



UNITING PEOPLE WITH LUPUS THROUGHOUT EUROPE

Formerly European Lupus Erythematosus Federation (ELEF)

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 our 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 rumble).

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 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 are available 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. What we cannot achieve alone, we look at 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 would 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 externally sick and that lupus has its toll on our health. Help us convey the message to the general public, but also to the doctors, the administrations, our workplace and employers, so that they understand many of us can live almost a 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 take fully our place to help you improve quality of life for all people with lupus.

From around Europe, in Brussels,

November 4, 2014

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