



Welcome to the first patient newsletter of the BSRBR-AS.

As we draw to the end of our second year of recruitment I am delighted to say that more than one thousand patients with Ankylosing Spondylitis (AS) or axial spondyloarthritis have agreed to join the register. This means that already there are enough patients in the register for us to begin our analysis to understand important issues for patients. As you will read below, Debbie Cook from NASS has been helping us to identify what are the priority research questions we should tackle. This includes identifying the major influences on quality of life, understanding the factors enabling patients to stay in work and determining whether biologic therapy improves fatigue to name just a few. In 2015 we will begin to look at the information you have provided but in order for us to have enough data to answer these questions it is really important for us that you continue to return the follow-up questionnaires. In future newsletters we hope to be in a position to share these results with you. If you would like to provide any feedback to us or have any questions, please drop an e-mail to bsrbr-as@abdn.ac.uk or call 01224 437141 and ask for the BSRBR-AS team.

Meanwhile I would like to thank you for your willingness to take part in the study and wish you a Merry Christmas and a Happy New Year.

*Professor Gary J Macfarlane
Chief Investigator*

Debbie Cook CEO from NASS

(National Ankylosing Spondylitis Society)

NASS is delighted to hear that the BSRBR-AS has recently recruited its 1,000th patient. This register plays a vital role in understanding AS on a wider scale. It has the potential to have a huge impact and play a vital part in future research into AS.

Recently I attended a Study Day with many AS clinicians and the Register team at Aberdeen and was given the opportunity to present on the NASS Research Priorities 2013–2018 paper which has been produced as a result of wide-scale consultation with AS patients and Health Care Professionals (HCPs). It was heartening to see that the team working with the register at Aberdeen and other colleagues were very keen to listen to patient views about research and use the register to progress some of the research proposals which are much needed in AS.

I am personally delighted with the work of the register and wish to thank all members of the BSRBR-AS Team and indeed all the HCPs across the UK who collect and input data to the register to enable us understand AS better in the future; their hard work and dedication is much appreciated.

For more information on NASS please visit:

www.nass.co.uk



