



UNITING PEOPLE WITH LUPUS THROUGHOUT EUROPE

Formerly European Lupus Erythematosus Federation (ELEF)

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

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