



Dear Doctor,

Thank you for the exceptional care you provide as we navigate the complexities of living with lupus. Your dedication, expertise, and commitment to our health and wellbeing are deeply appreciated. You have saved our kidneys, managed our treatment plans, and stabilised our lupus and for that, we are truly grateful.

Thank you for providing a safe space for us to ask questions without judgment. Your openness creates an environment where we feel comfortable sharing our concerns, seeking clarification, and gaining a better understanding of our condition. We value the importance of fostering open dialogue and appreciate your efforts in making us feel heard.

We want to extend our gratitude for the valuable information you provide us about youth groups and patient organisations. By connecting us with these support networks, you offer us a sense of community and belonging. The opportunity to engage with other People with Lived Experience (PWLE) who understand what living with lupus is like can be empowering. Thank you for recognising the significance of these connections and for actively encouraging our involvement.

While your dedication to our care is clear, the medical process can often feel overwhelming and confusing for us, leaving us in the dark about what to expect. Please try to alleviate this confusion by providing us with a clear understanding of the treatment process. Keeping us informed, sharing insights, and involving us in decisions about our care helps create an atmosphere of collaboration and trust, empowering us as active participants in our own well-being. We value your efforts to keep us involved every step of the way.

Having lupus can be daunting, but having one or two familiar doctors can greatly contribute to our sense of consistency, stability, and trust. This continuity of care allows for a deeper understanding of our needs and helps build a stronger patient-doctor relationship. This also helps us not receive conflicting messages from different doctors working in the same team, which can be confusing. We appreciate your consideration of the impact of changes within our healthcare team and your commitment to providing us with a sense of continuity.

Knowing you take part in lupus-related patient events is important. Your involvement in these events demonstrates your commitment to having a more holistic understanding of our condition, one that includes insights from our lived experiences. Thank you for being an active participant in these events.

As we work together in this fight against lupus, please remember that we are people first, with emotional needs beyond the purely medical aspects of our treatment. Your empathy and understanding play a vital role in creating a safe space where we can openly share our struggles, concerns, and vulnerabilities. Recognising our emotional well-being as an integral part of our overall care is invaluable as we navigate the ups and downs of our lupus journey.

We want to learn more about lupus! Education about our condition is crucial in effectively managing it. While we do appreciate the leaflets and information in the clinic waiting room, we also desire a deeper understanding that goes beyond these resources. Provide us with an education on lupus and signpost us to resources that will help us better understand our condition. By sharing your knowledge and explaining more about the intricacies of lupus, you empower us to become an informed patient and a better advocate for our own health.

We trust you and your treatment recommendations, but we want to be educated about potential side effects of treatments. An open discussion about possible side effects can be helpful in alleviating any anxiety or confusion we may feel. Lupus can be complicated and sometimes we may need time to come to a conclusion or make a decision about treatment. Your patience and lack of pressure or judgement are invaluable in allowing us to take the time we need to make the right decisions for ourselves. Thank you for your support and understanding in this regard.

A huge thank you to all doctors for all the information, care, and support you give to all of us every day. As young people with lupus from all around Europe, we stand united with you as a team in this common fight against lupus!

Lupus Europe 2<sup>nd</sup> Patient Panel on Youth,

Cassie, Cristina, Ivan, Lynette, Marina, Noelia, Roberta, Santhia, Sofia, Vilte