



**All Party Parliamentary Group on Skin
Parliamentary Meeting**

**Tuesday 28th February 2012
House of Commons, Committee Room 16**

Speakers:

Sir Paul Beresford MP, Chair, APPG

Mandy Aldwin, founder trustee of the Ichthyosis Support Group (MA)

Gemma Borwick, Learning and Development Manager, Changing Faces (GB)

Dr. Carole Easton, Deputy Chief Executive of Changing Faces (CE)

Prof. Andrew Finlay, Former President of the BAD and Former Head of Cardiff University's Dermatology Department (AF)

Parliamentary Members Present:

Jim Dobbin MP (Lab, Heywood and Middleton)

Baroness Masham of Ilton (Cross Bench)

Minutes

The Chair welcomed everyone to the meeting and introduced the speakers.

1. An introduction to the psychosocial needs of patients with skin conditions

GB began by describing the many different psychological effects of skin diseases. These included depression, anxiety, low self-esteem, embarrassment, fear of open and/or public spaces, feelings of hopelessness and isolation. She said that much of the literature in recent years pointed towards a link with lifestyle choices; feelings such as embarrassment and depression for example could cause serious damage to personal and professional relationships. A fear of public places could prevent a patient from taking part in social activities, and low self-esteem could significantly hinder career progression.

She said the slightest thing could trigger an emotional response. For example a patient with psoriasis of the hands may feel uncomfortable shaking hands with a stranger or exchanging money at the supermarket. An everyday task could be turned into a desperate struggle.

GM said skin conditions were often exacerbated by stress, which in most cases led to more stress, causing a vicious cycle.

In conclusion, psychological care needs to be integrated and there is an important role for all members of the Multi Disciplinary Team to meet patients' needs. In addition, there is an urgent need to address the funding gap between skin cancer and other skin conditions; the latter has received far less attention from policy makers in Government.

2. The personal experience

MA began by describing the nature of her condition (ichthyosis). She explained the difference between mild ichthyosis (1 in every 250 people – treated easily) and severe ichthyosis (rarer and much more debilitating). She said it was a genetic disorder with no cure.

MA explained how hard it was living with the psychological effects of ichthyosis. She said the public often confused ichthyosis with severe sun burn. This lack of awareness would often prevent a sufferer from going to school/work/social events, which would in turn limit the number of opportunities available to the sufferer.

She said the slightest change in lighting conditions often made her feel self-conscious about her image. The fact that the condition affected you head to toe ruled out the possibility of simply covering up. Skin would shed often, which in turn affected the clothes you wore, and personal relationships were often hard to maintain. Aside from questions of image, the pain was often enough to affect your day-to-day decisions.

In conclusion, she said raising awareness of the condition would help alleviate some of these problems but sufferers also needed help managing their condition on a day-to-day basis.

3. Work carried out by Changing Faces

CE described the work carried out by Changing Faces. She said the organisation was set up 20 years ago to help adults, children and families cope with differences in physical appearance. The organisation's main office is based in London with various offices in the English regions and the British countries and more plans to expand locally.

She said Changing Faces provided a toolbox of support mechanisms. These support mechanisms included self-help guides, group workshops, professional training and one-to-one consultations. Changing Faces also worked with employers to provide guidance, support and education.

She said Changing Faces was in the process of launching a campaign, of which the first phase is aimed at gathering evidence and raising awareness of psychological effects of skin conditions amongst health and social care professionals and commissioners. She said it was Changing Faces' aim to see psychological effects included in future quality standards.

Q and A Session

GB and CE were asked if Changing Faces educated at an undergraduate level. CE said Changing Faces had done some work but it was often hard to engage at this level. GB said dermatology training/coverage at a university level depended very much on the university.

Jim Dobbin MP acknowledged the fact that awareness was lacking. In order to tackle this he said it might be a good idea to hold a dinner with MPs present. The Chair said the APPGS had tried encouraging patients to write to their MP with mixed results – he said a dinner was certainly an option worth considering. He also said a debate in the House might well be an option – followed by another meeting.

ACTION POINT: The APPGS to explore potential follow-up activities.

Some members of the APPGS voiced their discomfort at hearing the word 'disfigurement' throughout the meeting. CE said Changing Faces was aware that it needed to be sensitive about the use of such language. GB said that Changing Faces endeavors to limit the use of the term disfigurement and prefers to use the name of the condition as much as possible.

4. Measuring the psychological effects of skin diseases

AF began by explaining his background in dermatology. He said that whilst he was at Cardiff University, measurement of psychological effects was a key area of his work.

He said skin diseases could affect a person's ability to work, study, and/or socialise. It could prevent them from going to the shops, from going to the beach, or from taking part in sporting activities. Indeed, given the scale of their impact, they could be likened to the effects of major medical conditions.

He said there were a number of methods available for measuring these effects. For instance, the Dermatology Life Quality Index (DLQI) questionnaire (developed in 1994) was designed specifically to measure the psychological impact of skin diseases. The questionnaire could also be modified for children and adolescents.

In conclusion he said the psychological effects of skin diseases could not be ignored. Their impact was too great to pass off as a secondary concern.

Conclusion

The Chair asked if any of the members had any comments.

Several members said they were concerned that the NHS was failing in its duty to provide robust and efficient dermatology services. The Group agreed psychological effects of skin diseases were not high on the agenda for many health professionals.

Adding to this point MA said that when she was twenty years old she did not attend a job interview with British Airways because of the severity of her condition. She said many people like her had lost out on key opportunities because of their condition.

The Chair thanked everyone for coming and called a close to the meeting.