

FUAN Patient Group Meeting

Saturday, March 23rd, 2013

Histopathology Seminar Room
2nd Floor, North Wing, St Thomas' Hospital, London SE1 7EH

- 10.30 RaDaR (Rare Disease Group on FJHN)**
Chair : Dr G.Venkat-Raman, Consultant Nephrologist, Queen Alexandra Hospital
10:30 Coffee, tea and registration
11.00 FJHN: Clinical presentation, diagnosis and treatment
Dr G.Venkat-Raman
12.00 Laboratory methods of diagnosis
Dr Tony Marinaki / Dr Lynette Fairbanks
12.40 Panel discussion on patients' perspectives & questions

1.30 Purine Metabolic Patients' Association

PUMPA committee open meeting: ALL WELCOME

- 2.00 pm Report by PUMPA PhD student: Adele Corrigan**
2.05 pm Report by PUMPA PhD student: Michelle Levene
Chair: Prof. David Perrett, Chairman of PUMPA
2.10 Introduction – What is Gout? – Prof. David Perrett
2.30 Food and Drink and Gout – Dr Liz Carrey
2.45 Treatment for gout – Dr Terry Gibson
3.00 Research and development – Dr Tony Marinaki
3.15 Question time

Nine patients / relatives with FJHN attended the meeting – a further 8 were unable to attend due to adverse weather.

The FJHN discussion was lively and inter-active and the patients and relatives asking a number of questions and making comments, based on their own personal experiences. The key items of interest included how to make the diagnosis early in affected relatives, and how the disease progression could be retarded or prevented. They welcomed the development of a national website and were keen to see the advent of a database / registry.