



# The All Party Parliamentary Group on Skin

58-60 Kensington Church Street, London W8 4DB  
Tel: 020 7368 1611



## Meeting of the APPGS, Tuesday 8<sup>th</sup> November

### Speakers

Sir Paul Beresford MP (SPB) - Chair, APPGS

Helen McAteer (HM) – Chief Executive, The Psoriasis Association

Dr Sandra McBride (SMB) – Consultant Dermatologist at the Royal Free Hospital

Claire Strudwicke (CS) –Patient Representative

### Minutes

SPB welcomed everyone to the meeting and introduced the speakers.

HM thanked the Chair and the group for hosting the meeting. She then provided an explanation of the Psoriasis Area and Severity Index (PASI) initiative and background to the PASI survey. She said the reason for carrying out the survey was to increase awareness of psoriasis and the PASI assessment tool.

DMB provided a brief overview of psoriasis and its effects. She asked members of the group how the disease effected peoples' lives. DMB agreed with members that the psychological effects of the disease could be just as debilitating as the physical effects. The impact on employment and relationships was discussed. DMB said it was common for sufferers to miss over 3 weeks of work a year, and that fear of public discrimination often prevented sufferers from taking part in certain public activities such as swimming or going to the beach.

DMB said attempts had been made to measure the psychological impact of psoriasis. She pointed out a graph, which used the Cumulative Life Course Impairment (CLCI) measurement. The graph showed how the life trajectory of a psoriasis sufferer could be blown off course as time progressed. SMB said due to the anecdotal nature of the evidence, this was not something you could put a figure on; however the purpose of the study remains the same - to try and normalise the average life trajectory of a psoriasis sufferer.

DMB briefly explained the significance of the PASI scoring system and its significance.

HM presented the results of the survey, which had over 670 respondents. One of the key findings was that both PASI, and the DLQI (Dermatology Life Quality Index) assessment tool, were being used at secondary care level, but there was no consistent frequency at which they were being used at a primary care level. 21 percent of patients were aware of PASI and 8 percent were aware of DLQI. 16 percent had been measured using the PASI and 9 percent with the DLQI (81 percent had not been measured with either tool). 84 percent had not had their physical symptoms measured, and 91 percent had not had their life impact measured.

HM said patients were using their results in different ways and were, in some cases, not making the most of them. Another key finding was the lack of knowledge surrounding the PASI and DLQI. 81 percent of respondents said they would be willing to have their PASI measured once they knew what it was. The results also suggested that patients who had had their PASI/DLQI measured would be willing to do so again.

Vat Registration No: 731 2849 39

Patient Advisor: Ray Jobling

Clinical and NHS advisers: Professor Irene Leigh, Dr Tim Mitchell, Dr Colin Holden, Professor Christopher Bunker,

Nick Evans, Christine Clarke, Dr Julia Schofield

Administrative Secretary: Berkeley Greenwood



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HM said that the areas with the lowest PASI awareness were Northern Ireland and the East Midlands. The highest levels of awareness were seen in London, South Central and the North East. She said that this is something that must be improved.

CS then described her personal experience as a patient. She said GP training in psoriasis was terrible and from her own experience, doctors tend to, quite literally, keep their distance from patients, causing further distress and upset to the patient.

SPB thanked the speakers and opened up a brief question and answer session.

The speakers concluded that more GP/patient education was needed, especially in terms of available treatments. HM said health professionals need to be encouraged to keep a record of psoriasis severity. Group members agreed it might be a good idea for the APPGS to revisit the psychological effects. SPB suggested tabling a debate in the Commons as a possible way forward (HM and SPB to liaise on this).

SPB thanked everyone for attending and called an end to the meeting.

**Mark Johnson**  
**November 2011.**