

Clinical update on the Barts Lupus Centre



**BARTS
LUPUS
CENTRE**

Welcome to the Summer 2018 edition of the Barts Lupus Centre newsletter. It has been six months since the last issue and new developments continue. We welcome new staff while others move to pastures new.

We continue to have a team of lupus specialists with rheumatologists, renal physicians, dermatologists, immunologist, nursing, physiotherapist, and psychologist. Our patients continue to engage in new initiatives such as our lupus focus group which has allowed experiences to be shared and for staff to gain insights for service developments. Our new twitter account is in its infancy but we hope to share lupus news through this portal. Lupus studies continue to help further knowledge and many thanks to those of you who contribute to departmental research. Hope you all enjoy our newsletter and wishing you all a Happy Summer.

Dr D Pyne, Centre Lead

Patient Focus Group

We ran our first lively patient focus group in February. The focus group provided invaluable help to further shape our service and to improve the health and wellbeing of lupus patients. Patients had the opportunity to meet others with lupus and offer ideas for service improvement. Many thanks for all of you who volunteered and have already participated. If you would like to attend future focus group meetings, please let your doctor know and we will contact you in advance. Patients have indicated a preference for the groups to run in the mornings and the sessions will typically run every 4th Tuesday morning of the month and last for approximately an hour and a half.



Staffing updates

We sadly bid farewell to Maria Vidal, our Lupus Clinical Psychologist, who leaves us for a new role outside of the Trust. Maria was replaced in May by Shireen Sultana, a cognitive behavioural psychotherapist. Shireen has more than 12 years NHS experience helping patients suffering with psychological distress. She will be running a monthly clinic to offer psychological support to lupus patients.

Mary Githinji, lupus nurse specialist, has moved into a research nurse role; she will be helping to recruit patients interested in taking part in a new study called BEAT Lupus – investigating the use

of the drug belimumab after rituximab treatment to assess whether lupus patients gain a more long lasting benefit than with rituximab alone.

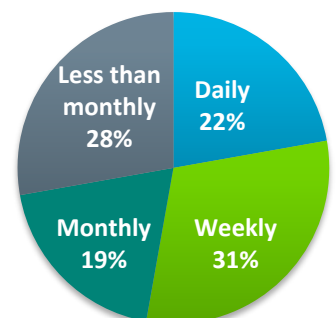
Mary's lupus clinic will be run by our newly appointed nurse Christelle Hunter, who leaves her previous role in plastic surgery at The Royal London Hospital. The telephone hotline which was manned by Mary is temporarily suspended until Marie starts her role.

Finally we welcome back Dr Jimmy Peters who previously worked in the Lupus Centre between 2015 and 2016. Dr Peters is appointed as Honorary Consultant Rheumatologist to set up a dedicated vasculitis service. Vasculitis (blood vessel inflammation) affects up to 30% of lupus patients. Dr Peters has extensive knowledge in vasculitis and currently also has a research post at the University of Cambridge.

Moving with times: social media use by patients

Over the past decade, the use of social media has grown exponentially. Many of you were involved in our survey on the use of social media platforms last year. We were surprised to see how many of you used lupus social media regularly.

Of the 84 questionnaires returned, 64% of lupus patients reported using online lupus information and support services and half of those accessed these at least once a week. The most frequently used social media sites were Facebook, followed by blogs, and YouTube videos. Although there were a variety of reasons behind using social media sites, the majority of patients searched for information on lupus and its treatments. 2/3 of lupus patients reported an overall positive benefit of using social media sites. Only 14% of respondents had concerns about using these sites because of worries that the information written was incorrect, and worries about sharing confidential information and their privacy.



Amount of time spent using social media platform



Psychological input in Lupus care: a 12-month pilot programme

Living with lupus can have a marked effect on psychological and emotional wellbeing with a high level of anxiety and depression. The diagnosis and subsequent treatment of lupus, together with identity and lifestyle changes, can prove problematic, with patients frequently reporting feeling overwhelmed and uncertain about the future.

These psychosocial challenges require careful assessment, however, the provision of direct psychological support within lupus clinics is limited. In order to help address this issue, funding was sought for a 12 month pilot of clinical psychology input within Barts Lupus Centre. Maria Vidal psychologist has summarized the patients' experience in the pilot programme.

Over this period 23 patients were referred to clinical psychology, with 3 appointments per patient on average. The pilot highlighted high patient satisfaction with 100% recommending the psychology input received and 70% indicating they would see psychology again.

The most prevalent presenting difficulties were adjustment to new diagnosis, information provision on lupus, anxiety, low mood and coping with pain.

"I've really appreciated the time with the psychologist. I can talk about lots of different things that affect me that are hard to talk to with my family. I wish it could go on for longer".

Meet the Lupus Team at Barts Lupus Centre

Rheumatology Consultants



Dr Dev Pyne
RLH/ME
NUH



Dr Myles Lewis
RLH/ME



Dr Angela Pakozdi
RLH/ME
WCUH

Renal Consultants



Dr Andi Cove-Smith
RLH/ME



Dr Ravi Rajakariar
RLH/ME
NUH

Dermatology Consultants



Dr Richard Bull
RLH/ME



Dr Malvina Krupovitz
RLH/ME

Histopathologist



Professor Mike Sheaff
RLH

Lupus Nurse Specialists



Mary Githinji
(Research)
RLH/ME



Christelle Hunter
RLH/ME



Jyoti Donnelly
WCUH

Psychologist



Shireen Sultana
RLH/ME

Lupus Physiotherapists



Abraham Newell
RLH/ME



Chloe Keith-Jopp
(Research)
RLH/ME

Barts Lupus Centre Hub:

Royal London Hospital - Mile End site (RLH/ME)

0208 223 8518

0208 223 8519

0208 223 8408

Clinics: Wednesday mornings

Spoke clinics:

Whipps Cross University Hospital (WCUH)

0208 539 5522 (Ext 6724)

Clinics: Tuesday mornings

Newham University Hospital (NUH)

0208 223 8518

0208 223 8519

0208 223 8408

Clinics: Friday mornings



Follow us on
twitter
@BartsLupus

We are excited to announce we have a new twitter account!! This account is designed to keep you up-to-date with news and information about the Barts Lupus Centre. We hope you will find these tweets useful and informative.



Barts Health: Safe and compassionate care