Speech for the Opening of SLEuro 2026 – on behalf of Lupus Europe

Dear friends and colleagues,
Good afternoon—and welcome to Lisbon.

It truly is wonderful to see so many familiar and new faces gathered here today. As President of Lupus Europe, it gives me enormous pleasure to welcome you to the European Lupus Meeting 2026. On behalf of Lupus Europe, and as proud co-organisers of this meeting, I warmly welcome physicians, researchers, nurses and allied health professionals, industry partners, and—very importantly—patients and patient advocates from across Europe and beyond.

Lisbon feels like the perfect place for us to meet. It is a city built on light, history and discovery. A city of bridges. And that is exactly why we are here: to build bridges—between countries, between disciplines, and above all, between physicians and patients.

A Meeting Built Together

What makes this year's meeting particularly special is not only the quality of the science—though the programme is genuinely exciting. It is the way it has been created.

This meeting has been built together. Not with patients invited in at the end. Not with a token session added. But through real collaboration from the start. Patients have helped shape themes, identify unmet needs, and ensure that the conversations here reflect what truly matters in daily life with lupus.

Quality of life. Fatigue. Treatment burden. Mental health. Pregnancy. Work. Long-term damage prevention. These are not just "soft" topics—they are central to living with SLE.

Because science does not happen in isolation. It happens in real lives, in real families, in real communities.

For many years, medicine was something done to patients. Increasingly—and thankfully—it is something done with patients. And this meeting reflects that change. So many thanks to Prof. Inês, Prof. Santos and the team, who have involved us from the start.

Why Patient Involvement Truly Matters

Patient involvement is not a trend. It is not a fashionable extra. It is fundamental to good science and good care.

As patients, our Patient Advisory Network members—10 of whom are here in Lisbon—live with lupus every single day. They live its unpredictability, its invisible symptoms, the trade-offs between benefit and side effects, and the quiet calculations that happen before saying yes to a treatment or committing to a plan.

Clinicians and researchers bring knowledge, expertise and rigour. But when lived experience and scientific expertise meet, something powerful happens. Research questions become more relevant. Endpoints become more meaningful. Communication improves, and trust grows.

At Lupus Europe, we see daily how informed and engaged patients make a difference—not only to their own health, but to the quality of research and healthcare systems more broadly.

But for this partnership to work, patients must have access: access to information, access to dialogue, and access to the scientific community.

Access to Knowledge – A Concern We Must Address

And this brings me to something important, which we in Lupus Europe find worrying.

Across Europe, we are increasingly seeing scientific meetings restrict patient participation. Often this is justified by reference to European regulations—particularly around pharmaceutical compliance and transparency.

Let me be clear: regulation matters. Transparency matters. Ethical standards matter.
But exclusion should not be the unintended consequence.

Too often, rules designed to prevent inappropriate promotion are being interpreted in ways that block patients from legitimate scientific exchange. Patients—particularly expert patients—are not marketing targets. They are stakeholders in the very research being presented.

When they are excluded, we widen the knowledge gap at exactly the moment when science is moving fastest. We risk creating one level of information for professionals and another, diluted level for everyone else.

In a world where misinformation can spread in seconds, limiting access to evidence-based information does not protect patients—it leaves them vulnerable.

SLEuro has chosen a different path—one based on trust, clarity and partnership.

We believe patients can participate responsibly. We believe ethical dialogue is possible. And we believe that knowledge, when shared appropriately, empowers rather than harms.

And honestly—if patients can manage complex treatment plans, keep track of blood tests, and pronounce medications that many of us still stumble over, I am quite confident they can handle a Kaplan–Meier curve.

A Moment of Real Progress – Across Europe

We are meeting at a remarkable time in lupus research.

Our understanding of immunopathogenesis continues to deepen. Targeted therapies are expanding. Precision approaches are becoming more realistic. The narrative of lupus is slowly shifting—from limitation towards possibility.

There is real momentum. And there is real hope.

But innovation in the laboratory must translate into access in the clinic. A breakthrough only matters if it reaches the person who needs it.

And this is where the European dimension becomes so important.

Europe is wonderfully diverse. Our healthcare systems differ. Our resources differ. Regulatory pathways and reimbursement decisions vary widely.

But lupus does not recognise borders.

A young woman here in Lisbon, a man in Warsaw, a teenager in Stockholm, or a grandmother in Athens may share the same diagnosis—yet experience very different realities when it comes to accessing specialists, diagnostics or new treatments.

If we are serious about progress, it cannot be progress for some—it must be progress for all.

That requires collaboration—between researchers, clinicians, patient organisations and policymakers. It requires us to combine scientific evidence with lived experience. Data informs. Stories connect. Together, they move systems.

When SLEuro and Lupus Europe work side by side, we strengthen our ability to advocate for equitable access across Europe.

Because real progress is not only about what we discover. It is about who benefits.

Looking Ahead – The Lupus Europe Poster Award

Before I close, I would like to briefly look ahead to the end of this meeting.

At the closing ceremony, Lupus Europe will present its very first Lupus Europe Poster Award.

This 500-euro award will recognise the best poster and poster explanation—as judged by a jury composed entirely of people living with lupus, members of our Patient Advisory Network, who are not healthcare professionals but who bring lived experience and a strong understanding of lupus research.

Importantly, this is not an award for the best “patient poster”. It is open to medical students, doctors and healthcare professionals, with particular encouragement for early-career researchers.

What makes this award special is its focus on engagement. The jury will be looking not only at scientific quality, but also at the ability to explain clearly—in accessible language—why the research matters to people living with lupus.

It is our way of encouraging dialogue between researchers and patients, and of recognising those who can truly bridge science and lived experience.

I hope you will all spend time in the poster area—and join us at the closing session to celebrate our first recipient.

Make the Most of These Days

Over the coming days, I encourage you to look beyond the lecture halls. If you are a clinician, seek out a patient advocate. If you are a patient, speak to a researcher. If you are early in your career, be bold—we are all here because we care about the same thing.

Some of the most meaningful collaborations begin not in formal sessions, but in informal exchanges. Have the conversation over coffee. Introduce yourself to someone whose work you admire.

Partnership requires humility. It requires listening. It requires recognising that none of us holds the full picture alone.

But when we align around our shared purpose—improving the lives of people living with lupus—remarkable things happen.

A Personal Note

When Lupus Europe was founded, the idea that patients would co-organise a major scientific meeting like this might have seemed ambitious—perhaps even unrealistic.

Today, it feels natural.

That change did not happen by accident. It happened because people in this room chose openness over hierarchy, dialogue over distance, and partnership over paternalism.

To our colleagues in SLEuro—thank you for embracing this collaboration so wholeheartedly. It makes a difference!

On behalf of Lupus Europe, I want to thank you all for being here. Thank you for your dedication. And thank you for walking this journey together.

I wish you an inspiring, collaborative—and yes, enjoyable—SLEuro 2026.