Clinical update on the 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.

Sun protective recipe against Lupus

Lupus skin rashes are extremely sensitive to light. Summer is on our doorstep, so let us review the rules of effective sun protection.

- Use broad spectrum sunscreen against both UVA and UVB
- Choose high SPF 30 or more, and 4-star UVA rating
- The sun is most harmful between 11 am and 3 pm
- Apply 1 teaspoon for face and neck, 6 teaspoons on the body
- Apply 15 minutes before going out and reapply every 3-4 hours and after swimming
- UVA goes through glass, consider applying Dermagard film to windows, Blue Shield for TV, computer and phone screens, and switching to LED lights
- Wear protective clothing like wide brimmed hats. Cotton is least UV protective, whilst lycra and polyester have better UV blocking ability.

Enjoy the summer!

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 Marie 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.

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.

Mile End Hospital, Bancroft Road, London E1 4DG, Telephone: 07789 934732 Follow us on Twitter @BartsLupus
Moving with times: social media use by lupus 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.

International Conferences

The lupus team has recently attended the 11th European Lupus Meeting of the European Lupus Society (SLEuro) in Germany. Dr Lily Wheeler’s project on social media use by our lupus patients attracted a wide international audience and prompted the Centre to set up a twitter feed for our lupus patients @BartsLupus which we hope you will follow.

Dr Oseme Etomi flew to Dubai earlier in the year to the 5th FIFA conference and talked on Fighting Inactivity in Lupus. Held under the patronage of the Prime Minister of the UAE the event was televised and covered by Gulf News. Through regular aerobic exercise lupus patients can reduce fatigue and risk of heart disease - if you would like a fitness assessment in our lupus physiotherapy clinic speak to your lupus doctor.

Most recently Dr Arabella Waller presented her findings of hair loss in lupus at the British Society of Rheumatologists (BSR) scientific meeting in Liverpool. Dr Waller found almost 60% of our lupus patients suffer with hair loss and many of them also report facial rashes and mouth ulcers. With treatment these symptoms can improve.

Since the last issue the team has had new publications in the field of lupus research…


Psychological input in Lupus care: a review of 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.”