

Report of the meeting held on 13 January 2015 in the immunology department, 6-8 pm

A hardy bunch of members braved bad weather and a bus strike to attend this interesting and informative meeting. Sandwiches, soft drinks and wine contributed to a convivial atmosphere.

Jose Drabwell, chairman, welcomed everyone.

Caroline Richmond, secretary, reported that we now have 125 members, and she recruits every week on clinic days. Most people join, but it will take a long time before everyone can be approached. We might have had a further 80-100 members had she not contracted a long-lasting virus infection – see below.

Jose reported from the annual meeting in Prague of IPOPI, <http://www.ipopi.org/>, the International Patient Organisation for Primary Immunodeficiency. It was an excellent international collaboration. They are planning a study to assess the burden of treatment and members will be approached to answer a questionnaire. Further, IPOPI has produced five new leaflets, all of which can be accessed from the website.

They are

- PIDs and gastrointestinal disorders

- PIDs and respiratory disorders

- When to give immunoglobulin replacement therapy

- Management after diagnosis

- SCIG (subcutaneous IgG) infusions – a practical guide for patients

Therapeutic advances

1. Rapid-absorption subcutaneous IgG

At the last meeting our specialist nurse Andrew Symes described a new product that was likely to come on-stream: subcutaneous IgG mixed with an enzyme that enabled it to be absorbed quickly, thus enabling a higher dose to be given, which in turn meant it needed to be given less often. It is mainly for people who self-inject at home. It costs more than the existing product, called Subcuvia. The hospital's drug and therapeutic committee have been asked to approve it. The wheels grind slowly!

Following this there was a discussion about self-injection. For most people this is a weekly task, injecting under the abdominal skin. But one member revealed that he did his own intravenous injections – he said there's a "satisfying pop" when the needle hits the vein!

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gut infection, which is closely related. Though she was ill for only 2 weeks she tested positive for a further two weeks and had been unable to recruit new members for our group because

The virtual consulting room

Andrew Symes and Sary Workman won a Royal Free award for Quality, Research and Innovation. This was for helping set up the patients group, the educational symposia they have put on, the research they conduct within the department, raising funds and awareness, the newsletter, and for the web-cam home therapy training. There will a full report in the next edition of Andrew's (printed) news magazine, out shortly.

Fundraising

There was a well-deserved round of applause for Kanchan Batra, who has raised £1000 for us; her husband asked all his friends to give money to the charities he supported. A proposal will shortly be made to raise funds to support a research project in the Immunology department.

The proposed phase 2 new building of the Royal Free/University College Institute for Immunology and Transplantation

This new institute is now at the stage where a planning application has been lodged with Camden Council. It will be located in the Pears building, named after a philanthropist who donated a sizeable amount of the cost. Caroline gave a short talk with slide show about the building itself – what it will do will be the subject of a future meeting.

The design was put out to tender and the winning proposal came from the world-renowned firm Hopkins Architects www.hopkins.co.uk/s/. They are designers of many celebrated buildings including the 2012 Olympic Velodrome, UCH's MacMillan Cancer Centre, and Portcullis House, where MPs have their offices.

The new building will be precisely on the site of the old Hampstead Hospital, on the Rosslyn Hill side of the existing hospital. It will have a slightly smaller footprint than the old hospital and will probably be 2 ft taller, but no-one knows for sure as the plans of the old hospital are lost. It will look like a modern version of its predecessor, and we saw slides of the old and new buildings for comparison. The brick will be red, trimmed with dressed stone, exactly matching the nearby church and school. It will be seven stories high but two of these will be below ground. It will house the Royal Free Charity and the Volunteer Offices; above these will be three floors of clinics, research labs, and offices. From Rosslyn Hill the building will block out the view of the grey concrete of the main hospital, which was designed in the sixties and completed in the seventies.

The top two floors will be patient accommodation. Though these have been described as a patient hotel this is misleading. Many patients have to travel from far afield. They don't need to be in a hospital ward but have clinical needs that can't be met by a Premier Inn or Travelodge.

Unsurprisingly, there has been local opposition. The most visible comes from the trustees of the deconsecrated St Stephen's church and the adjoining private kindergarten school. Their posters misleadingly claim the new building clashes with the colour of the church and the 'hotel' rooms will overlook the school. The RFH PID Group Board has already sent a letter to the Camden planning department supporting the new institute building because this is crucial to keeping your clinic at the forefront of international advances in the treatment of immunodeficiency disorders.