



January 2013

Scottish Early Rheumatoid Arthritis (SERA) Inception Cohort and Biobank NEWSLETTER

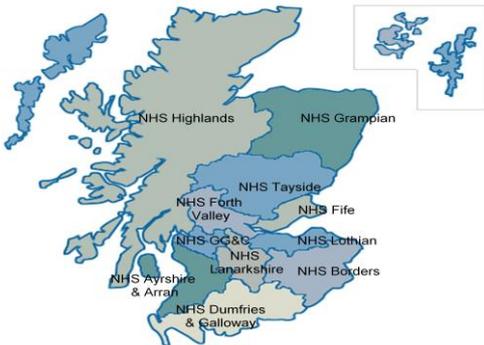
Welcome to our first newsletter for people taking part in the Scottish Early Rheumatoid Arthritis (SERA) study. We are very grateful to you for helping make this project a success. We hope that it will provide some answers to help in the fight against arthritis. We have made a great start to the project – more than 650 patients have signed up to take part, and we have more than 20,000 samples in the biobank. Researchers are already starting to use these to look for clues about why people suffer from arthritis, why the response to treatment varies, and many other questions.

We still need your help, though! In particular we are keen to find first degree relatives (parent, brother, sister, child) and friends (same sex and age, approximately) of patients, who would be willing to take part too. It would involve one study visit, time to fill in some questionnaires and a blood sample. Would you mind asking around your friends and family to see if anyone would like to help? Details on how to volunteer are outlined later in the newsletter.

Thanks!

Dr Duncan Porter (SERA Chief Investigator)
Consultant Rheumatologist,
Gartnavel General Hospital, Glasgow

NHS Boards



20 sites throughout Scotland are participating in the creation of this unique research resource

NHS Ayrshire & Arran - Ayr Hospital, **NHS Borders** - General Hospital, Melrose, **NHS Dumfries & Galloway** - Royal Infirmary, **NHS Fife** - Whytemans Brae Hospital, **NHS Grampian** - Aberdeen Royal Infirmary, **NHS Greater Glasgow & Clyde** - Gartnavel General Hospital, Glasgow Royal Infirmary, Inverclyde Royal Hospital, Royal Alexandra Hospital, Paisley, Southern General Hospital, Stobhill Hospital, Vale of Leven Hospital, Victoria Infirmary, **NHS Highland** - Raigmore Hospital, Inverness
NHS Lanarkshire, Hairmyres Hospital, Monklands DGH, Airdrie, Wishaw General Hospital, **NHS Lothian** - Western General Hospital, Edinburgh, **NHS Tayside** - Ninewells Hospital, Dundee, Perth Royal Infirmary

Thanks to your participation we have been able to recruit 650 study participants.

The samples and information you have donated will undoubtedly give us a better understanding of rheumatoid arthritis.

While it is always wonderful to welcome new participants into the SERA study it is equally important to continue to collect follow-up information from existing study participants, as this gives us a good picture of how your arthritis changes over time.

Can we ask you to remember to notify your study nurse of any change of address so that we can continue to follow you up and keep you posted of our progress via newsletters.

SERA AIMS

We would like to remind you of the main aims of SERA and just how important your individual contribution is in helping us achieve our goals.

- to recruit patients with arthritis as soon as possible after their diagnosis. This may give useful clues about why some people develop arthritis
- to find out how our patients respond to treatment over the next few years, and how their life and health is affected by having arthritis
- to collect samples of blood and urine that will allow 'cutting edge' scientific research into rheumatoid arthritis

What happens to my samples?

We thought that you might be interested to know what happens to your samples after you leave the clinic.

Shortly after collection some of the blood and urine samples are spun in a centrifuge. This is to separate the cells in the samples from the fluid which is then transferred into transport tubes. This step prepares the samples for the journey to the SERA biorepository. The samples are placed into a chilled shipment box and taken by courier to the SERA laboratory.

Upon arrival at the SERA laboratory, the samples are checked in to the sample management system and then divided into smaller portions and placed into uniquely bar-coded vials.



These barcoded vials are then placed on a plate and scanned into an inventory system which logs all samples and gives each a unique placement position.



The registration of each sample entering the biobank is centrally stored on an information management system and backed-up on secure servers.

Each samples physical location is recorded to allow audit and retrieval of specimens. This sample storage system de-identifies samples thus protecting the privacy of donors.



Samples are then stored within one of the minus 80°C freezers.

Use of the SERA resource

The real value of SERA will be realised once researchers use and analyse samples and data stored within the resource. Researchers wishing to analyse SERA data and/or samples must submit an application which will undergo review by the SERA Scientific Committee. The SSC comprises of academics and lay members (including four volunteers who have arthritis).

Decisions about granting access to SERA resources will be made by the Scientific Steering Committee who will apply a standard set of criteria to assess applications.

Applications which pass the approval process must then complete an agreement for access to data and samples prior to release of the resource. It is important to remember that we will NEVER disclose identifiable personal information to anyone!

We will keep you updated on any publications arising from the use of the SERA resource by posting details on the SERA website.

STUDY NEWS.....Can you diagnose RA from a urine sample?

Maybe... We have analysed samples from SERA study participants to see if urine can help us to diagnose RA and our results are promising.

We compared urine which 50 of you left when you joined the SERA study, with urine from 50 people who did not have RA. First we analysed the urines by capillary electrophoresis coupled mass spectrometry. This method identifies tiny protein segments in the urine called peptides. We then looked at differences in urine peptides in the two groups and found 195 differences. Some peptides were more and some were less common in the urines from you with RA.

Although these results are provisional they are exciting. They suggest that these 195 peptides could be used to diagnose RA.



This would be useful as it is sometimes difficult to make a diagnosis of RA at an early stage of the disease. There is also the possibility to make analysis with clinical information gathered as part of the SERA study, and we could also look closer at what peptides are different and see if this can help us better understand RA.

The next step, however, is to apply for funding so that we can analyse urine samples from all (650+) of you to confirm that urine peptides can be used to diagnose RA.

We are mindful that we can only carry out this work thanks to the samples you so generously donated – thank you !

SERA Group Meeting

In February we will hold the first SERA Group meeting bringing together the rheumatologists, nurses and scientists who are all part of the SERA team.

We will be updating the group on the progress we've made so far with establishing the SERA resource and will discuss the ideas and opportunities for future research.

We hope to be able to give you an update on this meeting in the next Newsletter.

Keeping you informed

We are already starting to analyse some of the samples within the SERA resource.

This research could not be undertaken without the data and samples you so generously provided and we would like to keep you informed of any findings for research arising from use of SERA samples and data.

We plan to do this through an annual newsletter and also post regular updates on the SERA website which is part of the SCAR website.

<http://www.scarnetwork.org/research/sera/>

Getting to know your SERA team.....A day in the life of a SERA research nurse!

Hello, I'm Maureen Todd, one of the SERA research nurses. I have been working on the SERA project for one year covering Glasgow, Clyde and Lanarkshire which involves 11 hospital sites and am thoroughly enjoying working on this study. Before SERA I worked in paediatric rheumatology research and was delighted to be offered the SERA post and stay within rheumatology.



One of the things I love about my job is that it is so varied. If there are no study visits scheduled in my diary I will attend one of the clinics to promote recruitment and keep the doctors up to date with any changes to the project. In some of the sites we are able to see a patient for a study visit at the same time as their clinic visit, if they are able to stay on for the visit, but generally we make an appointment for them to return for the study visit. Outwith clinic times the doctors will email me referrals either directly or via their secretary.

Some days I can spend a fair amount of time driving between sites depending on where my visits are. I can have days when all my visits are in the same place and other days where I am racing between three different sites to see our study participants. This means my days are extremely varied which I think allows for a more interesting and enjoyable work experience.

Despite working full time on SERA, I am trying to complete an MSc by Research at Glasgow University on Musculoskeletal disorders in children with Down's syndrome, I enjoy being involved with the Glasgow amateur theatre circuit, I sing in a band and on top of that have 2 small children, a husband and a dog to keep in check. I do like to keep busy!

Help us enhance the SERA resource – we need your HELP again!!

Over the past 18 months, our efforts have mainly been directed at collecting data and samples from study participants. We would now like to expand the SERA resource and collect data and samples from people who do not have rheumatoid arthritis. These volunteers would act as control cases and would include first degree relatives (your parent, child, sister/brother) and friends of the same sex and who are within 5 years either side of your age.

The data and samples collected from control cases are extremely valuable to researchers because they can be compared to patient 'cases' to look for genetic and other differences, such as lifestyle, that affect disease risk.

If you have a first degree relative or friend who would like to contribute to building this research resource, our project team would be delighted to take their call, answer any questions they may have and hopefully arrange an appointment. **PHONE 0141 330 7655 or speak to your SERA nurse**

Participation involves one short visit to complete some questionnaires and donate some blood and a urine sample. Travel expenses are also available.

We have SERA clinics Scotland wide, so even if your relative or friend lives outwith your Health Board area, they can attend one of many SERA sites listed on page 1 of the newsletter.

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THANKS FOR YOUR SUPPORT

