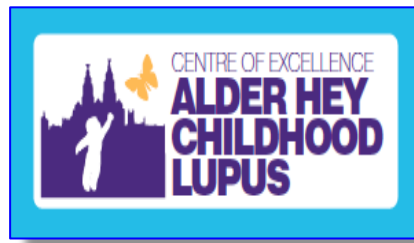




Alder Hey Children's **NHS**
NHS Foundation Trust



UNIVERSITY OF
LIVERPOOL

Lupus and You

Workshop for young people with lupus and their families

Summary Report



**Alder Hey Children's NHS Foundation Trust
19th March 2016**

**Report by The Lupus Team,
Centre of Excellence for Childhood Lupus at
Alder Hey Children's Hospital**

Background

Why a workshop?

The development of a workshop for young people with lupus and their families attending the UK's only paediatric Lupus Centre of Excellence at Alder Hey Children's Hospital was indicated for a number of reasons:

- Lupus is a rare in children and young people under the age of 18. Most patients within our service had never met another young person with the condition and described how isolating this could feel. Similarly parents and siblings wondered whether the concerns they felt for their children's health and future were unique or indeed might be shared amongst other families.
- The mental health needs of young people with chronic health conditions are well known and as a service we wanted to both support those needs as they arose whilst also looking to support the young people in developing resilience and copings strategies to minimise the impact of their condition and support them to live life fully.
- As a regional service and the UK's only paediatric lupus centre of excellence, our patients are spread out across a large geographical area. Travelling to additional appointments is therefore challenging both in terms of time taken away from education, work and social commitments but also due to the physical exertion required in the context of symptoms that often include fatigue and pain.

As a result, a day-long workshop was developed to be attended by the young people with lupus and their families located within the Institute in the Park on the familiar Alder Hey Children's Hospital site. The event was developed and run by representatives from the Lupus Multidisciplinary Team as well as colleagues from the hospital research facility involved in studying lupus.

Focus on Fatigue

As part of routine clinical practice, all lupus patients and their accompanying parent or guardian are asked to complete a clinic screening tool, providing a snapshot of their lupus related concerns in the weeks leading up to that clinic appointment. It is also designed to help patients to prioritise issues for discussion within that consultation. From this questionnaires it was clear that fatigue was one of, if not, the most commonly reported symptom of concern reported by both young people with lupus and their parents.

Focus on Research

We recently held an away day for the UK JSLE Cohort Study Group (more detail below) which was attended by some patients and parent representatives. These representatives were really interested to hear about the research being carried out and suggested that other families may also be interested to find out more. Additionally a recent survey of some young patients with lupus found that very few were aware of the UK JSLE Cohort Study. We therefore felt it would be helpful to dedicate some of the day to discussing research.

Attendees

The workshop was attended by:

- 9 staff members representing both the multidisciplinary team and research facility
- 7 families including
 - 6 young people with lupus
 - 2 siblings and
 - 10 parents
- Mr Kevin Weston, Chair of Lupus UK, also attended in order to represent the charity. As a parent of someone with lupus himself he also actively participated with the parents' activities.

Introductions and Icebreaker

After making the long journey on a chilly March morning, the young people and families arrived to a hot drink and biscuits. After making some informal introductions, staff and attendees were all encouraged to take part in an ice-breaker exercise involving sharing information about ourselves – the number of details shared corresponded to the number of toilet paper squares torn from a roll! Needless to say this prompted some smiles and did a great job of relaxing the group and setting up the tone of conversation and collaboration for the rest of the day.



Fatigue Workshop

Attendees were split into two groups; young people in one and parents/family members in the other.

A number of discussions were facilitated to consider the following:

- **What is fatigue?**
- **What impact does it have on your life?**
- **What influences how fatigued you feel?**
- **What have the families and young people already done to try to manage fatigue?**

These issues were considered in the context of a case discussion of a young person juggling the challenges of lupus in the context of everyday life

Emily Wilson (Clinical Psychologist) shared information regarding the role of psychology in supporting a young person with fatigue, focussing on the relationships between thoughts, feelings and behaviours.

Katie Dobson (Occupational Therapist) and Sue Kemp (Physiotherapist) discussed the importance of setting goals, managing activities, pacing and taking regular exercise.

All activities and discussion points were included within a workshop booklet given to all attendees. Information was also included regarding sleep hygiene, relaxation strategies, health eating and healthy lifestyles.

Fatigue Data

In order to consider the level of fatigue experienced by members of the group, the young people were asked to complete the Chalder Fatigue Scale and the Fatigue Severity Scale. The average score on the fatigue severity scale of patients attending the day was 5.1 (range 4 – 5.8) where people scoring above 3 points are considered to suffer with fatigue.

Young people and their families were asked to rate their perceived ability to manage fatigue and their confidence in being able to manage things better. The results compared their views before the fatigue workshop and again after. In all but one case, participants indicated that they felt more able to manage fatigue following the workshop.

Measures of Emotional Well-being and Quality of Life

Over the course of the day the young people and their parents were asked to complete some standardised questionnaire measures capturing data on emotional well-being (Paediatric Inventory of Emotional Distress), Resilience (Resiliency Scale) and Quality of life (PedsQL Core Module). The scores suggested there was a lot of variation in the extent to which young people were affected by and were coping with having lupus.

Research Workshop

We started off this session by giving an overview of what research is and then specifically moved on to describe the research that is going on in Liverpool and the rest of the UK, as part of the UK JSLE Cohort Study (see <https://www.liverpool.ac.uk/translational-medicine/research/ukjsle/about/>). Patients and families were then invited on a tour of the lab at the Institute of Child Health, University of Liverpool, Alder Hey Children's Hospital, where much of our laboratory research into lupus takes place.

Laboratory Tour

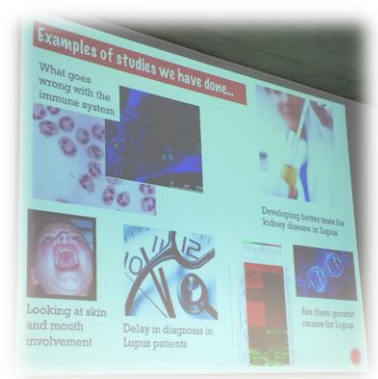
During the meeting we showed the group what happens to their blood in a video that the team have developed (see www.youtube.com/watch?v=EHBkvGNDg-A). We pointed out the machines used for different types of experiments. In the next part of the lab tour the patients and their families got the chance to look at some immune cells under the microscope.

Parents and young people asked questions about the problems the immune system has in lupus and wanted to know more about the experiments. Everyone seemed very interested in what we do and what we hope to achieve with the research.



Updating families about research

We asked patients and families if they wanted to know about research and if so, how they would like to find out about it. All the patients and families attending the day said they were interested in and keen to find out more about research. Most families already follow LUPUS UK on Facebook and felt this was a useful forum through which we could share new information. Families were happy to receive emails and felt they would read information that was sent to them this way. Some patients and families used Twitter. Other suggestions included a UK JSLE Cohort Study Facebook page. This session highlighted that different communication methods suit different families and moving forward we hope to improve how we communicate our work in different ways. Since this meeting we have a new section on the Lupus UK website which we will update regularly (see <http://www.lupusuk.org.uk/lupus-in-young-people/>)



Evaluation

All young people and their family members were asked to complete an evaluation form prior to leaving. The data suggested that attendees found the workshop to be helpful / convenient to attend.

Next Steps

The day concluded with a summary of the day's discussions and consideration of next steps. Attendees commented on having had an enjoyable day. This short summary report will be shared with all those who attended as well as being sent to Lupus UK and posted on the GenerationR website: www.generationr.org.uk

The next *Lupus and You* workshop for young people accessing the lupus service at Alder Hey Children's Hospital, is scheduled to take place on 24th September 2016 and will focus on medications and treatments for lupus as well as the issue of transition.

For more information or to request a full copy of this report please contact Lupus@alderhey.nhs.uk