Dear

INSERT YOUR NAME, ADDRESS and POSTCODE HERE

As a member of your constituency I am writing to you to bring to your attention a new All Party Parliamentary Group that the National Axial Spondyloarthritis Society (NASS) has established to help raise the profile of axial spondyloarthritis (axial SpA) including ankylosing spondylitis (AS) and support improved outcomes for those, like me, affected by these conditions.

Derek Thomas MP (Conservative, St Ives, West Cornwall and Isle of Scilly) and Lord Campbell-Savours (Labour Life Peer) have agreed to co-chair the group. Other Officers are: Rupa Huq MP (Labour, Acton and Ealing Central), Andy Slaughter MP (Labour, Hammersmith), Kerry McCarthy (Labour, Bristol East).

As you may be aware, axial SpA (AS) affects approximately 1 in 200 members of the adult population in the United Kingdom and has an average age of onset of just 24 years of age. A quarter of patients with axial SpA (AS) will develop complete fusion of the spine, while 50 per cent experience inflammation and damage to other parts of their body, particularly the skin, eyes and gut.

One of the key challenges for those with axial SpA (AS) is achieving early, accurate diagnosis. Unfortunately, however, this does not currently happen on a regular basis. There is an average delay of 8.5 years between the onset of AS symptoms and diagnosis for instance, and during this time the condition, and symptoms experienced, can deteriorate considerably. In my case, it took <number> years before I was diagnosed with axial SpA (AS). I cannot tell you how significant it was for me to finally receive my diagnosis – I could then learn how to live and work with my condition.  Despite the significant number of people affected by axial SpA (AS) – it is twice as commons as multiple sclerosis – awareness remains low, and healthcare professionals do not always recognise their signs and symptoms.

Whilst there are clearly a number of long-standing issues in the area, the recent publication of the first ever NICE Guideline for Spondyloarthritis (SpA) and supporting Quality Standard provides a unique opportunity to address these challenges and help ensure that those with SpA conditions receive the support they need. From previous experience, however, we will only be able to achieve improved outcomes if the guidelines are championed and commissioners and service providers receive the support they need to implement them successfully.

[You can read more about the APPG for Axial Spondyloarthritis, including upcoming activities here.](https://nass.co.uk/get-involved/campaign-with-us/appg/)

**I do hope that you will consider being a member of the APPG**. To share your interest, or for any further information in the meantime, please feel free to email me and Jill Hamilton at NASS on jill@nass.co.uk. The next meeting will take place on 29 January 5pm to 6.30pm in Portcullis House.

I look forward to hearing from you.

Yours sincerely,