

FACT SHEET

SURVEY II “LIVING WITH LUPUS”: CAREER/WORK SITUATION

Background

In 2009 an on-line global survey of the lupus community was undertaken to assess the effect of the disease on the lives of people with lupus: 1038 responses were received from 17 countries with 60% of the respondents from the US and 40% from Europe.

The three life areas on which lupus had a noticeable or highly significant effect were Career, Physical well being and Everyday activities. One of the key findings of the survey was the effect of lupus on employment, where almost 29% reported not having a job due to having lupus and those still working reported unusually large numbers of sick days.

Reason for Survey II Living with Lupus: Career / Work situation

The information from the indications of last year’s survey – despite lack of scientific value – is so strong, that the results need to be investigated further. These results must be proved and validated to be included in research where the patient’s voice has value.

This will be the first time a patient-driven survey will look at the relationship between the work situation and lupus.

It will also be the first European survey seeking to find answers for the ways lupus affects patients whether or not they are working.

This will be the first time a patient-led group will conduct a survey in the five largest language groups in Europe in order to provide a significant basis for analysis.

AIM of Survey II Living with Lupus: Career / Work situation

Results from this survey will be used to indicate the problems which LUPUS EUROPE should address; on individual or collective level/national or pan-European level.

The survey Living with Lupus: career / work will investigate

- **How many people with lupus are employed or unemployed.**
 - **If employed; has career change been necessary?**
 - **Working full time or at a reduced level?**
 - **If unemployed, the reasons may give suggestions for future actions.**
- **The survey will also address Fatigue, work productivity and activity impairment and general Quality of Life (Lupus QoL).**

The survey will be for all people with lupus in Europe able to respond to the five main languages to be reached through the LUPUS EUROPE national member groups.

Language – English, French, German, Italian and Spanish

Following the difficulties experienced with the previous survey (in English only) this survey is being presented in the five most used languages in Europe. This should enable ease of answering questions about personal situations. Using the pre-established Fatigue and Lupus Quality of Life assessment tools, we hope to be able to collect sufficient information, by language group, to be able to carry out an analysis.

By having the language versions of English (UK), French (FR), German (DE), Spanish (ES) and Italian (IT) we hope to ensure support from members speaking these languages and have a minimum of 200 responses from each.

Structure of survey

The introduction by Yvonne Norton MBE, Chair of LUPUS EUROPE, will outline the aims and means of the survey.

The survey consists of four sections, beyond the introduction:

- **Part 1** of the survey (sections 1-3) *includes demographic characteristics and the questions designed by LUPUS EUROPE about career/work*. These questions will address the key issue of having lupus and being employed/unemployed. These questions have been designed specifically for this survey and translated into the five languages. This section will be correlated, where possible, with responses to questions in the following sections.
- **Part 2** of the survey looks at fatigue and uses a validated methodology called the Fatigue Severity Scale. This part of the survey is contained in one question.
- **Part 3** of the survey looks at the effect of lupus on work and uses a validated methodology called the WPAI (Work Productivity and Activity Impairment) scale.
- **Part 4** of the survey looks at general Quality of Life measures and uses a validated Quality of Life methodology.

Parts 2-4 are based on existing platforms which meet the requirements for feasible research. Part 1 is planned to provide the same validity so the correlation between responses to the different parts will be applicable in an investigation into lupus and the work situation.

Ownership of data

The survey is conducted as an online survey only. All responses are gathered through the platform Survey Monkey and collected centrally disregarding the language versions. No IP-address is recorded. LUPUS EUROPE and the Steering Committee will perform the analysis of results towards presentation of articles and lectures at the most key venues of Lupus interest. LUPUS EUROPE aim to make the best use of this *our* data!

Project time schedule and key events

■ = Steering Committee (LUPUS EUROPE, UCB, Medical Advisory representatives)

■ = Language contacts

■ = National groups

■ = Presentation / results

Planning and Preparation

March 29th Final edition of LUPUS EUROPE input to introduction and Part 1

April 13th Legal approval for compliance to collaboration between pharmaceutical company, patients organization and medical experts.

April 15th Translation of text material externally

April 21st Translations to be reviewed and ensured to match the original version

April 29th Review of translations completed and final check of survey's presentation

Launch and run time of survey May 1st- August 15th

May 1st Launch by e-mail campaign to all national groups

May 10th World Lupus Day – official launch of survey at WLD celebrations and press release

June 1st Language contacts to be informed of response rate – decisions on how to improve take-up

June 16-19 EULAR Congress 2010, Rome – poster presentation on last year's result leading to this year's survey

June 24-27 9th International Congress on SLE, Vancouver – presentation on methodology and status

July 1st Language contacts to be informed of response rate – decisions on how to improve take-up

August 1st Language contacts to be informed of response rate - decisions on final actions to improve take-up

Analysis and preparations for publication and disseminating results

August 15th Survey closes

August 20th Final response results announced to language contacts

August 16th Analysis commences

Sep 22-26 LUPUS EUROPE Convention, Budapest – presentation on survey process and preliminary indications

Oct-Nov Abstract editing for presentations at key lupus events 2011

Dec-Jan Planning the communication strategy for the publication of results

Mar 2011 Finalizing the analysis period and proofing the results

Survey results – publication and dissemination

Apr-May Presenting methodology, top findings and final results at resp. 8th European Lupus Meeting in Porto April 6-9th and at EULAR Congress in London May 25-28th

Summer+ National initiatives to disseminate results to own members and to use these when addressing key issues in the political network.

Sep 2x LUPUS EUROPE Convention Denmark - workshop

Project organization

The Survey is set up using the free internet tool SurveyMonkey.
Tasks are described in the above time schedule.

Medical Advisory Panel Representatives:

- Professor David Isenberg, University College London, UK
- Professor Caroline Gordon, University of Birmingham, UK
- Professor Dr.Med. Matthias Schneider, Heinrich-Heine-University Duesseldorf, Germany

The Steering Committee of this project consists of LUPUS EUROPE (project coordinator, Vice chair Kirsten Lerstrøm and representatives Secretary + Trustee II Website), three members of the Medical Advisory Panel and representatives of UCB.

Language contacts:

- English – Yvonne Norton MBE, Chair, LUPUS EUROPE and Vice-Chair of LUPUS UK
- French – Fériel Bouabida, Secretary, LUPUS EUROPE and representing LUPUS France
- German – Simone Müller-Pretis, Trustee II (web), LUPUS EUROPE and representing the Lupus Erythematodes Selbsthilfegemeinschaft e. V, Germany.
- Spanish - Blanca Rubio, President of Federación Española de Lupus, Spain
- Italian – Stefania Di Masso, Chair LesToscana, Italian SLE Group, Italy