



## UNITING PEOPLE WITH LUPUS THROUGHOUT EUROPE

Formerly European Lupus Erythematosus Federation (ELEF)

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### Patient Panel project report

#### Executive Summary:

On November 2-4, LUPUS EUROPE organized a Patient panel, bringing together 10 Lupus affected persons from 7 countries to share their experience about “treatment”, with the view to help improve the quality of life of people living with lupus. The Panel was conducted through a series of interactive presentations, team discussions and working groups, and resulted in the issuance of 3 letters addressed respectively to People living with lupus, patients organizations, and the medical community, addressing how they each can help in this area. Those letters are presented in attachment and reflect the thinking of participants with respect to the issue at stake.

The key points coming from the two day event were:

- The person with lupus view of treatment is broad; it is both medicine based and non-drug. Infusion is only one part of the treatment picture. People with lupus categorize treatment in three ways – core treatment which includes infusion is seen as acute while pills are seen as for acute or maintenance needs.
- We define treatment as: **any product or activity that aims at improving the person with lupus’ quality of life.**
- The person with lupus definition of access includes ease of contact with HCPs and support services such as arm braces as well as availability to medicines. The individual’s adherence personal belief system can be reinforced or weakened by the relationship with the HCP.
- Patients will take new medicine provided they understand the reasons why and the side effects; management of patient expectations in terms of both drug (speed of noticeable onset) and relationship to support staff are important for continuing with treatment.
- There is a duality to the infusion experience as viewed by the person with lupus; it can either be viewed as an experience which emphasises their own incapacity or one which they view as contributing to their long term quality of life.
- Infusion is something patients accept as a consequence of their disease and improvements at the pre infusion stage, during the procedure and follow up were reported to be important areas for positively affecting the infusion experience.
- Sustainable and consistent relationships with infusion staff were considered important for a positive infusion experience.

#### BACKGROUND:

At the occasion of LUPUS EUROPE 2013 Convention in Paris, Professor N. Costedoat illustrated to the participants the critical issue of adherence to treatment (or more precisely, the lack of it). For many reasons, adhering to the prescribed treatment is a challenge for people living with Lupus, yet, “medicine only works if you take it”. Understanding this area is critically important to help people with lupus improve their quality of life. LUPUS EUROPE identified a sponsor to fund qualitative research “to Gain qualitative understanding of Treatment situation today from a patient point of view, to determine what actions could be take in the future with regards to ACCESS and ADHERENCE”.

A first event took place in preparation for the patient panel event. LUPUS EUROPE 2014 Convention in Helsinki dedicated a session to work on this topic, focusing on the definition of “WHAT IS TREATMENT”, and approaching the topic of ACCESS (is treatment available in quality, quantity, and at affordable price). More information on this is available in LUPUS EUROPE 2014 Convention minutes. The outcome of this work has then been used as starting point for the Patient panel held in Brussels early November.

## **WHAT IS TREATMENT :**

In Helsinki, LUPUS EUROPE delegates concluded that treatment should be viewed very broadly, defining it as “ANY PRODUCT OR ACTIVITY THAT AIMS AT IMPROVING THE PERSON WITH LUPUS’ QUALITY OF LIFE.” A Vivid expression of this was made expressing it as “What I would need on an island to live - Pills, sunscreen, rest, physiotherapist, healthy food, spiritual aspects, love,...” the participants further elaborated on a high level treatment map, identifying how various elements of this treatment could broadly differ, and would correspond also to different patterns in terms of Access and Adherence. In essence, the groups developed the following “treatment map”:

| CORE  | MEDICAL  | WELL BEING   |
|---|--|--|
| <b>ACUTE</b> <ul style="list-style-type: none"><li>• Pills</li><li>• Scan, RX, Blood tests</li><li>• IV, hospitalization</li><li>• Surgery, transplants</li></ul> | <b>PRESCRIBED</b> <ul style="list-style-type: none"><li>• Physiotherapist</li><li>• Pills for side effects</li><li>• Vitamins, Sunscreen...</li></ul>                | <ul style="list-style-type: none"><li>• Sport</li><li>• Yoga, Meditation</li><li>• Massage</li><li>• Social support</li><li>• Psychologist</li><li>• Family</li><li>• Peer/support group</li></ul> |
| <b>MAINTENANCE</b> <ul style="list-style-type: none"><li>• Pills</li><li>• Scan, RX, Blood tests</li></ul>  | <b>NON PRESCRIBED</b> <ul style="list-style-type: none"><li>• Vitamins, Sunscreen...</li><li>• Diet,</li><li>• Parallel Medicine</li><li>• Self medication</li></ul> |  |

The group insisted on the fact that treatment should really be viewed as ALL those elements combined, feeling too often, it was understood only to mean CORE - Acute treatment, or All Core plus Prescribed medication, but that for Lupus patients, non prescribed Medical and Well being had an equal importance in improving their health and quality of life, and in making treatment work as a whole.

The above treatment map was used as starting point for the Brussels patient panel. While it was not discussed or re-questioned specifically as part of the panel’s format, participants agreed with that view and with the structure provided, finding it most relevant to also understand adherence issues.

## **BRUSSELS PANEL PARTICIPANTS:**

The patient panel was conducted by and for people living with lupus.

The organization and the facilitating of the panel and its workshops/discussions was done by Bernadette Van Leeuw (with Lupus, Chair of lupus Belgium – FR, Trustee in charge with research at LUPUS EUROPE), Davide Mazzoni (Italy, with lupus, Patient partner in research), and Alain Cornet (Belgium, Treasurer Lupus Europe).

The panelists were recruited through lupus Europe network, seeking to bring in “new people” in the discussion, as representative as possible of the Lupus European community. All agreed English would be used as the working language. Participants were: Christine (34, Belgium-FR, African, Female), Sander(48, Netherlands, Male), Jane(45, UL, Female), Jeanette (35, Denmark, Female), Angela (28, Spain, female), Ana(22, Spain, female), Daniela (54, Italy, female), and Claudine (41, Belgium-NL, Female).

UCB staff, and Nick Hicks from Commutateur attended as Note takers and observers.



## **OPENING:**

The panel started on Sunday November 2 evening with a opening session around a drink where each participant introduced him/herself and his lupus story, and voices his hopes and/or fears ahead of this panel. Positive relations and trust were quickly established. The intro session continued with an informal dinner in a nearby restaurant.

On November 3<sup>rd</sup>, The day started with a presentation of LUPUS EUROPE and how this panel fits into LUPUS EUROPE’s strategic objectives and reason for being, a discussion of the Panel’s objectives, agenda and deliverables, and the review of the Helsinki definition of treatment and Findings. After answering questions of participants, the first panel workshop was launched on the theme of Adherence.

## SESSION #1 – ADHERENCE

In this workshop, after reviewing the definition of Adherence (“the extent to which the patient's history of therapeutic drug-taking coincides with the prescribed<sup>1</sup> treatment”), participants split into 2 groups where asked to answer the following questions:

- Is compliance the same for all treatments or is there a difference?
- What are obstacles to adherence in the broadest context for each treatment type
- Why do patients not follow the prescriptions?

The conclusions reported by the teams are as follows:



### Is (your) compliance the same for all treatments or is there a difference?

- “I always take pills, but not always sun screen”
- “If I stop taking pills I get a flare”
- “In the summer I use 50+ factor”.
- “You must be able to see the sun.”
- “Sometimes I see a physiotherapist and home visits allow me to get over any problems.”
- “I do not use sun screen in the winter”.
- “When I have no problems I do not take pills.”
- “I am tired of hospital doctors – I don’t do everything they

tell me – I hate going to hospital”

- “Must do what it says on the label”. “I almost died twice when I stopped”.
- “You really must have confidence in my doctor; how can you trust a doctor who doesn’t listen to you?”
- “Relationship between doctor and patient is very important – if you have it you know why it works and it is easy to take”
- “The doctor must treat me like an individual”. “My GP read up on lupus because I have it”.

### What are obstacles to adherence in the broadest context for each treatment type?

- “Pain stops me doing physiotherapy.”
- “When I have a flare I need someone else to tell me to take my pills.” “I need an alarm on my pill box”
- “It’s like having the first day of the flu every day”.
- Titration of steroids.
- “Pain can be a motivator and a de-motivator”
- Personal belief system.
- “Shame – I want to hide my pill box from others. Here with you its ok.”

### Why do you think (you)/patients do not follow the prescriptions?

- “It’s like the Mafia – you can’t see it but it’s always there”.
- “So tempted to do too much and I Must calm down when I am well.”
- “Doctors cannot see the disease.” “Patients need to be patient. Difficult period waiting for a new drug to work”. “There must be a consistency of message with doctors.”. “ You learn to go to the person who will look after you the quicker”



## SESSION #2 – CASE DEEP DIVE:

The discussion of Adherence revealed that there were a number of factors impacting adherence, affecting the perceived “Cost/Benefit” of adherence. The next session focused on deep diving into specific situations to better understand the impact of such mechanisms. 4 cases were considered: How treatment works (how does our understanding of the mechanics of treatment affects or not our adherence); The Dark side of treatment (how does our perception of side effects affects or not adherence); Coping strategies (how do behaviours to deal with the

<sup>1</sup> Or “self prescribed/targeted” in the case of non prescription medical and well being



teratment or its effects help or hinder adherence) and Conflicting Information (how does information from friends, doctors or any other source) affect our adherence.

The conclusions were as follows:

#### How treatment works :

- "Different people want different information on lupus and how it will improve their condition".
- "I am the engine so what goes in is important to me. I get stressed when I don't know what is going into my body".
- "Find diagnostic values right for you".
- "Need a treatment that is proven to work"

#### The Dark Side of treatment :

- "No way to step up treatment after IV."
- Doctors are reluctant to move up to big treatment.
- "Lupus treatment can cause problems with other areas so I prefer to live with fibromyalgia than lupus."
- "I lost two jobs due to hospitalization".
- "Employers must see you as productive – lack of understanding about time and consequences of infusion".

#### Coping strategies :

- "Avoid internet – spooky stories."
- "There is a need for information in the waiting room after a visit"
- "Need reliable sources of information".
- "Difficulty in providing good information in the short consultation period".
- "There is nothing on the internet about the problems of new medicines".

### SESSION #3 – UCB RESEARCH ON INFUSION

UCB shared with us some research they did they conducted on specific aspects of treatment, namely "infusion". Participants reacted and contrasted their expertise with the results shared by UCB. Then they gathered in two groups to discuss what could be done, concretely, to improve the Infusion experience. For confidentiality reasons, the outcomes of this part of the panel are not disclosed here, but they will be available to members at our convention



LIKE HOTIE  
INTERABLE CHAIRS,  
GOOD COFFEE  
INTERNET  
ATION POSSIBLE

MOBILE INFUSION  
↳ INDEPENDANT TROVES

WAITING TIME (ARRIVAL, DISCHARGE)  
↳ ADDITIONAL ACTIVITIES  
↳ NURSES DISCUSSION  
↳ PHYSIC / MASSAGE / ACTIVITY  
+ ACTIVITIES FOR OBSERVER  
WATCHING FILMS, EXERCISE

TABLETS ARE GOOD EASY USAGE W/O  
PRESSURE

CONNECTION PLACE FOR PATIENT ASSOCIATION  
↳ INFO ON DRUGS (FATIGUE)  
BIG PICTURE  
↳ HOW TO EXPLORE  
Reliable info on  
positive impact of  
exercise

## **NOVEMBER 4 OPENING:**

After a team dinner and a good night rest, we had a great opportunity to meet with professor Frederic Houssiau, leading expert in Lupus Nephritis who accepted to answer participants questions on Lupus and treatment. {transcript of the discussion not included here}

The following areas were raised during the session with Professor Frederique Houssiau.

- When can it be said that Lupus is flaring?
- When would you recommend going to a stronger therapy?
- Is Lupus still a disease of flare and remission?
- Flares and birth control is there a link?
- Is light exercise recommended for people with Lupus?
- Is it advisable to follow a special diet?
- Can dietary supplements help?
- Is it recommended to use vaccines?
- Can the long term side effects of steroids be prevented?
- Are there new drugs being tested for Lupus?
- Is it better to treat Lupus aggressively then move onto less strong therapy?
- Can Lupus be transmitted from mother to child?

## **SESSION #5 – GETTING CONCRETE:**

We recapped our work of the previous days, and concluded that treatment is a very broad topic, and that while Treatment only works if you take it, adherence is not easy. We agreed that Quality of Life in Treatment can be improved, and that our collective experience is important to bring solutions. We then focused at identifying how we concretely can help improve compliance and quality of life, by identifying actions that could be taken by players to help patients manage and improve “treatment adherence”. Panelists individually identified specific actions, messages, ideas on what could be done to improve the treatment experience quality of life, and via that – adherence to treatment and placed them on Flipcharts addressed to 4 identified target groups: Patients, Patient organisations, Medical community and Pharma companies. Panelists then commented and clarified their input in such a way that we gained overall consensus on the key messages we thought should be conveyed.



## **SESSION#6 – WRITING OUR LETTERS:**

Panelists split into 3 teams and translated the agreed message tracks into “open letters” to Patients, patient organisations, and the medical community. The input related to the Pharmaceutical industry has been gathered separately for further usage by LUPUS EUROPE but will not be subject of a letter per se.

Each team then presented and discussed its proposed letter frame with all panelists. For time constraints reasons, the letters had to be finalized after the panel. Comments have been collected by email and included prior to the 3 letters endorsement by all participants. Those letters, representing the essential contribution of the patient panel, are attached and will be further leveraged by LUPUS EUROPE to make the voice of people living with Lupus Heard.



We also attach to this report the summary done by Jane, Participant to this patient panel, which provides a participant’s insights into the event.

## **Our message to People living with lupus**

Dear Lupus fellow,

So, you too have been diagnosed with lupus...

This week, we, a group of people living with lupus in Europe met in Brussels with LUPUS EUROPE to discuss our lupus and how we can help each other improve our quality of life, having a particular focus on treatment. Here are a few things we would like to tell you:

Go to a doctor who really knows lupus. Don't hesitate to visit the best doctor, even if that means you need to spend some time travelling: lupus is a complex disease – everyone's lupus is a bit different from that of others, so it requires experience of seeing many patients to provide the best treatment. Always ask for the right doctor! When you visit explain well your symptoms, your feelings, and your concerns. Be frank, don't be afraid of asking questions, don't be ashamed! Before you go to the clinic, make a list of questions for the doctor... then remember to ask them. Sometimes, it is easy to forget an important issue or maybe you are not in your best day to lead a conversation: use your notes to make sure you have asked everything you were planning to [and if you are afraid of asking something to that eminent professor... maybe the nurse can help you].

Be actively involved in your illness and treatment. It is not just the doctor telling you what to do, it is also you agreeing that with him. Ask what the purpose is of each prescribed medicine, be in control of your situation: that will help you follow what the doctor and you agreed as treatment.

Ask your doctor how you could be involved in research. Maybe that is only having an extra blood test or filling in questionnaires, or maybe benefitting from a new treatment. Lupus is rare and complex, and we need a lot of research, so every patient that engages in research is truly helping our whole community. Keep yourself updated about your disease. Stay informed, but make sure your information comes from reliable sources!

Take your treatment regularly. Don't interrupt your treatment: it is important for your life. Even if you don't feel sick, you still have lupus. Understand what each medication is for what purpose and how it works: It might help you be motivated to take it. Tell the doctor why it may be difficult for you to adhere to your prescriptions. Together, you might be able to find a solution. Inform the doctors about any other drug or supplement you take. We can take many pills, sometimes interacting with each other, so your doctor should know what you take and if necessary adjust your treatment plan.

Stay in touch with your local patient organisation. They will supply you with important contacts, information, and good advice. We can help each other by exchanging our experiences. Your own experience can help others, and others can help you. Listen to what other patients tell you, but don't take decisions only according to what they said because our lupus symptoms are different, so what might work for one is not always good for others. Don't give up! Thanks to our patient support groups, you are never alone... and you are not the only one with lupus. We can all fight together against lupus!

Please do not forget: lupus is not the only thing in your life. When you get diagnosed, you have the impression everything else disappears and lupus becomes your entire life. Don't let that happen. Don't hesitate to speak about your illness, but also make sure to do other things, to follow your dreams and fulfil your ambitions. While lupus brings limitations, there are so many things that remain possible. Don't worry too much, but try to always be positive, keep moving, keep your life as much as possible like that of any other person.

Before we close our letter, we would like to say again a very important thing, one that can save your life, and will definitely improve your quality of life: Lupus can be like the mafia, even if you can't see it, it is always there. So take your medication because medication only works if you take it!

See you soon in one of our patients groups!

LUPUS EUROPE Patient Panel on Treatment,  
Jane, Jeanette, Claudine, Ana, Sander, Christine, Angela, Daniela, Davide and Bernadette  
November 2014

### **Our Message to the Medical Community,**

This week, a group of European people living with Lupus gathered in Brussels to search how we can improve adherence to treatment and the quality of life of our lupus patients across the continent. We would like to share with you what we found, and where we would very much like your support.

Dear Doctor,

First and foremost, THANK YOU so much for being there and bringing the CARE, with all your knowledge, experience and commitment to help me go through my journey with lupus. Without you, many of us would simply not be here, and others would have a miserable life. Thanks to you for your dedication and giving me the best care, your participation in research programmes, your continued education to better understand and treat lupus which all help me to have access to a better life. I need to benefit from the latest standards of care, like those produced by EULAR, which continuously reflect the collective expertise of the lupus experts around the world, so please, if you are not a lupus expert, refer me to the best specialist.

INFORMATION is critical for me to feel in charge and safe. Don't hesitate to over-communicate and tell me how I am doing. Please explain my blood test results to me, and other tests or examinations you have prescribed. Please tell me what it is for, and what it will tell us both about my lupus or the treatment. I may be taking many pills that I may not understand which each of them is for. It is so important for my commitment to taking them regularly, so please can you clarify this for me, and tell me which side effects I could experience? If I don't get information from you, I am likely to search the internet, even if I know this might not be very reliable. *You are the most reliable source I have, because nobody knows more than you about my illness!*

I want to help treatment progress. Is there any news, research, investigation results that you can share with me, maybe via our patient organisation? I might be interested in participating in a clinical trial, please could you keep me informed?

I trust your expertise, but sometimes I am concerned that you won't hear what I say. *I'm coming to hospital because I really feel sick and I need your help and care! If I feel I am a number, not a person, I lose motivation and trust.*

Sometimes, my pains aren't reflected in a blood test, but I really have them, don't treat me as if I'm crazy, LISTEN to me, I know something is happening! I need to feel understood, and to see your interest in my situation and problems, as the person I am rather than as name on the schedule. When I feel listened to, I can better explain my symptoms and I will ask questions, so that YOUR prescriptions become OUR treatment plan.

Even if I have known you for quite a while, with your white coat, your knowledge and your busy schedule, I might feel intimidated, or worry that I would take too much of your time. But when I feel your EMPATHY, and I become a person talking with you, I can better share what I really feel, what pain I have, what medicine I take... or not. I know many of you are so busy. In some countries, trained "lupus nurses" have a bit more time to listen to us before we have our appointment with you. My experience is that this makes communication easier, asking them things that I would not ask you as Doctor. Can we please work together so that we have lupus nurses in more places?

Please don't misunderstand what I have written : Many of you already live this day to day, but CARE, INFORMATION, LISTENING and EMPATHY are so important to all of us that we can't emphasise this enough.

Thank you so much to all of you, healthcare professionals, for all the care, Information, Listening and Empathy you already provide us everyday. We, the patients with Lupus from all around Europe would like to work more with you as a team to fight together against Lupus... and win our battles together!

LUPUS EUROPE Patient Panel on Treatment,

Jane, Jeanette, Claudine, Ana, Sander, Christine, Angela, Daniela, Davide and Bernadette

November 2014

## Our message to Lupus Patients organisations

Dear Patient Organisation team,

Thank you very much for being there for us! We appreciate all you are doing for us, in extending help, providing information, and connecting us. Thanks to your commitment and the work you do we can truly sense that we are not alone in dealing with lupus and that we form a community where we can find support and understanding.

We need you to stay active and to extend your reach to specialists that don't know about you, like dermatologists, or to smaller hospitals where people being diagnosed with lupus need even more support than in places where lupus experts are available to help ensure that each newly diagnosed person is offered the opportunity to find out community and to get the support they may need.

We need you to help us feel the hope, encouragement, support and energy rather than where we feel we are in a sickness competition (but leave a corner for that... it sometimes helps being allowed to grumble).

We look at you to help us understand and be informed objectively, with answers to our so many concerns and questions. Direct us to the right information, create platforms where we can share experience and support (but moderate platforms like Facebook so we can rely on it). We would love to find a place where we can leave messages and questions that get answered by trained moderators, nurses or doctors ... and a list of those questions previously raised, as we realize we so often face the same issues or have the same questions. Help us with leaflets or trusted and understandable books (at affordable price). We are thirsty for quality information. Give us tips and tricks on best practices and standards of care to help us know we are receiving the care we should.

We need you to stand up so that all of us across Europe get access to quality and affordable treatment, encouraging the right standards of care availability to all both in theory and in practice. If you could find a way to tell us of the hospitals or clinics that adhere to EULAR standards of Care or are lupus centres of excellence that would help us feel safer. We cannot achieve this alone, so we look to you to help us reach everyone. Our life would be much easier if we could avoid delays in treatment, duplicate medical testing, or worries for conflicting treatment thanks to a broad adoption of "patient held records", and we would have a better life if we could benefit from support to buy the so much needed sunscreen, particularly in the southern countries.

We often find it difficult to explain lupus, and we feel incomprehension or suspicion as people do not realize that even if we do not appear sick externally, lupus has its toll on our health. Help us convey the message to the general public, but also to the doctors, the administration, our workplace and employers, so that they understand many of us can live an almost normal life if modest adjustments are made. We would so much like a brochure for employers... and also one for teachers, so that children affected by lupus can find understanding rather than rejection.

We would like you to work together across lupus support groups across Europe to help improve the awareness of lupus and to harmonise the care we receive.

Please don't hesitate to tell us what we can do to help - trials, volunteering, testimonies, awareness raising and questionnaires: we want to help. We might start with small things, but keep us engaged, so that at our pace, little by little, we can fully take our place to help you improve quality of life for all people with lupus.

LUPUS EUROPE Patient Panel on Treatment,

Jane, Jeanette, Claudine, Ana, Sander, Christine, Angela, Daniela, Davide and Bernadette

November 2014



**LUPUS EUROPE PATIENT PANEL – VIEWED BY JANE ROBINSON, UK PANELIST**  
**November 2014 - Brussels, Belgium**

*I was asked to attend a patient panel that was organised by Lupus Europe thanks to a grant from UCB. The aim of the panel was to discuss experiences related to treatment: including using Plaquenil, intravenous treatment, use of sunscreen, physical exercise, etc. to better understand the topic and design initiatives that will help treatment adherence and improve quality of life during treatment.*

*The panel started on Sunday evening but due to Eurostar's train timetable I had to arrive on the Saturday evening. Brussels is a great, small city and it was good to be there especially with some amazing Indian summer weather. I enjoyed a stroll around the city, some shopping and some people watching whilst eating some seafood (with chips and mayonnaise of course).*

*On arrival at the Panel we were greeted by our hosts from LUPUS Belgium Bernadette Van Leeuw and Alain Cornet. We introduced ourselves and shared our lupus journeys along with hopes and concerns for the two days' work for which we had signed up. The Panel was held in English which dealt with my concern of being an inept linguist! There were representatives there from Belgium, Denmark, Italy, The Netherlands, Spain and of course myself from the UK. We found out more about the event and met some representatives from UCB. We also discussed the types of treatments that we had experienced as lupus patients. After a group dinner we had a relatively early night ready for the start of the Panel on the Monday morning.*

*We heard about LUPUS Europe and it's goals and objectives to help set the scene for the work that we were going to do. The first real session was where we discussed adherence to treatment including drugs, sunscreen etc. It was a good start as we each had stories of where we hadn't adhered to treatment for various reasons. I found it interesting to hear that most of the people there didn't always use sunscreen and why not for example. We also heard from UCB representatives who presented some work that they had done on a recent study. We had some sessions working in small groups to discuss treatments and barriers to compliance of treatment regimens and discussing potential solutions. In the evening we went to a traditional restaurant where mussels were their speciality and despite some rain for those that wanted it we had a quick tour of Brussels by night.*

*On the Tuesday morning we had a visit from one of the prominent lupus specialists in Europe, Professor Houssiau and we had a question and answer session. He was a great orator and answered some questions about lupus, its treatment and future developments for treatment. We then worked in small groups to summarise actions and to look at making some key points, suggestions and recommendations for lupus patients, our healthcare professionals, our support organisations and the pharmaceutical industry. The session finished with us drafting letters to these organisations with our recommendations.*

*UCB had a team of people filming our testimonials through interviews sharing our experience with lupus and how it had affected us. LUPUS Europe will use some of the video extracts to share our experience with other patients around Europe. This will be in the form of transcripts available on our website or other media, as well as short video's available on our website. UCB will also use the videos internally within their firm, to help their researchers better understand people living with Lupus. It's always daunting for me when a camera is pointed in my face but interviewer and filming crew were very professional and made it easier!*

*I met some lovely people and at the end there was plenty of sharing of email address and making connections through Facebook and LinkedIn. It was a great opportunity to learn from others and realise how lucky we are with the NHS in comparison to some of our European peers. I hope that the work that we did over the 2 days has helped LUPUS Europe deliver its goals and objectives. I also think that it was a great opportunity to tell the rest of Europe what LUPUS UK do and to look at ways of working together across Europe for the benefit of everyone that has lupus. The overwhelming feeling was that we could do more together as a collection of countries than we ever could as single countries.*

*Jane Robinson*

## ***“Un’esperienza davvero costruttiva ed entusiasmante”***

Desidero innanzitutto porgere un saluto a tutti voi, lettori di Icaro: pazienti, dottori, studenti, famigliari dei cosiddetti, in modo affettuoso, “lupetti” ... visto che questa è la prima volta che scrivo qualcosa per voi, nonostante sia “dei vostri” ufficialmente da ben 19 anni.

All’inizio di Novembre 2014 ho avuto l’opportunità di partecipare ad un’iniziativa di **LUPUS EUROPE**: un incontro con altri pazienti affetti da LES provenienti da vari Paesi europei, con lo scopo di collezionare informazioni relative al tema COME E’ LA VITA “IN COMPAGNIA” DEL LUPUS, e di utilizzare le idee raccolte per un confronto fra noi, per rendersi conto di quanto le esperienze di tutti siano importanti per soffermarsi a pensare sulla propria situazione e a comprenderne meglio le varie sfaccettature, per quanto ogni situazione sia diversa da tutte le altre. Inoltre il risultato del “nostro lavoro di due giorni pieni” verrà utilizzato per uno studio rivolto a cercare di migliorare lo standard di vita dei pazienti affetti da LUPUS.

La condizione per partecipare a questo “Panel”, che si è tenuto a Brussels dal 2 al 4 novembre scorso, era appunto quella di essere affetti da LES e di essere in grado di colloquiare fluentemente in inglese, lingua di scambio utilizzata fra tutti i partecipanti nella 3-giorni di “piacevole full immersion”.

Ripensando a come si è svolto il programma, egregiamente preparato e pilotato dai “padroni di casa” Bernadette ed Alain, noto quanto sia straordinario come delle persone di varia provenienza e di età diverse, che si incontrano per la prima volta la domenica pomeriggio, sembrassero tutte “amici di lunga data”, dopo solo una breve presentazione che ognuno di noi aveva fatto di se stesso. La sensazione è stata come una conferma che ciò che ci accomunava non fosse solo il LES, ma una particolare sensibilità che era entrata in qualche modo nel tempo a far parte del nostro carattere. E ciò che considero più straordinario ancora è un punto in comune a tutti quanti, che è poi anche un enorme punto di forza: la **grande POSITIVITA’** espressa, nonostante le difficili esperienze vissute o i vari problemi che ci si trova costantemente ad affrontare e la **grande SPERANZA e FIDUCIA nella ricerca**.

Insomma, per spiegarvi meglio, posso dire che il mattino seguente eravamo tutti a far colazione assieme, tutti “allegrementi muniti” del proprio contenitore porta-compresse, pronti ad affrontare la giornata, senza avere il timore di apparire come il “solito astronauta” atterrato a consumare lì il proprio pasto in pillole .... E ancora la facilità ad interfacciarsi e a collaborare nelle attività previste di “assemblaggio” informazioni .... La naturalezza con la quale ognuno di noi ha cercato di “scavare” dentro di sé nel fornire delle risposte effettivamente “reali” e non solo “di convenienza”. Ed è proprio questo che penso sia servito più di tutto: il praticare una sorta di introspezione ad alta voce, che ci ha aiutato a capire se un nostro anche piccolo comportamento poteva essere sbagliato, se determinate decisioni prese senza il consulto dei nostri medici non fossero appropriate ... è stato in pratica come scattare una fotografia dei vari momenti delle nostre giornate. Questo non esclude naturalmente che tutti noi abbiamo vissuto a volte dei momenti di sconforto ... ed è per questo che siamo grati a tutti: in primis a noi stessi per la forza di volontà che ci mettiamo, alle nostre famiglie che ci stanno sempre vicino, ai nostri compagni di vita che condividono con noi non solo le nostre giornate (belle o brutte che siano), ma anche la “compagnia del lupus cattivo ...”, a tutti i nostri medici ed infermieri che ci seguono con dedizione e pazienza, ai buoni amici che sanno esserci vicino nei momenti di bisogno e a tutti quelli impegnati direttamente o indirettamente nella ricerca o nel sostenerla. E, forte di questo ultimo pensiero, confido nel fatto che tutto il lavoro di gruppo svolto a Brussels, tutte le informazioni che saranno in seguito a ciò elaborate sotto forma di **tre distinti messaggi, rivolti rispettivamente**

- **alle persone affette da LUPUS** *(una sorta di vademecum, con alcuni interessanti consigli, in seguito alle nostre esperienze)*
- **ai medici e agli infermieri** *(con il nostro vivo apprezzamento per il loro lavoro e il riconoscimento dell’importanza della loro missione, con l’aggiunta di alcune impressioni e suggerimenti per il rapporto medico-paziente)*
- **alle associazioni di pazienti affetti da LUPUS** *(per il supporto offerto, per l’importante figura che rivestono e per la maggiore auspicata diffusione che si meriterebbero)*

dicevo appunto che mi auguro che tutto ciò potrà essere effettivamente costruttivo e di aiuto, ognuno per la propria parte, a tutti quelli che, in un modo o nell’altro, “vivono in compagnia del Lupus”.

Spero di poter fornire prossimamente le informazioni necessarie per accedere alla documentazione preparata, attualmente in elaborazione presso LUPUS EUROPE, prima della diffusione.

Vi terrò aggiornati e voi .... rimanete in contatto !

Un saluto e un grazie per l’attenzione da Brussels da

Daniela Rava

*(Gruppo LUPUS Piemonte)*