after the amendment was rolled out.

In the picture from Left to Right
Stephanie Heart, Rheumatology pharmacist
Paul Alcoat, Research Nurse/Rheumatology Specialist Nurse
Jane Gibson, Rheumatology consultant (clinical Lead)
Sarah Hailwood, Rheumatology consultant
Paula Dowie, Highly specialised Physiotherapist
We now have 81 centres with research governance approval, of which 71 have recruited at least one patient. 8 centres are open to recruitment but haven’t recruited just yet and 1 centre has some start up actions outstanding before getting the green light for commencing recruitment.

⚠️ Please keep trying hard to identify patients for the register in order that we can reach our targets.

Quarterly recruitment certificate winner 🌟

The “top recruiters” certificate for the quarter, July to September 2015 goes to the team at the Robert Jones & Agnes Hunt Orthopaedic Hospital in Oswestry. Congratulations!

Runners-up were Wolverhampton in second place and Newcastle in third place.

Output

The first data from the study were presented at BSR2015! The poster is available online at http://www.abdn.ac.uk/iahs/research/epidemiology/outputs-111.php

For this newsletter Dr Maxwell S Barnish (BSRBR-AS Study Analyst) has produced a summary of the first results from the study. We have been looking at how patients who are prescribed anti-TNF therapy (Humira or Enbrel) differ from those who are not, in terms of their demographic and clinical characteristics. Initially, we have analysed all baseline data that were made available to us in May 2015. Data from 1234 patients were available, 74% were men and the median age was 50 years. We found that patients starting anti-TNF therapy were on average, younger, had greater inflammation (CRP), poorer Bath AS Global Score, poorer general physical health (SF-12 physical score) and lower BMI than those not starting such therapy. Interestingly, BASDAI score, the central tenet of the NICE guidelines for anti-TNF prescription, did not predict whether or not patients were prescribed anti-TNF after the clinical factors listed above were taken into account.

Maxwell has been invited to give an oral presentation of this work at the Scottish Society for Rheumatology meeting in Aberdeen on the 30th and 31st October 2015.
DATA

Analysis is now underway and we want to emphasise how important data completeness is.

Baseline questionnaire return rates
- Overall baseline return rates are 78% for non-biologic patients and 68% for biologic patients.
- This means that for about ¼ of our patients baseline questionnaires are not returned.
- This makes the usefulness of the data for these patients very limited.
- If possible, patients should fill in the baseline questionnaires at clinic.

![Tip] Please review your procedures and try to persuade patients to complete baseline questionnaires at clinic.

Remember the usefulness of the study results are linked to the quality of the data.

Clinical follow up data
- We will soon be starting to analyse follow up data. Please make an effort to complete all scheduled follow up visit information for your patients, on the database at 3, 6 and 12 months, then annually for biologic patients, and every 12 month for non-biologic patients. If visits didn’t take place in the allocated time frame (+/-1 month) please record as an unscheduled visit.

Biologic start dates
- Please enter biologic start dates as soon as possible after the patient has started biologics. We began chasing sites with patients whose “intention to start biologic” was older than 6 months and it turned out that quite a few had started biologics without us knowing about it. Consequently we missed sending out 3 and 6 month questionnaires, and these data are now missing from the dataset.

Contact us
If you have any question or comments about the study please do not hesitate to contact the project team.
Email: bsrbr-as@abdn.ac.uk  Tel: 01224 437141
Web: http://www.abdn.ac.uk/iahs/research/epidemiology/spondyloarthritis.php
The map above shows all of our recruiting sites. You can see the different sites and the number band they have recruited within.

If you want to have a better look and see the actual numbers you can view the interactive map by pressing the Ctrl key and clicking here.