

Caring for a global problem

Rosemary Humphreys reports on the recent International Symposium on Atopic Dermatitis in Japan.

A chance conversation with Margaret Cox in January ... emails from Nottingham and Brazil in March ... and in May I was at Heathrow waiting for a flight to Japan. The 5th International Symposium on Atopic Dermatitis included a meeting on the Organization of Care arranged by a Brazilian Dermatologist, Dr Roberto Takoaka, to discuss better support for patients. I was to be the patient speaker.

After an uneventful flight and a train from Osaka to Kyoto, the conference venue, I met up the following morning with Roberto and his two colleagues, Valeria and Raquel. We compared notes about patient support groups in our countries. The Brazilian association has eczema support groups in eleven cities, but they are led by health professionals rather than patients, unlike the National Eczema Society. They were impressed with the NES leaflets and copies of Exchange I had taken with me. I loved the Sao Paulo group calendar they gave me. The children had drawn pictures of what they wanted to be when they grew up – everything from a ballerina to a fireman – and their eczema wasn't going to stop them!

Professor Hywel Williams of Nottingham chaired the meeting. He and I were the only British members (and I was the only lay person), but there were seven other nationalities. We started by reading the poem 'My **AD**orable Son' (**AD** for atopic dermatitis) in several languages. The poem crystallises the anguish of the mother of a baby with severe eczema and the conflicting advice she receives.

We had two German presentations. One was on current treatments – nothing that works for everyone, still no 'cure' but researchers are working on a range of options. I had puzzled over the second title – 'Atopic Schools'. Was there so much eczema in Germany? In fact it is a programme funded by health insurance companies to run weekend 'schools' for people of all ages to help them get control of their eczema and their lives. It seemed like a great idea.

My presentation looked at eczema from the patient standpoint. I highlighted the problems we face in living with eczema – as parents of babies, at school, in adolescence, finding employment, building relationships –

and in dealing with other people's attitudes in a society that often values image above everything. And then there's **the itch**.... I talked about the work of the NES in supporting, informing and educating patients, promoting research and working with health professionals. Finally, a picture of my grandchildren illustrated the growing problem of eczema, given the inherited atopic tendency.

Japan has a high incidence of eczema. We were shown an educational programme for adults based on the idea of 'know your enemy', reflecting the emphasis on education and information throughout the day. Several speakers said that, with no known cure for eczema, we had to accept this but work to change other factors, understand and try to adhere to our treatments to achieve long-term control.

Susan Tofte, a very experienced US dermatology nurse, emphasised this 'control not cure' theme, summarising her approach as:

- 'put out the fire';
- maintain control; and
- rescue flares.

She works with parents of children with eczema to develop effective bathing and moisturising routines. She described the work of the National Eczema Association (NEA), the US equivalent of the NES.

Roberto Takoaka told us about the development of patient support in Brazil. The Associação de Apoio à Dermatite Atópica (ADDA)'s mission is to improve the quality of life of patients with atopic dermatitis through art, science and education. They hold separate meetings for children with art and craft activities to get them to think beyond their eczema (hence the calendar). One idea was to find something that a child's eczema prevented him or her from doing, then see if they could do it following treatment – a goal-setting exercise that could work for adults too. AADA had conducted research among its members and discovered that while only 40% of patients and parents were satisfied with their treatments, 93% were satisfied with the support group!

What struck me strongly as the meeting ended was that, despite different nationalities, we had a common challenge – dealing with eczema. It is easy for patients and parents to become overwhelmed by eczema but it was heartening to meet people from around the world working to improve

our situation. We were using different strategies but everyone present had compassion and care for the patient. Not everyone has access to a national patient support group but, for some patients at least, emotional, educational and information needs were being met alongside their treatments. How unlike 40 years ago, when one was sent away with a tube of Betnovate 'to be applied as directed'! I also realised how lucky we are in the UK to have high-quality support from the NES.

It was very exciting to be in the architecturally stunning Kyoto Conference Centre, where the international Climate Change protocol was signed. Kyoto, the former Imperial capital, still has 50% wooden buildings and is a popular tourist destination for Japanese and foreigners. I managed to see some of its traditional temples, palaces and gardens, which I found fascinating. The Japanese are very welcoming and helpful and, despite the language difficulties, it is easy to get around.

I would like to thank the NES for giving me the opportunity to represent it and Roberto Takoaka and Hywel Williams for making it possible for me to attend this meeting.

Websites

The National Eczema Society's new-look website
www.eczema.org

NEA (National Eczema Association) (USA)
www.nationaleczema.org

AADA (Associação de Apoio à Dermatite Atópica) (Brazil)
www.aada.org.br

Oriented Patient Education Network in Dermatology
www.opened-dermatology.com