

2 July 2015 Meeting report, RFH immunodeficiency support group

A select group braved a heatwave and turned their back on the tennis at Wimbledon for a lively and interesting meeting.

Jose Drabwell chaired the meeting.

Membership: Caroline Richmond reported that we have 215 members but are missing email addresses for ten of these.

Patients' Day will be on Sunday 4 October in the hospital Atrium. It'll be free, including refreshments; a notice will be sent out shortly. To gauge the probable numbers we will ask people for a yes, no or maybe answer. This will allow us to plan the room layout and catering requirements. There'll be room for 150 people at most so it will be first come, first served. There will be room for essential carers. We'll need, and appreciate, volunteers to staff the registration and fundraising desks, move chairs and tables, hand microphones to audience members, run errands and help people find their way around. We hope, dear members, that you will come. There will be talks on nutrition, gut and bowel problems, infusion techniques, RFH research trials, gene research, and cognitive behavioural therapy. Workshops will be on chest physio, gut problems, home immunoglobulin treatment, relaxation & mindfulness, and gene research. Pharmaceutical companies will be invited, though new legislation limits the amount of promotion they can do directly to patients.

A discussion on IgG products revealed that they all differ slightly; some contain sucrose, to be avoided in diabetics; others contain high levels of IgA, which some people need. Royal Free policy is to tailor the product to the patient when needed, to change a patient's product if they have reacted badly, and otherwise to choose equally between the six products we stock. One product was withdrawn a few years ago and, had all our patients been solely dependent on it, it would have caused major problems.

Travel insurance: This is good advice on the PIDUK and UKPIPS websites. Jose, who travels extensively, pays £190 a year for unlimited travel from Staysure. HSBC and Nationwide offer free travels insurance for the under60s. It's important to declare existing conditions; if you don't, your policy is invalidated.

Two patients with lymphoma reported being quoted £1000 and £500 excess premium. Both decided they would prefer to pay their own transport home if they had to, which they didn't. The EEC and Australia give free emergency health care to tourists. Caroline was hospitalised in 2010 for pneumonia in Switzerland. The bill, when it came, was for £62, the same as a Swiss person would pay. It would have been higher had she wanted a private room or needed to stay more than 30 days. Take your antibiotics and E111 card with you and don't have live vaccines such as yellow fever. They are scarily dangerous for immune-deficient patients.

Dr **David Lowe**, our infections expert, advised us to go to a travel clinic - your local, or the Royal Free - for vaccines and malaria prophylaxis. Be extra careful in the southern hemisphere and avoid the central African belt. Use insect repellents, especially at dusk, avoid bites, cover up including wearing long trousers tucked into shoes, use the mosquito grilles on hotel doors and windows. Use a mozzie deterrent - **Sary** recommends Avon Skin So Soft. UK pharmacists sell doxycycline over the counter and it's not expensive - but be warned, it can make you hypersensitive to sunlight. Don't have ice in your drinks - it's made with tap water with added dodgy handling - and avoid food that can't be washed, cooked or peeled. Drink bottled water in hot countries.

And, finally, our nurses have a travel leaflet they can post or email to you. We'll put it on the website.

Patients survey: Many people haven't yet completed and returned the survey sent out in June.

Staff need this feedback so that they can offer the best service. If you haven't sent yours back yet then please do so; if you've mislaid it andrewsymes@nhs.net will post or email you another.